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.

Response to Inquiry questions
To begin with, we will attempt to answer the key questions posed by the committee.

1. How children and adolescents potentially at risk of developing mental health problems are identified and how those problems should be prevented.
   - As far as children with ASD are concerned, their problems are misidentified. Most mental health professionals have little training and no professional qualifications in ASD, therefore features of behaviour that are part and parcel of being ASD are often misidentified as being a result of mental illness. In addition, absolutely no account is taken of the kind of stress that is inflicted on children with ASD by basic services, such as education, because these are inappropriate to the needs of children with ASD. The behaviour of children with ASD is frequently `strange` in the eyes of neurotypicals (i.e. the non-autistic) and, as their stress levels rise, will become more challenging.
   - These problems can be prevented by the provision of services that are appropriate to the needs of children with ASD. This will require the establishment of autism specific standards in all services – particularly in education and healthcare. To take education as an example, this will require an adapted curriculum, quality indicators for school inspections and professional qualifications specific to ASD. On top of this, there will need to be an overhaul of legislation and policy, the effects of which we have analysed in our Briefing Paper, to support these standards, which are useless without adequate rights, or powers of enforcement. There is currently no accountability of service providers to service users. We deal with this issue in the next section `Our Evidence`.

In answering this first question, we have also answered the other questions posed by the committee. Any further explanation needs to be developed through our own evidence, to which we hope the committee will give proper consideration.

Our Evidence
Our website address is – www.autismrights.org.uk . We have produced several documents, some of which can be viewed on our own website, and others, such as our
The recent submission to the consultation on the Additional Support for Learning Amendment Bill 2008, which are available on the Scottish Parliament's own webpages. The most important of these, from the point of view of this inquiry, are our `Proposals for Autism Services in Scotland’ and our Briefing Paper `Incompetent, Abusive, or both? - Scottish Executive policy and legislation on Autistic Spectrum Disorder (ASD)’ which was published in April 2007, both of which are available to read on our webpages.

In our written evidence to this committee for its inquiry into child and adolescent mental health services, we refer you to our Briefing Paper, which covers the main areas of concern that we have in relation to current policies and legislation and their effects on the rights of people with Autistic Spectrum Disorders. Please note that these concerns centre in the main around 4 pieces of legislation, 2 of which pertain to mental health, and 2 sets of guidelines which relate to mental health. These are the Adults with Incapacity Act, Mental Health Act, clinical guidelines on ASD produced by the Scottish Intercollegiate Guidelines Network (SIGN) and the UK-wide guidelines on Munchausen's Syndrome by Proxy (MSBP).

Individually, each of these pieces of legislation and policy may result in a breach of the rights of people with Autistic Spectrum Disorders, but collectively they have the potential to devastate lives. To understand how this could happen, you first have to read the following points of information:

- The Adults with Incapacity Act - reclassifies Autistic Spectrum Disorders (ASD) as a `mental disorder`, when it is internationally classified as a developmental disability.
- The Mental Health Act - permits the forced drugging in the community of both adults and children with a `mental disorder`, through the use of Community Treatment Orders (CTOs). (Here it should be noted that the Department of Health's own study on international experience of the use of these powers in other countries found that they simply did not work.)
- The SIGN clinical guidelines for children with ASD - recommend the use of highly toxic drugs to control children with autism, without any recognition of the absence of appropriate services for these children and the effect that this has on their behaviour.
- It is common practice to blame parents for any perceived `problem` that a child with ASD may have - even to the extent of accusing them of having Munchausen's Syndrome by Proxy (MSBP). It should be noted that a disproportionate number of mothers of children with ASD have been accused of MSBP (some of whom have had their children taken into care), and that the government's guidelines on MSBP overlap with the international clinical criteria for a diagnosis of ASD.
- The complete absence of service standards (including a blanket ignorance amongst professionals about ASD across all service sectors), the generic nature of disability legislation, and the dependence of disability and human rights legislation on other
legislation for their practical use all combine to make people with ASD so much more vulnerable to the effects of the interaction of all of this legislation and policy. There is nothing to usefully support the rights of people with a disability that is quite different from either learning, physical or sensory disabilities. It also must be stressed that the Additional Support for Learning Act has rescinded rights and further diminished the minimal powers of enforcement that were available under the previous legislation with the Record of Needs, and has obliterated any future hope of accountability of local authorities to parents of children with ASD.

- As regards health service provision, it is usual practice to allocate those adults with ASD who are lower functioning to Learning Disabilities provision, even though ASD is quite different from learning disabilities, and those who are higher functioning to Mental Health provision, even where there are no mental health problems. This allocation influences all service provision, including that for children. The attitude that ASD is merely learning disability with a few add-ons, not a distinctive disability, and that higher functioning children, who have above average intelligence, are `disturbed` or badly behaved permeates all services.

THE EFFECTS OF DRUGS CURRENTLY RECOMMENDED FOR THE `TREATMENT` OF AUTISTIC CHILDREN IN SCOTLAND

As regards the SIGN clinical guidelines on Autistic Spectrum Disorder (ASD), the SIGN committee refused even to consider the well recognised benefits of dietary change and nutritional supplementation, specifically the casein-free / gluten-free (GF/CF) diet. Nor did they give any consideration to the quality of basic services, and the stress that this places on children with ASD, resulting in, at best, a failure to cope. Instead they gave repeated and prominent promotion to the use of mind-altering drugs in the `treatment` of children with ASD, namely Methylphenidate, usually Ritalin, and Risperidone. Here is some information about these drugs:-

Risperidone is approved by the US FDA for the `treatment` of anxiety in children with autism. It is an atypical antipsychotic - these are a newer kind of antipsychotic that is causing great concern because they are now considered even more dangerous than the old antipsychotics\textsuperscript{1}, which also happen to be much cheaper. The study that initially researched the ‘benefits’ of Risperidone for children with autism lasted a mere 8 weeks. Other studies have pointed to the extreme downside of putting children with a disability onto an extremely powerful drug\textsuperscript{2}, merely to control anxiety and aggression that is caused by inappropriate education, healthcare and social care, when the evidence for the efficacy of these drugs is of insufficient quality because studies have been too small or have lacked scientific rigour\textsuperscript{3}. These drugs are known to cause adverse cardiac events, and to double the risk of those that are fatal.

