

SUBMISSION FROM AUTISM RIGHTS

I thought I would tell you about my own personal experience and my group's experience with the EHRC.

My first contact (as an individual) was several years ago with the Disability Rights Commission's London office. I had to go through their switchboard to access `help`. The person on the end of the line had a completely wayward grasp of legal systems, never mind the law, and refused to give me the contact details for the Scottish office of the DRC. This person believed that I had to apply to an English court to get a place at an independent special school in England for my son, when you actually had to go through the Scottish Sheriff Courts to appeal for the funding from your own local authority for a placement. I was trying to alert them to discrimination within the education system, but could not get past their basic ignorance of the law.

This first experience should have put me off the DRC's successor, the EHRC. I decided to give them a second chance. They were no better. I approached the EHRC on behalf of our group, Autism Rights, and also on behalf of a family that I thought had a good chance of being a test case for a human rights legal case.

I have several times emailed and phoned various people within the EHRC, asking them to investigate what is happening to people with Autistic Spectrum Disorders within the mental health system, as perhaps the worst human rights abuses happening against people with ASD within Scotland. Whilst they are happy to fund `soft` legal cases involving physical access to restaurants, they have been unwilling over the past several years to make basic enquiries that would show that there are some staggering inadequacies within the mental health system as regards people with ASD. If someone like myself, who is a full-time carer, can put together a presentation to the Human Rights Cross Party Group of the Scottish Parliament that Amnesty's representative described as `compelling` and MSPs agreed required investigation, why is it that an organisation which, even at Scottish level, is funded to the tune of several million pounds, will not even engage in some basic fact-checking, even though investigations are supposedly part of their remit? I had to take several years to collect information to enable me to put together a complete case to the Human Rights CPG, with no expenses, no status and very little time.

I don't know of a single legal case or investigation that the EHRC has conducted in Scotland, apart from a disability discrimination case which they only picked up after it had been taken to the Court of Session - they then took it to the House of Lords where it was finally won (Archibald). The EHRC claimed to me that that they don't do human rights legal cases, but the SHRC doesn't have the power to take on legal test cases, whereas they do. So, who does have this remit in Scotland? Their `advice` is bamboozling, delivered in a carefully patronising tone. There is no humanity there. We asked for a meeting with their legal team, which they refused. They would not speak to the family concerned, only to their lawyer - which would have cost this family yet more money, but to absolutely no point, as the EHRC's legal team made it quite clear that they would not consider taking on a legal case of this kind.

I attach the 3 documents that our group, Autism Rights, recently submitted to the Scottish Human Rights Commission's consultation on its National Action Plan for

Human Rights. This includes an edit of my presentation to the Human Rights CPG. If you read this presentation, you can see the amount of work that has gone into it, the quality of the research, and the startling gaps in official statistics and reporting that leave people with ASD very vulnerable to the general ignorance of autism within the mental health system.

I still have all of the emails back and forth from the EHRC on file and can send these on to the committee if so required.

If it were up to me, I would abolish the EHRC and its army of jobsworths and ringfence the funding for legal aid for test cases and research involving service users such as ourselves. There would still be money left over to fund service improvements, such as training courses.

Fiona Sinclair
Autism Rights
30 April 2013

Scotland's National Action Plan for Human Rights – Autism Rights' supplementary submission

Three documents form the basis for Autism Rights' submission to SHRC's consultation on Scotland's National Action Plan for Human Rights. These are our completed 'Participation Form', Autism Rights' edited and referenced **presentation** to the Scottish Parliament's Cross Party Group on Human Rights, entitled '*Should people with Learning Disabilities and Autism be included within the provisions of the Mental Health Act?*', which forms the largest and most central part of the submission, and this document.

I would like to use the headings within the SHRC report 'Getting it Right?' to identify where Scotland's government and institutions are 'getting it wrong' for people on the autistic spectrum. To start to 'get it right', those institutions, the SHRC included, are going to have to acknowledge official failure and refusal to compile the statistics and qualitative evidence that would support what Autism Rights is saying, and that 'absence of evidence' does not equate to 'evidence of absence'.

* 1. Dignity and care

There are serious human rights issues for people on the autistic spectrum in 'care' environments, as has been demonstrated more than once by the BBC in its undercover documentaries - most recently the documentary on Winterbourne View hospital. Our **presentation** refers to issues of care both within and beyond the mental health system. Please refer also to our completed 'Participation Form' for a brief outline of problems and potential solutions.

Autism Rights believes that one of the reasons for the continued abuse lies in the common practice of keeping parents of people with ASD from knowing and seeing the care provision being made. Unfortunately, whilst parents like ourselves have fought for years to gain physical access to our children's schools and other service provision, and have striven over those years to find out what is actually happening to our children in these environments, there are other parents who leave everything to the 'professionals' and are then surprised when things inevitably go pear-shaped. It should also be noted that, irrespective of government policy on the rights of carers or legal status as a guardian, parents are very often excluded from decisions taken on their adult sons and daughters and their motives are frequently questioned by public servants who claim to be serving the interests of the person with ASD, but all too often are unwilling to accept the specific needs of people with ASD.

Because of the nature of autism, it is essential to co-ordinate educational and care plans between home and school or care establishment. Consistency is essential in the lifelong learning that people with developmental disabilities, such as ASD, need. There is much needed security in having open access arrangements for parents of people on the autistic spectrum, so that abuses can be picked up early on, and nipped in the bud. Even if those abuses are not directed at your own son or daughter, it is in everyone's interests to identify and stop abuse. It is too easy to claim that a person with ASD has assaulted a care worker and to place that person under a compulsory treatment order under the Mental Health Act, when it may very well be the 'care' worker or their service provider employer who is either incompetent in dealing with the behaviours that people with ASD display, or that the worker is the one doing the assault.

* 2. Health

I refer to our **presentation** in its entirety (which mainly addresses the human rights abuses inherent

in current mental health policy, practice and law), to the following weblinks and text from the Autism Treatment Trust, which address the special health problems associated with ASD and to the latest WHO / UNEP report on children's health. The most serious human rights abuses taking place against people with ASD in Scotland are happening within the Health and social care sectors, and there is no evidence of political action to deal with these abuses. On World Autism Awareness Day, Autism Rights is calling for this to change.

But first:-

<http://www.dailymail.co.uk/health/article-2292270/Doctors-said-son-constipated--fact-CANCER-Mothers-anger-doctors-missed-basketball-sized-tumour-11-TIMES.html>

- Doctors said my son was constipated - in fact, he had CANCER: Mother's fury after doctors missed basketball-sized tumour 11 TIMES as survival odds slashed to 40%

By LUCY LAING

PUBLISHED: 19:21, 12 March 2013 | UPDATED: 22:36, 12 March 2013

Although this story is from England, there are cases in Scotland that have received no media coverage that are as bad as this.

Autism Treatment Trust / Treating Autism review and conference
Conference

<http://www.autismtreatmenttrust.org/?p=2301>

<http://www.autismtreatmenttrust.org/wp-content/uploads/2013/03/FLYER-Conference-June-12-13th.pdf>

Review

Medical Comorbidities in ASD

A Primer for Health Care Professionals and Policy Makers

Dear Parents and Autism Professionals

As you are undoubtedly aware, the cost of autism—both human and financial—is enormous. The rate of ASD has continued to rise for more than two decades, now affecting one child in 50 in the USA and 1 in 64 in the UK. The increased rates can no longer be attributed to better recognition, and current scientific evidence demonstrates that ASD is medical in nature and treatable. Tragically, as headlines and the lived experience of thousands of families will attest, the medical needs of this population are often overlooked, misunderstood, or actively ignored. A paradigm shift is currently taking place in the scientific and medical community, offering greater potentials for intervention.

On this upcoming Autism Awareness Day, this message needs to be shared with families of children with ASD, teachers, health workers, government officials and all tax payers in the UK: that the new paradigm of autism as a treatable condition offers tens of thousands of people a better chance for an improved quality of life.

Please read and share our scientific review, 'Medical Comorbidities in Autistic Spectrum Disorders', which can also be viewed here

<http://www.autismtreatmenttrust.org/wp-content/uploads/2013/03/Medical-Comorbidities-in-Autism-Spectrum-Disorders-20131.pdf>

Sincerely,

Treating Autism Trustees and Autism Treatment Trust Trustees

Press Release

Please help us by sharing this press release with your media contacts.

2 April 2013

London, UK – ‘Medical Comorbidities in Autistic Spectrum Disorders’ a review prepared by British charities Treating Autism and Autism Treatment Trust, and officially launched on Autism Awareness Day, has been welcomed by medical and research professionals in UK, EU and USA. It details current research into health problems commonly experienced by people with autism, which are, however, routinely overlooked by the medical profession. It has far-reaching implications for the treatment of medical conditions existing simultaneously with autism (comorbidities).

In summary, the review shows that:

* Recent large-scale studies confirm that certain medical conditions are significantly more prevalent in people with autism compared to typical populations. A detailed assessment conducted by the CDC shows that children with autism had much higher than expected rates of all of the medical conditions studied, including: eczema, allergies, asthma, ear and respiratory infections, gastrointestinal problems, severe headaches, migraines, and seizures.

