

SUBMISSION FROM RONA MEMBURG

SP Bill 44 Autism (Scotland) Bill (as introduced)

Section 2(1) – Guidance by the Scottish Ministers

1. This must be robust as just as the guidance under the Education (Additional Support for Learning) (Scotland) Act 2004 shows a lottery per child, per family, per service, per region can make for good outcomes for some individuals with autistic spectrum conditions (ASC) but dangerous situations for others and stressful and distressing situations for parent carers (past media reports have shown this but still very little research on ASC carer outcomes and AS female outcomes).

Section 4 - Interpretation

2. Under section 4(1)(c) re research, a request to revise medical terms such as 'retarded' and other deficit 'medical' terms should be included. They are used as derogatory and deter inclusion whether that is in health or the community. Medical deficit language implies inability and disorder rather than prevention and enabling. This needs to include the World Health Organisation (WHO) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Disorders (ICD) review teams who are acting on new guidance now.
3. Also are the Disability Rights Commission (DRC) and Disability Discrimination Act (DDA) to be included anywhere as regulations on accessibility are very unclear as to where ASC is to be included. ASC has to fit under mental health (MH), learning disabilities (LD), sensory and is only partially recognised under communication access, ie, where does the sensory environment get included re glass glare, lighting, colour, paper formats, noise (even to be included under things such as pavement planning, crossing noise with lights). Missing this sector out has been shown for instance in disability access for buses where good guidance on wheelchair access missed out on access for walking frames or poor leg lifting. Please include guidance to include for instance the 'A' word because until we actually identify autism spectrum in its own right there will always be confusion as to whose role or department it comes under and of course misses out other needs such as neurological, sensory, perceptual and biological differences.

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Paragraph 5

4. Glad that 'condition' is recognised rather than 'disorder' as ASC is a neurological difference which implies there are benefits to society rather than a disorder which implicates cost to society. Hopefully this will be consistent through this Bill and the strategy as there is a mismatch at the moment. Hopefully it will also enable staffs to be enabling and value people with ASC then try to 'cure' them. Though this does not mean we do not have to use ASC friendly initiatives, identify and meet ASC health needs.

Paragraph 10

5. It would be good to put in a date or refer to an annual review and tie this up also with the strategy as both appear to only need either a review at some point or one annual review. As there has never been a consistent recognition or service or identification of needs and no identification on some ASC populations, ie, females, medical outcomes, then a consistent review date should encourage further findings/papers from many service types (five years annual enough to embed and disseminate?).

Paragraph 12

6. Again date needed and refer to 'community engagement' and 'patient focus and public involvement (PFPI) good practice' and add these into the strategy too so that every stakeholder knows how to include good participation as some consultation practices decide the outcome then frame questions on those to give out to the public and very poor practice has been evident where carers of ASC adults are included but the ASC adults themselves are missed out as being unable to participate, this is especially seen in some 'advocacy' circles. More adults with LD are evident in consultations than adults along the ASC spectrum.

Paragraph 13

7. 2011? LA and NHS?

Paragraph 15

8. Re third bullet point, add in that the proposed guidance should also identify the difference in male and female ASC service needs, ie, screening services, relationships health.
9. Re fourth bullet point, even though the 2004 Act gives good guidance on the ground in the run up to the transition for a young person (YP), those aged between 14 to 19 are still not being picked up/planned for until their last year of school and still not engaging with health, housing, employment and relationship/adult issues until the YP is due to leave. The most vulnerable at this stage are the most perceptually and wrongly perceived those YP diagnosed with Asperger Syndrome (research still much unknown on female YP and their later outcomes). Some may say we should not silo ASC/AS but if all aim to cover their needs, we will pick up other needs, ie, BI, ADHD, MS, LD/ASC, borderline diagnosis, MH.

Paragraph 17

10. And add in inclusion into generic services such as screening men and women and as a duty the differences needed as in the Equality and Diversity tools/acts/guidance with all the strands and ASC in mind as these will throw up wider needs i.e. older people's services.

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Paragraph 24

11. Add how this will be PR'd to carers and those with ASC as too often seen in LD services where staff own the guidance or strategies and those they were aimed for do not know they are theirs to act on and own for themselves. This also includes the strategy document.

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Paragraph 4

12. Re possible fourth bullet point, lack of ASC environmental and communication needs awareness costs the NHS higher as these individuals come into services later in crisis or with poorer health.

Paragraph 16

13. Now that we have the *Act against Harm* campaign, which ties in abuses to other population types, Highland for instance has tied this into the Adult Support and Protection (Scotland) Act. This helps include the perceived more able on the ASC spectrum but again this needs to be taught in schools as vulnerable YP do not know this act is for them to call upon not just have done to them or acted upon by staff. This should be firmly tied into the 'lifelong learning in 15' 2004 Act along with friendships, relationships and sexual health training

Paragraphs 17 to 20

14. The most stable needs count can be done via education as the needs are less transient in this population, AS numbers disappear for a few years before coming back into services at crisis point. This data should be shared throughout all local authority and NHS services and in turn clinics should share their data as housing and generic clinics as well as centres and employment need to know who to possibly plan for.

Paragraph 21

15. It is not just about being unprepared in using services but taking in preparing for independence and being better prepared for adult life and relationships, ie, going into employment and being able to deal with the multi relationship types and considering options and implications and possible dangers.

Paragraph 26

16. Suggest an extra point after paragraph 26 re the lack of data on life outcomes especially for women, again access to gender health, advocacy services which can be too 'pure' to meet ASC needs where all options and implications can be discussed for a real ASC self choice.

Paragraph 30

17. Add a gap in parents with ASC needs as very little data and a service assumption that all the ASC spectrum need care doing to them. Parents with ASC have trouble getting help for their children as it is their needs

are missed firstly and not assumed to exist, yet if it is a genetic cause, then services need to assume an ASC parental need.

18. I will also put in a response to the Scottish Government's consultation on its strategy.¹

Rona Memburg
25 September 2010

¹ Please note that this can be obtained in hard copy from the clerks to the Committee