



# The Scottish Strategy for Autism

# **The Scottish Strategy for Autism**



**John Cornock**  
(Self Portrait, pen, 2011)



**Rachel Hook**  
(Portrait of Mandi, coloured pencil, 2011)



**Fiona Birrell**  
(Portrait of Shona, pen, 2011)



**Scott Cation**  
(Portrait of Alister, felt tip pen, 2011)



**John Ellsworth**  
(Self Portrait, coloured pencil, 2011)



**Kubus Joss**  
(Portrait of Stuart, coloured pencil, 2011)



**Rachel Hook**  
(cover image - abstract painting, 2010)

The artists featured on the cover all attend Scottish Autism's Art Opportunities service. Art Opportunities is a day service for adults with autism specialising in arts and crafts based activities, from painting and drawing to textiles and glass work. They include the abstract painting by Rachel Hook which was painted for Young Talent 2010, an exhibition of artwork created by young people with disabilities.

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## Foreword

Autism is a national priority. Given the importance we all attach to this agenda, the development and creation of a new Scottish Strategy for Autism is vital to ensure that progress is made across Scotland in delivering quality services.

In September 2010, the Scottish Government consulted on the way ahead. The final Strategy is the result which will be delivered jointly with COSLA. The planned programme of activity is backed up with new resources of £10m over the next 4 years.

Strategic action is needed both nationally and locally. Children and adults on the autism spectrum each have a unique set of conditions which will not necessarily fall within the categories of learning disabilities or mental health, although these conditions may be present. Autism impacts on the whole life experience of people and their families. They need to be supported by a wide range of services such as social care, education, housing, employment and other community based services. A holistic, joined-up approach is necessary.

For the vision to be realised, concerted and shared action by all those involved is required. This is why we will be working closely together to deliver the improvements necessary for the people of Scotland.



A handwritten signature in black ink, appearing to read "Michael Matheson".

**Michael Matheson**  
**Minister for Public Health**



A handwritten signature in black ink, appearing to read "Douglas A. Yates".

**Councillor Douglas Yates**  
**COSLA**



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# Chapter 1

## The Autism Strategy



# Chapter 1: The Autism Strategy

## Introduction

This first chapter is a free-standing condensed version of the strategy which provides readers with an overview of what autism is and the challenges which individuals with the condition and their families face in everyday life. It then describes how the autism strategy will address their needs over the next 10 years.

Chapter 2 provides more detailed information on the issues contained in the overview for those who want to take more time to understand the issues in greater depth. It explains the context behind each of the recommendations and why these are critical to success.

Some of the recommendations are about reviewing and consolidating existing practice whilst others are about improving practice in the light of new learning. Some recommendations are directed at ensuring that there is greater clarity about the cost of services in meeting need and the benefits of strategic budget management, whilst others are focussed on cutting waiting lists for diagnosis and improving the diagnostic process itself. Some are about ensuring that the interests of those on the spectrum are appropriately represented in other areas of policy development and delivery, such as learning disability and self-directed support. Yet others concern themselves with training, research and scrutiny – all of which are needed to support change.

Linkages with the range of policies and frameworks from which people on the spectrum may benefit will be pivotal to success. The National Performance Framework<sup>1</sup> sets out strategic objectives, national outcomes, indicators and targets, which public bodies will work together to deliver for Scotland. These are supported by Single Outcome Agreements (SOA)<sup>2</sup> which set out local priorities, expressed as high-level outcomes, which public sector partners will work together to deliver for their communities. A range of more targeted policy frameworks sit below SOA, which allow partners to focus on particular topics or groups in more detail. Many of these frameworks, for example, *Additional Support for Learning*<sup>3</sup>, the *Carers Strategy*<sup>4</sup> and *Getting It Right For Every Child*,<sup>5</sup> will impact on the lives of people with autism and their carers. More detail on these policies and frameworks is given at Annex 1, whilst Annex 2 gives some background information about the numbers of people who have the condition. Part of the challenge will be in negotiating and

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<sup>1</sup> <http://www.scotland.gov.uk/Publications/2007/11/13092240/9>

<sup>2</sup> <http://www.scotland.gov.uk/Topics/Government/local-government/SOA>

<sup>3</sup> <http://www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL>

<sup>4</sup> <http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

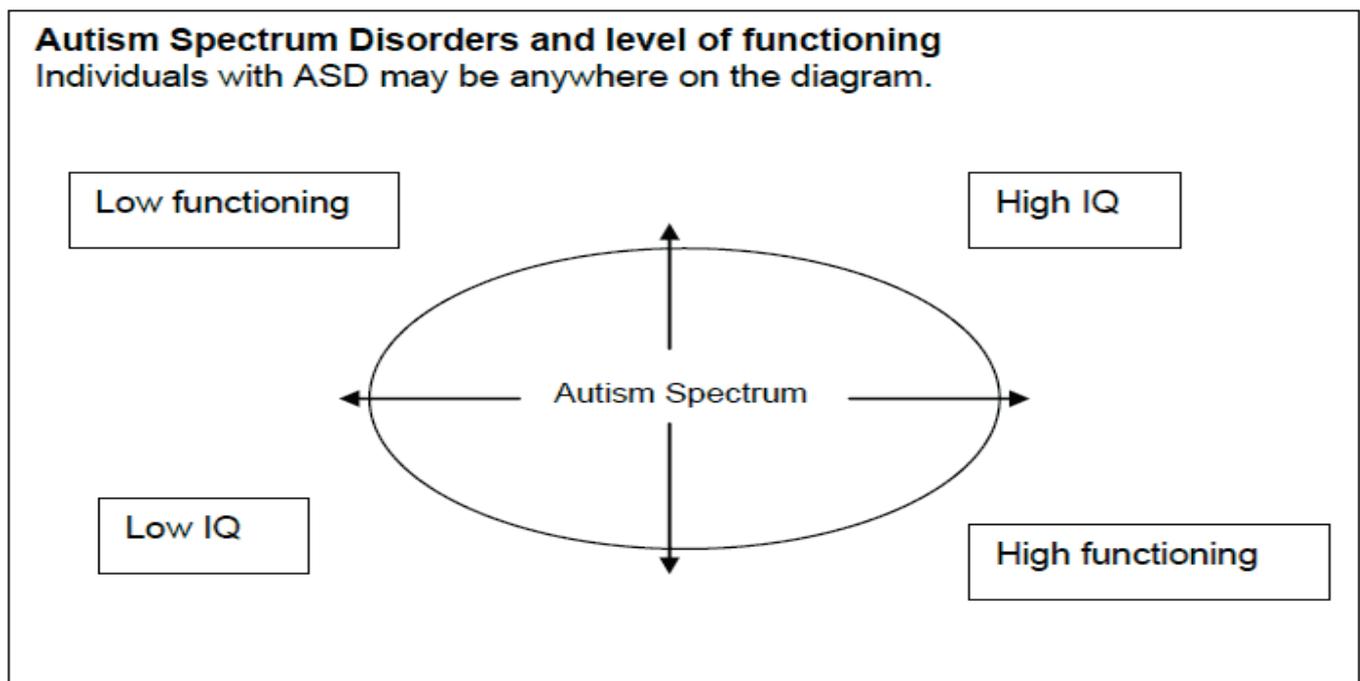
<sup>5</sup> <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

agreeing how the needs of those on the autism spectrum can be understood, integrated and evaluated within these critical structures. Partnership approaches, commissioning service redesign, delivery and performance improvement will be key features in the continuation of this work.

Strong leadership is needed to translate these aspirations into reality, which is why the Autism Spectrum Disorder(ASD) Reference Group that led earlier work has reconvened and has been expanded to provide that leadership. This Group consists of users, carers, local and central government representatives, voluntary organisations, NHS staff and academics. It has made a commitment to continue to collaborate throughout the programme to deliver effective care and support for those who require it.

## What is autism?

Autism is a lifelong developmental disorder more commonly referred to as autism spectrum disorder (ASD) but also known as autism spectrum condition (ASC). ASD affects people differently with some individuals being able to live independently. Others will need very specialist support.



What everyone will have in common is difficulty in 3 areas of functioning, sometimes referred to as the triad of impairments.

People experience problems with:

- Communication – both verbal and non-verbal, e.g. difficulties with use and interpretation of voice intonation, facial expressions and other communicative gestures;

- Reciprocal social interaction – this includes the ability to understand what someone else might be thinking in a real-time situation and to understand the need for social ‘give and take’ in conversation and overall interaction;
- Restrictive, repetitive and stereotypical routines of behaviour – these may involve enthusiasms held by a person with ASD (which may be very restricting for their family, friends and colleagues but may also be psychologically distressing or inhibiting for the individual with ASD).

## What is the Autism Strategy for?

Autism has been the subject of a number of initiatives<sup>6</sup> over the past decade. Considerable efforts have been made to improve diagnosis and assessment, to create consistent service standards, to match resources to need and to underpin this with appropriate research and training opportunities. These significant contributions now need to be harnessed into the development of a national 10 year autism strategy that addresses the entire autism spectrum and the whole lifespan of people living with ASD in Scotland.

The Scottish Government, working in partnership with the Convention of Scottish Local Authorities (COSLA), the two national autism organisations, a wide range of service users and professionals, has spoken to individuals on the spectrum and their families to hear at first hand what their concerns are and what changes are needed. We will continue to work in this way as we make progress together. A draft autism strategy was consulted on widely. Its recommendations are far-reaching and will impact upon all professions, across all disciplines involved in the provision of public services. They need to be put into effect as soon as practically possible.

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<sup>6</sup> Public Health Institute of Scotland Autistic Spectrum Disorders Needs Assessment Report, 2001  
<http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/Resources/PHIS>

SIGN publication No 98) Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders <http://www.sign.ac.uk/guidelines/fulltext/98/index.html>

Commissioners of health and social care services for people on the autism spectrum, Policy and Practice Guidance, (2008) <http://scotland.gov.uk/Publications/2008/03/27085247/0>

Education for pupils with autism spectrum disorders, 2006, HMIE  
<http://www.hmie.gov.uk/documents/publication/epasd.html>

National Guidance on the Implementation of Local Area Coordination, Scottish Government, (2008).  
<http://www.scotland.gov.uk/Publications/2008/03/27092411/0>

A Guide to Getting it right for every child (GIRFEC) (2008)  
<http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

## The language we use

It is important to explain the choice of language and terminology used in the document because the complex nature of the autism spectrum gives rise to a range of personal and professional perspectives. Although this means that it is not easy to find a common language that reflects the views of the various groups, what we have tried to do is reflect the diversity of the community in a positive way.

More generally, we recognise that there is a need to be sensitive about the use of words like “disorder” or “impairment”. These are clinical terms that are understood in those settings and included in sections of that nature. However, we know that many individuals on the autism spectrum do not accept those terms, preferring to stress that they have a different way of being in, perceiving and engaging with the world and those with whom they share it. At the same time, some individuals on the spectrum face significant challenges in their daily living and are in need of high levels of support specifically tailored to their needs.

The autism strategy follows a logical order. We begin with a vision which describes where we want to get to. This is underpinned by values that need to be at the heart of the autism strategy as a whole and at the heart of the behaviour of all those who are responsible for implementing it. There are also main aims to be addressed such as achieving best value for services and cross-agency working. There are also recommendations which have already been consulted on and which set out the long term direction. Some can be achieved immediately. Others will take longer. That is why the national Autism Spectrum Disorder (ASD) Reference Group has added goals which are steps along the way. These ensure that we are clear about what needs to be done within 2 years, 5 years and by the end of the programme.

## Our vision

**Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.**

## Our values

Underpinning values will be:

- **Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- **Privacy:** people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens;
- **Choice:** care and support should be personalised and based on the identified needs and wishes of the individual;

- **Safety:** people should be supported to feel safe and secure without being over-protected;
- **Realising potential:** people should have the opportunity to achieve all they can;
- **Equality and diversity:** people should have equal access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination.

People with ASD should expect to have the support of professionals working in their best interests to make these values a reality.

## **Our goals**

These will help us to make sure we have addressed all the recommendations by the time the autism strategy concludes. We have divided the goals into three parts – Foundations (by 2 years), Whole-life journey (by 5 years) and Holistic-personalised approaches (by 10 years). Some goals will principally be for one discipline to deliver whilst others will require a multi disciplinary response. All goals and recommendations will be fully explored through the production of a work plan to ensure that the recommendations are appropriate and fulfilled in the time frames. Table 1 illustrates this.

### **Foundations: by 2 years**

1. Access to mainstream services where these are appropriate to meet individual needs.
2. Access to services which understand and are able to meet the needs of people specifically related to their autism.
3. Removal of short-term barriers such as unaddressed diagnoses and delayed intervention.
4. Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis).
5. Implementation of existing commissioning guidelines<sup>7</sup> by local authorities, the NHS, and other relevant service providers.

### **Whole life journey: by 5 years**

1. Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism.
2. Access to appropriate transition planning across the lifespan.
3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas.
4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.

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<sup>7</sup> <http://scotland.gov.uk/Publications/2008/03/27085247/0>

## **Holistic personalised approaches: by 10 years**

1. Meaningful partnership between central and local government and the independent sector.
2. Creative and collaborative use of service budgets<sup>8</sup> to meet individual need (irrespective of what the entry route to the system is).
3. Access to appropriate assessment of needs throughout life.
4. Access to consistent levels of appropriate support across the lifespan including into older age.

To ensure the development of comprehensive services that meet the needs of children, adults and older people on the autism spectrum, and a method for which service providers can self-evaluate their processes, the following indicators, although not conclusive, are provided as examples of best practice. It is envisaged that these be used to identify outcome-focused actions that may be achieved over the two, five and ten year timeline of the autism strategy, as agreed locally. Clearly, each indicator has a number of related tasks and processes; it would be for each service provider to detail actions under each indicator.

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<sup>8</sup> <http://scotland.gov.uk/About/publicservicescommission>

## Ten indicators for current best practice in the provision of effective Autism Spectrum Disorder (ASD) services<sup>9</sup>

ASD provision should include:

1. A local Autism Strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.
2. Access to training and development to inform staff and improve the understanding amongst professionals about ASD.
3. A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.
4. An ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff.
5. A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services.
6. A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.

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<sup>9</sup> Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. (SIGN publication No 98) <http://www.sign.ac.uk/guidelines/fulltext/98/index.html>  
Education for pupils with autism spectrum disorders, 2006, HMIE  
<http://www.hmie.gov.uk/documents/publication/epasd.html>  
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McKay, T & Dunlop, AW (2004) The Development of a National Training Framework for Autistic Spectrum Disorders, NAS & University of Strathclyde.  
National Performance Framework (2007), Scottish Government  
<http://www.scotland.gov.uk/Publications/2007/11/13092240/9>  
Brown, K & White (2006) exploring the evidence Base for Integrated Children's Services, Scottish Executive [www.scotland.gov.uk/Resource/Doc/90282/0021746.pdf](http://www.scotland.gov.uk/Resource/Doc/90282/0021746.pdf)  
The Autism Toolbox, An Autism resource for Scottish Schools  
[www.scotland.gov.uk/Resource/Doc/266126/0079626.pdf](http://www.scotland.gov.uk/Resource/Doc/266126/0079626.pdf)  
Learning Together: Meeting needs of children and young people with Autism Spectrum Disorders.  
Quality Indicators Learning Disabilities, NHS QIS (2004)

7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.
8. Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.
9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.
10. A self-evaluation framework to ensure best practice implementation and monitoring.

## **Our aims and recommendations**

Implementing the 26 recommendations is key to achieving our vision. Some recommendations are about reviewing and consolidating existing practice whilst others are about improving practice. This is why we have aligned them to aims and renumbered the recommendations. However, all are geared towards ensuring improving services and access to services for people on the autism spectrum.