Read More http://www.autismtreatmenttrust.org/?page_id=2341

Although one would not realise it, from a study of UK media coverage, the public relations of autism `charities` or government documentation, there is absolutely no evidence whatsoever that increasing numbers of children presenting with ASD are a result of `better diagnosis` or that autism is genetic in origin - although the epigenetics of autism are no longer in doubt. There is a growing body of evidence that autism is a whole body disease and that it is, as Professor Martha Herbert has described it, more a case of *autisms*, than a single disorder, with environmental aetiology. The scientific evidence is overwhelming that people with autisms have immunological and metabolic disorders. There are many chemicals in our environment today that affect both the immune and endocrine systems - the latter regulates the body's metabolism. For that reason, I've included links to the recently published WHO/ UNEP report on the science of endocrine disruption.

Rather than adopting a position of denial as regards the environmental causation of disease and disability, we would like to see action to investigate and treat these environmental diseases, which would also enable the prevention of further environmental morbidity for the population as a whole. There could be no better respect for the human right to good health.

On 19 February 2013, the United Nations Environment Programme (UNEP) and the World Health Organization (WHO) released *The State of the Science of Endocrine Disrupting Chemicals – 2012 <http://ehp.niehs.nih.gov/1306695/>

See also, “The Impact of Endocrine Disruption: A Consensus Statement on the State of the Science.” <http://ehp.niehs.nih.gov/1205448/>
PDF Version<<http://ehp.niehs.nih.gov/wp-content/uploads/121/4/ehp.1205448.pdf>>

Summary for Decision Makers

https://docs.google.com/file/d/0B9XQ-aL6_WCgc1FPaJJaSjBUT1E/edit?usp=drive_web&pli=1

* 3. Where we live

All of the other services will dictate where people with ASD live. `Inclusion`, as currently promoted, is too often used to impose services that are unacceptable and inappropriate and effectively curtail the life chances of people with ASD, through failing to provide the education and healthcare that they need. It is clear that, whilst a small minority of people with ASD will manage to look after themselves with little in the way of support, others will need full time care, which society has demonstrated it is not prepared to provide. As parents, we would like the political classes to ditch the dogma and listen to those who love people with ASD, rather than those who are making careers out of them. As I have outlined in our **presentation**, the mental health system is too often used as the `default setting` for social care of autistic adults.

* 4. Education and work

Education

All of the testimony and evidence that we have collated down the years from both parents and professionals shows that those running the education system demand conformity at all costs, irrespective of the individual needs of children with disabilities. Children with Autistic Spectrum Disorders are particularly disadvantaged, as they are generally shoehorned into one or other type of provision that is not geared to their particular needs. The system conflates education with schooling, and does not acknowledge the holistic educational needs of children with ASD.

The recent investigation by the Scottish Parliament's Justice Committee, which discovered that illegal `informal exclusions` are used by schools to deal with children with ASD is one indication that the education system is simply covering up its incompetence and inhumanity. See `*Vexed questions over school exclusions*` below. Another indication would be the proportion of children with ASD who are being prescribed psychoactive drugs, such as Ritalin and Risperidone, ostensibly to control their inevitable failure to cope with their schooling. However, such statistics do not exist. As described in Autism Rights' presentation, the extent of such drugging could be around US estimates of 56%, as overall prescription of these drugs to schoolchildren is very high - 1 in 5 children in some areas of Scotland. There are no studies on the long term effects of these drugs on the developing brains of children, but research has demonstrated that they atrophy the brain and that beneficial effects of these drugs are of a temporary nature, whilst the negative effects are life-limiting. Further references are available within the **presentation**, but these 2 weblinks gives a good idea of some of the negative implications of current policy and practice on the psychotropic drugging of children:-

<http://www.madinamerica.com/2013/03/medicating-adhd-diagnosis-and-the-long-term-effects-of-the-medications/>

http://www.thestar.com/news/canada/2012/09/26/adhd_drugs_suspected_of_hurting_canadian_kids.html

Autism Rights raised the issue of `informal exclusions` 6 years ago in our Briefing Paper and in our submissions to government consultations on education. It has taken this long for parliamentary politicians and just one Scottish publication to catch up.

<http://www.tes.co.uk/article.aspx?storycode=2093069>

- The secret exclusions

Article | Published in TES Newspaper on 22 April, 2005 | By: Jon Slater

article about illegal exclusions in English schools
<http://www.tes.co.uk/article.aspx?storycode=2344981>

- 'Secret' exclusions of ASD children
Published in TESS on 16 February, 2007

My letter to the editor
<http://www.tes.co.uk/article.aspx?storycode=6318854>

- Vexed questions over school exclusions
News | Published in TESS on 8 February, 2013 | By: Emma Seith
`Children with disabilities such as ADHD (attention deficit hyperactivity disorder) and autism were especially likely to be on the receiving end of informal exclusions, they reported. For the families involved, it happened repeatedly and was “just a way of life”. These families were also the “least empowered to deal with or challenge” what was happening, the witnesses said.`

See also this article on the Lamb Report, which sums up the nature of the problems besetting the families of children with SEN. Although reporting on the English school system, its conclusions apply equally to Scotland;-

<http://www.tes.co.uk/article.aspx?storycode=6029890>

Work

Whilst most people on the autistic spectrum may not be able to get a job, there is no reason why they cannot undertake useful and rewarding work. Various estimates suggest that between 6 and 13% of people on the autistic spectrum can hold down a job, with a greater or lesser degree of support. Of course, that is based on current educational and healthcare provision, which fails so many people with autism. If these services were to improve, along the lines suggested by Autism Rights, the percentage of those who could work or hold down a job would undoubtedly be considerably higher. Under current `inclusion` dogma, specialist workplaces have closed and are not being replaced by alternatives. When official government policy, such as the Autism Strategy, is discussing `investing to save` in relation to only 6 – 13% of the autistic population, without even any apparent realisation of the historical associations implied by such language, we are getting a true picture of the unsavoury nature of official attitudes towards people with mental disabilities such as autism.

*** 5. Private and family life**

Autism Rights' Briefing Paper of 2007, entitled `Incompetent, Abusive, or both? - Scottish Executive policy and legislation on Autistic Spectrum Disorder (ASD)` warned of the negative and potentially oppressive consequences of legislation enacted in the early years of the Scottish Parliament:- <http://www.autismrights.org.uk/drupal/node/6>

We were particularly concerned with regulation and policy on datasharing and with the Adult Support and Protection Act, which gives a poacher / gamekeeper role to local authorities. All of the feedback that we have had since that time has merely confirmed that we were right. Other organisations have finally woken up to the threat posed by *every* child being given a `Named Person` to check on their progress throughout their childhood – the Scottish Parent Teacher Council, quite rightly, see this as an abrogation of the role of parents, see:-

<http://www.tes.co.uk/article.aspx?storycode=6297723>
- What's in a named person?

Letters | Published in TESS on 26 October, 2012 | By: Eileen Prior
However, whilst effective opposition to the datasharing of England's `ContactPoint` scheme has resulted in a good amount of press coverage and recommendations to avoid the negative effects of

datasharing - <http://www.nuffieldfoundation.org/sharing-childrens-personal-data>

there has been no realisation, let alone scrutiny, of the almost identical arrangements in place in Scotland.

Indeed, it is actually inaccurate to use the term `datasharing`, as the government's policy and regulation makes explicit that *opinion*, professional or otherwise, will be shared between public servants. Several of our members have found that inaccurate and even defamatory accounts of themselves and their families have been recorded by public servants. The supposed safeguards do not exist – the UK Information Commission is ineffectual in, if not averse to, the enforcement of Data Protection laws and cannot or will not force a local authority or a health board to change misinformation and erase defamatory materials. Even a Sheriff's judgement cannot overturn the injustice of false accusation.

These records, precisely because they are shared, multiply injustice and deny services to those in need. As stated in Autism Rights' Briefing Paper, there are particular dangers for people with ASD and their families, because of the lack of knowledge of the nature of their disability amongst professionals in public services. In order to try to access public services, families are forced to open up every area of their private lives to intrusive questioning, but are denied a reciprocal right to information about their rights and to the quality and nature of available services. It is often the case that the information supplied in good faith by families is then used to deny them the very services they need.

* 6. Safety and security

The rest of this document, our **presentation** and our completed `Participation Form` outline the key threats to the safety and security of people with ASD. However, we have since learnt of another major gap in statistical data that shows the lack of evidence for claims made in support of improvements to services for people on the autistic spectrum.

An MSP has asked a series of parliamentary questions, based on our **presentation**. This has confirmed some of the information in the **presentation**, but has also thrown up another disturbing feature of the mental health system. It is not just the case that Fatal Accident Inquiries are not mandatory within the mental health system, when they are within the prison system – it is that there is *no data on the numbers of people who die whilst receiving compulsory treatment*. Given the very serious health and life-shortening effects of the drugs used in the mental health system, this is a quite staggering omission.

SCOTTISH PARLIAMENT

WRITTEN ANSWER

4 March 2013

Index Heading: Health and Social Care

Alison McInnes (North East Scotland) (Scottish Liberal Democrats): To ask the Scottish Government how many deaths of patients compulsorily detained under provisions in the Mental Health (Care and Treatment) (Scotland) Act 2003 have been attributed to patient safety incidents in each of the last five years.

(S4W-13177)

Mr Michael Matheson MSP:

The Scottish Government do not hold figures which specify the number of deaths of patients whilst

receiving compulsory treatment under the Mental Health (Care & Treatment) (Scotland) Act 2003.
SCOTTISH GOVERNMENT

*** 7. Living in detention**

Please see our **presentation** for information on the treatment of people with ASD within the mental health system.

