

Towards an Autism Strategy for Scotland

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Towards an Autism Strategy for Scotland

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The Scottish Government has been working to make things better for people who have autism. They want everyone who has autism to be accepted by their own community. They want people with autism to have meaningful and satisfying lives.

A lot of work has been done, but now the Scottish Government want to know what you think about their plans for the future.

You can get a longer version of this information, which explains things in more detail. It is on the Scottish Government's website at <http://www.scotland.gov.uk/Publications/2010/09/07141141/0>

The list of recommendations (the things we plan to do) are at the end of this paper. These come from the longer version of this information. This will help you give answers to the questions we have asked.

If you need more information contact

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Autism

Autism is a lifelong condition. It is usually called autism spectrum disorder or ASD.

Autism affects people in different ways. Some people are able to live independently. Others need a lot of support.

Everyone who has autism has problems with

- Communication
- Getting on with other people
- Routines and behaviour

Some people with autism are quite clever, but do not have the skills they need to be able to keep a job or to live independently.

The Government has done some work to find out how many people with autism live in Scotland. It needs to know this so that it can plan the support that people need. They think that about 1 in every 100 children have autism. There are more boys than girls.

What has been done so far

The Scottish Government has already done a lot to make things better for people with autism. They have

- Set up an Autism Spectrum Disorder Reference Group
- Written information for health and social care staff who work with people with autism.
- Done a lot of work to help doctors and others identify people with autism.
- Set up one-stop shops in Edinburgh and Glasgow to offer information and support to adults with autism.
- Given money to set up the National Centre for Autism Studies at Strathclyde University.
- Improved training about autism for front-line staff in health and social care.
- Set up a Scottish autism network to help people with autism find services that can help them.
- Made sure that there was better information for health professionals, parents and carers

They have made new laws to make sure that all children and young people get the extra help they need at school.

They have also told local councils and health boards what they need to do to make things better for people with learning disabilities, including people with autism.

What we plan to do next

The Autism Spectrum Disorder Reference Group will

- Tell Government Ministers how things are changing for people with autism every year.
- Help people with autism and carers to be involved in making local plans for services.
- Check that good support services for people with autism are available
- Hold events so that people can share good ideas
- Give councils, health boards and others advice about how to provide good services for people with autism
- Improve the training on autism that is available
- Look at research that will help people with autism deal with some difficulties they face

Have your say

Now the Scottish Government wants to know what you think about their plans.

You can tell the Scottish Government what you think by answering the questions at the end and sending them by email to peter.kelly@scotland.gsi.gov.uk

or by post to

**Peter Kelly
Scottish Government
Care & Support Team
Adult Care & Support Division
Are 2ER
St Andrew's House
Regent Road
Edinburgh EH1 3DG**

If you have any questions contact Peter Kelly on 0131 244 2249.

Send your answers back by **Thursday 9 December 2010**.

Because this is a Scottish Government consultation we have to ask for some information about you.

Name _____

Address _____

1.1: Do you represent a group?

Yes tell us the name of the group _____

No

1.2: Can we share your answers with the public?

Yes

No

1.3: Can we share your name with the public?

Yes

No

1.4: Can we share your address with the public?

Yes

No

1.5: Can we get in touch with you again if we want to talk to you about your answers?

Yes

No

You are welcome to say things about any of the work that we have done so far. We particularly want to know what you think about these things.

Diagnosis - Recommendations 6-15

Have we understood the issues?

What is your view on what we plan to do?

Are there other things we should add?

Are there examples of good things happening in your area?

Support for people who need it most - Recommendations 16-20

Have we understood the issues?

What is your view on what we plan to do?

Are there other things we should add?

Are there examples of good things happening in your area?

Standards - Recommendations 21-22

Have we understood the issues?

What is your view on what we plan to do?

Are there other things we should add?

Are there examples of good things happening in your area?

Staff education and training - Recommendation 23

Have we understood the issues?

What is your view on what we plan to do?

Are there other things we should add?

Are there examples of good things happening in your area?

Research - Recommendations 24-26

Have we understood the issues?