**The Scottish Government will provide strategic leadership on improving the lives of people affected by autism. It will lead on creating a strategic vision for the development of services and support for people with autism, their families and carers.**

- It is recommended that the ASD Reference Group is reconvened on a long-term basis to include COSLA membership to oversee developments and to progress change. It should produce an annual report to relevant Ministers and the political leadership of COSLA. **1**
- It is recommended that the ASD Reference Group works collaboratively, and offer support, to COSLA, NHS, criminal justice and other relevant public bodies to offer support to Local Authorities to effect the implementation of the various autism guidelines. **2**
- It is recommended that the ASD Reference Group explores the benefits of ASD lead officers with the Association of Directors of Social Work and with COSLA to establish how rollout across Scotland might best be achieved. **3**
- It is recommended that the ASD Reference Group meets with representatives of both SCSWIS and HIS, as well as other relevant regulatory bodies, such as those in education and criminal justice, with a view to learning about current developments and ensure that the needs and wishes of those on the spectrum are taking into account in future programmes. **4**

**Achieving best value for services for people affected by autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve.**

- It is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole. Particular attention should be paid to his 'invest to save' assertion that if 4% of those with Asperger's were given appropriate support into work this would ultimately mean that those individuals may not require services and could contribute to the economy. **5**
- It is recommended that the effectiveness of implementation of the Commissioning guidance is reviewed by the ASD Reference Group by facilitating an audit of current service commissioning. **6**
- It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD. **7**
- The ASD Reference Group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan. **8**
- It is recommended that the ASD Reference Group hosts an event to evaluate and recognise good practice in Scotland to disseminate models of practice, to evaluate success, recognise benefits and limitations and agree how to develop good models across the country in a way that is cost-effective. **9**
- It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions. **10**
- It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD. **11**
- It is recommended that an evaluation of existing research is commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and to the commissioning some pieces that would be of particular practical value to people with ASD and their carers. **12**

**People with autism, and their families and carers, should be involved at all levels in decision making.**

- It is recommended that the ASD Reference Group explore options for developing user and carer capacity to be able to participate in local planning processes. **13**
- It is recommended that the SDS Strategy Implementation Group and the SDS Bill Reference Group ensure representation from the autism community so that their interests are taken into account as further developments take place. **14**

**The capacity for cross-agency working will be developed through stronger networks, best practice and training. This will help deliver cost-effective support and interventions.**

- It is recommended that existing reports on the work of Scottish Autism Services Network are formally evaluated with a view to assessing its long-term viability and effectiveness. **15**
- It is recommended that the ASD Reference Group contributes to a review of the SIGN guidelines and in doing so, considers where and how best this innovation might be replicated for adults and other relevant professions. **16**
- It is recommended that the Training Sub-Group of the main Reference Group is reconstituted and strengthened by the inclusion of an SCLD representative to undertake an audit of existing provision and to take evidence from grass roots trainers with a view to recognising strengths and gaps as well as identifying the means by which to further improve what is on offer. **17**
- It is recommended that good practice transition guidance is developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions. **18**

**For adults, getting a good quality diagnosis is the key foundation that will lead them to understanding their condition and for the best support to be made available to them.**

- It is recommended that a request is made to NHS QIS, as the body into which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of ASD in adults. **19**
- It is recommended that approaches are made to the Royal College of Physicians and Surgeons to establish the feasibility and desirability of disseminating ASD materials in e-CPD formats. **20**

- It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings. **21**
- Initiatives to address waiting lists for assessment should include consideration of further training on the use of ADOS, ADI-R, 3di and DISCO to meet increased levels of demand. **22**
- It is recommended that the ASD Reference Group explore the ways diagnostic processes for adults and children are different and how this should inform practice. **23**
- It is recommended that the directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland is reviewed, updated and re-distributed. **24**
- It is recommended that a review is conducted with a view to updating and re-distributing the quality diagnostic standard if it is found to continue to be of benefit. **25**

**There are many people with autism who would like to work but who face significant barriers to getting and sustaining a job. We will support them through training, creating opportunities and improving access to the workplace.**

- It is recommended that the supported employment framework for Scotland is evaluated in terms of its impact on employment and employability for people with autism. **26**

## What happens next?

Much is yet to be achieved. Recommendations for change range in content from some carefully formulated ideas to glimmers of what may prove useful but which will require further scoping and consideration, before a decision can be taken as whether to proceed or not. Waiting for perfection is not an option. Financial and other constraints should not detract from long-term strategic planning but should instead inform our approach to prioritising and re-forecasting the timescales for outcomes of programmes of work.

We will put in place robust arrangements to ensure delivery of the recommendations. The ASD Reference Group will lead in the monitoring and tracking of improvements in service provision for people with autism and their families. The ASD Reference Group will be chaired by the Scottish Government, supported by COSLA and include representatives of key stakeholders, including those from the statutory, voluntary and private sectors, the new scrutiny body SCSWIS<sup>10</sup>, as well as people with ASD. The ASD Reference Group will report annually on progress and review the autism strategy by this means.

The ASD Reference Group will develop an action plan for its work to ensure that progress is continually monitored. The Group will meet 6 times a year and will publish its minutes, papers and reports on the Scottish Government website.

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<sup>10</sup> SCSWIS now the Care Inspectorate

**Table 1**

LINKING GOALS, AIMS and RECOMMENDATIONS(R)							
TIME RELATED GOALS ↓ Aims and ACTIONS →	Strategic Leadership	Achieving Best Value for Services	Collaboration and involvement	Cross Agency Working	Diagnosis, Intervention and Support	Wider opportunities and access to work	TIME RELATED GOALS ← AIMS and ACTIONS →
FOUNDATIONS 0-2 years	R1 R2 R3 R4	R5 R6 R7 R8 R9 R10 R11 R12	R13 R14	R15 R16 R17 R18	R19 R20 R21 R22 R23 R24 R25	R26	FOUNDATIONS 0-2 years
WHOLE LIFE JOURNEY 2-5 years	R1 R2 R4	R7 R8 R9 R10 R11	R13 R14	R16 R18	R22 R23 R24 R25	R26	WHOLE LIFE JOURNEY 2-5 years
HOLISTIC PERSONALISED APPROACHES 5-10 years	R1 R2 R4	R7 R8 R9 R10 R11	R13 R14			R26	HOLISTIC PERSONALISED APPROACHES 5-10 years
GOALS <i>(The work towards these goals will be a main focus throughout the periods identified and sustained over the full period once achieved)</i>							
FOUNDATIONS: by 2 years		WHOLE LIFE JOURNEY: by 5 years		HOLISTIC PERSONALISED APPROACHES: by 10 years			
<ol style="list-style-type: none"> <li>1. Access to mainstream services where these are appropriate to meet individual needs;</li> <li>2. Access to services which understand and are able to meet the needs of people specifically related to their autism;</li> <li>3. Removal of short-term barriers such as unaddressed diagnoses and delayed intervention.</li> <li>4. Access to appropriate post diagnostic support for families and individuals (particularly when there is a late diagnosis).</li> <li>5. Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers.</li> </ol>		<ol style="list-style-type: none"> <li>1. Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism</li> <li>2. Access to appropriate transition planning across the lifespan</li> <li>3. Consistent adoption of good practice guidance in key areas of education, health and social care across all local authority areas.</li> <li>4. Capacity and awareness building in mainstream services to ensure people are met with recognition and understanding of autism.</li> </ol>		<ol style="list-style-type: none"> <li>1. Meaningful partnership between central and local government, and the independent sector</li> <li>2. Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is)</li> <li>3. Access to appropriate assessment of needs throughout life</li> <li>4. Access to consistent levels of appropriate support across the lifespan including into older age.</li> </ol>			



## Chapter 2

# The strategic context



## CHAPTER 2: The strategic context

### Introduction

This chapter moves on from chapter one to consider in depth what needs to happen next in order to create an Autism Strategy for Scotland. In this introduction the need for an ASD Reference Group is recognised and is placed in the context of the National Performance Framework, the lifelong nature of autism and the role of assessment in identifying the needs of people with autism, leading to rights-based outcomes. This chapter looks to what still needs to be achieved: the process of identifying gaps in provision leads to a series of 26 recommendations about how to improve support in order to improve the quality of life of people with autism. The recommendations honour the vision and values which underpin the autism strategy and have the wellbeing of people with autism as central and fundamental. This chapter also takes account of responses to the 'Towards a Strategy'<sup>11</sup> consultation.

The recommendations lead to six aims and linked action. For successful implementation, it is essential that there is strategic leadership, an intention to achieve best value for services, collaboration and involvement in decision-making, cross-agency working through stronger networks, high quality diagnosis, intervention and support ensuring improved quality of life and leading to wider opportunities including employment.

Our long-term vision requires societal change and so must be shared and advanced for true equality of opportunity to become a reality for everyone, including carers, so that they are not toiling alone with what can be very testing circumstances. Partnership working between central and local government and engagement with the independent sector will be pivotal to success. The Concordat has heralded a renewed recognition of the importance of joint working to maximise the benefits for individuals. This approach is also central to *The same as you?*<sup>12</sup> and *Getting It Right for Every Child*.<sup>13</sup>

The work undertaken to date has led to important guidance, creative models of practice and substantial improvements in the quality of life for many people on the spectrum. What is needed now is to ensure that what works well in some localities is applied across Scotland and brings with it consistency, without compromising local flexibility and accountability.

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<sup>11</sup> <http://www.scotland.gov.uk/Publications/2010/09/07141141/0>

<sup>12</sup> <http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

<sup>13</sup> <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

## **The Scottish National Performance Framework**

As the National Performance Framework<sup>14</sup> makes clear, the purpose of Government is to create a more successful country with opportunities for all to flourish. Its high level emphasis on participation, cohesion and sustainability will resonate with those on the spectrum and their families as critical aspects of service design and delivery. The aspirations of the National Performance Framework are translated into national outcomes in which public services are of high quality, continually improving, efficient and responsive to local people's needs. There is recognition, too, of the importance of tackling significant health inequalities and of giving children the best start in life as well as getting to a point where everyone is able to live a longer, healthier, life. The outcomes promote a society where we are encouraged to be lifelong learners and to accept that we have a contribution to make and responsibility for our own behaviours and those of others.

These elements form the basis for each of the annual Single Outcome Agreements (SOA) that each local authority reaches with central government. SOAs ensure that local outcomes are included to take account of local variations and priorities.

### **Autism lifelong: gauging the need for generic and specialist services**

The needs of people on the autism spectrum are lifelong. It is very important that services recognise this and work together to make sure that moving from one stage of a person's life to another is planned for and managed as smoothly as possible, that transitions are managed better and indeed minimised. It is common for people with ASD to have a range of conditions. These may include, but are not limited to, learning disability and mental health<sup>15</sup> issues. Such individuals often have complex needs that have a direct impact on their health and wellbeing as well as their overall quality of life. It is essential therefore that the services that are commissioned and developed are both generic and specialist where needed, across the lifespan.

### **Autism Lifelong: the early years**

The Scottish Government and its partners in local government and the NHS are giving high priority to redesigning services around the principles of prevention, early identification of problems and early intervention by service providers who will work together to meet the needs of the individual child - i.e. the principles which underpin Getting It Right for Every Child. These principles are particularly evident in the Early Years Framework which reflects robust international evidence that a child's early years have a very significant influence on a child's future health, wellbeing, social

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<sup>14</sup><http://www.scotland.gov.uk/Publications/2007/11/13092240/9>

(awaiting the revised publication)

<sup>15</sup> Mental health Strategy for Scotland 20011-15 – a Consultation September 2011

<http://www.scotland.gov.uk/Publications/2011/09/01163037/0>

development, educational attainment and employability. Early identification of problems and early intervention can not only help turn around the life of a child, but there is evidence that this can lead to significant financial savings to service providers later in a child's life. The Early Years Framework and the associated social policy frameworks aimed at addressing poverty and health inequalities are designed to help break Scotland's historic and inter-generational cycles of poverty, poor health, poor educational outcomes and unemployment.

Following a review of screening, surveillance and health promotion activity by the Royal College of Paediatrics and Child Health, the then Scottish Executive issued guidance on the key recommendations contained in that review in 2005. *Health for All Children 4: Guidance on Implementation in Scotland* (commonly known as Hall 4) contained a core programme of contacts which every child and young person should receive. Hall 4 introduced a tiered programme of support and intervention, ensuring that children and young people receive the level of care that they require, according to assessed need. A Hall 4 Implementation Network was established to assist with implementation and, through working with this group, concerns regarding implementation of certain aspect of Hall 4 were identified as requiring further clarification or guidance. These issues were discussed and proposals for the future were consulted on in Summer 2010.

Following that consultation, the Scottish Government issued *A New Look at Hall 4 – the Early Years – Good Health for Every Child* guidance in January 2011. It sets out the way forward for the successful delivery of Hall 4 in the early years. It supplements the 2005 guidance – *Health for All Children 4: Guidance on Implementation in Scotland* – and addresses key issues identified as requiring further clarification. The guidance is aimed at front-line practitioners involved in the delivery of health services to children and their families as well as managers of these services. Whilst aimed at the NHS, it recognises the need for multi-agency and multi-disciplinary working in order to deliver the best quality of care and support for children and their families in the vital early years.

Its recommendations include the introduction of a 24-30 month review to pick up a range of development issues including communication and language skills, vision, hearing and oral health; parental concerns and issues; family relationships as well as being a key point of delivery for health promotion messages, e.g. healthy eating, stimulation and play, behaviour management and physical activity. We are in the process of setting up a short-life Working Group to agree the core issues which should be addressed and recorded at the 24-30 month review. The Group is expected to produce a report in the Spring 2012.

In January 2010, following a period of consultation, the Scottish Government issued guidance on the use of the new, national Personal Child Health Record (the Red Book). Prior to this, each NHS Board used their own local version of the Red Book which limited its usefulness when the child was either referred for specialist services into one of the main children's hospitals or transferred to another NHS Board area. The new Red Book contains a checklist for parents for 'Development Firsts' which acts as a guide to parents on when their child should be undertaking certain activities. These pages should be used as a guide for parents who are encouraged to

use the Red Book throughout the early years. Parents who have concerns about their child's development should speak to the relevant health professional.

Some children will have been identified as likely to require additional support before they start nursery school. In these circumstances education authorities should seek and take account of relevant advice and information from appropriate agencies and individuals at least six months before the child is expected to start nursery. This advice and information will help the education authority to establish the child's additional support needs and to determine the provision and adequacy of additional support required. A similar process must be undertaken before a child with additional support needs transfers from pre-school provision to primary school and from primary school to secondary school. However, the timescale for the planning of a transition is longer and the duty to seek and take account of relevant information and advice from appropriate agencies or persons should be completed no later than 12 months before the transition.

### **Autism Lifelong: the school years**

All children and young people will experience transitions as they move through the various stages of schooling, and each transition should be understood as a process rather than an event. This includes entry to pre-school provision; transfer to primary school and through the different stages of primary and secondary school and, in particular, to post-school provision. Some children and young people may also experience changes in their school education at other times as a result of a transfer to another school or a break in their education. Equally many day-to-day transitions occur and may offer both challenges and opportunities. It is important that arrangements are in place to ensure that any changes make sense to the person concerned and are as smooth as possible.

This is particularly important when changes involve a child or young person with additional support needs and the education authority and other agencies should take account of the way in which these changes affect the provision of additional support. Early and timely planning is required to ensure continuity and progression and the responsibilities on education authorities and other partners are set out in statute. Transition planning should be co-ordinated by one person and where there is multi-agency involvement then a lead professional should be involved.

The Supporting Children's Learning Code of Practice sets out detailed guidance on planning for changes specifying the duties on education authorities and the time frame within which these duties should be carried out.

### **Autism Lifelong: the transition to adult life**

The transition to post-school life can be daunting and therefore legislation places specific duties on education authorities to help prospective school leavers with additional support needs to make the transition from school to post-school life successfully. These transition arrangements should be clear so that the leaver and all those involved know exactly what is happening, when it is happening and who is involved. The effectiveness of this process should be monitored and reviewed. Under

the Education (Additional Support for Learning) (Scotland) Act 2004 (as amended), the remit of the Additional Support Needs Tribunal for Scotland has been expanded, allowing it to consider references in relation to an alleged failure of an authority to comply with any of its duties in relation to post school transitions. School leaver destinations should be recorded and knowledge about the duration of the individual's time at the first and subsequent destination has the potential to inform transitions planning effectively and to sustain necessary support over time.

## **Autism Lifelong: the adult years**

Given the lifelong nature of autism, it is essential that there is continuity of care and support at a level appropriate to each individual. For some, ongoing care needs are comprehensive. For others, a thin thread of contact and support is sufficient to sustain wellbeing and ensure inclusion. Access to appropriate assessment of needs is therefore essential throughout life. This will go some way to ensuring access to appropriate and consistent levels of support across the lifespan, including into older age.

## **Assessment of need**

A care needs assessment is an assessment carried out with the user and care professionals to find out what outcomes are important to the individual, their care needs and how they might best be met. It is variously known as a 'community care assessment', a 'joint needs assessment' or a 'single shared assessment'. Single shared assessment is the streamlining of the assessment process to enable the needs and outcomes for the individual to be identified and subsequent interventions and services put in place. Shared assessment ensures that at any one time a lead professional, rather than a number of different people, co-ordinates the assessment, ensures that agreed services are put in place and acts as a point of contact<sup>16</sup>.

Work has been underway since 2006 on developing an approach based on user and carer outcomes. The approach is called Talking Points – a personal outcomes approach<sup>17</sup> to assessment, planning and review. It aims to shift engagement with people who use services away from service-led approaches. This involves everyone working together to achieve the best possible effect on the individual's life. The philosophy of this approach is one that emphasises the strengths, capacity and resilience of individuals, builds upon natural support systems and includes consideration of wider community based resources.

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<sup>16</sup> <http://www.scotland.gov.uk/Topics/Government/local-government/SOA>

<sup>17</sup> <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/>

Following assessment for individuals with complex care needs the assessment, their care needs and regular reviews of their needs will be organised as part of a process called Care Management. This is:

- A process in which an individual's needs are assessed and evaluated, eligibility for service is determined, a care plan is prepared and implemented, services tailored to individuals needs are provided, and needs are monitored and re-assessed;
- focussed on people with complex, or frequently or rapidly changing needs; and
- undertaken by a range of professionally qualified staff in social work and health, with appropriate training, skills and experience.

Original guidance on care management was developed in 1991 and a further update was released in 2004<sup>18</sup> with the aim being to refocus care management on people with complex or changing needs and on extending the range of professionals undertaking care management.

## **Aims and recommendations**

The policy context that heralds the autism strategy gives a framework for implementation. However, policy processes continue to evolve and may require new responses over time. Each of the six aims addressed in the sections that follow take account of the policy context and indicate ways forward.

### **1) Strategic Leadership**

The Scottish Government will provide strategic leadership on improving the lives of people affected by autism. It will lead on creating a strategic vision for the development of services and support for people with autism, their families and carers.

#### **The ASD Reference Group**

The implementation of the autism strategy requires national leadership on a long term basis. An ASD Reference Group has been reconvened. This will ensure the promotion of good practice for local agencies working together and will highlight the advantages of sharing budgets to encourage the development of services that cross health/social care, educational and skills development boundaries. It is recommended that the ASD Reference Group is reconvened on a long-term basis to include COSLA membership to oversee developments and to progress change. It should produce an annual report to relevant Ministers and the political leadership of COSLA (**Recommendation 1**).