*** 8. Access to justice and the right to an effective remedy**

<http://www.scottishhumanrights.com/abouthumanrights/helpwithhumanrights>

- the question of what the EHRC actually does in Scotland remains a mystery. The last legal case on disability that was sponsored by the EHRC was some years ago and was set in train by the individual (Susan Archibald) who was eventually supported in a House of Lords case. Such absence of support is why legal cases remain no threat to the established order of things, as this section of the SHRC's website makes clear:-

Legal aid

Obtaining legal advice can be costly and take time. The Scottish Legal Aid Board may be able to offer assistance in limited circumstances.

Advice and information is not going to stop human rights abuses - only legal or political action will do so, and people in Scotland have less access to legal redress because of the lack of choice of legal representation, the absence of class action lawsuits, the very narrow focus of Judicial Review and the reduced availability of legal aid or assistance - see **presentation** for details as regards the mental health system and people with ASD, where these problems are especially acute.

In spite of the high hopes for the Tribunal system, some are calling for a return to the courts because of the bias towards those facing Mental Health Tribunals and the failures to uphold the right to a fair hearing in the operation of some Tribunals. In one case, a family and their legal representative were excluded from discussions between their health board and Tribunal members - that would not happen in a court of law. Please see our **presentation** for further information on current deficiencies in the policy and practice of regulation and law within the mental health system as regards the rights of people with ASD.

In conclusion, Autism Rights has outlined some of the ongoing human rights abuses taking place against people with Autistic Spectrum Disorders in its submission to the SHRC. The three documents submitted make the case, not just for inclusion in an `action plan`, but for action.

Autism Rights is calling for these actions to be taken:-

1. The removal of people with Learning Disabilities and Autistic Spectrum Disorders (ASD) from the provisions of the Mental Health Act.
2. Equality of healthcare for people with autism.
3. An inquiry into the treatment of all people with ASD within the mental health system.

Given the statistical and regulatory black hole into which people on the autistic spectrum fall, it is impossible to ascertain the full extent of the abuses and discrimination being perpetrated against them, hence the need for an inquiry.

www.autismrights.org.uk

EDIT OF AUTISM RIGHTS' PRESENTATION TO THE SCOTTISH PARLIAMENT'S CROSS
PARTY GROUP ON HUMAN RIGHTS, TUESDAY 19TH FEBRUARY 2013
Should people with Learning Disabilities and Autism be included within the provisions of the
Mental Health Act?

Just over 11 years ago, 'Scotland on Sunday' ran an article, entitled '[Autistic adults locked up after false diagnosis](#)', about the sectioning and enforced drugging of autistic people within mental institutions. No action whatsoever has been taken to rectify that situation, in spite of calls for a government inquiry from people as respected as Paul Shattock, who is the President of the World Autism Organisation¹. Eleven years have passed during which time the Scottish Executive established the ASD Reference Group to advise and action government policy on autism, and many other initiatives, directly or indirectly concerning services for people with autism, have been launched and re-launched. However, the situation of some of those who were incarcerated at that time has become much worse and others have become ensnared in the mental health system since then. At that time, eight people were known about directly, but the true numbers were not known then (although it was believed that up to 20 people were affected) and they are not known now. Paul Shattock and others believed that some of those people may have been in mental institutions for 30 years – a report by the Mental Welfare Commission did confirm that there are some people in that category within the mental health system, but did not give their diagnoses. In any case, the psychiatrists who have given or confirmed these diagnoses are unwilling to look again at them, even if they had the expertise to diagnose Autistic Spectrum Disorder (ASD), rather than schizophrenia, which is the usual diagnosis they give to people on the spectrum. We know of at least 2 suicides amongst those eight people, and others whose health, both mental and physical, is irreparably damaged by years of enforced medication with the very toxic drugs that are routinely used in psychiatric practice in most of the western world and, it seems, inescapably in Scotland. It must be emphasised that none of these people had committed a crime.

We're not being listened to

For almost 2 years, a very small but active group of people within Autism Rights have been trying to bring this issue to the attention of the government and to MSPs, with absolutely no success at all. We don't see this as our own failure, as we are all parents of people with Autistic Spectrum Disorders, and do not have the resources to undertake the kind of lobbying that comes with paid employees and millions of pounds of state funding obtained through service contracts and grants. Only two organisations (the Scottish Disability and Equality Forum and PASDA) have given their backing to our call to take people with Learning Disability and ASD out of the provisions of the Mental Health Act, even though we have asked all of the major disability charities within Scotland, including 2 who, in responding to the 2 previous reviews of mental health legislation and policy, stated their belief that the Mental Health Act should be reviewed to that effect. It is therefore not surprising that neither the current Mental Health Strategy nor the proposals for review of the Mental Health Act contain even a mention of this issue.

Indeed, civil servants have decided that the responses to the consultation on the Mental Health Strategy should not be placed on the Scottish Government's website and should only be accessible by visiting the Scottish Government Library in Edinburgh. The civil servants have given two contradictory reasons for this decision – the initial reason being that the decision not to publish these consultation responses online was taken prior to the launch of the consultation and the other reason given was, owing to the large number of responses, they did not have the resources to attempt online publication. It should be noted that the more recent consultation on the update to the government's policy on Learning Disability services, 'The Same As You?',

garnered roughly the same number of responses to those from the consultation on the Mental Health Strategy – over 300 – and yet, in spite of the much greater number of people affected by mental health policy, the civil servants have chosen to put ‘The Same As You?’ responses on the Scottish Government's website. So, as access to the consultation responses in the Scottish Government Library is limited by time, opportunity and money and copies of only ‘a few select responses’ are available, charged on a cost recovery basis, it is impossible to gain an insight into the overall mix of opinion and testimony from the consultation exercise.

This restriction of access has closed debate and discussion on an area of public policy that has a direct bearing on the human rights, not just of people with Learning Disability and ASD, but for all those who come into contact with the mental health system at some point in their lives, and for their families. It has also, very conveniently, enabled those who currently dominate professional bodies and the health and social care sectors to claim unanimity with their opinions and beliefs. Whilst we would all welcome the commitment to increase the provision of psychological and other therapies contained in the Mental Health Strategy, this is not going to happen without the provision of resources specifically for this purpose, and those resources will only materialise if the government is willing to rein back the empire builders within the system. Otherwise, the whole system will continue to throw money at ‘treatment’ that does not workⁱⁱ and is, particularly for people on the autistic spectrum, catastrophic. This clamping down on public debate and discussion is in marked contrast to the current international debate surrounding the new diagnostic guidelines for psychiatry, the DSM V. There is now a healthy debate about this update on the DSM IV, specifically about the pathologising of normal behaviour.ⁱⁱⁱ That this debate is being led on both sides by psychiatrists is an indication of the growing controversy around the subjectivity of psychiatric diagnoses and the almost total reliance on psychotropic drugs for ‘treatment’ within the mental health system. The question is, why is the Scottish Government ignoring not only this international debate, but also the home-based activism which is challenging the noted inadequacies and inhumanity within the Scottish mental health system^{iv}?

Why the Mental Health Act and system is discriminatory

We do not see the removal of people with ASD from the provisions of the Mental Health Act as a panacea, but a first step in eradicating a historical anomaly in which people with ASD were deposited in mental hospitals – indeed the chairman of the school board of my son's former school was keen to remind parents of this. The mental health system should not be the ‘default setting’ for the ‘care’ of people who have an Autistic Spectrum Disorder – and the Royal College of Psychiatrists recognises that this is happening^v.

People with Learning Disabilities, including those with Autistic Spectrum Disorders, are currently included within the provisions of the Mental Health Act under the definition of ‘mental disorder’, irrespective of whether or not they have a mental health problem, whereas people who are addicted to drugs or alcohol are specifically *not* included within the provisions of the Act^{vi}. This is entirely discriminatory towards people with mental disabilities, as it is overwhelmingly the case that ‘substance abusers’ pose the biggest threat of serious violence towards the public^{vii}. As both the Millan Committee and the McManus Review backed a review of this situation^{viii}, the consultation on the Mental Health Strategy for Scotland: 2011-15 should have included consideration of this, but did not. The finalised 2012-15 Strategy and the government's proposals for review of the Mental Health Act likewise fail to address this issue.

Whilst significant problems are created for people with Learning Disabilities by being

automatically included in the provisions of the Act under the term `mental disorder`, the dangers of inclusion for people with ASD seem to be much worse, given the current behavioural diagnosis for ASD. Indeed, the Mental Welfare Commission has acknowledged that mental health practitioners are divided between those who categorise ASD as a disability and those who believe it to be a mental illness^{ix}. The fact also that the diagnostic criteria (DSM and ICD) list and define psychiatric disorders and include ASD amongst these would seem to confirm its status as a mental illness, but for the fact that Learning Disabilities and other disabilities and medical conditions are also included. That mental health practitioners should be confused over the true nature of autism after significant sums of public money have been thrown at autism services reveals the extent of the ignorance of ASD within the mental health system and its resistance to enlightenment and good practice. It is only when you undertake some background reading, that you realise that that it is accepted practice to medicate for `challenging behaviour`, `aggression` or `self-injurious behaviour`^x and that no perceptible distinction is made in practice between those who are mentally ill and those who have a mental / intellectual disability^{xi}.

