

SUBMISSION FROM AUTISM RIGHTS

1. To begin with, I will answer the questions contained in the call for evidence for the Autism (Scotland) Bill.

Policy Memorandum and Financial Memorandum accompanying the Bill

2. The Policy Memorandum fails to draw the very obvious conclusion from the picture of failure that it paints, that all the various “initiatives” that it outlines have failed to make improvements to services because of the absence of any usable standards for those services. A generic approach to standards, whether mainstream or to incorporate adaptations for people with disabilities, is unusable for people with an autistic spectrum disorder (ASD), because of the specialist needs of this population.
3. The Financial Memorandum fails to make a good case for the Autism (Scotland) Bill. If there are no costs, then there are no benefits from this Bill. **The real point is not cost, but who is bearing that cost.** The reality is that costs are being downloaded, financially and in every other way, onto people with ASD and their families. Many of us are taxpayers, and we are paying for the services enjoyed by everybody else. No cognisance has been taken in the Scottish Government's submission relating to the Autism (Scotland) Bill of the costs of not providing services appropriate to the needs of people with ASD, not least the irreparable damage to the health of people with ASD and their parents and the loss of income to families like ourselves, who are forced to provide the services that local authorities refuse to provide.
4. Autism Rights commends the stipulation made in the Explanatory Notes to the Bill that all stakeholders – including groups representing people with ASD – ***“will be actively involved in the development of the Autism Strategy` and its accompanying Guidance `rather than only being able to respond through the consultation process”***. It is therefore of concern to us that the Scottish Government's recently published draft autism strategy was put together by the recently re-constituted ASD Reference Group, which contains only professionals, civil servants and representatives of service provider businesses. Not a single representative of a service user organisation, such as our own, has been considered for membership of this policy-making body. This is bad enough in itself, but the ASD Reference Group and its sub-committees have made significant mistakes to which one legal challenge has been made successfully and to which others will undoubtedly follow, without the inclusion of service users in discussion and formulation of policy.

Consultation the Scottish Government carried out prior to the introduction of the Bill

5. What Scottish Government consultation? The consultation was carried out by Hugh O'Donnell MSP, not by the Scottish Government. We

believe that it should not have been possible for contributors to this consultation to hide behind a cloak of anonymity. If public servants hold views that are prejudiced towards people with ASD and their families, it should, at the very least, be a matter of public record through online publication.

6. Hugh O'Donnell's consultation asked a series of questions, I'd like to incorporate our answer to the first question here, as it encapsulates our approach to the whole issue of an autism bill—

Q.1 Would people with autism in Scotland benefit from a national strategic approach?

7. Only where there are national **standards** specific to the needs of people with ASD, **enforcement** of those standards by government, **accountability** for services through enforcement of standards and equal **rights** to those services. There have been “duties” placed upon local authorities and health boards for years, and it has made no difference whatsoever to the provision of appropriate services for people with ASD.
8. For Autism Rights' suggestions on how to frame the appropriate standards, see our *Proposals for Autism Services in Scotland*—
<http://www.autismrights.org.uk/AutismRightsProposals.html>
9. In further analysis of the real reasons for the absence of services appropriate to the needs of people with ASD, I have split the rest of this evidence into 4 main sections. Supporting references follow on from the end of this text.

Examples of failure – absence of appropriate services caused by—

10. Absence of specific funding, caused by absence of **statistics**. One of the main recommendations of the Public Health Information Service (PHIS) *National Needs Assessment Report on ASD*, 2001, was that the government must gather statistics on the number of people with ASD in Scotland. Please see Autism Rights' evidence on the 2011 Census to the parliament's EET committee for a fuller analysis of this issue.ⁱ
11. Absence of enforceable **standards**. It is the central government's job to enforce standards through legislation and statutory regulation. There is no need for local “adaptations” and local accountability does not exist for minority groups. The oft-claimed “**postcode lottery**” for services is a red herring. The issue here is **standards** and these are not set by local authorities.ⁱⁱ
12. Absence of specific funding, caused by absence of **statistics**. Nearly ten years after the publication of the *National Needs Assessment on ASD*, there are still no statistics available. If “surveys” were going to provide that information, successive governments have had ample opportunity to put these in place.

