

**PE1494/B**

I am pleased to be able to submit evidence on behalf of Autism Rights in support of this petition. Autism Rights has been campaigning for over 2 years now, calling for people with Autistic Spectrum Disorders (ASD) to be taken out of the provisions of the Mental Health Act. The collective experience and evidence of Autism Rights' members is that the Mental Health Act is not compatible with the European Convention on Human Rights.

We are calling for amendments to the Mental Health Act when the Scottish Government presents its Mental Health Bill to the Scottish Parliament in 2014. As a whole, the Mental Health Act underpins a system which hands inordinate amounts of power to those who run it. Scrutiny of the Act must include scrutiny of the system. Legislation should not be divorced from its impact on real people nor fail to take account of real life. It is clear that the deficiencies of the Mental Health Act and its system are much greater than the discrimination that they inflict on people with ASD through including them in the provisions of the Act as a `mental disorder`.

At the Health and Sport Committee's recent `Ask the Health Secretary` session, the Cabinet Secretary was asked 2 questions that I had sent in. He stated that he or his depute would be happy to meet with Autism Rights, that he belongs to a `listening government` and that he wanted to see `justification` for a review of the Mental Health Act. My letter to him, requesting that I meet with him to explain our case for taking people with ASD out of the provisions of the Act, would have arrived that day. I have since received a reply from the Minister for Public Health, refusing to meet with me and stating for the second time that the Scottish Government is not prepared to reconsider its `position` on the Act. Neither I nor my colleagues are miracle workers. It was also notable that, when questioned by Richard Lyle MSP about a possible timescale for review of the Act, the Cabinet Secretary omitted to give any kind of answer. This should be set in its historical context.

In 2001, the Millan Committee agreed with some Learning Disability organisations that people with disabilities should not be included within the provisions of the Mental Health Act, but it considered that such a review should be deferred until an unspecified point in the future. The Mental Health Act 2003 was based on the main recommendations of the Millan Committee. The enactment of the Adults with Incapacity Act should have laid the foundations for a review of mental health legislation. The next review, in 2009 – the McManus Review – also agreed that the inclusion of people with Learning Disability (and, by implication, those with ASD) within the provisions of the Mental Health Act should be reviewed but, given the restrictions laid down by civil servants on the focus of the McManus Review, this did not feature in the main recommendations of their report, and so was again sidelined. Various minor amendments have been made to the Act in recent years, but not one has included even mention of the review that we seek.

Around the time that the Millan Committee was deliberating on what was to become the 2003 Act, there was press coverage of the abuses happening to people with ASD within the mental health system. There were also petitions by Jim Mackie and others, a meeting of some of the affected families with the then Depute Minister for Health, Frank McAveety, and BBC TV's `Frontline Scotland` investigative series produced a programme that consisted of interviews with these families. The press coverage has all but disappeared from the internet, the minutes of the McAveety meeting have likewise disappeared, no action was taken as a consequence of the meeting, and the BBC was prevented from broadcasting its programme and now claims not to have even a single copy of this programme. The broadcast was stopped by a court interdict brought by a Scottish

health board, ostensibly because of the inclusion of one of their patients in the programme.

It has become all but impossible to exert pressure on this parliament or its government through media coverage. The Scottish media now have no interest in this issue. Quite what has changed, we can only speculate about. It leaves us with little option but to compile a report for the United Nations, who may decide to help us. We have asked everybody else. With the help of my colleagues, I will be writing a 'shadow report' for the UN's oversight of the UK's implementation of the Convention on the Rights of Persons with Disabilities (UNCRPD). Given the interest shown in the US mental health system (to which the Scottish system is similar) by the UN's Special Rapporteur on Torture, I will be sending him a copy of this 'shadow report', because we certainly believe that the treatment of those people with ASD that we know of within Scotland's mental health system does constitute inhuman and degrading treatment – Article 3 of the ECHR. We believe that we can make the case that Articles 2, 5, 6, 8, 13 and 14 are also being breached.

People with ASD end up in the mental health system because the Mental Health Act does not require them to have a mental illness before becoming subject to its powers. The Act permits forced drugging and incarceration on the basis of 'challenging behaviour'. Together with other factors, this creates the the misconception that people with ASD are more prone to mental illness:-

- 1) Adult Services do not exist for people with ASD. Current access to services is either through Adult Learning Disability or Mental Health services. Many adults with ASD are directed to Mental Health services, which are geared towards the use of psychotropic drugs.
- 2) Psychiatrists do not recognise key autistic behaviours, at least partly because of a lack of training. The diagnosis for ASD is currently a behavioural one and there is little or no training of psychiatrists of the behavioural, let alone the medical, characteristics of ASD.
- 3) People with ASD suffer from the almost total absence of services that are designed to meet their special needs, even to the extent of being subject to abusive practices, and they will exhibit, quite naturally, signs of distress that are then diagnosed as mental illness.
- 4) There are medical illnesses that can present as mental illness, the most well-known of which is porphyria (as per 'The Madness of King George'). People with ASD are known to possess immunological and metabolic disorders, some of which can result in behaviours that are misdiagnosed as mental illness.
- 5) It is known that, within the population as a whole, about 10% are unable to metabolise psychotropic drugs. Given the immunological and metabolic disorders experienced by people with ASD, it is clear that there is a much greater danger to people with ASD from psychotropic drugs. The associations between violence and self-harm and some anti-depressants are recognised, albeit not widely publicised. So, even the prescribing of these group of drugs to people with ASD is potentially dangerous, as it can be the beginning of a treadmill of psychotropic intervention.
- 6) Physical illness is often overlooked: 'challenging behaviour' can often be the result of pain from medical conditions as diverse as a brain tumour, acid reflux, impacted wisdom tooth, chronic gut disorders