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<sup>18</sup> <http://www.scotland.gov.uk/Publications/2005/02/20728/53035>

## Autism guidance

Published Scottish Government guidance is available for wider dissemination<sup>19</sup>. It is recommended that the ASD Reference Group works collaboratively with, and offers support to COSLA, NHS, criminal justice and other relevant public bodies to effect the implementation of the various autism guidelines. (**Recommendation 2**).

## Increasing public and professional awareness of autism

The advantages of having local lead officers in gaining increased public awareness of autism and in developing and sustaining local supports are considerable. It is recommended that the ASD Reference Group explores the benefits of ASD lead officers with the Association of Directors of Social Work and with COSLA to establish how rollout across Scotland might best be achieved (**Recommendation 3**).

## The role of scrutiny bodies

On 1 April 2011 the work of the Care Commission passed to a new body, Social Care and Social Work Improvement Scotland (SCSWIS). Regulation of independent healthcare has passed to Healthcare Improvement Scotland (HIS).

The main changes are:

- to require SCSWIS and HIS to develop inspection plans in line with best regulatory practice. This will allow the new bodies to develop risk based and proportionate plans for inspections and move away from cyclical inspections based on minimum frequencies set out in legislation;
- new provision to allow emergency cancellation of registration and emergency condition notices which can take effect immediately;
- new duties to require local authorities and health boards to take account of SCSWIS and HIS reports when commissioning or contracting for services.

New provisions have been inserted in Part 6 in relation to complaints handling by the Ombudsman in the Scottish Public Services Ombudsman Act 2002. The aim of these amendments is to bring about a simpler, more consistent and more effective approach to dealing with complaints about public services. The Ombudsman must publish a statement of principles concerning relevant complaints-handling procedures of bodies and persons that are listed in Schedule 2 to the Scottish Public Services Ombudsman Act 2002. The Ombudsman will have powers to publish model complaints-handling procedures and to specify who must comply with them.

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<sup>19</sup> For example: A National Training Framework for Autistic Spectrum Disorders (2004); A Literature Review for Autism (2006)

<http://www.hmie.gov.uk/documents/publication/HMIE%20Literature%20Review.pdf>

The Developing Social Interaction and Understanding in ASD Pack (2007); Commissioning Guidance (2008) <http://scotland.gov.uk/Publications/2008/03/27085247/0>

The Scottish Autism Services Network <http://www.scottishautismnetwork.org.uk/>

Policy into Practice Accreditation Report (2009), and The Scottish Autism Toolbox (2009)

<http://www.scotland.gov.uk/Resource/Doc/266126/0079626.pdf>

All listed authorities including, SCSWIS and HIS will be expected to comply with these principles when dealing with complaints about how they have exercised their own functions. SCSWIS will be expected to take them into account when dealing with complaints from service users, someone acting on their behalf or any concerned member of the public – concerning the provision of a care service to the service user, the provision of a care service generally; or about SCSWIS functions. SCSWIS is not responsible for handling complaints out with its area of regulatory responsibility, though it will refer complainants to the most appropriate body.

HIS will be expected to comply with these procedures when dealing with complaints about independent healthcare. The 2010 Act also places duties on SCSWIS, HIS and other regulatory bodies to cooperate with one another when required.

In addition to the regulatory implications of this Act, other regulatory bodies relevant to the general wellbeing of people with ASD might be expected to make a valuable contribution to the work of the Reference Group. These would include bodies that provide scrutiny of educational opportunities and criminal justice system treatment of people with ASD.

It is recommended that the ASD Reference Group meets with representatives of both SCSWIS and HIS, as well as other relevant regulatory bodies, such as those in education and criminal justice, with a view to learning about current developments and ensure that the needs and wishes of those on the spectrum are taken into account in future programmes (**Recommendation 4**).

## **2) Best value for services**

Achieving best value for services for people affected by autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve.

### **The economic impact of autism**

People with ASD have a right to the information, equipment, assistance and support services necessary to live a fully productive life with dignity and independence of choice, and to feel included in society. Understanding of autism should be improved across all public services to ensure that the pace of progress meets increasing public expectations. This work will be particularly challenging in a climate that will be about doing a lot more with a lot less. Existing work on the economic costs of autism (Knapp<sup>20</sup>) should be applied to the Scottish context to inform strategy and planning leading to positive impacts both for individuals and for the economy as a whole (**Recommendation 5**).

### **Planning and identification of need**

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<sup>20</sup> Knapp, Martin and Romeo, Renée and Beecham, Jennifer (2009) Economic cost of autism in the UK. *Autism*, 13 (3). pp. 317-336. The National Autistic Society

The Concordat emphasises the importance of outcomes for people whilst stressing that statistical returns need to have a clear purpose that assists with outcome delivery. This means that SOAs are now the principal tool for laying out and evaluating progress at local level. So devising another set of Partnership in Practice agreements is not feasible. Importantly, influencing SOA content can be achieved through user and carer capacity-building training.

Identification of those on the spectrum is another matter. Whilst the Scottish Consortium for Learning Disability (SCLD) is at an early stage in collecting information on those with ASD, it is working directly with local authorities to build on the quality of the information available.

It is two years since the ASD Commissioning Guidance for health and social care commissioners was published. This tool will be further highlighted with local authorities and promoted as a useful resource to demonstrate good community care outcomes. It is therefore recommended that the effectiveness of implementation of the Commissioning Guidance is reviewed by the ASD Reference Group by facilitating an audit of current service commissioning (**Recommendation 6**).

Research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision is needed. Relevant findings will inform the revision of guidance for commissioners of services for people with autism (**Recommendation 7**).

### **Key determinants of service provision**

The ASD Reference Group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan (**Recommendation 8**). This recognition of autism as a lifelong condition allows policy and planning to be aware of a life stages approach, of the need for a range of services and of the importance of the holistic view of autism.

### **Good practice models - Learning from pilot projects**

It is evident that the one stop shops that were developed for adults have been both successful and challenged in meeting demands. Nevertheless, they continue to function and are highly valued by users, carers and professionals alike. In some areas of Scotland there is evidence that others have tried to adapt this model of working for themselves but it is also clear that the approach is not embedded across Scotland. There is a need to disseminate outcomes of funded pilot projects more widely and to engage with local initiatives that signal good practice models that would be of wider benefit (e.g. The Pines Centre for Children and Families Affected by ASD, Inverness - A partnership between Highland Council, NHS Highland, National Autistic Society Scotland and Children in Highland Information Point Plus).

It is recommended that the ASD Reference Group hosts an event to evaluate and recognise good practice in Scotland to disseminate models of practice, to evaluate

success, recognise benefits and limitations and agree how to develop good models across the country in a way that is cost-effective (**Recommendation 9**).

### **Multi-agency pathways to interventions**

The interventions that we have in mind are largely health based. Post-diagnostic support is hugely important and services need to address provision of early and appropriate interventions across the whole age range. Agencies need to continue to work together alongside the voluntary sector to develop flexible and timely interventions.

As soon as a child is diagnosed a range of interventions should be considered in relation to each child's specific needs. Therapeutic interventions may include work on improving communication, learning to be more flexible in accepting change and tolerating social approaches, anger and/or anxiety management, help with eating, sleeping, bathing and toileting as well as coping with sensory issues. These interventions are best delivered by ASD multi-disciplinary intervention teams. Parents should be considered as co-therapists.

Some children with Asperger's Syndrome cope well in a structured school environment and are doing well academically but their difficulties are strongly manifested in social situations outside the classroom, at home and in the community. In cases like this parents are often left with little support. Services need to recognise this group and to be able to provide these parents and young people with appropriate interventions and support.

For these issues to be fully explored it is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions. (**Recommendation 10**).

### **The autism spectrum**

It is also essential that more able individuals with ASD do not go unrecognised or are misdiagnosed and that there is sufficient expertise for working with them. Learning disability services may not be appropriate providers of diagnosis or ongoing support for these individuals. Similarly adult mental health services have not traditionally worked with them either. However, there is increasing awareness of the need to be better informed about these disorders and develop better approaches to those adults on the spectrum who do not have a learning disability.

It is therefore recommended that consideration is given to the specific supports needed for the more able individuals with ASD (**Recommendation 11**).

## **The evidence base**

It is essential that the findings from quality research are disseminated and put into practice. There is also a need to address those issues of concern for individuals and families affected by autism. The existing models of support need to be evaluated further in order to identify interventions which are effective and lead to good outcomes for people on the autism spectrum. Parents and carers, for example, would like further research on sleep problems experienced by those with autism as well as on how to manage the anxiety with which many individuals struggle.

More specifically, a clear conduit for feeding in research information that updates, endorses and improves clinical practice is essential. A recent helpful example is the Parent-mediated communication-focused treatment study (PACT<sup>21</sup>). This concluded that, whilst they were unable to recommend the addition of the PACT intervention to treatment as usual for the reduction of autism symptoms, a clear benefit was noted for parent-child social communication. A simple means of communicating about ongoing work could be a web page listing to heighten the profile of the numerous projects that are going on across Scotland.

It is recommended that an evaluation of existing research is commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and to the commissioning some pieces that would be of particular practical value to people with ASD and their carers (**Recommendation 12**).

## **3) Collaboration and involvement in decision making**

People with autism, and their families and carers, should be involved at all levels of decision-making.

### **Local planning processes**

Working through SOAs is still evolving. People who use services and those who advocate on their behalf need to familiarise themselves with the SOA for their area in order to be able to influence its future content, to participate in local planning processes, and to ensure that the specific needs of those on the autism spectrum are identified, addressed and continuously reviewed (**Recommendation 13**).

### **Self-directed support**

Beyond diagnosis, individuals are also entitled to have their need for community care services assessed under the National Health Service and Community Care Act 1990, a right which is supplemented by the Disability Discrimination Act 2005 which requires that services need to make reasonable adjustments for disabled adults. This includes people with ASD. The Scottish Government has launched the self-directed support strategy which is a key component of the drive to personalise and tailor

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<sup>21</sup> [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)60587-9/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)60587-9/abstract).

support flexibly so that individuals can exercise more choice and control in their lives. All of these policies are directed at ensuring that individuals have far more say in what supports they choose to use.

Self-directed support (SDS), including direct payments, provides individual budgets for people to buy their own support packages to meet their assessed personal, educational, social and healthcare needs, including those of people on the autism spectrum. Practice varies across local authorities in the extent to which health resources have been integrated into SDS packages.

The SDS strategy provides a framework for significant change in the way support is provided, and within that gives consideration to the ways self-directed support can most appropriately be used to meet the needs of particular groups.

The Scottish Government has also consulted on proposals to bring forward a Bill which will provide the legislative framework for more people to direct their own support. This will consolidate and modernise existing laws and create a positive framework for self-directed support. There will also be provision to widen eligibility for direct payments to a number of user groups and situations including carers.

It is recommended that the SDS Strategy Implementation Group and the SDS Bill Reference Group ensure representation from the autism community so that their interests are taken into account as further developments take place (**Recommendation 14**).

#### **4) Cross agency working through stronger networks**

The capacity for cross-agency working will be developed through stronger networks, best practice and training. This will help deliver cost-effective supports and interventions.

##### **The need for information - Scottish Autism Services Network (SASN)**

Individuals and families need information at the point of diagnosis and beyond. They have to be able to make sense of a diagnosis of autism to move forward and professionals need to have sound information and advice to offer on all aspects of daily living. This is why *The same as you?* review contains a specific recommendation to set up a national network on ASD which became the Scottish Autism Services Network (SASN), hosted by the National Centre for Autism Studies at the University of Strathclyde. They, in turn, worked closely with the National Autistic Society to form links to their Autism Services Directory, which is a comprehensive directory of the services available in a local area.

SASN is widely recognised as a hub of direction to services for people affected by ASD and as a means of providing information, sharing advice and emotional support. It was able to establish a number of networks across Scotland on a cross-cutting basis involving disciplines in education, health, social work and the third sector. It is seen to be unique and at the leading edge of inter-professional development in this

field as there is no known similar autism specific network within Europe. However, it has struggled to be self-financing since the original funding ended and is maintained through volunteers and a skeleton staff.

Highlighting and disseminating good practice is essential for sustained and meaningful progress on an equitable basis across Scotland. We need to have an understanding of what kinds of projects and support meet the particular needs of this client group and have proven to give good outcomes. It is important to know what has been demonstrated as working, as other agencies can benefit from the experience of those who set up and work on these projects. This kind of information should be disseminated throughout the rest of the country for all agencies to learn from the experience. Sharing the learning gained from a variety of initiatives can also help local agencies to make decisions about the good use of scarce resources.

Key government policies and publications over recent years aim to improve services and support people with disability but apply also to people who are on the autism spectrum, whether or not they have a disability. Local authorities and health boards would benefit from having a central resource which showed how legislation, guidelines and statutory obligations fit together. This would give greater clarity and would encourage agencies to work better together to meet their statutory obligations. It would include reminding them of their obligations under the equality and human rights legislation to ensure equality of access to mainstream public services.

It is recommended that existing reports on the work of Scottish Autism Services Network are formally evaluated with a view to assessing its long-term viability and effectiveness (**Recommendation 15**).

### **The SIGN Guideline - A matched evidence base for adulthood**

The SIGN Guideline No 98<sup>22</sup> produced in 2007 for children and young people up to the age of 18 summarised the evidence base on ASD, suggested audit targets and research ideas and described how to share information with families and carers. It has been internationally acclaimed as ground-breaking and has been developed as an e-module to be more accessible worldwide via the SIGN website at [www.sign.ac.uk](http://www.sign.ac.uk). This medical education innovation is due to go live by the end of 2011 and represents an important development in the dissemination of evidence-based information about ASD for both the public and professionals. It will be subject to review, possibly in 2011/12.

Diagnosis is not limited to childhood and it is recommended that the ASD Reference Group contributes to a review of the SIGN Guidelines and in doing so, considers where and how best this innovation might be replicated for adults and other relevant professions (**Recommendation 16**).

Scotland is fortunate in having such a wide range of educational and training resources available both at national and local level which meet a wealth of practical

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<sup>22</sup> <http://www.sign.ac.uk/guidelines/fulltext/98/index.html>

and academic needs from awareness-raising and capacity-building through to the completion of Masters and Doctorate degrees. However, no system can ever fully address what is required because there will always be new parents and professionals looking for information and advice and the knowledge that we have about ASD and its management will continue to develop and will affect training programme content. There is a need to review the literature on appropriate interventions for people on the autism spectrum in order to ensure that professionals are working on the most up to date information. There is also a need to collaborate with local service providers on how best to support front-line staff by providing appropriate ASD training. The work currently being done to review the classifications for diagnosis (DSM-V, ICD-11) will be significant and staff will need to be trained to understand the outcomes of these deliberations. If genetic and metabolic screening were to become common practice, improved training opportunities would be needed for broader and effective interdisciplinary working.

There are also other training initiatives that are ongoing from which those with ASD could benefit more by specific time being taken to assess their relevance and make the appropriate bridges to maximise those benefits. An example is that the National Implementation Group for the learning disability strategy *The same as you?* agreed to focus on promoting health improvement and tackling health inequalities for people with learning disabilities as its priority. The definition of learning disability for the purposes of *The same as you?* includes people with ASD, whether or not they also have a learning disability and the change programme relating to health improvement and health inequalities takes account of the health needs of this group. The strategic objectives of this change programme are to deliver better health and better care for people with learning disabilities and ASD. An essential element of the change programme is that health boards participate in a learning network to enable Boards to share good practice and experience.

An audit of existing training provision building on the earlier work of the National Training Framework for Autism should be undertaken: this will identify gaps in training and training standards. It is recommended that the Training Sub-Group of the main Reference Group is reconstituted and strengthened by the inclusion of an SCLD representative to undertake an audit of existing provision and to take evidence from grass roots trainers with a view to recognising strengths and gaps as well as identifying the means by which to further improve what is on offer (**Recommendation 17**).

### **Good Practice Transitions Guidance**

It is recommended that good practice transition guidance is developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions (**Recommendation 18**) so ensuring more continuity of support and greater well being.

## 5) High quality diagnosis, intervention and support

A good quality diagnosis is the key foundation for both children and adults that will lead them to understanding of their condition, the recognition of individual strengths and challenges, enabling the best support to be made available to them.

### Approaches to diagnosis and management

It is recommended that a request is made to NHS Quality Improvement Scotland (QIS), as the body into which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of ASD in adults (**Recommendation 19**).

### Continuing professional development

Further it is recommended that approaches are made to the Royal College of Physicians and Surgeons to establish the feasibility and desirability of disseminating ASD materials in e-CPD formats (**Recommendation 20**).

### National waiting lists for diagnosis

The pilot that examined whether waiting lists could be reduced by local teams being trained by a specialist ASD assessment team to undertake diagnoses was very successful and has survived in some parts of Scotland. It has been referenced by the new NICE guideline<sup>23</sup> on ASD in children and young people as a useful approach. However, as a model, this approach has not been taken up by other areas in the manner in which it was envisaged and in many areas waiting lists are substantial.

It is therefore recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays (**Recommendation 21**) and that the ASD Reference Group considers and responds to these findings.

### Diagnostic training needs

Initiatives to address waiting lists for assessment should include consideration of further training on the use of ADOS, ADI-R, 3di and DISCO to meet increased levels of demand (**Recommendation 22**).

### Age related differences in diagnostic approaches

It is recommended that the ASD Reference Group explore the ways diagnostic processes for adults and children are different and how this should inform practice (**Recommendation 23**).

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<sup>23</sup> <http://www.nice.org.uk/CG128>

## **Diagnostic directory**

It is recommended that the directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland is reviewed, updated and re-distributed (**Recommendation 24**).