Mental Health institutions, as currently constituted and run in Scotland, are wholly unsuitable places for the `treatment` of any autistic person who may be deemed to be mentally ill. People whose disability is mostly defined in terms of their impairments in communication and social interaction, are thrown in with drug addicts and alcoholics^{xii}, and with people whose mental illness arises from traumatic events in their past, including abuse. There is no-one who has any real idea of how they are feeling, or why they might be behaving the way they do. They will be given drugs, usually against their will, intended to pacify and control them. When these drugs have the opposite effect^{xiii}, the doses are increased, and other drugs will be added into the mix at some point. Although care plans must specify the psychoactive drugs that are prescribed, drugs that are used to control epilepsy, for example, do not have to be noted^{xiv}. For people on the autistic spectrum, who have known immunological and metabolic disorders^{xv}, and who are therefore unable to metabolise these drugs, resulting in intoxication and the creation or increase of apparently psychotic behaviours, it is the beginning of a pharmaceutical treadmill leading to brain damage, tardive dyskinesia (drug-induced Parkinson's) and massive weight gain, leading in turn to diabetes and heart disease^{xvi}. It is estimated that the extent to which being in the mental health system shortens lifespan is anywhere between 10 and 25 years. Given the fact that people with Learning Disability (there is no separate collation of statistics for people with autism within the mental health system) make up 11% of those in mental institutions when they represent just 2 – 3% of the population and stay, on average more than twice as long as those without a Learning Disability within these institutions^{xvii}, they are at far greater risk of dying prematurely^{xviii}. In any case, their quality of life can be irreparably damaged.

Although people with ASD and those with Learning Disabilities can be forced to take psychotropic (psychiatric) drugs in a community setting – at home, or in a care setting – most Compulsory Treatment Orders (CTOs) are for incarceration within mental hospitals.

There are some pretty tortuous arguments put forward for the use of drugs to `treat` autism or its supposedly `co-morbid` conditions. There is no understanding, let alone investigation, of the `antecedents to the presentation of challenging behaviours` observed in autism. How can you have `functional analysis` of behaviour, as advised in the NICE guidelines for adults with autism, when those who are employed to care for people with autism are entirely ignorant of ASD and its associated behaviours, never mind its associated health issues^{xix}? And how can you put in these same guidelines that physical disorders should be ruled out first when carrying out a diagnosis, when the ASD training recommended some years ago by the Royal College of Psychiatrists^{xx} is not happening or is being repudiated by individual psychiatrists who are

supported in their beliefs by Mental Health Tribunals and indeed the Mental Welfare Commission itself?

There are 5 things that lie behind 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^{xxi}.
- 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.

Some examples

We do know that there is a wider inequality of healthcare for people with autism, and that also needs urgent investigation. In spite of the existence of NHS Scotland's Quality Indicators for Learning Disabilities, children with ASD in large parts of Scotland are being denied treatment for bowel disorders. As a consequence of this, they then require surgery because of faecal impaction and mega colon, the latter of which is usually a condition found in elderly people who are seriously ill. Imagine the distress that you would feel if you had such a disorder - and then imagine not being able to communicate this distress, and how a psychiatrist might interpret this. Even 'normal' health problems are neglected - whether an impacted wisdom tooth, or a brain tumour.

Medical professionals should know that epilepsy and autism are closely associated – a proportion of the autistic population has epilepsy – but these problems go further than that: over 80% of people with ASD have some sort of seizure activity going on, which is often sub-clinical, and this can cause hallucinations^{xxii}. These are then improperly medicated by medical professionals who are ignorant of the problems faced by people with ASD.

One family was told that their son was not expected to live at one point, purely because of the effects of these drugs - the psychiatrists still didn't cut the dosages^{xxiii}.

Basic monitoring of health within mental hospitals is haphazard and inadequate – with 25% of long stay patients being found to have no record of health checks^{xxiv}. The MWC and the government think that annual and 15 month health checks are adequate for people who are being forced to take some of the most toxic drugs on the market. Absolutely no account is being taken of individual

tolerance of these drugs, in spite of guidance recommending psychiatrists seek specialist medical advice where this is needed^{xxv}.

No debate, no discussion and no data

There have been at least 2 suicides of people with ASD in the past decade, although neither their disability nor the distress inflicted on them prior to their deaths were mentioned in press reports. However, in a 2011 report, Dr Alex Mitchell of Leicester University said that deaths from drug side effects in the mental health system as a whole were 4 times greater than suicides^{xxvi}. Given the aforementioned drug intolerance suffered by people with ASD, their death rate will be substantially higher.

There are no statistics for the proportion of people with ASD being prescribed psychotropic drugs, but the fact that, in one health board area, there are more than 1 in 5 schoolchildren being given Methylphenidate^{xxvii} (Ritalin), is a very good indication that children with ASD in some Scottish health board areas may be being drugged at levels seen in the US, where it is estimated that over half (56%) of the children with ASD are prescribed at least one psychotropic drug^{xxviii}. Indeed, at the Scottish Executive organised Aviemore conference on autism, one of the psychiatrists pointed out that the estimates of the percentage of people on the autistic spectrum who are prescribed psychoactive drugs is between 20-70%

As with the revelations of abuse contained in BBC Panorama's exposé of Winterbourne View hospital, the vulnerability of people with ASD, combined with the absence of parental access to these facilities, can mean that it is people with ASD who are accused of violence (which is then controlled by drugs), when they are actually the victims of assaults and other abuse.

The safeguards and the safeguarders

The Mental Welfare Commission (MWC) will not monitor or investigate the collective situation of people with ASD who are currently being `treated` under the Mental Health Act, because autism is not classed as a `client group`, even though no such stricture exists within the Act.

No objective criteria is yet used by the MWC to assess which individual cases they will investigate. They give the impression that every case is investigated – it is not.

The MWC bases its decisions on whether or not to investigate upon its visits to mental hospitals and other service provision. They do not record contact by the families of people who are compulsorily detained, so cannot keep track of what is happening to particular groups, such as those with ASD.

The MWC rely on mental health practitioners themselves to inform them of mistakes, abuse and the non-implementation of Recorded Matters^{xxix}.

The McManus review (2009) of the Mental Health Act recognised that there is a low take-up of Advance Statements, where people can set out how they wish to be treated if they become mentally ill. No such right exists for people with ASD, because they are not deemed to have capacity^{xxx}.

Independent Advocacy for people within the mental health system is a good idea in principle, but in practice can mean that someone who has no emotional investment in, nor knowledge of the individual, can interfere with the role of a parent. Local authorities are part of the mental health system, particularly in providing Mental Health Officers, who are usually social workers, and they also fund Advocacy services. Whilst it is evident that there are some good advocates in Scotland, it is also clear that conflicts of interest affect the conduct of others.

The Mental Health Act and its system

There are no statistics on the numbers of people with Autistic Spectrum Disorders within the mental health system, so no assessment can be made of the length of time they are in the system, nor the impact that this has on their lifespan or health.

Diagnosis of 'mental disorder' is made upon leaving compulsory treatment, not at arrival, so there is further scope for misdiagnosis of people with ASD.

Some young people with ASD are being 'led' into mental health services, upon transition to adult services, in spite of the inclusion of people with ASD within 'The Same As You?', the government's guidelines for Learning Disability Services.

Legal representation at Mental Health Tribunals is wholly inadequate: there is a paucity of appropriately qualified or experienced lawyers working in mental health law – around 20 lawyers specialise in this area of law. Just 3 legal firms in Scotland carry out three-quarters of all legal aid work for such tribunals^{xxxii}. For people with ASD, there is the added complication of their disability, which is not well understood by members of the legal profession, any more than the other professions. It has been claimed that some lawyers fail to prepare adequately prior to tribunal^{xxxiii}.

The only right of appeal to a tribunal decision is to go to Judicial Review, which involves a lengthy wait of many months and substantial amounts of legal aid.

The Mental Health Tribunal for Scotland (MHTS) itself deals with complaints made against it^{xxxiii}. The Mental Welfare Commission is not the complaints handling organisation for the mental health system in Scotland. This is the job of the SPSO, which does not possess the necessary specialist knowledge of the system, which insists on complaints being lodged within a year of problems arising and which will not take complaints that may result in legal proceedings^{xxxiv} (Mental Health Tribunals are, by definition, legal proceedings).

Although prisoners who die in custody will be accorded a Fatal Accident Inquiry (FAI), no such right exists for Mental Health Patients.

As parent activists, we do not find that there is a willingness amongst those charged with the formation and implementation of autism policy to listen to 'missing perspectives'. The exclusion of our sons and daughters is mirrored in our own experiences of being treated like the 'awkward squad' who will simply not go away nor shut up. This exclusion is as inhumane as the exclusion of parents from decisions taken on the care and treatment of their sons and daughters while they are receiving compulsory 'treatment' in the mental health system, in spite of all official guidance or legal rights as guardians. To quote one parent:-

'It was heartbreaking seeing him suffer there for 12 years, locked up for hours on end in a padded cell, thrown to the ground and sat on by so-called trained staff and treated worse than a criminal'

Autism Rights is calling for these actions to be taken:-

1. The removal of people with Learning Disabilities and Autistic Spectrum Disorders (ASD) from the provisions of the Mental Health Act.
2. Equality of healthcare for people with autism.

