

# The Scottish Strategy for Autism

## Overview



**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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# **The Scottish Strategy for Autism**

## **Overview**

## 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**

# 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.

The full strategy, which is available on the Scottish Government website, goes into greater detail for those who want to take more time to understand the issues in 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>

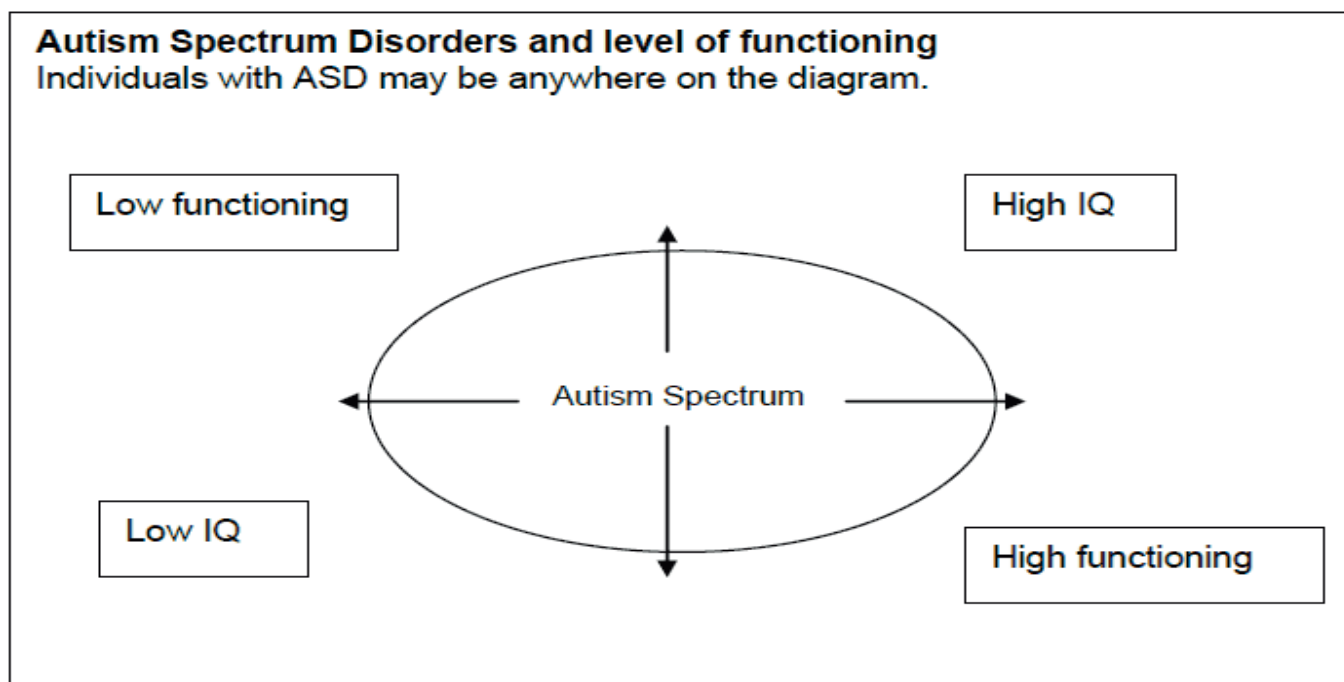


agreeing how the needs of those on the autism spectrum can be understood, integrated and evaluated within these critical structures. Partnership approaches, commissioning service redesign, delivery and performance improvement will be key features in the continuation of this work.

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.
7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.

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

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
<b>GOALS</b>							
<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>			

## **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.

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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**

ADI-R	Autism Diagnostic Interview-Revised
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
COSLA	Convention of Scottish Local Authorities
CPD	Continuous Professional Development
DISCO	Diagnostic Interview for Social and Communication Disorders
GIRFEC	Getting it right for every child
HIS	Healthcare Improvement Scotland
NAS	National Autistic Society
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
PHIS	Public Health Institute of Scotland
SCLD	Scottish Consortium for Learning Disability
SCSWIS	Social Care and Social Work Improvement Scotland – The Care Inspectorate
SIGN	Scottish Intercollegiate Guideline Network
SOA	Single Outcome Agreement
3di	Developmental, Dimensional and Diagnostic Interview

## References

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  - 2 Single Outcome Agreements, Scottish Government, 2007  
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  - 4 Caring Together and Getting It Right for Young Carers, The Carers Strategy for Scotland 2010-2015, Scottish Government, 2010  
<http://www.scotland.gov.uk/Publications/2010/07/23153304/0>
  - 5 A Guide to Getting it right for every child (GIRFEC)(2008)  
[www.scotland.gov.uk/gettingitright](http://www.scotland.gov.uk/gettingitright)
  - 6 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>
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<http://www.sign.ac.uk/guidelines/fulltext/98/index.html>
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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)

## 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/ni/2011/27/pdfs/ni\\_20110027\\_en.pdf](http://www.legislation.gov.uk/ni/2011/27/pdfs/ni_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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