## **Standards and scrutiny**

Although the quality diagnostic standard has been widely distributed across the country what is less well known is the extent to which it is being used and the value that is attached to it by the multi-disciplinary teams that provide the service. It is recommended that a review is conducted with a view to updating and redistributing the quality diagnostic standard if it is found to continue to be of benefit (**Recommendation 25**).

## **6) Wider opportunities**

Access to a range of leisure, educational, health, housing and work opportunities are important throughout life and have the potential to result in improved wellbeing. There are many people with autism who would like to work but who face significant barriers in getting and keeping a job. Support will be offered through training, creating opportunities and improving access to the workplace.

### **Developing employment opportunities**

The Scottish Government is committed to removing barriers which stand in the way of effective transitions into employment. It has developed, together with COSLA, a Supported Employment Framework for Scotland. Its aim is to provide the mechanisms necessary to support a disabled person's move to paid employment in the open labour market in a systematic and effective way. At its heart is the desire to see a more consistent, person-centred approach to supporting those who want to work. The Framework has been launched and will be further promoted amongst Councils.

To ensure that the needs of people on the autism spectrum are taken account of, there is an ASD representative on the Employment working group which focuses on employment for people with learning disability and people with ASD. There is also a very active SASN Employability Network.

The Employability team, who assisted the development of the Framework, has funded a new national project at SCLD to consider the job opportunities that are available to people with learning disabilities and those with ASD. They will highlight the challenges facing people looking for jobs and identify how councils, health boards and private companies can create employment opportunities. SCLD and SASN have collaborated on a series of Employability events hosted by local authorities in several Scottish cities.

It is recommended that the supported employment framework for Scotland is evaluated in terms of its impact on employment and employability for people with autism (**Recommendation 26**).

## **Summary**

The strategic context means that by their nature these recommendations are far-reaching: their intention is to drive change to ensure shifts in knowledge and understanding about autism that will result in the best possible services and in every individual with autism being met with respect, fairness, acceptance and positive aspirations that ensure meaningful and satisfying lives.

As work progresses against the two, five and ten year goals, recommendations will have an action plan, a timescale, and measures of success that take account of where we are now in order to ensure that collectively we are where we want to be at the end of the process.



# Annex 1

## Related Government policy

### Annex 1: Related Government policy

The purpose of this Annex is to set out the details of what the Scottish Government and its partners delivered in response to the findings of the PHIS<sup>24</sup> ASD Needs Assessment Report under 5 main themes. It also provides an account of other policies from which individuals with ASD may be able to benefit. These include both national and local initiatives.

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<sup>24</sup><http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/Resources/PHIS>



## **Public Health Institute of Scotland Needs Assessment Report on services for people with ASD**

PHIS was commissioned by Scottish Ministers to carry out a needs assessment of services for people with autism spectrum disorders (ASD) in Scotland. The aim of the PHIS ASD Needs Assessment Report was to provide information for service commissioners on the best available knowledge about autism spectrum disorders and current service provision in Scotland and guidance on how these services might better meet the needs of both children and adults with autistic spectrum disorders in the future. The report published in December 2001 described a patchwork of services and made 32 recommendations that set out what ideal services should look like.

Scottish Ministers accepted that a specific programme of work was required which led to the formation of the ASD Reference Group which grouped priorities under 5 categories for action of improving diagnosis and assessment, matching resources to need, standards and monitoring, staff training and education and research.

### **Theme 1: Diagnosis, assessment and interventions**

#### **A SIGN Guideline**

A major recommendation of the PHIS Report was that the Scottish Intercollegiate Guideline Network (SIGN) should develop evidence based clinical practice guidelines on ASD for the National Health Service (NHS) in Scotland. These are derived from a systematic review of the scientific literature and are designed to accelerate the translation of new knowledge into action to reduce variations in practice, and improve patient-important outcomes.

An evidence-based guideline for children and young people with ASD was developed and published in 2007 (the SIGN guideline on children and young people with autism spectrum disorders (ASD) (SIGN 98)).<sup>25</sup> SIGN 98 has been well received nationally and internationally and indications are beginning to emerge that it is influencing clinical practice both as regards assessment and clinical interventions. A formal impact assessment of SIGN 98 is expected.

The guideline considered the evidence base in the world literature from 1996-2006 with regard to screening, assessment and clinical interventions. SIGN 98 was published in June 2007 and took 3 years to complete. In its remit and outcome, the guideline represented the most comprehensive summary of the evidence base on ASD to date. Important targets for audit and research were incorporated, as well as recommendations for information to be shared with families and guidance for ASD assessment rigour in future studies. The guideline also included versions for parents/carers and young people (the product of a young persons' focus group during guideline development).

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<sup>25</sup> <http://www.sign.ac.uk/guidelines/fulltext/98/index.html>

The evidence base for screening, assessment and clinical interventions in the 0-18 age group has been said to have extensively benefitted parents, families and clinicians over subsequent years both in Scotland and beyond, although its impact has not yet been assessed objectively.

The National Institute for Clinical Excellence (NICE) is producing its own guideline for England and Wales but has specifically narrowed its remit as it regards the work of SIGN 98 as being optimal for the whole of the UK, especially in relation to clinical interventions. International attention has been focussed on SIGN's achievement with regard to guideline number 98. SIGN 98 has also been chosen as one of two SIGN guidelines (from over 100 that have been published so far) to be developed as an 'e-CPD' module, accessible internationally (to all professionals and non-professionals) via the SIGN website [www.sign.ac.uk](http://www.sign.ac.uk).

### **Improving diagnostic methods and waiting times**

It was evident that, whilst early diagnosis of ASD was of crucial importance, lengthy delays were common. A project team was therefore set up in 2004 to examine whether this issue could be reliably addressed by local teams trained by a specialist ASD assessment team.

Four local multi-agency ASD assessment teams in Argyll and Clyde were trained in diagnostic assessment. Their assessments of 38 children and young people using the Autism Diagnostic Observation Schedule-Generic (ADOS-G) were video-recorded and independently assessed by the specialist team. This resulted in a high level of correspondence between the diagnoses of the local teams and of the specialist team. The number of assessments carried out increased and there was a considerable reduction in waiting times.

This study demonstrated the potential feasibility of creating local, multi-agency ASD assessment teams, which will serve to reduce waiting times, improve clinical skills at a lower level of specialism and thereby improve the overall quality of ASD service.

Two of the four teams in the original study (Helensburgh and Cowal and Bute) have continued to function independently from the specialist team, meaning that ASD assessment waiting lists in their catchment areas have remained low. One team (Paisley) ceased to function straight after the study was completed due to inability of the differing agencies to organise funding and staffing. The fourth team (North Argyll) initially functioned well after the study but has recently encountered funding and staffing difficulties. The study<sup>26</sup> has been published by the international peer-reviewed journal 'Autism' as the work provides important insights about the feasibility of establishing community-based diagnostic teams for children referred for suspected

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<sup>26</sup> A comparison of a specialist autism spectrum disorder assessment team with local assessment teams. McClure, I; Mackay, T; Mamdani, H and McCaughey, R. Autism. Vol. 14 (6) 589-603;373369;1362-3613 (2010).

ASD. It has also been referenced by the NICE guideline<sup>27</sup> on ASD in children and young people as an example of innovative assessment practice.

### **A good practice example**

#### **The development of ASD diagnosis for adults in the South East and Tayside (SEAT) Learning Disabilities Managed Care Network Area - Lothian, Fife, Forth Valley and Borders.**

The Regional ASD Consultancy Service (RASDCS) is a Tertiary level multi disciplinary team with staff from each of the four Health Board Areas in South East Scotland and has been running since 2002. It is a "virtual" team with one full time member of staff and the others giving time in special interest sessions or by arrangement with their managers.

As of August 2011:

- 4 Consultant Psychiatrists
- 1 Staff Grade Psychiatrist
- 3 Consultant Clinical Psychologists
- 1 Consultant Speech & Lang Therapist
- 3 Specialist Nurses
- 1 Specialist Registrar
- 1 Administrator

The team receives referrals from the age of 18. Average age of referral is 38. RASDCS operates at Tertiary level; referrals are accepted from General Adult Psychiatry or Learning Disabilities Services. Direct referral or referral by GP is not possible. Referral may be for Assessment, Diagnosis or Advice. RASDCS can not take ongoing responsibility for care.

The team currently receives about 8-10 referrals per month. Referrals at this level take an average of 10 hours to assess, frequently with very considerable individual variation. A key aspect is the likelihood of an extensive time commitment required by staff.

These referrals are often very complex and may be for second or even third opinion. Several members of the team may see them to ascertain different perspectives. No one test is appropriate for all and each individual referral may be assessed using a different combination of tools. Autism Diagnostic Interview-Revised (ADI-R) is used where appropriate. Diagnostic Interview for Social and Communication Disorders (DISCO), Autism-Spectrum Quotient (AQ), Empathising Quotient (EQ), Systemising Quotient (SQ), Krug Asperger's Disorder Index (KADI), Social Communications Questionnaire (SCQ) and a range of neuropsychological assessments, language assessments etc may also be used. Psychiatrists carry out psychiatric interviews. Early developmental history is gathered by whatever means possible (interviews with parent if available, partner, family member, early medical records, school reports etc).

There is a clear Diagnostic Care Pathway document which is adhered to and audited regularly so there is a consistent method of addressing an inconsistent type of referral.

Evaluation forms are completed by the referrer and the clients themselves in order to maintain quality and improve it where necessary. Clinical Governance support is provided by CGST in Lothian. Recent analysis carried out by CGST found that 100% of referrers returning evaluation forms felt that the service met their expectations. Of the people referred to the Service 100% found it useful to have been referred to the team and 93% felt their expectations had been met.

<sup>27</sup> <http://www.nice.org.uk/guidance/index.jsp?action=download&o=55240>

Some team members are involved in ASD research projects and may recruit from clients on the database (subject to NHS Ethics Committee approval)

### **Other Diagnostic progress**

An ASD diagnostic care pathway for Community Learning Disability Teams (CLDT) has been piloted in Lothian and has been introduced across the 8 CLDTs in Lothian. This is also being introduced by Forth Valley and Borders CLDTs

The one day "Understanding and working with adults with Asperger's syndrome" courses continue to run at Number 6 (Asperger Centre in Edinburgh). These are co-facilitated by NHS and Autism Initiatives staff and are open to NHS and Council staff across Lothian.

The SEAT MCN Professional Development group have been running 8 week courses for non registered staff across the four Health Board areas. This includes a day on ASD. This is delivered by RASDCS team members. Additionally, a series of seminar days are being run for registered staff and this includes days on a variety of ASD related topics under the heading of "Good Autism Practice?"

### **Next Steps**

Maintenance of the Regional ASD Consultancy Service is always an issue. It would be helpful to have more committed and funded time from General Adult Psychiatry. It may be logical to join Adult Neurodevelopmental services, currently under consideration.

NHS Education Scotland (NES) also worked on improving ASD diagnostic capability across Scotland. Using evidence provided by SIGN 98 they supported professional training through:

- Partnership funding with the Autism Resource Centre, Glasgow enabling 98 Scottish diagnosticians to be trained over a 3 year period in the Diagnostic Interview for Social and Communication Disorders (DISCO);
- Training in the Developmental, Dimensional and Diagnostic Interview (3di) for 43 professionals involved in the assessment and diagnosis of children and young people with ASD;
- Ninety-seven delegates attending 3 full day regional seminars on promoting evidence-based practice;
- The commissioning of a scoping exercise on the Autism Diagnostic Observation Schedule (ADOS) which resulted in provisional agreement about the content of ADOS training including outline specifications for Scottish training materials. Grampian Health Board received funding to develop the recommendations of the scoping.

## **Addressing information needs**

To promote effective working and to improve efficiency a directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland was produced in 2006 with copies being distributed widely within Primary Care and across the country.

Alongside activities directed at professionals, there was recognition of the importance of parents having information about ASD following diagnosis. NES conducted a national consultation exercise and developed a booklet. This provides parents who receive a diagnosis of ASD for their child with easily accessible, appropriate and unbiased information. In 2006 copies of the booklet were distributed to all diagnostic teams and centres in Scotland. It can also be accessed at:

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

The Government funded the National Autistic Society in 2006 to develop a complementary information resource, Next Steps, which was distributed through educational settings when a child is believed to have ASD. The pack aims to:

- increase understanding, knowledge and awareness of autism spectrum disorder (ASD);
- ensure that parents, families and individuals with an ASD can access relevant information and services;
- provide information, advice and support to individuals with an ASD and their carers;
- help individuals with an ASD receive the support they need to fulfil their potential;
- provide information on local services that may be available to people with an ASD;
- improve general awareness of autism and provide advice to health, education and care professionals working in the field.

The Scottish Autism Services Clinical Network was another useful vehicle for sharing information. It fulfilled an important function and was well attended but its activity tapered off due to insufficient funds.

## **Theme 2: Matching resources to need**

### **Partnership in Practice Agreements**

Local agencies were asked to set out their plans for future services development in the 2004-07 and 2007-11 Partnership in Practice Agreements (PiPs). These agreements outlined a broad variety of service development proposals at local level, ranging from appointing a development worker to audit ASD services, to developing specialist care pathways for people with ASD. Some concentrated on developing a short breaks strategy whilst others converted areas within existing day services to make them autism-friendly. In addition, service users were active in delivering training.

## ASD Database

A related activity to the national audit was the setting up of a database of people with ASD - again to assist with planning for the future. The Scottish Consortium for Learning Disability (SCLD) manages the eSay project which collects *The same as you?* statistics for people with a learning disability and those with ASD. The annual statistics were published in 2009 for the first time by the Consortium. This data is now being collected from local authorities on an individual record basis instead of aggregate tables which will improve data quality and allow more flexible analysis in the future.

## Commissioning guidance

Policy and practice guidance for commissioners of health and social care services for people on the autism spectrum<sup>28</sup> was published in 2008 which sets out existing models of good practice to inform service developments in local areas. It is clear that this guidance is appreciated and used at local level to assist them in the planning and commissioning of services.

### The Renfrewshire experience

The local authorities are currently in the process of developing an Adult with ASD Strategic Action Plan. The overarching vision for the strategy is to ensure that appropriate services for adults with ASD are developed across Renfrewshire which are inclusive in ways that are important to them and enables people to make choices about their lives and lifestyles. In developing the plan they have taken account of existing policies, strategies and guidance including the Commissioning Services guidance. Progress to date includes:

- An ASD Coordinator post within the Renfrewshire Learning Disabilities Services (RLDS) management structure to take forward the aims of the strategic action plan including monitoring, reviewing and developing ASD services for adults;
- RLDS ASD Diagnostic Service has recently been created in response to an identified need to improve the pathway and waiting times for ASD diagnosis and assessment; the service offers a multi-disciplinary approach to assessment and diagnosis and is provided by clinicians highly skilled and trained in ASD diagnosis; this service has significantly reduced referral waiting times.
- Flexi-Care offering a flexible community based service to children and adults with learning disabilities or ASD; the project recognises the need to maximise individuals opportunities for social interaction and community involvement and offers a wide range of social and leisure opportunities including children's clubs, social groups and befriending; the project has developed strong links with the local community by recruiting and training local people as volunteers and sessional workers to provide personalised supports to individual clients;
- ASD Clinical Coordinator; a new autism specialist post has been created following the roll-out of the Glasgow Resource Centre to cover NHS Greater Glasgow and Clyde area; the post will be shared between Renfrewshire and Inverclyde and will involve assessment, diagnosis and post diagnostic support.

<sup>28</sup> <http://scotland.gov.uk/Publications/2008/03/27085247/0>

### **The Fife experience**

In consultation with local stakeholders, their ASD Co-ordinator has drawn up an ASD Action Plan for 2010 – 2012. Examples of key outcomes from this plan to include:

- People with ASD have support to communicate in the way most appropriate to them;
- People with ASD have access to trained and experienced advocacy support;
- People with ASD participate in consultations about the development of autism services;
- A multi-agency approach is provided to young people with ASD from school to adulthood;
- People with ASD are fully involved in the development of their own services using a person-centred planning approach;
- Services build on an individual's assets to develop communication, behaviour support, skills acquisition, skills maintenance and grown in the ability to function independently;
- Local plans, strategies and Single Outcome Agreement reflect outcomes for individuals and families affected by ASD;
- Service design incorporates a lifelong learning approach that seek to continue personal progress and achievement for each individual, not just containment;
- Individuals with ASD are encouraged and supported to maximise their potential and have purposeful lifestyles by learning life skills, to enable them to participate in further education and employment /occupational activities.

### **The South Ayrshire experience**

The Commissioning Guidance has influenced practice to ensure integration between primary care and specialist services and social care through engaging in active discussion with health partners about autism services in the local Learning Disability Lead Officers group.

As part of the review process within the team, a carer's assessment has been offered to carers of adults on the autism spectrum and the carer's views are taken into account within the review documentation used. Some carers have now employed personal assistants to support their child with ASD.

South Ayrshire has created a Social Worker post to work specifically with people on the autism spectrum. This has resulted in a clearer pathway for referral and has created more awareness of the gaps within the current services. Local service providers are now accessing autism specific training on a more regular basis and more information of autism services out with the local authority has been gathered.

### **Partnership in Practice: diagnosis in Fife**

Over the last fifteen years in Fife, three specialist NHS-led ASD assessment teams received the majority of ASD referrals for children.

Assessment and diagnoses took place in clinics and the assessment and diagnosis teams consisted of health professionals. Waiting lists had grown to over two years. The West Fife Autism Spectrum Pilot (WASP) was set up in 2007-8 to investigate the

feasibility of local, multi-agency teams of professionals working together to assess and identify children suspected of being on the ASD spectrum. A key focus of the process was to use information gathered in the child's school and community and coordinate the process through the child's school. The major aims of the pilot included:

- making diagnosis faster;
- making identification and diagnosis more accessible to parents and professionals;
- making diagnosis and identification more based in the child's learning context;
- developing pathways for joint planning between agencies for intervention;
- involving parents fully in the assessment process.