13. Whilst statistics on the numbers of children with ASD are still open to dispute, there have been no credible attempts to gauge numbers of adults with ASD, particularly those currently either inpatients or outpatients of mental health hospitals or units. **These statistics are necessary to plan and properly budget for ASD services.**
14. It is the job of governments to establish these figures and to establish how many of these adults are being subjected to a regime of dangerous drugs, simply to avoid expenditure in properly caring for them. Services that are specifically for adults with ASD in Scotland make provision for a tiny number of adults with ASD and are subject to renewal or revocation of contracts.
15. Absence of enforceable standards. Training will only be delivered effectively if standards dictate that qualifications must be obtained. At present there are few qualifications available in ASD - the Scottish Vocational Qualifications (SVQs) for carers and the professional post-graduate course in ASD at Strathclyde are the only ones in Scotland.
16. There are no educational standards for children with an ASD - no adapted curriculum, no quality indicators for school inspections, no teaching qualification - just un-assessed day release "courses", and not even that in some cases. Postgraduate courses at Strathclyde and Birmingham universities are cross-professional and are not teaching courses. As a teacher said to me, "I don't want to know *about autism*, I want to know *how to teach children with autism*". Educational centres of excellence will be needed to provide **a range of educational provision**, as many local authorities expect most autistic children to be taught within mainstream classes.
17. **Autism Rights is also calling for independent assessment of need to be embedded within legislation for ASD.** This is one of the rights specified within the European Charter of Rights for Persons with Autism.ⁱⁱⁱ The **Lamb Report**, which was commissioned by the UK Department of Education, recently recommended that educational assessments should be independent of service providers. The Department of Education has accepted this recommendation.

Downloading costs onto people with ASD and their families – school exclusion, part-time and home education, loss of income and pensions, drugging by default, damage to health, both mental and physical

18. Psychotropic (Psychiatric) Drugs are the default "treatment" of choice, in the absence of services that have autism-specific standards. Years of inappropriate and stressful experiences cause considerable distress to children and adults with ASD – but there is no official acknowledgement of this, because of the drive to keep down costs. All too often the health service compounds the distress caused to people with ASD, which manifests itself as `challenging behaviour`, by using psychotropic (psychiatric) drugs to attempt to control these externalised behaviours, rather than meet the needs of the person. This usually results in making

these behaviours worse, because of the metabolic and immunological disorders that have been identified in people with ASD. No account has been taken within current policy of the severe, life-shortening health effects of these drugs.^{iv}

The “active involvement” of service users must be a prerequisite of Autism policy formation, because of mistakes made by those representing professionals and service provider businesses

19. A closer look at some of the government's `initiatives` reveals a track record that is somewhat less competent than the version presented in the draft autism strategy.

20. **Autism Toolbox** - the “**Autism Toolbox**” is nothing more than a series of “tips”, very much along the same lines as those available on Teacher.Net for some years prior to the publication of the Autism Toolbox. This is no substitute for educational standards specific to ASD, including a **mandatory** teaching qualification in ASD or Special Education, neither of which is currently available in the UK.

21. **Parent's successful legal challenge to government policy.** One parent has been successful in forcing the Scottish Government to change its guidance on the teaching of children with ASD.^v Christine Mahoney, with the support of Govan Law Centre, pointed out that the Scottish Government's guidance on the education of children with ASD, their Autism Toolbox, was misleading in its advice as regards Applied Behaviour Analysis (ABA), which is the main educational methodology used in the USA. Moreover, the independent experts brought in by the Scottish Government to review the guidance “concluded that the inaccuracies contained within the ABA section were so significant that they could not be supported by any of the prevailing views. Now the entire ‘overview of interventions’ section is to be rewritten after the experts found other factual inaccuracies”.