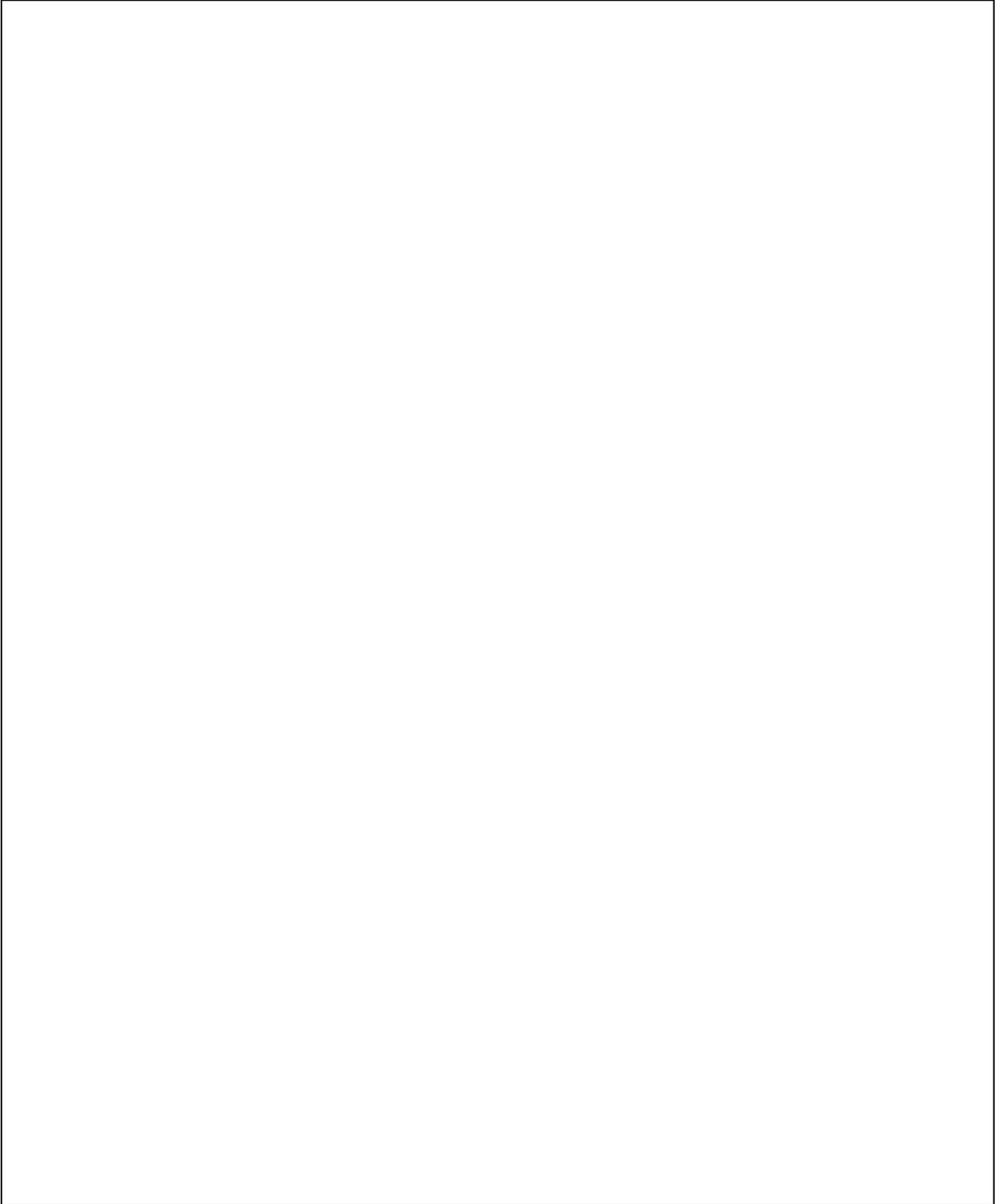
What is your view on what we plan to do?

Are there other things we should add?

Are there examples of good things happening in your area?

General

Do you think we have missed anything out?

A large, empty rectangular box with a thin black border, intended for the user to provide their answers to the question above.

Send your answers back by **Thursday 9 December 2010.**

List of recommendations (things we plan to do). These come from the longer version of this information.

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.

3-4

RECOMMENDATION 2

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.

3-5

RECOMMENDATION 3

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.

3-9

RECOMMENDATION 4

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.

3-10

RECOMMENDATION 5

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.

3-10

RECOMMENDATION 6

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.

3-26

RECOMMENDATION 7

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.

3-27

RECOMMENDATION 8

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.

3-27

RECOMMENDATION 9

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.

3-27

RECOMMENDATION 10

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.

3-28

RECOMMENDATION 11

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.

3-28

RECOMMENDATION 12

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.

3-28

RECOMMENDATION 13

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

3-28

RECOMMENDATION 14

It is recommended that agencies and services develop a menu of interventions including therapeutic interventions and counselling for children, young people and adults with an ASD that are immediately available, appropriate and flexible to individual need.

3-31

RECOMMENDATION 15

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

3-32

RECOMMENDATION 16

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.

3-36

RECOMMENDATION 17

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.

3-37

RECOMMENDATION 18

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.

3-38

RECOMMENDATION 19

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.

3-42

RECOMMENDATION 20

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.

3-45

RECOMMENDATION 21

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.

3-46

RECOMMENDATION 22

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.

3-50

RECOMMENDATION 23

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.

3-53

RECOMMENDATION 24

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.

3-55

RECOMMENDATION 25

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.

3-55

RECOMMENDATION 26

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.

3-55



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