The pilot ran between October 2007 and June 2008. Twenty primary school pupils (with parental consent) were identified to participate. Schools which the pupils attended were asked to participate in the project and were requested to chair and coordinate meetings. There were 2 main meetings held for each child. The meetings all involved professionals together with the parents. The first meeting was used for introducing the project, agreeing the information-gathering process and the necessary tasks involved for each of the professionals. The second meeting was scheduled approximately 6-8 weeks later. By then professionals had carried out their assessments. The professionals brought their findings to the second meeting to share views and came to an agreed multi-agency position regarding the pupil. The multi-agency team of professionals could agree:

- diagnosis of ASD;
- no diagnosis of ASD;
- no consensus of diagnosis and refer to the NHS ASD team for further assessment.

Conclusions from the pilot were that:

- the feasibility of setting up multi-agency community based teams in schools to diagnose straightforward ASD cases and non ASD cases was confirmed;
- it was feasible to make decisions about when to refer children to the specialist ASD service; results indicated that referrals to FAST for school aged children could be reduced by 50% if this model was rolled out, with 75% of younger children and 25% of older children being given a definitive decision;
- a significant impact on waiting lists for ASD diagnosis could be made;
- professionals and parents involved were able to appreciate the benefits of this model of working in terms of: earlier diagnosis, a more natural assessment environment and improved links to support.

A group was set up to oversee the implementation of the ASD joint care pathway across Fife. A central data base was developed to monitor the service; audit outcomes and validation of the decision-making process. A guidance manual was compiled to provide:

- clear guidelines for all staff about the ASD joint care pathway process;

- a clear explanation for parents of the entire assessment / decision process ;
- exemplars of standardised documentation (e.g. meeting agendas, screening tools, observation schedules, history-taking forms etc).

A permanent senior administrator has been appointed. An official launch for all parties to raise awareness of the new development has taken place as well as follow up twilight sessions in each area to support the delivery of the new service, address issues raised at local level and take feedback. Finally, an evaluation framework has been developed to identify the impact and outcomes of the process on an ongoing basis.

## **Pilot Projects**

To test how best to match resource to need, the Scottish Government funded a number of pilot projects. These included developing services for young people at the transition from children's to adult services in Highland and creating a specialist day resource in Aberdeenshire offering support, advice and training to users, parents and staff so that individuals with ASD can feel part of their community. Projects were also supported to develop respite and short breaks, to increase the capacity of advocacy organisations to work with ASD and to create Social Employment Firms.

Particularly significant is the creation of one-stop shops which developed innovative adult services in Greater Glasgow (Autism Resource Centre) and in Lothian (Number 6).

The Autism Resource Centre (ARC) houses a range of clinical and non-clinical staff. It is a partnership between Glasgow City Council, Greater Glasgow and Clyde NHS, the National Autistic Society, the Scottish Society for Autism and Strathclyde Autistic Society, offering the following services:

- Information Base – advice and information in person, over the phone or through various media, via the information officer; library of current books, articles and service information; computer access to a range of online resources; operation of a duty system so that visitors have access to further specialist support and/or advice;
- Training – training to all individuals e.g. professionals, carers and clients; a wide range of training options are provided from one day autism awareness training to high level diagnostic training; training is also available on an outreach basis;
- Adult Autism Service – diagnosis and assessment (via community based clinics); individual & group interventions; support and linking to services; drop-in facility; user-led interest groups;
- Development Team – strategic planning for autism services; partnership working with mainstream services and care groups; ensuring standards of service delivery for all individuals with Autism Spectrum Disorders; helping Greater Glasgow and Clyde Health Board and Glasgow City Council ensure that they meet national standards through involvement in a range of Parliament/Executive-

led reference groups; ensuring consultation and participation for people with ASD.

To date the ARC has received over 1,200 referrals – primarily for diagnosis and assessment. An independent evaluation of the ARC conducted by the National Centre for Autism Studies included surveys of the experience of service users and service providers. The report states “Figures show that a very high percentage of service users who filled in this questionnaire felt they had been listened to and were involved in decisions about their support where applicable. Additionally, 87% of participants felt that their overall experience at the ARC was ‘very positive’ or ‘positive’.”

The ARC provides training to approximately 1,500 people per year at a range of levels to a wide range of professionals and carers. Evaluations show that 95% and above of people who attend this training find it be ‘relevant’ or ‘very relevant’ to their everyday practice.

In addition, the ARC works closely with Glasgow City Council’s Working Group on ASD – which is an elected member led multi-agency group aiming at addressing the needs of all people on the autism spectrum and their families. This group in turn has 3 sub-groups on Employability, Housing and Criminal Justice. In this respect the work of the ARC links very closely into Glasgow’s Single Outcome Agreement with the Scottish Government, particularly with the themes of Healthy, Working, Learning and Safe.

In Lothian, a one stop shop for adults with Asperger’s syndrome was initially funded from 2005-2008. Autism Initiatives was awarded the tender and is committed to its continuation beyond the grant funded period. The aim is to provide a venue for people with Asperger’s syndrome to access a range of services including social activities, specific advice, information and support. Outreach support is provided across the Lothians and there is a training programme for professionals. There is an extensive volunteer programme. There are specific groups for women, men with co-morbid mental health problems and/or offending behaviour and a social group for 16-19 year olds. This service was also externally evaluated.

In terms of benefits the outputs have been:

- *605 individuals have accessed the service since February 2005 on over 32,000 occasions;*
- *Over 20,000 phone enquiries;*
- *180+ volunteers have been involved, over 50 are still active;*
- *2,000+ have attended training;*
- *17,000+ attendances at various social groups*

Service users describe outcomes in the following ways:

- “There is calmness, acceptance, a welcoming feeling. You can come and know it’s alright; it’s OK to come here. Whatever is happening you can fit in, there is a structure but it’s not rigid.”

- “I didn't have enormous expectations, you get used to not having expectations, I try not to set my expectations too high but I am quite satisfied.”
- “Concerns have been absolutely listened to and taken into consideration. There has been no judgement; there is complete acceptance and help.”
- “The trust, care and unstinting support shown to my family has been fantastic - after many years of very sketchy support - finally an organisation who understands.”
- “My son started a college course - something we never thought possible. I cannot speak highly enough of the workers and management they always put my son's needs first, the difference their input has made to our lives is unbelievable.”
- 80% of service users felt positive or very positive about their overall experience;
- 100% of parents and carers feel that their family member has benefited from the service or support they received.

The benefits in terms of outcomes for local authorities and health boards are:

- Pre and post diagnostic support provided by No 6 is greatly valued by the local NHS diagnostic service;
- Training for staff from local authority and NHS and others including voluntary organisations enables more effective ways of working leading to more appropriate care provision;
- Access to extensive library and information resource for staff;
- Record of people being successfully supported into employment;
- Record of people being enabled to commence and remain in Further and Higher Education;
- Record of tenancies being maintained;
- Record of mental ill health being monitored and early referral made where necessary;
- Record of potential offending behaviour being noted and managed.

Crucially, the budget for the service is now made from statutory funding (4 Lothian local authorities and NHS Lothian), contributions from Autism Initiatives and significant levels of fundraising each year. They are also developing associated services for adults with Asperger's syndrome that generate income and can partly offset some of the Number 6 costs. They continue to develop a range of activities within limited resources and to assess which aspects of the service have the greatest impact on the development and maintenance of successful lifestyles.

### **Local Area Coordination and ASD Co-ordinator/ Lead Officer posts**

Local area co-ordination (LAC) was introduced to Scotland in 2000 following the national review of services to people with learning disabilities (*same as you?*) and is seen as a ground-breaking way to support individuals and families and to strengthen communities' capacity to be inclusive.

The LAC approach promotes the rights of people with support needs to live ordinary lives within their local communities and is focussed on developing a relationship with the individual, the family and communities. The aim is to increase or support inclusion by supporting people to develop their individual capacity and working with communities to develop their capacity for inclusion.

LACs engage with the most isolated people within our communities, in many cases people on the autism spectrum, who may not be accessing social care services. National Guidance issued in 2008 to local agencies to promote further development of local area co-ordination by showing how this role can be pivotal in delivering personalised services and self-directed support.<sup>29</sup> The Scottish Government has also funded a national development post to help support and further develop local area coordination across Scotland.

**Local Area Coordination Case Study**  
**'Our House' – a family's story:**

All of my children have a degree of autism and we wanted the Housing Association to fund an extension. I knew from the other professionals that the Housing Association would respond by suggesting we move. However, we love our house. We have spent a lot of time, effort and money adapting it to suit our needs. Moving was not a solution.

Our Occupational Therapist sent an assessment to the Housing Association, however it had never been acknowledged. The Local Area Coordinator put me in touch with an organisation that did feasibility studies. A study was completed with plans and there was a written report highlighting proposed alterations. The Local Area Co-ordinator dealt with all the contacts to arrange this study. I could not understand why nobody had told me about this organisation before.

When our Local Area Co-ordinator became involved I knew at last, I was not alone. "I am more convinced than ever that Local Area Co-ordination is the way forward to supporting families who struggle with the obstacles that everyday life throws at them."

From SCLD, Making Connections, 2006

As well as the LAC approach to service delivery, several ASD Co-ordinator posts funded by Scottish Government were created, for example, in Forth Valley, Borders and Fife to see if having a specialist lead officer would be able to deliver better outcomes for people at local level.

In Fife, it is estimated that some 600+ children and young people are on the autism spectrum, together with approximately 2,630 adults, many of whom remain undiagnosed. The question that is being asked is 'where are they?' with Fife being committed to working closely with this population to ensure that services are coordinated and meet need.

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<sup>29</sup> <http://www.scotland.gov.uk/Publications/2008/03/27092411/0>

Benefiting from Scottish Government funding for one year, and since funded by Fife Council and NHS Fife, the creation of an ASD Coordinator post in 2008, has helped. Working in partnership with, and influenced by, local support groups, Fife Action on Autism (FAOA) and PHAD (People with High-functioning Autistic Disorders) (Fife), has assisted in identifying key priorities by undertaking a process described as 'reflect, review, revise and initiate'.

With a clear focus on outcomes for this population and working in partnership with FAOA and PHAD (Fife), a work plan was initially developed by the Co-ordinator which, in turn, influenced content to an ASD Action Plan 2010 – 2012, addressing:

- Post-school transition and adult services;
- Diagnostic and post-diagnostic pathways for adults;
- Criminal Justice / Police;
- Equality and diversity;
- Data collation;
- ASD training and increased awareness;
- Dissemination of information on local and national developments;
- Low-level support and preventative options;
- Increase public awareness of ASD;

Whilst ASD is not explicitly mentioned within Fife's Single Outcome Agreement, the following themes have been identified as being pertinent to meeting local outcomes for those affected:

- Building a stronger, more flexible and diverse economy;
- Creating a well educated and skilled Fife;
- Improving health and wellbeing in Fife;
- Making Fife's communities safer.

Going some way to meeting these outcomes, the ASD Co-ordinator has supported a number of local initiatives, including:

- Fife Council Library Service: development of a Static Autism Resource.
- NHS Fife: development of the Autism Spectrum Community Assessment.
- Fife Council Social Work & NHS Fife: input into drafting local plans and strategies.
- Fife Constabulary: host to a criminal justice ASD development event.
- Development of a local ASD newsletter published 4 monthly.
- A number of events held and projects initiated to increase public awareness of ASD.
- Local college: development of a local employment taster scheme – to pilot 2010 / 11.
- Employment: assisted representatives of local Job Centre Plus in the development of ASD training material.

The post has demonstrated the need for co-ordination across services and will build upon, strengthen and capitalise on existing services.

Representatives of PHAD summarised the benefits as being that 'there is such relief that finally there is someone taking on board all the difficulties and challenges that our families, and people on the autism spectrum, face on a day-to-day basis. The benefits of us working together have created vast opportunities to share our knowledge and good practice with so many others who can make a difference. Creating links on a multidisciplinary level and forming strategic plans which will help to create a chain of continued and much needed valuable and guided support.'

## **Employment and Training**

A natural aspiration for many individuals with ASD is that they should be able to secure meaningful employment and be able to contribute to the economy of Scotland. Many people on the autism spectrum have the ability to do some form of work, but need personalised support to find work and ongoing support to maintain and progress in employment.

### **Employment Case Study**

Social Firms are a form of Social Enterprise and one possible employment route. Autism Initiatives has worked with several autism specific agencies in Scotland to facilitate the development of Social Firms. Establishing Social Firms encourages an inclusive and supportive approach to those who are seeking work. A Social Firm can be developed around the specific skills and interests of individuals and groups. The Social Firm project, initially for 2 years, was based around the post of a Social Firm Coordinator whose aim was to facilitate the development of Social Firms and has now moved on with the appointment by Autism Initiatives of an Enterprise Manager.

In April 2010 Autism Initiatives celebrated the opening of its first Social Firm - "the gallery on the corner". The gallery on the corner is a business which offers a variety of employment experiences in an inclusive arts business. The gallery and creative studios offer traineeships in retail and creative employment and can include attendance at college. A second Social Enterprise is now being developed at the Hermitage Golf course in Edinburgh.

The Framework for Supported Employment in Scotland (2010) outlined that this support needs to be personalised and it needs to be consistent. This is particularly critical for people who will have difficulty dealing with change as things will need to be progressed at the individual's pace. Such personalised support may need to be ongoing as, although confidence and self-esteem may improve through participation in the work place, this can be severely set back if things do go wrong.

It also benefits the employer, as well as wider society, by demonstrating positive social inclusion. The increased levels of income can help both individuals and families as long as proper professional welfare rights advice is available at all stages of the process, including when dealing with the various benefit agencies on an ongoing basis. This is a potential pitfall for people with difficulties in communication and who may have literacy/numeracy issues as well.

There is a need for specialist employment provision which should be developed as resources become available. Such provision would work to:

- Develop specialist knowledge of the condition so that appropriate support can be provided to secure a good job;
- Provide tailored 1:1 advice, support and guidance that puts the individual jobseeker at the centre and in control of the process;
- Provide disability awareness to employers, enabling them to value the qualities people with ASD bring to a job and understand the support required to make the job a success.

#### **Employment Case Study**

Intowork, an Edinburgh based voluntary organisation, introduced a specialist employment service for people on the autism spectrum over 10 years ago, recognising that traditional employment services focused on adults with learning disabilities did not meet the needs of those with autism or Asperger's syndrome. Intowork assists people with ASD to move into open paid employment and currently supports over 60 people with ASD in mainstream employment plus a further 45 in the pre-employment stage.

The Scottish Government is committed to providing more choices and chances for young people and support in moving into positive and sustained post-school destinations. 16+ Learning Choices will ensure that every young person has an effective post-16 transition. The focus will be on encouraging all young people to stay in learning past 16 as the best way of ensuring their long term employability and ensuring that they have the opportunity to reach their potential. The Government appointed a national transitions officer to work with local authorities and partners to support transition pathways for young people who are most at risk of missing out on education and training opportunities, including those with autism.

### **Theme 3: Standards and scrutiny**

#### **A quality standard for ASD diagnostic services**

It is undoubtedly vital that people with ASD and family carers have a clear indication of what can be expected from a diagnostic service. To aid this, the diagnosis sub-group of the ASD Reference Group published a quality standard for ASD diagnostic services which also provides a checklist for multi-disciplinary teams providing an ASD service. This has been widely disseminated and used across Scotland.

The quality standard makes it explicit that a quality service should:

- Take place within the context of a multi-disciplinary AND multi-agency service involving professionals with ASD training;

- Understand that diagnosis ought to be a process which supports the development and progress of an individual;
- 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;
- Recognise and acknowledge cultural differences of all individuals and families;
- Dedicate sufficient time for assessment in keeping with consensus timeframes;
- Give individuals of all ages access to a service appropriate to their needs in their locality;
- Make a diagnosis if appropriate regardless of whether there are statutory services available;
- Use internationally recognised diagnostic criteria and specify which criteria have been used;
- 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;
- Use information drawn from observation, standardised interview and clinical experience in a variety of contexts such as home, school, workplace and the community;
- 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;
- Produce a document to state diagnosis, which criteria and tools were used to assess, and describe any co-morbid conditions;
- Give clear sensitive verbal explanations of the syndrome and provide quality written information;
- Refer on for any medical or other assessment as appropriate or relevant genetic counselling;
- Offer a follow-up appointment, preferably face-to-face, for the individual to ask further questions;
- Offer clear explanations if a diagnosis of autism is not made (and any differential diagnosis) and offer second opinion as appropriate;
- Provide information about post-diagnostic services such as support groups.

## Scrutiny

Her Majesty's Inspectorate of Education (HMIE) conducted a specific inspection of educational provision for children and young people with ASD across Scotland.<sup>30</sup> This inspection followed an integrated assessment approach using a multi-agency (education, health and social care) team and included consideration of:

- how far pupils with ASD have access to a broad and relevant curriculum to ensure they are learning;

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<sup>30</sup> <http://www.hmie.gov.uk/documents/publication/epasd.html>

- 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.

The subsequent report highlighted current good practice, identified gaps in provision and made recommendations for the way forward for education. Inspectors found much good practice in relation to the work of education authorities and school and other professional practice that supported pupils with ASD. They suggested more attention needs to be paid to which approaches to learning and teaching actually work for this group of young people. Targets set out in individualised educational programmes needed to have appropriate breadth and level of challenge and that those with responsibility for delivering services to pupils with ASD should ensure consistency in the quality of services provided. They emphasised that teachers and support staff should be provided with high quality training to enable them to meet the needs of pupils with ASD to ensure that these pupils do not miss out on the educational opportunities they deserve.