3. An inquiry into the treatment of all people with ASD within the mental health system.

Given the statistical and regulatory black hole into which people on the autistic spectrum fall^{xxxv}, it is impossible to ascertain the full extent of the abuses and discrimination being perpetrated against them, hence the need for an inquiry. Perhaps then we will get the chance to put forward our own suggestions for both the prevention and treatment of mental distress in people with ASD.^{xxxvi}

SOME INFORMATION ABOUT AUTISM RIGHTS

Autism Rights is established to research, lobby and campaign for the human rights of people with Autistic Spectrum Disorders (ASDs) in Scotland, in particular to campaign for the provision of appropriate health treatment, education, social welfare and justice.

The founding members of Autism Rights are all parents and carers of people with an ASD and were long-standing members of the now defunct Cross-Party Group on Autistic Spectrum Disorders of the Scottish Parliament.

We are the only national service user-led group in Scotland campaigning for the rights of people with an Autistic Spectrum Disorder and their families. Full membership of Autism Rights is open to people with an ASD resident in Scotland and parents and non-professional carers of people with an ASD who support our aims and objectives. We do not provide services for people with ASD, so we can speak up without fear of the loss of funding for services.

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

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- i Around this time, BBC Scotland's `Frontline Scotland` investigative series produced a programme which featured some of the families involved. This programme was never broadcast, as Fife Health Board served an interdict preventing broadcast on the basis that one of the people featured was an inpatient in one of their hospitals and, they claimed, did not have capacity. I have been informed by the BBC that they no longer possess a copy of this programme – hence my use of clips from `Elle S'appelle Sabine` to give those attending the meeting of the Scottish Parliament's Human Rights Cross Party Group an idea of the damage inflicted on people with Autistic Spectrum Disorders (ASD) by psychotropic (psychiatric) drugs. See this YouTube clip for a graphic illustration of the effects of psychotropic drugs on someone with an Autistic Spectrum Disorder (ASD) before and after 5 years of incarceration in a mental institution:-
http://www.youtube.com/watch?v=qyp97e_MWKI

It should also be noted that the affected families met with the then Depute Minister for Health, Frank McAveety, to discuss the treatment of their sons within the mental health system. No action resulted from this meeting, and the transcript of the meeting is no longer in existence, although it was originally uploaded to the Scottish Executive's website.

See also:-

http://www.bbc.co.uk/radio4/youandyours/yy_20041028.shtml

- transcript of the "You and Yours" programme on Autism Misdiagnosis, broadcast by BBC Radio 4 on 28 October 2004.

- ii <http://news.bbc.co.uk/1/hi/health/7170167.stm>
- Last Updated: Friday, 4 January 2008, 03:02 GMT

Learning disability drug warning
Doctors are being warned not to routinely give people with learning disabilities anti-psychotic drugs to curb aggressive behaviour. An Imperial College London study of 86 patients found the drugs were no more effective than being given none at all.

iii <http://www.reuters.com/article/2012/05/10/us-psychiatry-dsm-idUSBRE8490WQ20120510>

- Psychiatrists say diagnosis manual needs overhaul

By Kate Kelland LONDON | Thu May 10, 2012 2:22pm EDT

LONDON (Reuters) - Many psychiatrists believe a new edition of a manual designed to help diagnose mental illness should be shelved for at least a year for further revisions, despite some modifications which eliminated two controversial diagnoses.

<http://dsm5-reform.com/supporting-evidence/>

<http://dsm5-reform.com/the-open-letter-to-dsm-5-task-force/>

iv <http://www.heraldscotland.com/mobile/news/home-news/uk-supreme-court-overrules-scottish-judges-on-two-human-rights-cases.1354106825>

- UK Supreme Court overrules Scottish judges on two human rights cases

Published on 28 November 2012 David Leask

One of the new cases involved the first time the Supreme Court had been asked to consider the Mental Health (Care & Treatment) (Scotland) Act 2003, and the right of a patient in non-state or psychiatric hospital to appeal the level of security imposed on them.

The Supreme Court has now ruled that the Scottish Government has been acting illegally since May 2006. This is as a result of the failure of the various administrations over the past six years to pass enabling legislation.

The decision is a constitutional “first” in Scotland, as it has never before been held in this country that Ministers were bound to bring statutory provisions into force.

The principal solicitor in the case for the appellant was Frank Irvine of Frank Irvine Solicitors, Glasgow, acting for a patient at Leverndale psychiatric hospital in the city.

He has been compulsorily detained in Leverndale, which is not a state hospital, since 1995. He believes he is detained in conditions of excessive security and that his quality of life, his liberty and his prospects for release would be improved were he to be transferred to an open ward.

Mr Irvine said: “Clearly this ruling is to be welcomed not just for our client but for the many individuals who have been denied a right of appeal enshrined in law and passed by the Scottish Parliament.

“It is clearly the case that the absence of this particular right of appeal has had a detrimental impact on many individuals progress from hospital into the community.

“It is to be hoped that the Scottish Government respond immediately to this ruling passing the relevant Statutory Instrument to allow all individuals detained within locked psychiatric facilities the right of appealing their current level of security.”

http://www.mhtscotland.gov.uk/mhts/files/members_area_files/Newsletter_December_2012.pdf

- December 2012 Newsletter- Mental Health Tribunal for Scotland, see page 26

v <http://www.rcpsych.ac.uk/publications/collegereports/cr/cr136.aspx>

- CR136. Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders

vi <http://www.legislation.gov.uk/asp/2003/13/contents>

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

<http://www.legislation.gov.uk/asp/2000/4/notes/contents>

- Explanatory Notes to Adults with Incapacity (Scotland) Act 2000

16. Mental disorder is defined at section 87 and the definition is the same as in the Mental Health (Scotland) Act 1984, section 1: mental illness or mental handicap however caused or manifested.

Following the Mental Health (Public Safety and Appeals) (Scotland) Act 1999, personality disorder is included in the definition of mental illness. In line with the 1984 Act, a person should not be regarded as mentally disordered by reason solely of immoral conduct, sexual deviancy or dependency on alcohol or drugs nor does the definition cover people who simply act imprudently. People who are temporarily under the influence of alcohol or drugs are not to be regarded as mentally disordered, although those whose mental faculties are impaired due to past alcohol or drug abuse do fall within the definition.

87 Interpretation - EXCERPT

"mental disorder" means mental illness (including personality disorder) or mental handicap however caused or manifested; but an adult shall not be treated as suffering from mental disorder by reason only of promiscuity or other immoral conduct, sexual deviancy, dependence on alcohol or drugs, or acting as no prudent person would act;

HOWEVER -

<http://www.legislation.gov.uk/asp/2003/13/section/328>

- Mental Health (Care and Treatment) (Scotland) Act 2003

Part 23, Section 328 would appear to contradict the above, except that autism is frequently but erroneously described as a learning disability, where it should properly be described as a developmental disability:-

328 Meaning of "mental disorder" (1) Subject to subsection (2) below, in this Act "mental disorder" means any-

- (a) mental illness;
- (b) personality disorder; or
- (c) learning disability,

however caused or manifested; and cognate expressions shall be construed accordingly.

vii <http://www.guardian.co.uk/society/2010/sep/06/substance-abuse-mental-illness-crimes?INTCMP=SRCH>

- Substance abuse, not mental illness, causes violent crime

Study finds people with drink or drug addictions have similar rates of violent crimes whether or not they have a mental illness

Randeep Ramesh, social affairs editor guardian.co.uk, Monday 6 September 2010

<http://www.independent.co.uk/life-style/health-and-families/health-news/mentally-ill-not-more-violent-says-study-2072187.html>

- Mentally ill not more violent, says study

By Jeremy Laurance, Health Editor Tuesday, 7 September 2010

People with mental illness are no more likely to commit violent crimes than ordinary members of the public – unless they have abused drink or drugs, researchers say.

Substance abuse is the chief cause of violent crime and increases the risk equally in people with and without mental illness, researchers at the University of Oxford found.

<http://www.independent.co.uk/life-style/health-and-families/health-news/mentally-ill-people-nearly-five-times-more-likely-to-be-victims-of-murder-than-general-population-8521493.html>

- Mentally ill people nearly five times more likely to be victims of murder than general population

Jeremy Laurance Wednesday, 6 March 2013

<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.

<http://www.network54.com/Forum/281849/message/1173353922/Mental+Health+Bill+will+do+nothing+for+public+safety,+research+shows>

<http://www.psychminded.co.uk/news/news2006/dec06/ctos.htm>

- CTOs do not work...and that's according to the evidence base

December 12, 2006

Community treatment orders will help protect the public from mentally people who kill, says the government. But what of the evidence for such a claim, asks Adam James?

viii <http://www.scotland.gov.uk/Publications/2009/08/07143830/0>
- Limited Review of the Mental Health (Care and Treatment) (Scotland) Act
2003: Report (McManus Review)

<http://www.scotland.gov.uk/Publications/2009/08/07143830/7>
- CHAPTER SEVEN OTHER ISSUES

‘In the course of our consultation, we received extensive submissions from several bodies, especially the Mental Welfare Commission, the Royal Colleges, carers and users groups and the Tribunal service. Many of the points raised are covered in the substantive text above. However, some of the points did not fall neatly within our headings and we propose, in this chapter, to address the outstanding points with which the Review Group is in agreement.’