22. The Autism Toolbox had dismissed ABA out of hand, but had elevated an “eclectic” approach to autism education well above this, in spite of the absence of any research evidence for the effectiveness of this approach, even where teachers have received some training in autism. The US standards for autism education give the “eclectic” approach a poor rating for effectiveness, but give ABA a high rating, due to the quality of the research evidence available.^{vi}

23. **Scottish Intercollegiate Guidelines Network (SIGN) clinical guidelines** - should be completely reviewed in the light of changes to be made to the Autism Toolbox. The change that has been forced by Christine Mahoney to the Autism Toolbox should, logically, be extended to the SIGN clinical guidance, which is also dismissive of ABA. Even though the SIGN guidance is supposedly a set of clinical guidelines, it also gives guidance on educational methodologies.

24. Moreover, the SIGN committee was, as with the ASD Reference Group,

composed entirely of service providers, with not a single representative of a service user organisation. As such, no cognisance was taken by the SIGN guidelines of the parlous state of autism services and the effect that this has on the health and wellbeing of children and young people.

25. **Scottish Autism Services Network (SASN)** - the “participation principles” of the SASN stipulate that all participants must “respect” the views of others, but prohibit discussion on anything other than “good practice”. Parents who have tried to participate in this network have been utterly demoralised by this proscription, as they have not experienced any “good practice”. It is surely sensible to have open and honest discussion of policy and practice.

Regressive legislation and policy

26. Legislation, regulation and policy that have been introduced over the past ten years, whilst generally perceived as a driver to improvements in services, have entrenched and exacerbated some very regressive practice.^{vii} To give an example, some parents have faced the threat down the years that, if they did not agree to a course of drug “treatment” for their son, that their son would be sectioned and forced to take the drugs anyway. Now, the new Mental Health Acts for both Scotland and the rest of the UK have simply formalised this practice through the creation of community treatment orders (CTOs), which are a means by which the mental health system can force both adults and children to take psychotropic drugs in the community, rather than within a hospital or unit.^{viii}
27. Autism Rights' view of the **Mental Health Act** accords with a key recommendation by the Millan Committee which was endorsed by the McManus Review of 2009 - that people with learning disabilities should be taken out of the provisions of the Mental Health Act.
28. This issue merits just one paragraph in the McManus Review, and it is buried in chapter 7 under *Other Issues*.^{ix} It is not in the list of recommendations made, in spite of its revolutionary nature as regards historic and current service provision for people with learning disabilities. In consequence, the Scottish Government has failed to respond to this issue in its response to the McManus Review. No mention is made anywhere in the McManus Review of ASD, so we must surmise that the review group included ASD within learning disabilities.
29. How much longer do we have to wait before yet another opportunity arises to review mental health legislation, to reflect the needs of people with learning disabilities and ASD, who are routinely subjected to control by dangerous drugs, as a consequence of poor to non-existent service provision and wholly inadequate understanding of ASD by service providers, most importantly mental health services?
30. Autism Rights' view of the **Adult Support and Protection (Scotland) Act 2007** is endorsed by both Inclusion Scotland and People First,

although Inclusion Scotland's analysis of this Act did not take into account the additional problems of this Act for people with ASD, or indeed those with learning disabilities.^x In spite of concerns that were initially expressed by politicians of the human rights implications of this legislation, and our own concerns about the strong likelihood of conflicts of interest, no action has been taken to review or otherwise re-examine this legislation.

31. To conclude, if we don't see real progress on the issues that we have raised in this evidence, Autism Rights believes that it is only a matter of time before a human rights case is brought to a successful conclusion in the courts.
32. ***One parent summed up our feelings about "the system" - "it just seems to me that, over the years, we have spent more and more money employing more and more people to stop our children getting the things they need."*** 'EQUAL RIGHTS - NOT ENDLESS FIGHTS' www.autismrights.org.uk

Fiona Sinclair, on behalf of Autism Rights
8 October 2010

ⁱ Evidence to Scottish Parliament's Economy Enterprise and Tourism Committee (the lead committee on the census) on 2011 Census for Scotland. Links for our written evidence and submissions by members in support of this evidence—

<http://www.scottish.parliament.uk/s3/committees/eet/papers-10/eeep10-09.pdf>

(go to Agenda item 2, Note by the Clerk click on EET/S3/10/9/5, which will take you to our evidence).

<http://www.scottish.parliament.uk/s3/committees/eet/papers-10/eeep10-12.pdf>

(go to Agenda item 2, Note by the Clerk, and click on EET/S3/10/12/6 - see Autism Rights' Submission 3 for the numbered points that provide a critique of the final draft of the Census question.)