Services for people with ASD are also included in joint inspections of learning disability services. A joint inspection of services in Ayrshire, bringing together Social Work Inspection Agency, NHS Quality Improvement Service (NHSQIS), the Care Commission, HMI Education and HMI Constabulary was carried out in 2006.<sup>31</sup> It recommended that the partnerships publicise their services so that people know what is available, particularly in relation to self-directed support and carer's assessments. Procedures and staff training to support adults should be amended and further improved. They were also encouraged to ensure all action plans enable and sustain independence to promote greater inclusion in the community.

HIS has conducted a programme of visits to NHS Boards from October 2004 onwards and has looked at services for children and adults with learning disabilities in Scotland during 2008-2009 to check how well health services are meeting people's needs. Their findings were published in the report 'Tackling Indifference' which has already been referred to. Its recommendations have been accepted by Government and ways of implementing these are under active consideration.

The then Social Work Inspection Agency inspected all 32 authorities. Within children's services the Agency noted that systems were not consistently well developed to ensure a smooth transition for young people into adult services. Similarly services for adults varied widely. Recently there has been some indication by a few authorities that this area of service is being reviewed.

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<sup>31</sup> [www.scotland.gov.uk/Resource/Doc/169182/0047132.pdf](http://www.scotland.gov.uk/Resource/Doc/169182/0047132.pdf)

## Theme 4: Staff education and training

An incidental development that coincided with the life of the ASD Reference Group was the publication of a National Training Framework for Autistic Spectrum Disorders (Mackay & Dunlop 2004, referred to here as the Framework).<sup>32</sup> This revealed gaps in the training of professionals involved in the education, health care and support of people on the autism spectrum. This was evident across all professions at all levels. The framework mapped the level of training required by professionals predicated on their role and the extent of their professional contact with people on the spectrum. The framework also addressed the need for parents and individuals on the spectrum to have access to training.

A number of courses were already in place at postgraduate level. It was recognised that undergraduate or equivalent opportunities for autism specific training was less available. As the research informing the development of the Framework highlighted gaps that might be met through Scottish Vocational Qualifications (SVQ), the Autism Reference Group supported new developments in the range of formal qualifications that could be accessed by those employed in social care. Scottish Vocational Qualifications (SVQ) are available at various levels of the Scottish Credit and Qualifications Framework (SCQF). Individuals employed within the social care sector including in management posts are required to have the appropriate award at the suitable level. Consequently a Professional Development Award (PDA), Certificate in Supporting Individuals with Autistic Spectrum Disorders (SQF Level 3, SCQF level 7) and Certificate in Managing the Support of Individuals with Autistic Spectrum Disorders (SVQ level 4, SCQF Level 8) were developed.

A particular need was also identified by the Scottish Autism Reference Group to scope the training needs of Allied Health Professionals (Dunlop and MacKay, 2004).<sup>33 34</sup> This exercise led to NES, NHS Scotland developing an online learning resource which is available through their website. This resource is designed for any professional who is working in the healthcare system at the primary care level (e.g. General Practitioner; Allied Health Professionals (e.g. dieticians, occupational therapists, physiotherapists, podiatrists and speech and language therapists), Dentists, Opticians, Public Health Nurses; District Nurses; Practice Nurses; and Dental nurses). It can be accessed on the following link [www.nes.scot.nhs.uk/asd](http://www.nes.scot.nhs.uk/asd). Following an overwhelming positive evaluation in 2009, highlighting multiple visits by almost 2000 users over an 18 month period, the Autism Centre for Education and Research (ACER) University of Birmingham has been commissioned to fully update the resource.

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<sup>32</sup> MacKay, T.A.W.N. & Dunlop, A.W.A. (2004) The Development a National Training Framework for Autistic Spectrum Disorders, A Study of Training for Professionals Working in the Field of ASD in Scotland. Glasgow: National Autistic Society & University of Strathclyde

<sup>33</sup> Dunlop, A.W.A. & MacKay, T. (2004) A scoping exercise towards the development of a Multidisciplinary CPD resource for Primary Care Professionals in Autistic Spectrum Disorders, Edinburgh: NHS Education for Scotland

<sup>34</sup> NHS Education for Scotland (Learning Resource on Autism Spectrum Disorders (ASDs) for GPs and Primary Care Practitioners

A continuing focus on training for those working in the field of autism spectrum has led to a project, the key aim of which is to ensure the autism specific content of all training, either award or non award bearing, is of good quality. The Autism Training Accreditation project is a joint project, developed by The National Centre for Autism Studies and The Scottish Society for Autism. The outcome of this 2 year project is the development of training standards that will underpin the curriculum for a customised award that will enable individuals and organisations to gain accreditation of the training they deliver by accessing the Certificate in Training in Autism (Dunlop, Tait and Robinson, 2009).<sup>35</sup>

## **Theme 5: Research**

The Medical Research Council (MRC) focuses on research on bio-medical issues and the Chief Scientist Office within the Scottish Government takes the lead in working in collaboration with them on a number of ASD specific pieces of research. The Medical Research Council resources can be accessed by the following webpage <http://www.mrc.ac.uk/index.htm>

More specifically, 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 aimed to identify variables which may predict the need for a diagnostic review in a small minority of cases.

The study provided a rich account of symptomatology and history but lacked standard measurement of global functioning or IQ. While these were not necessary for diagnosis, it would limit the usefulness of the dataset for a future follow up study of developmental trajectories in ASD. The study showed people with ASD had the reliability of a specialist diagnostic service which did not rely on standardised instruments but used a naturalistic play based assessment. The results indicate the importance of both detailed parental account and direct observation of the child. It concluded that a specialist national second opinion service for ASD has a key role in identifying cases complicated by subtle or unusual presentation or co-morbidity. It is likely that there will continue to be a need for tier four services for ASD.

The Scottish Government also held a conference in November 2005 to focus on developments and research in relation to health and autism and 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.

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<sup>35</sup> Dunlop, A-W., Tait, C and Robinson, A. (2009) Policy into Practice: Accreditation Project Report. A Collaborative Autism Education & Training Project Supporting the Development of ASD Accreditation Standards for Trainers and Developing personal accreditation routes for ASD training participants. The Scottish Government

The 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 was 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 Scottish Autism Services Network was then created to ensure greater dissemination and exchange of information, specialised knowledge, research and good practice for professionals across Scotland. The network was to:

- Provide a hub for direction to services for people affected by ASD
- Provide structure for sharing advice and receiving support
- Have an internet presence for information provision
- Consult with users, families and professionals towards responsive development of the network to meet what the ASD community in Scotland needs
- Work inclusively and in partnership with any relevant organisation
- Enable partnerships between relevant organisations for training, research and practice
- Directly influence the knowledge base across multiple professional disciplines.

## Wider policy developments

### *The same as you?*

The Scottish Government has long recognised the need to ensure that there is effective service provision in place for those with autism spectrum disorders (ASD). Going back to 2000 *The same as you?* review of services for people with learning disabilities<sup>36</sup> made recommendations to improve the quality of life for individuals of people with learning disabilities and extended to include people with autism spectrum disorders, whether or not they also have a learning disability.

The national implementation group (SAYIG) is co-chaired by the Minister for Public Health. The main aim is to assist people with learning disabilities and those with ASD to be included in community life, in education, in leisure and recreation, in day opportunities and in employment.

However, whilst merging the needs of both groups can sometimes be helpful it can also be counterproductive where, for example, people on the spectrum can be excluded from potential interventions because they do not have a learning disability. For the last 2 years SAYIG has focused on reducing health inequalities and this has clearly benefitted both groups. NHS Boards have submitted 'change programmes' to the Government in which they identify what their local priorities are which range from improving general hospital care to addressing sexual health issues for people with a learning disability and for all those with autism.

There is a strong evidence base that makes this work urgent. A seminal report was the 2004 Health Needs Assessment Report: People with Learning Disabilities in Scotland<sup>37</sup> which highlighted the significant health inequalities experienced by people with learning disabilities and which showed that national health promotion initiatives were failing to address the different health needs that this group have. So learning disability quality indicators were published to coincide with that report which included a range of criteria for measuring the effectiveness of both general and specialist learning disability services.

More recently, SAYIG has been taking forward the recommendations in Scottish Government's health promotion Equally Well strategy which are:

- that NHS Boards should target health promotion and health improvement action better for people with learning disabilities and others who may need support to access information;
- that each NHS Board should have a designated senior post responsible for ensuring people with learning disabilities receive fair and equitable treatment from health services, and

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<sup>36</sup> <http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

<sup>37</sup> <http://www.healthscotland.com/documents/1040.aspx>

- that the Government should lead development of a framework for regular health assessments for people with learning disabilities in all NHS Board areas.

Much of what underpins this activity is the need to safeguard the interests of those who may be unable to represent themselves. Sadly, Scotland has had fatal accident inquiries in recent years into the deaths of people with a learning disability and the then Minister for Public Health and Sport re-emphasised to Health Board Chairs their obligations to make lasting improvements and act on the findings and recommendations of these inquiries as a matter of urgency.

In 2007, in response to the findings of the 2 Fatal Accident Inquiries, the then Minister asked the Chairs of NHS Boards to submit action plans to address the significant concerns in the delivery of general hospital care for people with learning disabilities. To assist Boards in this task, the Scottish Government invited Boards to submit proposals for funding to help develop services and practices for people with learning disabilities, ensuring consistency and best practice across Scotland. The Scottish Government provided £3m in funding in 2009/10 towards this. A key requirement in receiving the funding was for Boards to designate a senior post with responsibility for fair and equitable care. In NHS Dumfries & Galloway and NHS Tayside, the funding was being allocated to ASD-specific activity.

The learning disability quality indicators have also been reviewed by the then NHS QIS in the Tackling Indifference Report published in 2009<sup>38</sup>. The key finding of the report is that NHS Boards need to get better at understanding the needs of people with learning disabilities to make sure that they get the healthcare they need. They recognised almost all NHS Boards have taken on the Scottish Enhanced Services Programme in primary care for adults with learning disabilities and there has been good work done to include people with learning disabilities in national screening programmes. Specific learning disability liaison nurse posts have also been central to supporting people with learning disabilities as well as in assisting health staff to understand their needs.

Although historically associated with learning disability, recent research done raises the matter that most of those on the autism spectrum may not have a learning disability. A published research paper by the Social Care Institute for Excellence highlights the various issues faced by many people on the autism spectrum who do not have a learning disability.<sup>39</sup> The key messages from the research paper are:

- Outcomes for adults with autism spectrum disorder (ASD) are generally poor. Many people with ASD experience unemployment; mental and physical ill-health, discrimination and social exclusion;
- The evidence base evaluating services for people with ASD is weak;
- There are significant variations between individual adults with ASD, so that 'one size fits all' practices are ineffective. Evidence suggests that adults with

<sup>38</sup> <http://www.healthcareimprovementscotland.org/default.aspx?page=12535>

<sup>39</sup> <http://www.scie.org.uk/publications/briefings/briefing32/index.asp>

ASD benefit from services, e.g. employment and care which adopt autism-specific approaches delivered via specialist, multi-disciplinary teams;

- Access to social care is often problematic, compounded by the complexities of the autism spectrum, by other health-related difficulties, the impact of eligibility criteria and the lack of specific services for adults with ASD;
- The transition period of moving from children's services to those for adults is problematic;
- Individuals with ASD and additional intellectual disability generally have fewer problems in accessing support, often provided by local learning disability services. However these services may struggle to support individuals with additional or complex needs;
- The condition and needs of more 'able' individuals with ASD may go unrecognised or be misdiagnosed;
- More information is needed about individuals with ASD and additional sensory processing differences to enable them to access services;
- Too few health or social care staff have sufficient expertise or experience for assessing or working with people with ASD;
- Research is needed to investigate the lower take-up of social care among people from minority ethnic and cultural groups, women and older people with ASD.

The report concluded that a personalised approach based on an understanding of the nature of the condition and individual need, sensitively supported by local specialised expertise and multi-agency collaboration, would appear to offer a better outcome for adults with ASD. A prescriptive 'one size fits all' approach to services, support and facilities is not effective. A prudent investment in research which has practical relevance will lead to an improved understanding of the effects of services.

To conclude, some individuals with autism may never come into contact with services and are able to function well without additional support. Others may benefit from mainstream approaches targeted at improving outcomes for children and young people such as *Getting it right for every child*, or at those in transition to adult services. Yet others may benefit from policies that have a particular theme such as employment, independent living or self-directed support. Mainstream service or a combination of mainstream services will not suit everyone and specialist support may then be the most appropriate option.

## Support for children and young people

### Curriculum for Excellence

Curriculum for Excellence<sup>40</sup> prepares children and young people for the challenges of life in the 21<sup>st</sup> century. It builds on the strengths of Scotland's education system. It will raise standards for every child. It plans to enable every child to become a successful learner, confident individual, effective contributor and responsible citizen.

It links knowledge in one subject area to another helping children understand the world and make connections. It develops skills so that children can think for themselves, make sound judgements, challenge, enquire and find solutions. For professionals, it enables them to teach more creatively, bringing learning to life; empowering the experts. It reaches out to industry and enterprise to bring real life to learning. For young people, it offers personalisation and choice within a broad curriculum. It balances the importance of knowledge *and* skills. It's designed to nurture successful, effective, confident and responsible young people.

Children and young people are entitled to a curriculum that includes a range of features at the different stages. Children and young people are entitled to experience:

- a curriculum which is coherent from 3 to 18;
- a broad general education, including the experiences and outcomes which are well planned across all the curriculum areas, from early years through to S3;
- a senior phase of education after S3 which provides opportunity to obtain qualifications as well as to continue to develop the four capacities (successful learner, confident individual, effective contributor and responsible citizen);
- opportunities for developing skills for learning, skills for life and skills for work with a continuous focus on literacy, numeracy and health and wellbeing;
- personal support to enable them to gain as much as possible from the opportunities which *Curriculum for Excellence* can provide;
- support in moving into positive and sustained destinations beyond school.

Curriculum for Excellence is a curriculum for all, including those children and young people with additional support needs, and wherever learning may be taking place.

### ***Getting it right for every child (GIRFEC)***

*Getting it right for every child*<sup>41</sup> is the Scottish Government's child-centred approach to children's services, including services which support children with disabilities. It aims to improve working across the boundaries of education, social work, health, police and the third sector so that the child and family experience one team to

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<sup>40</sup> <http://www.ltscotland.org.uk/understandingthecurriculum/whatiscurriculumforexcellence/index.asp>

<sup>41</sup> [www.scotland.gov.uk/gettingitright](http://www.scotland.gov.uk/gettingitright)

support them. This approach involves streamlining and simplifying services to remove the complexity and duplication that currently confuse families. It focuses on improving outcomes for children by adopting an approach that is based on partnership, shared language and common tools that support a single system for identifying, assessing, and planning to address children's needs.

*Getting it right for every child* aims to create a network of support around the child to promote well-being. This network will always include family and/or carers and the universal health and education services. Where there are concerns about children's well-being, there is a National Practice Model designed to help practitioners to pick up those concerns appropriately and deal with them in a timely and proportionate way. Sometimes this can be done through a single agency; at other times, because of the complexity of the child's situation, an inter-agency response will be necessary.

### **Support for Learning**

While most of our children and young people respond well to the opportunities for learning provided by our schools we also know that without extra help some will not benefit fully from education. The Education (Additional Support for Learning) (Scotland) Act 2004 ("The 2004 Act") as amended by the Education (Additional Support for Learning) (Scotland) Act 2009 ("The 2009 Act") sets out a framework for supporting children's learning. The legislation aims to ensure that all children and young people receive the additional support required to meet their individual needs and help them to become successful learners. It places a duty on education authorities to identify, meet and keep under review the additional support needs of all pupils, including those with ASD. It promotes collaborative working among all those supporting children and young people and sets out parents' rights within the system.

The 2009 Act makes certain amendments to the 2004 Act and was passed by the Scottish Parliament on May 20, 2009 and received Royal Assent on June 25, 2009. The 2009 Act aims to create a stronger, better system for supporting children's learning. It clarifies responsibilities, establishes new rights for parents to request a place for their child in a school in another education authority, requests for specific assessments and for advocacy and mediation to help resolve disputes and extends the jurisdiction of the Additional Support Needs Tribunal for Scotland.

Children or young people may require additional support, long or short term, for a variety of reasons to enable them to make the most of their school education and be fully included in their learning. The Code of Practice includes some examples but the list is not exhaustive nor should it be assumed that inclusion on the list inevitably implies that additional support will be necessary. It is important for education authorities to consider the needs of the individual child. However, the 2009 Act does deem that all looked after children and young people have additional support needs unless the education authority determines otherwise.

The Scottish Government has produced a Code of Practice which explains the duties on education authorities and other agencies to support children and young people's learning and to provide guidance on legislative provisions and case studies. Education authorities and other appropriate agencies, such as NHS Boards, are

under a duty to have regard to the Code of Practice when carrying out their functions under the Support for Learning legislation.

### **Communications and engagement**

Parents, children and young people need to have access to information. They should, where possible, be involved fully in discussions and decisions. Children and young people should have the opportunity to make their views known about decisions that affect them. The Scottish Government funds Enquire, an independent advice and information service about additional support for learning managed by Children in Scotland. Enquire provides information to parents and professionals.