‘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.’

ix

http://reports.mwscot.org.uk/Visiting_monitoring/LearningDisabilityCensusReport2010/LearningDisabilityCensusReport2010.aspx

- Learning Disability census report 2010

x <http://www.sign.ac.uk/guidelines/fulltext/98/section6.html>

<http://www.bmj.com/content/346/bmj.f857>

- Head to Head: Maudsley Debate

Does the emphasis on risk in psychiatry serve the interests of patients or the public? No
BMJ 2013; 346 doi: <http://dx.doi.org/10.1136/bmj.f857> (Published 12 February 2013)

Cite this as: BMJ 2013;346:f857

1. Matthew Large, medical superintendent

‘Mental health professionals, the courts, and governments have placed too much faith in risk assessment. It does not work. It has distracted clinicians from a broader consideration of our patients, their illnesses, and their best interests. We should downgrade risk assessment and return to our real and enduring duties as doctors and consider what people can do, what they want to do, and how we can help them recover.’

xi <http://www.rcpsych.ac.uk/workinpsychiatry/faculties/intellectualdisability/training.aspx>

- Training – Faculty of Psychiatry of Intellectual Disability

Research and reading: Reading List

http://reports.mwscot.org.uk/Visiting_monitoring/LearningDisabilityCensusReport2010/LearningDisabilityCensusReport2010.aspx

- Learning Disability census report 2010, see section on Diagnosis, Table 7, which makes clear that 38% of men on compulsory orders had just a diagnosis of Learning Disability, without any diagnosis of mental illness or personality disorder. For women, the proportion is nearly half that of men – 20%.

http://www.nes.scot.nhs.uk/media/846015/interactive_mh_act_resource_apr_11_.pdf

- Mental Health Care and Treatment Act 2003

Theme: Mental health and learning disabilities

Career stage: General

Overview: A resource for Mental Health Nurses working with people with mental health problems, in recognition of the fact that they have specific statutory responsibilities as well as practice responsibilities under the Act.

Publication date: 30-04-2011

xii <http://www.bbc.co.uk/news/10384033>

- 23 June 2010

Concerns raised over psychiatric unit admissions

Some people are being "inappropriately" admitted to Scotland's secure psychiatric units, a study has found.

‘The report said in some cases violent criminals and sex offenders had been mixed with vulnerable adults, such as under-18s and people with learning difficulties.’

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- xiii <http://www.breggin.com/>
http://breggin.com/index.php?option=com_content&task=view&id=187&Itemid=93
- xiv www.mwscot.org.uk/media/51774/Consent%20to%20Treatment.pdf
- Consent to Treatment: A Guide for Mental Health Practitioners, MWC 2010
- xv http://issuu.com/treatingautism/docs/medical_comorbidities_in_autism_spectrum_disorders
- xvi <http://www.psychminded.co.uk/news/news2010/july10/Anti-psychotics-likely-to-cause-brain-damage001.html>
- Anti-psychotics likely to cause brain damage, new study claims
EXCLUSIVE July 7, 2010 by Angela Hussain
- http://www.psychminded.co.uk/news/news2008/April08/Antipsychotic_medication002.htm
- The anti-psychotic myth exposed?
April 2, 2008
Anti-psychotics are not effective long-term, shrink the brain and almost triple the risk of dying early, a London NHS psychiatrist and academic has written in a new book. Isn't it about time for a deep examination of the validity of such drugs asks Adam James?
- <http://www.expert-reviews.com/doi/abs/10.1586/ern.11.87>
- Summary
Expert Review of Neurotherapeutics
July 2011, Vol. 11, No. 7, Pages 943-946 , DOI 10.1586/ern.11.87
(doi:10.1586/ern.11.87)
Theme: Schizophrenia - Key Paper Evaluation
Brain tissue changes and antipsychotic medication
Basant K Puri
- <http://www.neuroleptic-awareness.co.uk/>
http://www.neuroleptic-awareness.co.uk/?Neuroleptic_Induced_Iatrogenic_Conditions
- <http://psychrights.org/States/Alaska/CaseXX/3AN-08-493PS/JacksonOnNLtoxicity.pdf>
- The pharmaceutical companies dominate drug research, which is why the effects of their drugs on the brain are ignored:-
<http://www.madinamerica.com/2012/04/playing-hide-and-peek-with-psychiatric-drug-studies/>
- <http://www.ahrp.org/cms/content/view/273/146/>
- the drivers behind drugging of children
- <http://www.ahrp.org/cms/content/view/886/9/>
- the corruption behind the `Teen Screen` programme
- <http://www.bmj.com/content/324/7334/383.2>
- Authors of guidelines have strong links with drugs industry
BMJ 2002; 324 doi: <http://dx.doi.org/10.1136/bmj.324.7334.383/a>
(Published 16 February 2002)
Cite this as: BMJ 2002;324:383.2
Most guidelines on clinical practice are written by experts with undisclosed links to the pharmaceutical industry, researchers from Toronto, Canada, say in an article in the journal of the American Medical Association (JAMA 2002;287:612-7).
In a survey of nearly 200 authors of 44 clinical guidelines, 87% of respondents admitted to financial links with one or more pharmaceutical companies. Over half of the authors had been paid to conduct research, over a third had been an employee or consultant, and two thirds had received fees for speaking.
On average each respondent had links with 10 companies, including companies whose products they recommended in guidelines. Only one of the 44 guidelines carried a declaration of the authors' competing interests.
- Fine for fraudulent claims made by manufacturer of Risperdal
<http://www.bloomberg.com/news/2012-04-11/jnj-told-to-pay-1-1-billion-penalty-in-arkansas-risperdal-trial.html>
- J&J Ordered to Pay \$1.1 Billion Penalty Over Risperdal

By Eric Francis, Jef Feeley and David Voreacos - Apr 12, 2012 8:04 PM

<http://www.ahrp.org/cms/content/view/863/9/>

- Big Pharma's Criminal / Civil Settlements
Tuesday, 28 August 2012

xvii

http://reports.mwcscot.org.uk/Visiting_monitoring/LearningDisabilityCensusReport2010/LearningDisabilityCensusReport2010.aspx

- Learning Disability census report 2010

xviii <http://www.ageofautism.com/2009/12/autisms-harsh-reality-the-death-of-harry-horneroberts.HTML###tp>

xix <http://guidance.nice.org.uk/CG142/Guidance/Appendices/pdf/English>

<http://guidance.nice.org.uk/CG142/Guidance/pdf/English>

Quite how Scottish psychiatrists are going to abide by these guidelines, we don't know – they state that psychotropic drugs should be tried for 3-4 weeks, and `if there is no indication of a clinically important response`, that they should be discontinued after 6 weeks. The people with ASD who are currently under CTOs who are known to us have been forced to take these drugs for many years.

xx <http://www.mwcscot.org.uk/publications/investigation-reports/>

- Mr Q Enquiry, 1st January 2009, page 17

PARLIAMENTARY QUESTIONS ON AUTISM TRAINING

Question S2W-26126: Rosemary Byrne, South of Scotland, Scottish Socialist Party, Date Lodged: 22/05/2006

To ask the Scottish Executive what the costs were of providing training in the treatment of autism in each year from 1999 to 2005, broken down by NHS board.

Answered by Lewis Macdonald (01/06/2006): There are a range of therapies and interventions for managing autism spectrum disorders and the SIGN guideline currently being developed will contain recommendations for effective interventions based on current evidence.

Information about the costs of training in this range of interventions is not held centrally.

Current Status: Answered by Lewis Macdonald on 01/06/2006

Question S2W-26127: Rosemary Byrne, South of Scotland, Scottish Socialist Party, Date Lodged: 22/05/2006

To ask the Scottish Executive what the costs were of providing training in the diagnosis of autism in each year from 1999 to 2005, broken down by NHS board.

Answered by Lewis Macdonald (01/06/2006): Information about the costs of training in the diagnosis of autism is not held centrally.

The Scottish Executive is supporting four training pilot projects in the use of diagnostic tools to develop expertise in diagnosis across a wider range of professionals.

Current Status: Answered by Lewis Macdonald on 01/06/2006

<http://psychoticdisorders.wordpress.com/bmj-best-practice-assessment-of-psychosis/>

<http://psychoticdisorders.wordpress.com/>

<http://www.jopm.org/perspective/narratives/2011/03/28/psychosis-possibly-linked-to-an-occupational-disease-an-e-patient's-participatory-approach-to-consideration-of-etiological-factors/>

- Styrene and toluene can cause apparent `mental illness`

xxi <http://www.bbc.co.uk/news/uk-england-bristol-19162516>

- 7 August 2012 Last updated at 15:28

Winterbourne View abuse report calls for changes to care

<http://www.independent.co.uk/news/uk/home-news/private-hospital-patients-were-routinely-abused-8015612.html>

- Private hospital patients were 'routinely abused'
Nina Lakhani

<http://www.bbc.co.uk/programmes/b01nq1cg>

- Second-Class Patients?
Wednesday 08 August 2012

<http://www.heraldscotland.com/news/health/backlash-over-care-costs-as-many-at-risk-give-up-services.18006359>

The Scottish Parliament's Justice Committee looks into the matter of 'informal exclusions' of children with ASD and the effect that this has on their future prospects.