Further correspondence with Scottish Minister for Enterprise, Energy and Tourism and General Register Office for Scotland and with professional bodies. One of the main recommendations of the Public Health Institute for Scotland (PHIS) National Needs Assessment on Autistic Spectrum Disorder (ASD) of 2001 was that there was a pressing need for reasonably accurate statistics of the numbers of people with ASD.

<http://www.scottish.parliament.uk/s3/committees/equal/reports-10/eor10-04.htm#annb>

EXCERPT

25. A recurring theme in the Committee's work, has been the lack of available baseline equalities data on which comprehensive and meaningful scrutiny of equalities impacts can be undertaken. The Committee has encountered the same difficulties in relation to scrutinising this Act.

26. The Committee is also concerned about the lack of data monitoring that is undertaken. Whilst it recognises that data regarding age and gender is monitored effectively, there are gaps in data on other equalities strands. The Committee is particularly concerned by the gaps in ethnicity data and lack of awareness of ethnicity monitoring being a legal requirement. There is a need to capture these statistics so that the Mental Welfare Commission can make a comprehensive assessment of whether the Act delivers on its equalities duties.

27. The Committee acknowledges that there are challenges in capturing this data, however, it believes that these challenges are not insurmountable, if for example there were to be greater flexibility in terms of when the data is collected. It supports the point made by NHS Health Scotland that awareness raising and guidance for NHS staff can help to overcome these barriers. The Committee believes that NHS Health Scotland initiatives on equalities training should be further encouraged.

28. The Committee learned that there is no quantitative data captured regarding religion, sexual orientation or disabilities (other than learning disabilities). The Committee recognises that some qualitative data on these equality strands is captured by the Mental Welfare Commission through the assessments it makes on visits to people subject to the Act. The Committee however is keen to ensure that as complete and accurate a picture of people subject to the Act is established. The Committee asks the Scottish Government to consider the scope for capturing more data regarding all the equality strands.

ⁱⁱ <http://www.nationalautismcenter.org>

- US National Standards for autism. **As currently framed, neither the current proposals for Scotland, nor the Autism Strategy for England will actually provide Standards for Autism Services.** Already, the Westminster government is refusing to accept a major thrust of the Autism Strategy—

<http://www.communitycare.co.uk/Articles/2010/03/03/113941/autism-strategy-no-requirement-to-set-up-specialist-teams.htm>

- Autism strategy: No requirement to set up specialist teams. Without development of specialist services, there is no hope of providing appropriate services for people with ASD. The denial of the need for specialism has obstructed service development, that is why the NAS and other autism campaigners were insisting on this provision within the Autism Strategy.

ⁱⁱⁱ <http://www.autismeurope.org/publications/rights-and-autism-2/>

<http://www.autismeurope.org/publications/rights-and-autism-2/charter-of-rights-4/>

^{iv} <http://www.dinahm.pwp.blueyonder.co.uk/index.htm>

- information on the effects of neuroleptics (antipsychotics) on people with ASD

<http://www.ahrp.org/cms/content/view/604/67/>

- antipsychotics and children <http://www.ahrp.org/cms/content/view/727/9/>

- Another Risk of Death Linked to Atypical Antipsychotics. Thursday, 23 September 2010. "The risk was greater for individuals prescribed atypical rather than conventional drugs." Antipsychotic Drugs and Risk of Venous Thromboembolism: Nested Case-Control Study BMJ. Full report available at— <http://www.bmj.com/content/341/bmj.c4245.full.pdf>

US Psychiatrist and expert witness who has successfully testified on behalf of people who have been damaged by psychotropic drugs—

<http://www.breggin.com/>

http://breggin.com/index.php?option=com_content&task=view&id=51&Itemid=92

http://breggin.com/index.php?option=com_content&task=view&id=38

<http://www.youtube.com/watch?v=hW0XjrBpb2U&NR=1>

http://www.youtube.com/watch?v=qyp97e_MWKI&feature=related

Elle s'appelle Sabine (Her Name is Sabine) – clips from the film by French film actress Sandrine Bonnaire, making her directorial debut in this film about her autistic sister, Sabine Bonnaire. If you want to be able to compare the difference between a person with autism before and after 5 years of incarceration and enforced medication, this it.