The 2009 Act places a duty on local authorities to publish and provide to all parents of all children with additional support needs, and young people with additional support needs a wide range of information about their arrangements, procedures and policies in relation to additional support needs. If there is a disagreement, authorities and schools need to have clear procedures in place for resolving these including mediation, dispute resolution and finally an appeal to the Additional Support Needs Tribunal for Scotland (ASNTS). The Act also places a duty on Scottish Ministers to provide an advocacy service available on request and free of charge for children, young people and parents in relation to the proceedings of the ASNTS.

### **Autism Education Toolbox**

The Scottish Government has introduced a number of specific initiatives to support inclusion in education. If we are to succeed in developing and sustaining inclusive practice to meet the needs of children then teachers need to be well prepared and appropriately supported. The Government has supported the development of a National Framework for Inclusion to identify the values and beliefs, professional knowledge and understanding and the professional skills and abilities expected of student teachers and qualified teachers. The Framework promotes the principle that achieving inclusion is the responsibility of all teachers in all schools. Together with the Inclusive Practice Project at the University of Aberdeen it will develop and embed inclusive education principles within teacher training. In addition learning and teaching materials have been developed so that all teachers can learn how to make their learning in the classroom more inclusive for pupils.

The Government commissioned and published an Autism Toolbox<sup>42</sup> in 2009 which was written by a professional multi-agency team. Its aim is both to support education authorities in their planning of services for children and young people with autism spectrum disorders and practice in the classroom.

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<sup>42</sup> <http://www.scotland.gov.uk/Resource/Doc/266126/0079626.pdf>

## Personalisation and protection

### Self-directed support

People who use care and support services, including people with autism, should have choice and control over their support. They should have as much autonomy as possible over their own decision-making. They should be empowered to tailor flexible support, based on their own needs and agreed outcomes, and not on assumptions. In short, support should be designed around the citizen and not the service.

Self-directed support is a term that describes the ways in which individuals can exercise this greater choice and control. The Scottish Government and COSLA, through their 10-year strategy on self-directed support, are committed to driving a cultural shift, with self-directed options becoming the mainstream approach. The Government is investing £3.6m in 2011/12 to support the strategy. In addition, the Government has consulted on a draft Bill on self-directed support. The draft Bill will say that councils must give the person a choice of options:

- Having a direct payment
- Choosing the services you want and asking the council to arrange them for you
- Letting the council decide what services are right for you
- A mix of these options.

In addition the Bill will:

- introduce the language self-directed support into social care law;
- provide a consistent, clear framework in law, imposing duties on local authorities, to set out the options available to citizens and to make it clear that it is the citizen's choice as to how much control they want to have;
- widen eligibility to those who have been excluded up to this point and;
- consolidate, modernise and clarify existing laws on direct payments.

To keep track of the Bill's progress see:

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

To find out more about self-directed support see:

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

## Independent Living

The Scottish Government announced funding for 2008-11 to support work in developing independent living, with the aim of ensuring that disabled people feel valued as individuals and have the same choice, control and freedom as any citizen. Independent living does not mean living by yourself or fending for yourself. It covers every aspect of an individual's life - maximising the opportunities for disabled people to participate fully in society and live an ordinary life - at work, at home and in the community.

The Government, public sector bodies and disabled people's organisations have agreed a [\*Shared Vision for Independent Living\*](#) and are working together to identify ways to break down the barriers which stop disabled people fulfilling their full potential in areas such as housing, transport, employment and education. The right to independent living is also set out in Article 19 of the UN Convention on the Rights of Disabled People.

The Scottish Government has published 'The Principles of Inclusive Communication: An information and self-assessment tool for public authorities.'<sup>43</sup> Encouraging consistency of approach, it is intended the document be disseminated widely and used to aid people with communication support needs access services effectively and participate, as equal partners, in the development of policy and service improvement.

People with autism spectrum conditions are represented on the national reference group and as part of the Independent Living in Scotland project, to support an understanding of what independent living means for people on the autism spectrum.

## Adult Support and Protection (Scotland) Act 2007: Part 1

The Adult Support and Protection (Scotland) Act 2007 (ASP Act) is a progressive step in responding to harm against those adults most at risk in society. It puts in place modern and strengthened measures to enable greater protection for those adults in Scotland who are most at risk of harm. The Act commenced on 29 October 2008.

The ASP Act defines adults at risk as:

- individuals aged 16 years or over,
- who are unable to safeguard themselves, their property, rights or other interests, and
- are at risk of harm and because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than others who are not so affected.

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<sup>43</sup> <http://www.scotland.gov.uk/Publications/2011/09/14082209/0>

The Act defines harm to include all harmful conduct and, in particular, includes conduct which causes physical harm, conduct which causes psychological harm (e.g. by causing fear, alarm or distress), unlawful conduct which appropriates or adversely affects property, rights or interests (e.g. theft, fraud, embezzlement or extortion) and conduct which causes self-harm.

The Act provides greater protection to those at risk of harm through powers and duties to investigate and intervene in situations where concern exists. It requires the Mental Welfare Commission, Social Care and Social Work Services Improvement Scotland, the Office of the Public Guardian, all councils, chief constables of police forces, the relevant Health Board to co-operate in investigating harm and provides professionals with the tools to support and protect adults at risk. It also places a duty on those organisations to co-operate in investigating suspected or actual harm and places a duty on Councils to make inquiries and investigations to establish whether or not further action is required to stop or prevent harm occurring.

The ASP Act is one part of a suite of legislation that can be used to protect people from harm; the Adults with Incapacity (Scotland) Act 2000 (AWI Act) and the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHCT Act) are also available and practitioners can use different sections across the legislation which best suit the needs of the adult at risk of harm.

The overarching principle of Part 1 of the ASP Act is that any intervention in an individual's affairs should provide benefit to the individual, and should be the least restrictive option of those that are available which will meet the purpose of the intervention. Together with the overarching principle, guiding principles must be taken account of when performing functions under Part 1 of the Act and these are:

- that the wishes and feelings of the adult at risk (past and present) are considered.
- the views of other significant individuals, such as the adult's nearest relative; their primary carer, guardian, or attorney; or any other person with an interest in the adult's well-being or property;
- the importance of the adult taking an active part in the performance of the function under the Act;
- providing the adult with the relevant information and support to enable them to participate as fully as possible;
- the importance of ensuring that the adult is not treated less favourably than another adult in a comparable situation; and
- the adult's abilities, background and characteristics (including their age, sex, sexual orientation, religious persuasion, racial origin, ethnic group and cultural and linguistic heritage).

Adult protection is a sensitive issue and should continue to be addressed sensitively, endeavouring to strike an appropriate balance between protecting people and enabling them to live fulfilling lives. It sends a clear message that harm and neglect of those adults most at risk is not acceptable. The Scottish Government Act against harm website <http://www.actagainstharm.org/> provides further information.

## **The Protecting Vulnerable Groups Scheme**

The Protecting Vulnerable Groups Scheme (PVG Scheme)<sup>44</sup>, has commenced, and this will help to ensure that people who have regular contact with vulnerable groups in Scotland through regulated work do not have a known history of harmful or abusive behaviour. It is a new membership scheme that will replace and improve upon current disclosure arrangements for people who work with children and protected adults. It will strike a balance between proportionate protection and robust regulation. People who are known to be unsuitable to work with children and/or protected adults will not be able to become members of the PVG Scheme and they will be barred from working with one or both of these groups.

The PVG Scheme's system of continuously updating scheme members' records with any new vetting information (conviction information and other information which the police consider relevant) means that people whose behaviour suggests that they may have become a risk to vulnerable groups will be quickly identified. This will enable action to be taken by Disclosure Scotland and by the individual's employers.

As well as strengthening protection for vulnerable groups, the PVG Scheme will reduce bureaucracy. It will be quicker and easier than the current previous disclosure system to use and reduce the need for PVG Scheme members to complete and process a detailed application form every time a disclosure check is required. The workforce will be phased into membership of the PVG Scheme over four years to minimise the administrative burden on employers and to allow plenty time for people to become familiar with it.

It only applies to people who work with children and protected adults and it does not apply to personal arrangements that parents may make with friends and family to look after their child or to work in positions where there is no opportunity to cause harm to vulnerable groups.

## **Reshaping Care for Older People**

The Scottish Government is currently giving priority to ensuring that older people receive the care, compassion, support and dignity they need and deserve. This involves working closely with partners in Health, Local Government and the third and independent sectors to radically reshape the provision of care for older people. We are looking to ensure the highest quality care for every older person, every time. This will require, amongst other things, a step change in the integration of health and

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<sup>44</sup> <http://www.scotland.gov.uk/Topics/People/Young-People/children-families/pvglegislation>

social care and in joint working with other agencies and the voluntary sector. Through our public engagement, and in discussion with stakeholders there is a strong sense that for too long structural issues have taken priority: there is a now a determined effort to ensure that from now on the person receiving care and using services, and not organisational boundaries, will be at the centre of delivery the length and breadth of Scotland. The programme of work entitled 'Reshaping care for older people'<sup>45</sup> will link closely with the Health Quality Strategy<sup>46</sup>, Dementia Strategy<sup>47</sup>, and Carers' Strategy<sup>48</sup>.

With regard to autism and Asperger's syndrome, a range of needs in younger and older people will benefit from this work on Reshaping Care. Many (if not most) older people already have one or more long term conditions, so it will make sense to ensure that the Reshaping Care work makes appropriate links to people with differing community care needs e.g. mental health, physical disability, learning disability, and so on.

Critical to this work is the Integrated Resource Framework (IRF)<sup>49</sup> which has been developed jointly by the Scottish Government, NHS Scotland and the Convention of Scottish Local Authorities (COSLA). Its purpose is to enable health and social care partners to develop financial and management information which can inform the process of service redesign by clinicians and care professionals, and facilitate the re-alignment of resources to improve patient and population level outcomes, and enable shifts in the balance of care from institutional to non-institutional settings.

### **Carers Strategy, Caring Together 2010-2015**

Recognising the significant contribution made by Scotland's estimated 650,000 unpaid carers, the Scottish Government with COSLA published in July 2010 a new strategy for carers in Scotland. The vision is that carers are recognised as equal partners in care and supported in their own right by statutory and voluntary services. Carers are now, and will remain, fundamental to strong families and partnerships and to resilient and cohesive communities. The key outcomes of the strategy, which are linked to the Government's national outcomes, are:

- Improved emotional and physical well-being of carers;
- Increased carer confidence in managing the caring role;

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<sup>45</sup> <http://www.scotland.gov.uk/Topics/Health/care/reshaping>

<sup>46</sup> <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/NHSQuality>

<sup>47</sup> <http://www.scotland.gov.uk/Publications/2010/09/10151751/0>

<sup>48</sup> <http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

<sup>49</sup> <http://www.shiftingthebalance.scot.nhs.uk/initiatives/sbc-initiatives/integrated-resource-framework/>

- The ability to combine caring responsibilities with work, social, leisure and learning opportunities – a life outside of caring and not experiencing financial hardship as a result of caring;
- Carer involvement in planning and shaping the services and supports required.

### **Young Carers Strategy, Getting it Right for Young Carers 2010-2015**

The Scottish Government with the Convention of Scottish Local Authorities (COSLA) also published a Young Carers Strategy *Getting it Right for Young Carers* in July 2010. It is a stand-alone strategy but has key links to the adult strategy, *Caring Together*, also published in July 2010. This strategy will:-

- Increase profile of young carers' issues
- Will encourage partners such as schools to identify young carers
- Will encourage mainstream services, especially schools and the health service, to support children and young people who are young carers.
- Ensure young carers will be children and young people first and foremost

Both the Caring Together and Young Carers Strategy are in their second year of implementation.

### **Social Housing Allocations**

The Housing (Scotland) Act 1987, as amended by the Housing (Scotland) Act 2001, sets out the right for anyone aged 16 or over to be admitted to a housing list. Once admitted to a housing list, it is for the social landlord (Local Authority or Registered Social Landlord) to determine the priority of the application in line with their allocations policy. This policy will be based on the criteria identified within the Act that states what should and should not be taken into account when allocating housing.

The Housing (Scotland) Act 2001 introduced legal duties on landlords to encourage equality of opportunity and outcomes and provide services in a way that promotes equality. This is reinforced by the Scottish Housing Regulator's performance standard that all landlords are regulated against.

Current legislation requires that reasonable preference should be given to applicants who fall within the criteria below:

- Are homeless people or are threatened with homelessness; or
- Living in houses that do not meet the tolerable standard; or
- Are living in overcrowded houses; or
- Have large families; or
- Are living in unsatisfactory housing conditions.

Social landlords should give reasonable priority in the allocation of their housing to all of the categories outlined above and they are free to decide on what factors they take into account when defining 'unsatisfactory housing conditions'. Factors that are normally taken into account fall into 3 main categories:

- Mental or health issues;
- harassment or abuse issues; and
- social, community or family support.

Some landlords also take social, community and family support into account when allocating houses. This is of particular relevance when dealing with individuals with autism who may rely on family support. A landlord has the flexibility to decide on the priority this category is given when allocating a house.

However, the priority that will be placed on autism in allocating housing will vary between landlords therefore, it is important that the landlord is made aware of the severity of the condition and is engaged with social workers/medical professionals or support agencies from the outset of the application.

### **A good practice example**

Glasgow City Council, with input from housing and autism representatives, have produced a resource for Registered Social Landlords (RSL) and other housing agencies to inform them of the needs of people with an autism spectrum disorder (ASD).<sup>50</sup>

In March 2011, the Scottish Government published an online practice guide on social housing allocations to support social landlords to understand their requirements and make use of the flexibilities they have. It also includes real experiences and approaches which Scottish social landlords use to respond to common issues.

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<sup>50</sup> [www.glasgow.gov.uk/.../PracticalGuideforRSLsHousingASDmarch10.pdf](http://www.glasgow.gov.uk/.../PracticalGuideforRSLsHousingASDmarch10.pdf)





## Annex 2

# Prevalence and incidence



## Annex 2: Prevalence and incidence

The prevalence estimates in the Public Health Institute of Scotland's (PHIS) ASD Needs Assessment Report suggested 60 in every 10,000 people are affected by ASD. More recent studies suggest that a rate of around 1 in 100 is currently the best estimate of the prevalence in children and adults.<sup>51 52</sup>

Diagnosis for school age children is vastly improved both in its sophistication and in its consistency. This has led to benefits for some adults in the extended family of those recently diagnosed children whereby they have come forward to ask for their own diagnosis as they recognise similar behavioural patterns within themselves. There is no one single explanation of why more people appear to be diagnosed with the condition. It is probable that a mix of factors is coming into play including increasing public and professional awareness, improved diagnosis, wider diagnostic criteria or a combination of all the above.

As part of its acceptance of the PHIS recommendations, the then Scottish Executive undertook an audit of services for people with ASD in 2004.<sup>53</sup> Its remit was to provide information for service commissioners on the best available knowledge about ASD and current service provision in Scotland, and guidance on how these services might better meet the needs of both children and adults with ASD in the future. The intention was to assess the extent to which national prevalence rates could be regarded as a sound basis on which to plan services. It was also the first time that social and health care planners for both children and adult services attempted to quantify the incidence of ASD in their locality. Whilst the ultimate analysis carried a number of reservations about the reliability of the findings, acknowledging its patchiness and the likelihood of underestimation, it did provide a much clearer picture than had existed up until that point. It meant that many planners did take the opportunity to discuss the findings together and to plan appropriate interventions at local level.

The overall picture that emerged was that 35 children per 10,000 were diagnosed with ASD, making a total 3,400 children and young people. Within this, the highest rate was for the 5-10 age group where there were 49 children diagnosed per 10,000 population. Incidence figures have varied across Health Boards from 16 in Forth Valley to 102 in Highland and 299 in Orkney. For the 11-15 age group, there were 27 children and young people diagnosed per 10,000 population which drops to 16 per 10,000 population for the 16-18 age group.

The higher rates for the 5-10 and preschool age groups was thought to have been due to a combination of better reporting procedures and improved diagnosis in recent years. The rate per 10,000 population for preschool children at 42 was less than the rate for 5-10 year olds. It could have been expected that the pre-school data should

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<sup>51</sup> [www.esds.ac.uk/doc/5269/mrdoc/pdf/5269technicalreport.pdf](http://www.esds.ac.uk/doc/5269/mrdoc/pdf/5269technicalreport.pdf)

<sup>52</sup> <http://archpsyc.ama-assn.org/cgi/content/abstract/68/5/459>

<sup>53</sup> [www.scotland.gov.uk/Resource/Doc/1095/0001881.pdf](http://www.scotland.gov.uk/Resource/Doc/1095/0001881.pdf)

have been of equal or better quality than the 5-10 age group because of improved reports but much diagnosis takes place after the age of 3 because the behaviours associated with the condition may not be displayed before then. Other significant findings were that 20% of children with ASD were reported as having learning disabilities with two thirds of diagnosed primary school children attending mainstream schools. Around one third of children with ASD were specifically diagnosed with Asperger's syndrome.

Moving to adults, 645 adults were identified in the audit, 1 in 7 of whom was described as having Asperger's. The data here was less robust. Eight of the 15 NHS Boards were able to provide complete information but 4 could not do so. NHS Lothian conducted a file review so that its data was possibly the most accurate. Given these limitations, we see that 24% of people were in the 18-24 bracket, 63% were aged 25-29 and 12% were over 50 years of age. The rate was highest for the 18-24 age group where for Scotland there were 5.1 people diagnosed per 10,000 population. This changes to 3.2 for the 25-49 age group and again to 0.6 for the 50 plus age group. As before, these lower rates probably reflect a combination of better reporting procedures and improved diagnosis over the years. As with the children's data, the rates of diagnosis vary considerably between NHS Board areas from 0.8 per 10,000 population in Lanarkshire to 8.7 people diagnosed per 10,000 population in Orkney.