<http://www.tes.co.uk/article.aspx?storycode=6318854>

- Vexed questions over school exclusions
News | Published in TESS on 8 February, 2013 | By: Emma Seith

<http://www.tes.co.uk/article.aspx?storycode=6322203>

- Aberdeenshire's ASN figures alarm
News | Published in TESS on 1 March, 2013 | By: Elizabeth Buie
Completely inconsistent support for pupils with additional support needs in Scottish schools

<http://www.scotland.gov.uk/Publications/2013/02/7808/5>

The Scottish Executive's former head of special education finally agrees with those of us who warned that the ASL Act would simply be used to deny our children their right to an education appropriate to their needs.

<http://www.tes.co.uk/article.aspx?storycode=6134008>

- Just where are we with co-ordinated support plans?
News | Published in TESS on 11 November, 2011 | By: Mike Gibson

<http://www.tes.co.uk/article.aspx?storycode=6006538>

- Costs play role in failure to create CSPs
News | Published in TESS on 19 December, 2008 | By: Emma Seith

<http://www.heraldscotland.com/news/education/special-needs-shake-up-call.19410137>

- Special needs shake-up call
Andrew Denholm Education Correspondent
Wednesday 14 November 2012

Government's policy group get their facts wrong on autism education

<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

xxii <http://www.ncbi.nlm.nih.gov/pubmed/9501741>

- 1 Am J Psychiatry. 1998 Mar;155(3):325-36.
Schizophrenia-like psychosis and epilepsy: the status of the association.
Sachdev P.
Neuropsychiatric Institute, Prince Henry Hospital and School of Psychiatry, University of New South Wales, Sydney, Australia.

xxiii <http://www.ageofautism.com/2009/12/autisms-harsh-reality-the-death-of-harry-horneroberts.HTML##tp>
<http://www.telegraph.co.uk/news/uknews/1533926/Look-what-they-did-to-my-Janis.html>

xxiv <http://www.mwscot.org.uk/publications/visit-monitoring-reports/>

- Left Behind 1st January 2012
The quotes below, from this MWC report, give a clear indication of the incompetent and wholly inadequate monitoring of physical health within the Scottish mental health system:-
'A record of physical health checks, as required in „Delivering for Mental Health“, was absent in around 25% of case files examined.'
'We expect Individuals who are in hospital for lengthy periods should have physical health checks on at least an annual basis.'

‘The Scottish Government’s “Delivering for Mental Health” (2006) requires, where possible and appropriate, that every individual with severe and enduring mental ill-ness has a physical health assessment at least once every 15 months.’

xxv <http://www.rpsych.ac.uk/files/pdfversion/OP67.pdf>

- Physical Health in Mental Health Final Report of a Scoping Group (2009), Royal College of Psychiatrists, London. Occasional Paper 67.

‘Acting on abnormal physical findings

Psychiatrists are medically trained doctors. Some remain highly involved in physical healthcare throughout their careers and other specialise in areas where physical assessments are performed less frequently. All prescribers must remain competent to detect and minimise physical consequences of prescribed drugs. However, not all psychiatrists will feel competent to interpret abnormal tests (such as abnormal glucose measurement) and to manage them. Liaison with colleagues from primary and secondary care is essential when results of physical assessments fall beyond an individual’s level of competence.’

One of the founding members of Autism Rights has been forced to seek refuge in Spain, after her son indicated that he could not continue to live under the restrictions imposed upon him by his CTO and the attitudes of mental health practitioners towards him. His parents have paid for many thousands of pounds of medical tests over a number of years which have shown that he has some apparently rare medical conditions which mean he presents as mentally ill. Although these tests have been performed by reputable medical laboratories under the direction of internationally renowned doctors, his health board refuse to conduct their own tests to check these results. The original press article appeared in the 30th September edition of ‘The Sunday Post’.

<http://www.paisleydailyexpress.co.uk/renfrewshire-news/2012/10/04/mum-forced-to-flee-with-autistic-son-calls-for-inquiry-into-his-treatment-87085-31961612/>

- Mum forced to flee with autistic son calls for inquiry into his treatment
Oct 4 2012 by Chris Clements, Paisley Daily Express

<http://www.dailyrecord.co.uk/news/scottish-news/dad-defends-wife-who-fled-1352528>

- * By Heather Greenaway * 1 Oct 2012

<http://www.heraldscotland.com/news/home-news/autistic-son-and-mother-flee-uk.19018803>

- MONDAY 1 OCTOBER 2012
Autistic son and mother flee UK

<http://www.thesun.co.uk/sol/homepage/news/scottishnews/4564986/Gran-fled-to-save-sons-life.html>

- Gran fled to save son’s life
By BEN ARCHIBALD
Published: 01st October 2012

xxvi <http://www2.le.ac.uk/offices/press/press-releases/2011/august/psychiatrists-failing-to-adequately-monitor-patients-for-metabolic-side-effects-of-prescribed-drugs>

- Psychiatrists failing to adequately monitor patients for metabolic side-effects of prescribed drugs
People treated in psychiatric settings are receiving inadequate medical monitoring following high risk antipsychotic medication
Issued by University of Leicester Press Office on 10 August 2011

xxvii Methylphenidate can, as with SSRIs, *create* psychosis – which is then ‘treated’ with antipsychotic drugs.

xxviii <http://www.bloomberg.com/news/2012-05-24/more-than-half-autistic-kids-prescribed-mood-medicines.html>

A National Needs Assessment Report on Child Mental Health in Scotland pointed out that there was a steep rise in the numbers of children with ADHD and ASD suffering from mental health problems. This is undoubtedly caused by poor service provision, but also by the use of psychotropic drugs. There is also a basic problem with identifying mental illness in the absence of knowledge of autistic spectrum disorders and their attendant behaviours.

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

- drug effects on children

xxix <http://www.mwscot.org.uk/good-practice/notifying-the-commission/>
- Notifying the Commission

www.rcpsych.ac.uk/docs/Recorded%20Matters%20FINAL%20REPORT.doc

- Recorded Matters Working Group (September 2009)

Recorded Matters were regarded as being a means to bring some reciprocity to bear within the Mental Health Act, enabling the patient to specify some part of their treatment. As this report shows, this section of the Act is just not working, because it relies completely on the honesty of the Responsible Medical Officer (RMO).

Whistleblowers

There is still no effective support for whistleblowers – whether they be professionals, families or service users. That is not going to change in a target-driven culture that dismisses the concerns of such whistleblowers. As the UK government's adviser on inclusion, Rob Greig, pointed out in the aftermath of BBC Panorama's expose on the abusive practices at Winterbourne View private hospital, there is absolutely no point whatsoever in having what is largely a self-assessment system based on targets, if you repudiate the evidence of malpractice, mismanagement or incompetence provided by service users, their families and whistleblowers.

<http://www.heraldscotland.com/politics/political-news/sturgeon-urged-to-extend-failings-inquiry.1330571038>
<http://www.heraldscotland.com/politics/political-news/whistleblower-wins-battle-over-nhs-incident-reports.1329966241>

<http://www.heraldscotland.com/comment/letters/a-helpline-for-nhs-whistleblowers-is-long-overdue.19572591>

- NHS whistleblowers helpline to be set up

Perhaps this title suggests one safeguard that should be created, in a range of measures to support whistleblowers and defend the rights of users of public services:-

<http://www.bbc.co.uk/news/health-21341766>

- 6 February 2013 By Nick Triggle, Health correspondent, BBC News
Stafford Hospital: Hiding mistakes 'should be criminal offence'

xxx There is an inconsistent and lax approach to capacity within the mental health system, as this MWC report on long stay patients illustrates:-

<http://www.mwscot.org.uk/publications/visit-monitoring-reports/>

- Left Behind 1st January 2012

‘However, 34% of individuals, for whom it would have been appropriate, did not have an assessment of their capacity recorded. In some wards staff said it was not an issue, the staff member did not know or there was no system in place to record this.’

xxxi <http://www.heraldscotland.com/news/health/cuts-spur-fears-for-mental-health-tribunals-1.1085548>

- Cuts spur fears for mental health tribunals

Wednesday 16 February 2011

xxxii <http://www.mhtscotland.gov.uk/mhts/News/News>

- Law Society for Scotland - Code of Conduct for mental health tribunal work (28 September 2012)

The Law Society of Scotland by way of its Mental Health and Disability Sub-Committee, supported by its Professional Practice Committee, has published a new code of conduct for those solicitors conducting mental health tribunal work. The Code of Conduct was developed following a number of concerns from stakeholders in this field (including the Mental Welfare Commission, the Scottish Independent Advocacy Alliance and the Scottish Legal Aid Board) and to provide support and guidance to the profession.

xxxiii http://www.mhtscotland.gov.uk/mhts/About_Tribunal/Complaints

www.siaa.org.uk/documents/ExperiencesofMentalHealthTribunals.pdf

Mental Health Tribunal for Scotland: Experiences of Independent Advocates and Service Users

- see ‘Issues that have arisen’, pages 4-6 and Appendix 1 ‘Frank’s Story’, page 9. Also evidence from PAS, D&G - account of experience of Jack, page 7. In particular, this extract from ‘Frank’s Story’:-

`At the Tribunal, everyone was surprised to discover that the main concern of the Tribunal was not the contents of the report, but whether or not a diagnosis of Autism was a significant enough change of diagnosis from Learning Disability, to merit the case coming in front of them at all. Their findings were that it was not and therefore the Tribunal would not hear the case and responsibility for his continued detention would be passed back to the RMO & MHO.`

- So, a supposedly `expert` MHTS panel did not think that a change in diagnosis from Learning Disability to ASD warranted use of their time

xxxiv <http://www.spsso.org.uk/how-complain/organisations-we-take-complaints-about>
<http://www.spsso.org.uk/how-complain/matters-we-can-and-cannot-consider>

xxxv STATISTICS

All of the statistical measures avoid measurement of those with ASD, in spite of the recommendation in the 2001 PHIS National Needs Assessment report for Autistic Spectrum Disorders that these were necessary, in order to draw up budgets for service provision. (PHIS = Public Health Institute for Scotland, which has since been merged with another organisation to form NHS Health Scotland)

The new Mental Health Strategy blithely states that 1% of the Scottish population is on the autistic spectrum, in spite of the fact that none of the statistics back this up – apart from those for children. The School Pupil Census gives 7,801 pupils with ASD (out of a school population of 670,511).