<http://www.medicalnewstoday.com/medicalnews.php?newsid=23937>

- Children with autism have distinctly different immune system reactions compared to typical children 06 May 2005

<http://www.medicalnewstoday.com/medicalnews.php?newsid=22178>

- Autistic children's abnormal metabolic profile findings 03 Apr 2005

^v <http://www.tes.co.uk/article.aspx?storycode=6048622>

- Government guidance on autism to be rewritten as mum finds flaws News | Published in TESS on 25 June, 2010 | By: Emma Seith

^{vi} <http://www.nationalautismcenter.org>. US National Standards for autism

^{vii} See Autism Rights' Briefing Paper, Briefing Paper *'Incompetent, Abusive, or both? - Scottish Executive policy and legislation on Autistic Spectrum Disorder'*

<http://www.autismrights.org.uk/BriefingPaperIndex.html>

<http://www.autismrights.org.uk/MainText.html>

^{viii} <http://www.opsi.gov.uk/legislation/scotland/acts2003/20030013.htm>

Mental Health (Care and Treatment) (Scotland) Act 2003 asp 1

<http://society.guardian.co.uk/socialcare/story/0,,1951251,00.html>

- Charities vow to challenge new mental health bill David Brindle Saturday November 18, 2006 The Guardian. Charities and groups representing care professionals warned yesterday that the government faces a bitter fight over its mental health bill. The legislation aims to introduce powers of compulsory community treatment and enable preventive detention of people deemed to have dangerous and severe personality disorders.

<http://www.guardian.co.uk/guardianpolitics/story/0,,2016802,00.html>

- Peers curb plan to detain mentally ill Tania Branigan Tuesday February 20, 2007 The Guardian. Peers defeated the government yesterday again over its plans to detain and treat people with mental health problems who have committed no offence. Conservative, Liberal Democrat, crossbench and rebel Labour peers voted by 186 to 115 to ensure that detention and compulsory treatment is permitted only if it is "likely" to help the patient.

The mental health bill aims to safeguard the public by allowing the detention and enforced treatment of people with personality disorders considered a potential danger to themselves and others. But opponents - including many medical professionals - say it lacks proper safeguards and fear it could prove counter-productive, by deterring people with problems from seeking help.

<http://news.independent.co.uk/uk/legal/article2338389.ece>

- Mental Health Bill will do nothing for public safety, research shows By Jeremy Laurance, Health Editor Published: 08 March 2007. The biggest reform of mental health

legislation in 50 years will be thrown into disarray today by research showing a key aspect of the proposals is unlikely to work. Government measures to force patients discharged from psychiatric hospitals to continue taking their drugs, do not improve the safety of patients or the public, according to an international review of research.

^{ix} <http://www.scotland.gov.uk/Publications/2009/08/07143830/0>

- Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: Report. `Learning disability and the law - Persons with learning disability complained to the Review Group about the inclusion of learning disability in the Act. We understand the Millan Committee recommended that this should be reviewed and that the then Government accepted this in its policy paper "Reviewing Mental Health Law". Now, eight years on from Millan, the Review Group feels that it is time this was done.`

See also:-

<http://www.scottish.parliament.uk/s3/committees/equal/reports-10/eor10-04.htm#annb>

^x <http://www.scottish.parliament.uk/business/bills/62-adultSupport/b62s2-aspassed.pdf>

Adult Support and Protection (Scotland) Bill, as passed

<http://www.inclusionscotland.org/news/story.asp?id=2092>>

Bill Scott of Inclusion Scotland raises some major questions in respect of legislative provisions affecting disabled people. This article was first published in the journal of the Scottish Legal Action Group (SCOLAG) about the Adult Support & Protection Act.

<http://www.inclusionscotland.org/news/story.asp?id=2184>

- Locked out again Tuesday, 16 December 2008. User-led groups have been sidelined from vital discussions that could give social workers sweeping powers to invade disabled people's homes. John Pring reports.