Overall, more than half (55%) of the adults with ASD that were known to partnerships also had learning disabilities. In addition, nearly one third of these adults had other behavioural or biomedical conditions, 10% had both a learning disability and a physical impairment and 3% had mental health problems.

Since the time the survey was conducted, some authorities have built on this data to continue local planning. The Scottish Government now collects data on the number of school children with autism. The Pupils in Scotland 2010 publication and the Independent School census (September 2008) record the number of children for reason of support of autism spectrum disorder as being 6,506 which is closer to 1 in 100.

The prevalence figures outlined in Table 2 are estimates of the total number of people with autism spectrum disorder by local authority area, based on the prevalence rate of 90 in 10,000 people from the Office of National Statistics survey of the mental health of children and young people in Britain (2005). The ratio of males to females was found to be 4:1. Not all of this population will need formal community care services. Many will need life time support. However, it is clear from the figures that wider community services, such as housing, transport, sport and leisure, should be taking account of the range of needs of this population.

**Table 2 - Estimated prevalence figures by local authority area (2005)**

Location (Caps -city status)	Population 2006	Estimated ASD 90/10,000	0 to 4		5 to 9		10 to 14		15 to 19		20 to 29		30 to 65		Total					
			M	F	M	F	M	F	M	F	M	F	M	F						
Aberdeen	206880	1862	90	23	113	94	24	118	97	24	121	95	24	119	197	49	246	696	174	870
Aberdeenshire	236260	2126	103	26	129	108	27	135	110	28	138	109	27	136	225	56	281	794	199	993
Angus	109320	984	48	12	60	50	13	63	51	13	64	50	13	63	104	26	130	368	92	460
Argyll & Bute	91390	823	40	10	50	42	10	52	43	11	54	42	11	53	87	22	109	307	77	384
Clackmannanshire	48900	440	21	5	27	22	6	28	23	6	29	23	6	29	46	12	58	164	41	205
Dumfries & Galloway	148030	1332	64	16	81	68	17	85	69	17	86	68	17	85	141	35	176	498	124	622
Dundee	142170	1280	62	15	77	65	16	81	66	17	83	66	16	82	135	34	169	478	120	598
East Ayrshire	119290	1074	52	13	65	55	14	68	56	14	70	55	14	69	113	28	141	401	100	501
East Dunbartonshire	105460	949	46	11	57	48	12	60	49	12	61	49	12	61	100	25	125	355	89	444
East Lothian	92830	835	40	10	51	43	11	53	43	11	54	43	11	53	88	22	110	312	78	390
East Renfrewshire	89290	804	39	10	49	41	10	51	42	10	52	41	10	51	85	21	106	300	75	375
Edinburgh	463510	4172	202	50	252	212	53	265	216	54	270	214	53	267	441	110	551	1559	390	1949
Falkirk	149680	1347	65	16	82	69	17	86	70	17	87	69	17	86	142	36	178	503	126	629
Fife	358930	3230	156	39	195	164	41	205	167	42	209	165	41	206	341	85	426	1207	302	1509
Glasgow	580690	5226	253	63	316	266	66	332	271	68	339	268	67	335	552	138	690	1953	488	2441
Highland	215310	1938	94	23	117	99	25	124	100	25	125	99	25	124	205	51	256	724	181	905
Inverclyde	81540	734	36	9	44	37	9	46	38	10	48	38	9	47	77	19	96	274	69	343
Midlothian	79290	714	35	9	43	36	9	45	37	9	46	37	9	46	75	19	94	267	67	334
Moray	86750	781	38	9	47	40	10	50	40	10	50	40	10	50	82	21	103	292	73	365
North Ayrshire	135490	1219	59	15	74	62	16	78	63	16	79	62	16	78	129	32	161	456	114	570
North Lanarkshire	323780	2914	141	35	176	148	37	185	151	38	189	149	37	186	308	77	385	1089	272	1361
Orkney	19770	178	9	2	11	9	2	11	9	2	11	9	2	11	19	5	24	66	17	83
Perth & Kinross	140190	1262	61	15	76	64	16	80	65	16	81	65	16	81	133	33	166	471	118	589
Renfrewshire	169590	1526	74	18	92	78	19	97	79	20	99	78	20	98	161	40	201	570	143	713
Scottish Borders	110240	992	48	12	60	50	13	63	51	13	64	51	13	64	105	26	131	371	93	464
Shetland	21880	197	10	2	12	10	3	13	10	3	13	10	3	13	21	5	26	74	18	92
South Ayrshire	111670	1005	49	12	61	51	13	64	52	13	65	51	13	64	106	27	133	375	94	469
South Lanarkshire	307670	2769	134	34	168	141	35	176	144	36	180	142	35	176	292	73	365	1035	259	1294
Stirling	87810	790	38	10	48	40	10	50	41	10	51	40	10	50	83	21	104	295	74	369
West Dunbartonshire	91240	821	40	10	50	42	10	52	43	11	54	42	11	53	87	22	109	307	77	384
West Lothian	165700	1491	72	18	90	76	19	95	77	19	96	76	19	95	157	39	196	557	139	696
Western Isles	26350	237	11	3	14	12	3	15	12	3	15	12	3	15	25	6	31	89	22	111
<b>Total</b>	<b>5116900</b>	<b>46052</b>	<b>2229</b>	<b>557</b>	<b>2787</b>	<b>2342</b>	<b>586</b>	<b>2926</b>	<b>2387</b>	<b>597</b>	<b>2983</b>	<b>2358</b>	<b>569</b>	<b>2827</b>	<b>4863</b>	<b>1216</b>	<b>6077</b>	<b>17205</b>	<b>4301</b>	<b>21512</b>



## Annex 3

# Summary of recommendations



## **RECOMMENDATION 1**

It is recommended that the ASD Reference Group is reconvened on a long-term basis to include COSLA membership to oversee developments and to progress change. It should produce an annual report to relevant Ministers and the political leadership of COSLA.

## **RECOMMENDATION 2**

It is recommended that the ASD Reference Group works collaboratively, and offer support, to COSLA, NHS, criminal justice and other relevant public bodies to offer support to Local Authorities to effect the implementation of the various autism guidelines.

## **RECOMMENDATION 3**

It is recommended that the ASD Reference Group explores the benefits of ASD lead officers with the Association of Directors of Social Work and with COSLA to establish how rollout across Scotland might best be achieved.

## **RECOMMENDATION 4**

It is recommended that the ASD Reference Group meets with representatives of both SCSWIS and HIS, as well as other relevant regulatory bodies, such as those in education and criminal justice, with a view to learning about current developments and ensure that the needs and wishes of those on the spectrum are taking into account in future programmes.

## **RECOMMENDATION 5**

It is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole. Particular attention should be paid to his 'invest to save' assertion that if 4% of those with Asperger's were given appropriate support into work this would ultimately mean that those individuals may not require services and could contribute to the economy.

## **RECOMMENDATION 6**

It is recommended that the effectiveness of implementation of the Commissioning guidance is reviewed by the ASD Reference Group by facilitating an audit of current service commissioning.

## **RECOMMENDATION 7**

It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD.

## **RECOMMENDATION 8**

The ASD Reference Group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan.

## **RECOMMENDATION 9**

It is recommended that the ASD Reference Group hosts an event to evaluate and recognise good practice in Scotland to disseminate models of practice, to evaluate success, recognise benefits and limitations and agree how to develop good models across the country in a way that is cost-effective.

## **RECOMMENDATION 10**

It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions.

## **RECOMMENDATION 11**

It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD.

## **RECOMMENDATION 12**

It is recommended that an evaluation of existing research is commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and to the commissioning some pieces that would be of particular practical value to people with ASD and their carers.

## **RECOMMENDATION 13**

It is recommended that the ASD Reference Group explore options for developing user and carer capacity to be able to participate in local planning processes.

## **RECOMMENDATION 14**

It is recommended that the SDS Strategy Implementation Group and the SDS Bill Reference Group ensure representation from the autism community so that their interests are taken into account as further developments take place.

## **RECOMMENDATION 15**

It is recommended that existing reports on the work of Scottish Autism Services Network are formally evaluated with a view to assessing its long-term viability and effectiveness.

## **RECOMMENDATION 16**

It is recommended that the ASD Reference Group contributes to a review of the SIGN guidelines and in doing so, considers where and how best this innovation might be replicated for adults and other relevant professions.

## **RECOMMENDATION 17**

It is recommended that the Training Sub-Group of the main Reference Group is reconstituted and strengthened by the inclusion of an SCLD representative to undertake an audit of existing provision and to take evidence from grass roots trainers with a view to recognising strengths and gaps as well as identifying the means by which to further improve what is on offer.

### **RECOMMENDATION 18**

It is recommended that good practice transition guidance is developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions.

### **RECOMMENDATION 19**

It is recommended that a request is made to NHS QIS, as the body into which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of ASD in adults.

### **RECOMMENDATION 20**

It is recommended that approaches are made to the Royal College of Physicians and Surgeons to establish the feasibility and desirability of disseminating ASD materials in e-CPD formats.

### **RECOMMENDATION 21**

It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings.

### **RECOMMENDATION 22**

Initiatives to address waiting lists for assessment should include consideration of further training on the use of ADOS, ADI-R, 3di and DISCO to meet increased levels of demand.

### **RECOMMENDATION 23**

It is recommended that the ASD Reference Group explore the ways diagnostic processes for adults and children are different and how this should inform practice.

### **RECOMMENDATION 24**

It is recommended that the directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland is reviewed, updated and re-distributed.

**RECOMMENDATION 25**

It is recommended that a review is conducted with a view to updating and re-distributing the quality diagnostic standard if it is found to continue to be of benefit.

**RECOMMENDATION 26**

It is recommended that the supported employment framework for Scotland is evaluated in terms of its impact on employment and employability for people with autism.



# Glossary



## Glossary

ADI-R	Autism Diagnostic Interview-Revised
ADOS-G	Autism Diagnostic Observation Schedule-Generic
ARC	Autism Resource Centre
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
ASNTS	Additional Support Needs Tribunals for Scotland
AQ	Autism-Spectrum Quotient
CGST	Clinical Governance Support Team
CLDT	Community Learning Disability Teams
COSLA	Convention of Scottish Local Authorities
CPD	Continuous Professional Development
DISCO	Diagnostic Interview for Social and Communication Disorders
DSM	Diagnostic and Statistical Manual of Mental Disorders
e-SAY	electronic database for collecting annual statistics on people with learning disabilities and/or autism spectrum disorders
EQ	Empathising Quotient
FAST	Fife Autism Spectrum Teams
FAOA	Fife Action on Autism
GIRFEC	Getting it right for every child
HIS	Healthcare Improvement Scotland
HMIE	Her Majesty's Inspectorate of Education
ICD	International Statistical Classification of Diseases and Related Health Problems
KADI	Krug Aspergers Disorder Index
LAC	Local Area Coordination
MRC	Medical Research Council
NAS	National Autistic Society
NES	NHS Education for Scotland
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
PiPs	Partnership in Practice agreements
PHAD	People with High-functioning Autistic Disorders
PDA	Professional Development Award
PHIS	Public Health Institute of Scotland
PVG	Protecting Vulnerable Groups Scheme
RASDCS	Regional ASD Consultancy Service
RLDS	Renfrewshire Learning Disabilities Services
RSL	Registered Social Landlords
SAY	<i>The same as you?</i>
SAYIG	<i>The same as you?</i> Implementation Group
SCLD	Scottish Consortium for Learning Disability
SCSWIS	Social Care and Social Work Improvement Scotland (The Care Inspectorate)
SCQ	Social Communication Questionnaire
SCQF	Scottish Credit and Qualifications Framework
SEAT MCN	South East and Tayside Learning Disabilities Managed Care Network
SIGN	Scottish Intercollegiate Guideline Network

SOA	Single Outcome Agreement
SQF	Scottish Qualifications Framework
SVQ	Scottish Vocational Qualifications
SQ	Systemising Quotient
WASP	West Fife Autism Spectrum Pilot
3di	Developmental, Dimensional and Diagnostic Interview





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# Signposting



## Signposting

**Autism Education Trust** - was launched in November 2007 with funding from the Department for Children, Schools and Families. It is dedicated to co-ordinating and improving education support for all children on the autism spectrum in England.  
<http://www.autismeducationtrust.org.uk/>

**Autism Initiatives** - is a parent-led charity and a member of both the Autism Alliance and the Confederation of Service Providers for People with Autism (CoSPPA).  
<http://www.autisminitiatives.org/>

**Autism Resource Centre** - is an innovative development for people with autism and their carers in Greater Glasgow. The service operates as a partnership between Glasgow City Council, NHS Greater Glasgow and Clyde and voluntary organisations, including the National Autistic Society, Scottish Society for Autism and Strathclyde Autistic Society.

[http://www.nhsggc.org.uk/content/default.asp?page=s762&loc\\_id=3015](http://www.nhsggc.org.uk/content/default.asp?page=s762&loc_id=3015)

**Camphill Scotland** - one of the largest support networks for children, young people and adults with learning disabilities, mental health problems and other support needs.  
<http://www.camphillscotland.org.uk/>

**Celtic Nation Autism Partnership**- is working at the front line of national and international efforts, to improve the quality of life for people with autism.  
<http://www.celticnationsautism.eu>

**Department of Health** - Fulfilling and rewarding lives: the strategy for adults with autism in England  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

**Health Talk On line** - People's stories: see, hear and read their experiences. Healthtalkonline is the award-winning website of the DIPEX charity.  
<http://www.healthtalkonline.org/Autism/>

**Independent Living in Scotland** - This website is for disabled people and the Independent Living Movement and its allies in Scotland. It aims to strengthen the Movement by helping people to Get Connected! and by providing resources and tools so that disabled people can Get Active! and become better equipped to be part of the solution. [www.ilis.co.uk](http://www.ilis.co.uk)

**Learning Disability Alliance Scotland** - is a campaigning organisation that helps people with learning disabilities and their families express their views to politicians on a local and national stage. It works with service users from a number of Scotland's leading voluntary organisations. Over the last few years, it has been involved in campaigns to extend the concessionary travel scheme to all DLA recipients, for

greater control and choice in community care services and for better support for older families still caring for adult sons and daughters. <http://www.ldascotland.org/>

**National Autistic Society Scotland** - provides a range of advice and information services to people affected by autism and professionals/students. NAS help people at any stage in their life, from parents receiving a diagnosis for their child, an adult with autism looking for advice on supported employment, to professionals looking for the latest research.

[http://www.autism.org.uk/en-gb.aspx?nation=scotland&sc\\_lang=en-GB](http://www.autism.org.uk/en-gb.aspx?nation=scotland&sc_lang=en-GB)

- Autism Helpline 0808 800 4104
- Autism Services Directory [www.autism.org.uk/directory](http://www.autism.org.uk/directory)

**NHS Education for Scotland** - Learning Resource on Autism Spectrum Disorders <http://www.nes.scot.nhs.uk/asd/>

**NHS National Institute for Health and Clinical Excellence (NICE)** guideline Autism Spectrum Disorders in children and young people (September 2011) <http://www.nice.org.uk/CG128>

**Northern Ireland Autism Act 2011** - [www.legislation.gov.uk/nia/2011/27/pdfs/nia\\_20110027\\_en.pdf](http://www.legislation.gov.uk/nia/2011/27/pdfs/nia_20110027_en.pdf)

**Number 6** - is a service for adults (16 and over) with High Functioning Autism (HFA) or Asperger Syndrome (AS) who live in the Lothians. The service is provided by Autism Initiatives UK and was officially launched in June 2005, with the opening of the Number 6 One-Stop Shop. <http://www.number6.org.uk/>

**Research Autism** - is a charity which provides free, impartial and scientifically accurate information about autism treatments and therapies. <http://www.researchautism.net/pages/welcome/home.ikml>

**Self-Directed Support Scotland** - The Scottish Government's Self-Directed Support website - your one stop shop for information on Self Directed Support in Scotland. <http://www.selfdirectedsupportscotland.org.uk/>

**Scottish Autism** – is an autism charity that exists to help those diagnosed with autism to lead full and enriched lives and become valuable members of the community they live in. They seek to maximise the individual potential of all those on the autistic spectrum and the organisation is dedicated towards helping them and those who additionally offer support to achieve this aim. [www.scottishautism.org](http://www.scottishautism.org)

- Help and advice 01259 720044

**Scottish Autism Service Network** - Part of the National Centre for Autism Studies at the University of Strathclyde, Glasgow. It provides a professional network for autism in Scotland, with the primary aim of building the capacity of the workforce to

make a difference to the lives of people with autism and their families. The Scottish Autism Service Network structures support networking, access to impartial information through our information hub on their website.

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

**Scottish Centre for Autism** - The Centre works with children and young people age 0-18 years who may have Autistic Spectrum Disorder.

[http://nhsggc.org.uk/content/default.asp?page=s762&loc\\_id=24&loc\\_serv\\_id=2002](http://nhsggc.org.uk/content/default.asp?page=s762&loc_id=24&loc_serv_id=2002)

**Scottish consortium for learning disability (SCLD)** – is a consortium of partner organisations who work together to encourage best practice in the support of people with learning disabilities through training, information, consultancy, research and public education.

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

**Social Care Institute for Excellence** (autism section)

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

**Skills for Health** - Autism skills and knowledge list -

[www.skillsforhealth.org.uk/.../1716-autism-skills-and-knowledge-list-for-workers-in-generic-social-care-and-health-services.html](http://www.skillsforhealth.org.uk/.../1716-autism-skills-and-knowledge-list-for-workers-in-generic-social-care-and-health-services.html)

**Welsh Government – Autism Strategy**

<http://wales.gov.uk/topics/health/nhswales/majorhealth/autism/?lang=en>



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