<http://www.scotland.gov.uk/Topics/Statistics/Browse/School-Education/suppupils2011>

The ESAY guesstimates for the numbers of adults give a figure of just under 3,000.

<http://www.sclcd.org.uk/sclcd-projects/esay/publications-and-resources/statistics-releases>

and, as their figures are drawn from local authorities, ESAY have themselves suggested a reason for why these are not reliable figures:-

<http://www.heraldscotland.com/news/home-news/council-cuts-hit-hundreds-with-learning-disabilities.18620082>

So where are the other 40,000 people with ASD?

If there is not a substantial number of people with ASD in the mental health system, then that raises several very important issues:-

- 1) Are they in there, but have principal diagnoses of mental illness or Learning Disability (in which case, they are receiving care that is inappropriate to their needs)?
- 2) Given the average 10 - 25 year drop in life expectancy, they have been killed off by drugs - especially by the use of polypharmacy.
- 3) There has been a ten-fold increase in the numbers of children with ASD. The best international statistics reckon that there has been a 7 fold increase, taking into account widening of diagnostic criteria and improvements in diagnosis. When a 7% or 70% increase should be cause for serious concern and thorough investigation, why is a 700% increase failing to precipitate urgent investigation?
- 4) The proportion of very highly functioning adults with ASD is very much higher than amongst children with ASD.

Of course, apart from the last one (which is somewhat tongue in cheek), these are not mutually exclusive

xxxvi <http://www.guardian.co.uk/society/2012/dec/13/mental-health-patients-new-rights>

- Mental health patients to be given new rights

Patients to be allowed to choose consultants, a move that will give them parity with those with physical health problems

Denis Campbell The Guardian, Thursday 13 December 2012

This an English initiative that should be replicated in Scotland.

<http://www.kcl.ac.uk/iop/depts/hspr/research/ciemh/mhn/projects/litreview/LitRevAgg.pdf>

- Inpatient Violence and Aggression: a literature review. See Conclusion, and specifically:-

`Many of the causes of aggression and the skills used in preventing and managing aggression were centred on communication and interaction.`

So, people whose disability is defined by their impairments in communication and social interaction are doubly disadvantaged, as they cannot pick up on social cues and the mental health practitioners who work with them need to be knowledgeable and skilled in interacting with people with ASD.

<http://psychoticdisorders.wordpress.com/bmj-best-practice-assessment-of-psychosis/>

General mental health approaches

Soteria House (United States)

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

Open Dialogue (Finland)

<http://www.madinamerica.com/2012/06/open-dialogue/>

<http://www.madinamerica.com/2011/11/%EF%BB%BFsolutions/>

<http://www.madinamerica.com/2012/09/finland-the-pre-seminar/>

<http://www.madinamerica.com/2012/09/more-from-finland/>

Autism-specific approaches

http://www.autism.com/index.php/symptoms_self-injury

http://www.autism.com/index.php/symptoms_seizures

http://www.autism.com/index.php/symptoms_sensory_overview

<http://www.autism.com/index.php/related%20disorders>

http://www.autism.com/index.php/treat_edu_plans

<http://www.autism.com/index.php/adams>

Participation Form
Scotland's National Action Plan for Human Rights

Views are sought from all individuals and organisations who have experience or expertise that can help to shape Scotland's National Action Plan for Human Rights.

The Scottish Human Rights Commission will be collecting and analysing all responses received before the 29 March 2013. Early responses are appreciated.

Unless respondents request that their views remain confidential or anonymous all responses will appear online with the name of the organisation or individual. Contact details will not appear online.

- Please tick this box if you do not wish your response to appear online.
- Please tick this box if you are happy for your response to appear online but not your name or the name of your organisation.
- Please tick this box if you would prefer we did not link to your website.

Name:

Fiona Sinclair

Organisation (where appropriate):

Autism Rights

Website:

www.autismrights.org.uk

Email address:

fiona@autismrights.org.uk

Contact telephone number:

01292 500211

This form can be returned by post to: Dr Alison Hosie, Scottish Human Rights Commission, 4 Melville Street, Edinburgh, EH3 7NS, or sent as an electronic or scanned document to actionplan@scottishhumanrights.com

You can also fill out this form online at www.scottishhumanrights.com/actionplan

Participation Form Scotland's National Action Plan for Human Rights

1. Based on the evidence presented in the report *Getting it right? Human rights in Scotland*, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland's National Action Plan for Human Rights?

Human rights abuses taking place in public services, specifically those against elderly people and people with learning disabilities and Autistic Spectrum Disorders. The human rights abuses taking place against people on the autistic spectrum are the worst human rights abuses taking place in Scotland today, because some are life-limiting, some can undoubtedly be categorised as cruel, inhuman and degrading treatment, and they occur throughout the lifespan and in a range of settings. The worst human rights abuses taking place against people with Autistic Spectrum Disorders are those taking place within the mental health system.

Autism Rights' recent presentation to the Scottish Parliament's Cross Party Group on Human Rights, entitled 'Should people with Learning Disabilities and Autism be included within the provisions of the Mental Health Act?' has been edited and referenced and forms the largest and most central part of our submission to the SHRC's consultation on Scotland's National Action Plan for Human Rights. The rest of our submission is contained in this form and the document 'Scotland's National Action Plan for Human Rights – Autism Rights' supplementary submission', all of which are attached to our covering email. Other Autism Rights' documentation is referenced where appropriate. These documents make the case, not just for inclusion in an 'action plan', but for action.

2. What specific and achievable actions do you consider would best address the concerns you identify in your response to question 1?

The very fact that not a single official body or organisation has investigated the known human rights abuses taking place against people on the autistic spectrum means that it is left to Autism Rights, as a self-supporting, campaigning group, to act as human rights defenders. We have outlined a number of inconsistencies and omissions in official reports, data gathering and statistics, which make it much harder to find out just how bad the overall situation is. In a supposedly 'mature democracy', there ought to be taxpayer-funded investigation of these abuses, followed by policy change and legislative review, repeal and amendment.

We are campaigning for people with Autistic Spectrum Disorders (ASD) to be taken out of the the provisions of the Mental Health Act, for equality of healthcare for people with autism and for an inquiry into the treatment of all people with ASD within the mental health system. We make the case for these changes within our submission to Scotland's National Action Plan on Human Rights.

Further measures that would address abuses against people with ASD are covered in Autism Rights' 'Proposals for Autism Services', which can be accessed on our website -

<http://www.autismrights.org.uk/drupal/node/8> . We outline below some of the main points in these proposals:-

Participation Form Scotland's National Action Plan for Human Rights

- 1) Service Standards that are specific to the needs of these groups of people – generic standards are of no use in enforcing rights or ensuring accountability of those making decisions or of those providing services.
 - 2) Self-assessment of public services is based on sometimes irrelevant criteria too often used to rebuff legitimate criticism of these services and results in continual bureaucratic expansionism at the expense of adequate levels of service provision. For that reason, there must be robust and independent complaints procedures, which do not exist at present, as complaints are handled by the very bodies against whom complaints are being made.
 - 3) There is a complete absence of legal redress for people on the autistic spectrum, because of the absence of autism-specific standards in public services, the absence of class action lawsuits in Scots Law, the absence of equal reverence and equality of arms of much recent legislation, the administration and paucity of legal aid and a culture of official bigotry and maladministration. All of this needs to be tackled with vigour. Government and its agencies – and this includes Scotland's human rights organisations - need to acquire the determination to put a stop to an official culture where lessons are continually re-learnt but never applied.
 - 4) There is a particular problem of representation of people on the autistic spectrum, given the nature of this disability and the fact that the vast majority of those on the spectrum are incapable of defending themselves or of fully representing their interests. Representation is dominated by multi-million pound businesses that have charitable status, regardless of their funding, which is 89.1% - 99% provided by the state. These businesses are also written into government policy on datasharing, in spite of the absence of accountability or responsibility on their part (such as the exclusion of charities from FOI legislation). Direct representation of people on the autistic spectrum should be the norm, by their parents and other carers and by those people on the spectrum who are able to represent themselves. It is not acceptable that those who have a several direct conflicts of interest in speaking truth to power should dominate representation of a vulnerable group of people. Representation should include dissenting and critical voices.
 - 5) Parents and carers should have open access to enable collaboration with service providers on the nature and quality of services, and to provide a protection against abuse. Institutional abuse is not a thing of the past, and prevention of access to premises – as was shown in the BBC documentary on Winterbourne View – has made it much easier to cover up abuse. Inspection regimes and `self assessment` will continue to fail those who are abused and those who have the courage and decency to blow the whistle on abuse, at the risk of their own health and livelihoods.
-