

These responses are from a consultation event facilitated by the Scottish Autism Network at the University of Strathclyde on Saturday 13th November 2010. Those attending worked in small groups and included parents, individuals with AS and professionals. These notes are as recorded at the time.

Overview comments about the document

Group Notes and Recommendations	Additional Comments
Strategy a good precursor to Bill	
Great strategy if done under the Bill as there would be enforcement of the recommendations and accountability	Who would be enforcing and to whom would they be accountable?
View of autism is out-of-date	
Aspirations are good, but strategy should not focus on learning difficulties or mental health issues. Autism falls in the middle Need autism to be recognised as a separate condition	Autism should not be constrained to mental health problems Needs separate funding
Targets need to be set in relation to Strategy	Grassroots want things implemented and disseminated quickly
Link to work of Children's Commission	
Many of the initiatives, particularly the generic ones, have never been heard of in relation to ASD. (E.g. Local area coordinators, Transition Officer, SCLD)	
The make up of the ASD reference group was called into question for its lack of representation from people with Asperger syndrome, specifically a person who was solely representing the AS community and not professionals working in the field	
The language used is not 'strategic' but 'tactical' i.e. not a strategy but a collection of (good) tactics	
Document not easy to read. Too 'wordy' with too many acronyms	

Diagnosis Recommendations 6-15

<p>General approval noted for this set of recommendations</p>	
<p>There is a need for Diagnostic standards</p>	<ul style="list-style-type: none"> • There should be autism standards in every service • More quality control • Properly funded
<p>There is a need for Counselling standards</p>	<ul style="list-style-type: none"> • Properly funded
<p>Any strategy must be clear on the expectation of diagnostic pathways being in place. Equity of services should be the aim across Scotland. Services should be needs led although diagnosis does not routinely lead to help</p>	<ul style="list-style-type: none"> • Good practice in some areas was recognised but there needs to be agreement/ clarity of services offered
<p>Referrals-there needs to be services to be referred to</p> <p>Focus money on services, especially for adults</p>	<ul style="list-style-type: none"> • Resources are under strain due to wide remit • Must be recognition of the difficulties people with ASD have 'in making the first steps' in accessing services • Post-diagnostic services are poor. Move effort into post-diagnostic services. • Need for immediate availability. Address panic around every-day events. For adults who are living independently'
<p>Particular problems were highlighted with general psychiatry</p>	<ul style="list-style-type: none"> • There is a serious lack of appropriate mental health services/support • General Psychiatrists are not 'experts' in the field • Properly funded • Unrecognised co existing conditions or incorrect diagnosis along with inappropriate (and therefore ineffective medication) is unacceptable

A more holistic treatment approach is needed	
SIGN Guideline need reviewed in light of recent new research Biomedical inventory NICE should be involved	<ul style="list-style-type: none"> • SIGN Guideline for adults was welcome- may be as effective as SIGN 98 in harmonising diagnostic process/ ongoing care for individuals. • Consultants and GP's must have an open mind. Traditional thinking needs to be challenged • Assessment of treatments/causation
Suggestion of establishment of 'neuro-developmental diagnostic centres' that work across the age span (children – adults)	
Glasgow was given as an example of service redesign- the new pathway was poorly accepted by some and felt to be discriminatory, particularly in relation to the non-white population who culturally may have difficulties with the stigma of a referral through the mental health route	
Recognition of ASD within the Criminal Justice Service	<ul style="list-style-type: none"> • Training within system. Ability to refer for diagnosis
Continuity needed across Scotland	

Support for people who need it most Recommendations 16-20

Access to lifelong learning	
Support and training (not within the confines of learning difficulties)	<ul style="list-style-type: none"> • Available to everyone, at least one hour a week. ASD specific
An evaluation of the employment framework absolutely essential.	<ul style="list-style-type: none"> • Viewed by some as one of the most significant recommendations <u>must</u> be effective and must be 'beefed up' within the strategy.
Less research and more therapeutic services. ASD specific services	<ul style="list-style-type: none"> • Therapeutic services deprioritised at present

Everyone with AS should have an advocate	
Money for services should be 'ring-fenced'	<ul style="list-style-type: none"> • At present the Scottish Government has no plans to ring-fence services • No funding to implement Carers Assessment
<p>Cost effectiveness is good- do not spend any money on things that do not work or on 'vanity projects'</p> <p>Cost-effectiveness should not be the only criteria as to where services are cited</p>	<ul style="list-style-type: none"> • Most tend to be inner-city based
Sharing of good practice models	<ul style="list-style-type: none"> • The ARC: Glasgow • Number 6: Edinburgh • Specialisterne Glasgow
Strong recognition was expressed on the need and value of an ASD hub for recognition/ dissemination/ evaluation of good practice across Scotland.	
Every local authority/CHCP should have an ASD lead officer who is accessible to parent/carers and people with ASD	

Standards Recommendations 21-22

<p>Need for autism-specific standards/enforcements/rights</p> <p>At present there is 'eclectic' support due to no standards being in place</p>	<ul style="list-style-type: none"> • ASD should be recognised as a separate condition
<p>Recommendation 21</p> <p>Unclear statement. Issues around dissemination.</p>	<ul style="list-style-type: none"> • What will the benefits be?
Poor service delivery	<ul style="list-style-type: none"> • Services are failing in the middle • Parents delivering 75% of care with no budget
There should be separate funding for ASD.	<ul style="list-style-type: none"> • New category, not funded in the same way. 'A unique condition'
Strategy has not addressed issue of compulsory training for professionals	<ul style="list-style-type: none"> • No recommendations linked to recommendations in training

in contact with people with ASD	framework in terms of actually taking up training
Enable service users to make policy	

Staff education and training Recommendation 23

Need to review up-to date information the professionals are using	
<p>Deficit in medical training across all areas</p> <p>More training for medical establishment. Diagnosis should be made by a competent practitioner</p> <p>Should be a two way partnership between doctor and patient</p>	<ul style="list-style-type: none"> • Insufficient expertise with ASD. • Adult mental health professionals urgently require ASD specific training and in understanding that ASD is, and will continue to be, part of their caseload. • Arrogance of some medical professionals. 'Who is the service run for?'
Currently no overall strategy for supporting children at school	
Nothing in recommendations about training for service providers, benefits agencies etc.	
Little support available for transition into Higher/Further education	<ul style="list-style-type: none"> • More information on how to access support
<p>Better training for teachers</p> <p>Pedagogy to include treatments/tools</p>	<ul style="list-style-type: none"> • Limited training for teachers at present • More need for practical application of training within classrooms • For example: ABA, SonRise
<p>Better training within the Criminal Justice Service</p> <p>Better education for people in prison with ASD.</p>	<ul style="list-style-type: none"> • Awareness of ASD within the Criminal Justice Service

Research Recommendations 24-26

Research should not be controlled by pharmaceutical companies	
Who controls discussions into the commissioning of new research?	<ul style="list-style-type: none"> • Who controls the budget relating to commissioning evaluation of existing research.

Funding made more readily available	<ul style="list-style-type: none"> At present funding is difficult to access. Medical Research Council recommended various aspects that required research, but no funding is available
Not enough research into adults/ ageing	
More evaluation of approaches	
More collaboration in research is required.	

New Recommendations

- Development of a visual map of services across Scotland- this would aid the recognition/dissemination and evaluation of good practices.
- The ASD community should be encouraged and enabled to support itself through various methods.

Other comments:

What is the strategy for managing ‘the strategy’ and ensuring its implementation?

Will it be guidelines with no mandatory rights?