Once in the mental health system, it is almost impossible for someone with ASD to be free of it. The collective situation of people with ASD in the mental health system is never investigated. As stated by the retiring chief executive of the Mental Welfare Commission (MWC) - 'We do not record or monitor ASD specifically and this not (sic) required by us under the Mental Health (Care and treatment) (Scotland) Act, 2003.':-

## Autism Rights' Submission to Petitions Committee for Petition PE01494: Mental Health Legislation

- The MWC does not collate statistics on the numbers of people with ASD who are subject to compulsory treatment under the Mental Health Act
- MWC Monitoring Reports do not monitor people with ASD, as they are not one of the `client groups` of the MWC
- The MWC will only conduct individual investigations on people with ASD, from which lessons are supposed to be learned, but there is no evidence of their application.
- The MWC does not hold information on the numbers of requests to investigate treatment under the Mental Health Act made by the families of people with ASD
- The Mental Welfare Commission does not record the number of contacts made by families of people diagnosed with ASD who ask for further information or advice from it, nor does it record when contact was made during visits to services.

These statistical and informational `black holes` are further exacerbated by a more general absence of data and checks and balances in the mental health system.

- The MWC does not publish statistics on the numbers of deaths of people who are receiving compulsory treatment under the Mental Health Act, and can only give a breakdown of these statistics according to the type of order – see numbers below for the past year<sup>\*</sup>
- There are no mandatory FAIs in the mental health system (unlike the prison system)
- The MWC does not collate statistics on any of the other notifications, such as assaults, that should be reported by healthcare staff
- The MWC does not have the authority to conduct general inquiries
- Decisions on which individual investigations to pursue are not based on written objective criteria
- Formal procedures for individual investigations are based mainly on the skills and experience of MWC officers
- Complaints about treatment within the mental health system are made to the Scottish Public Services Ombudsman, and cannot be made if legal action is to be taken. Mental Health Tribunals are, by definition, legal action.
- Complaints about the conduct of Mental Health Tribunals can only be made to the body that runs these – the Mental Health Tribunals for Scotland (MHTS)

The MWC does not collate any information other than from those who work in the mental health system:-

[http://www.mwscot.org.uk/media/100310/notifying\\_the\\_commission\\_nov\\_2013.pdf](http://www.mwscot.org.uk/media/100310/notifying_the_commission_nov_2013.pdf)

Where are the checks on those who operate the mental health system? How can you possibly enforce compliance to guidance, regulation or law, when all the power is held by those who are employed in the mental health system?

The ongoing international debates on the mental health systems of western / `developed` countries

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\* Deaths  
Compulsory Treatment Order: 43  
Community Compulsory Treatment Order: 20  
Emergency Detention: 2  
Interim Compulsory Treatment Order: 2  
Short Term Detention Certificate 11

are entirely missing from Scotland. You would not believe that there is intense debate elsewhere on the subjectivity of psychiatric diagnoses, the nature and causes of mental illness, the system's total reliance on psychotropic drugs as `treatment`, the adverse effects of these drugs and the need for transparency of research results, to include publication of negative research results. No-one in this parliament is probably even aware that a pharmaceutical corporation has just been given the largest ever fine for a single product – the antipsychotic drug Risperidone – a total of \$2 billion handed out by the US Department of Justice. This fine was for marketing fraud under the Medicare system – persuading doctors to prescribe this drug for purposes for which it had not been approved, including to children. In Scotland, Risperidone is approved by SIGN for `anxiety` in children with ASD. But then, debate within Scotland has effectively been closed by the decision taken not to publish the responses from the government's consultation on its Mental Health Strategy on its own website – a decision that the Cabinet Secretary says he did not know about, and will overturn. We hope that this is one declaration he is willing to honour.

The Scottish Government and Parliament have to take especial care in their future deliberations on policy and legislation that affects people with ASD. The case can be made, with a purported £3 million lifetime cost for each person with ASD and an Autism Strategy that stipulates a policy of `investing to save` only for the 6 – 13% of the autistic population who are considered to be able to hold down a job, that there is an economic incentive in including people with ASD in the provisions of the Mental Health Act because it makes it far more likely that they will at some point be forced to take drugs that are known to shorten life-expectancy, being the most important contributors to the average 10 – 25 year decrease in life expectancy of those who receive compulsory `treatment` under the Mental Health Act.

We hope that the Scottish Parliament will take heed of the Reid Foundations' Final Report of the Commission on Fair Access to Political Influence, to which we contributed, and make sure that `marginalised voices` like those of Autism Rights and Psychiatric Rights Scotland are invited to give evidence to the Health and Sport Committee, both as regards this petition and at the committee stages for the forthcoming Mental Health Bill. As the commission pointed out, there is a massive bias towards organisations that receive government funding as against expert groups like our own, and no account is taken of the power of patronage to subvert debate along `acceptable` lines.

References for the information contained in this submission can be found in the Autism Rights' response to the Scottish Human Rights Commission's consultation on its Scottish National Action Plan (SNAP) on Human Rights:-

<http://scottishhumanrights.com/application/resources/documents/SNAP/ParticipationResponsesReport.pdf>

- see pages 190-220

Fiona Sinclair, on behalf of Autism Rights, 9<sup>th</sup> December 2013

[www.autismrights.org.uk](http://www.autismrights.org.uk)

**`Equal Rights, Not Endless Fights`**