As for the effects of psychostimulants such as Ritalin on children, drugs that are used to `treat` children labelled as ADHD and are now recommended (at least in the SIGN guidelines) to `treat` children with autism, they have resulted in major damage to the health, and indeed the mental health, of children\textsuperscript{4}. It must be noted that use of these drugs do result in some fatalities, because of the cardiac events that they cause\textsuperscript{5}.
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There are additional reasons why prescribing these drugs to children with ASD is particularly unwise. Because of the communication problems that all of these children possess, and the widespread ignorance of ASD amongst medical professionals and other service providers, challenging behaviour can be a result of an undiagnosed health problem. One child that we know of died because of an undiagnosed brain tumour – his behaviour had markedly deteriorated in the months before his death. We also know of another case where an adult had suffered for 4 years with an impacted wisdom tooth and under the ‘chemical constraint’ of these highly toxic psychiatric drugs, before his medical needs were attended to by health professionals in a specialist facility for people with ASD. Once his tooth was removed, his ‘challenging behaviour’ immediately ceased.

It is also the case that children with ASD are known to have distinctly different immune system reactions compared to typical children and to have metabolic disorders, which markedly affect the way that they metabolise psychiatric drugs, resulting in even greater damage to their physiological and mental health.

These drugs should not be recommended for the ‘treatment’ of anyone, let alone for a child, and let alone for a child with a disability. The European Charter on the Rights of Persons with an Autistic Spectrum Disorder specifically bars the use of such drugs for the control of people with an ASD – yet this is the main use of these drugs, largely because of the absence of appropriate standards in services.

Some leading psychiatrists claim Ritalin and other drugs prevent later illegal drug misuse - contrary to studies which demonstrate the opposite. Others are pretty honest about the effects of these psychotropic drugs on the brain - they cause the brain to atrophy. The full effects of these highly toxic drugs (the most toxic drugs, apart from those used in the treatment of cancers) on the developing brains of children is not known. What is known is that a Congressional Committee in the United States of America has been uncovering huge conflicts of interest within psychiatry, with ‘opinion formers’ failing to disclose research grants and consultancy payments from the very pharmaceutical corporations who manufacture the drugs they are supposed to be researching. This reflects concern expressed by the House of Commons Select Committee on Health’s report into the Influence of the Pharmaceutical Industry, that political and economic changes have resulted in too close an association between medical research, the medical profession and this industry. Indeed, we know that such apparent corruption or illegal activity is not confined to the US.

ABSENCE OF APPROPRIATE SERVICES

Autism Rights shares a growing consensus amongst parents and other carers of people with ASD that government is simply in denial about the true state of service provision for people with ASD and about the legislation and policy that will exacerbate an already intimidating atmosphere, where local authorities and health boards avoid developing, let alone providing, appropriate services by abusing the powers that they already posses. It is clear that central government uses the arms-length provision of services through local authorities, to avoid responsibility for these abuses. It also very conveniently allows them to deny that they take place.
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It is clear that these abuses of power are of inestimable utility in preventing any progress in the improvement of services because of the individual battles that each family must engage in, to have a chance of obtaining services that are in any way appropriate to the needs of their child. That way, collective action can be undermined by the fear that what little a family may have will be taken away. There is the additional threat of victimisation – a significant number of parents have informed us that they notice a worsening of their child’s behaviour, if they make a complaint about educational provision. We know that families who refuse to ‘put up and shut up’ can face protracted battles over guardianship when their child reaches 16 years of age.

Government denial does not merely involve their refusal to openly acknowledge abuse of power by local authorities and health boards, who are the service providers, it further extends to a denial that there is any increase in the numbers of children who have an ASD. This, of course, means that we have a situation where budgets for service provision are lagging well behind the need for services. The situation is desperate, but unrecognised, except for a few articles in the media. Even so, where services are provided, there is a huge amount of misspend on inappropriate and downright wasteful provision, such as expensive and unassessed courses for teachers, where professional training would cost much the same and deliver the quality of education that is needed, thereby preventing the routine use of psychotropic drugs to control children with ASD, which are themselves expensive and cause physiological and mental damage that is of far greater cost.

ENVIRONMENTAL TOXINS AND THEIR NEUROTOXIC AND IMMUNOLOGICAL EFFECTS

This denial of any increase in the numbers of children presenting with ASD is not purely to avoid expenditure on service provision. We all know that it is inseparable from the issue of what causes ASD, and the liability which that might entail. Contrary to the ‘line’ adopted elsewhere, Autism Rights believes that the jury is still out on causes of ASD – it is completely illogical to use epidemiological research to attempt to ‘prove’ the cause of a disease or disorder. Politicians of all hues would be outraged if any scientist or government official were to attempt to justify a refusal to conduct clinical research on cancers by claiming that epidemiological research proved that there was no connection between, for instance, radiation and some cancers.

Although there are some very encouraging developments in the US, there is currently 10 – 20 times the expenditure on genetic research than there is on environmental research into the possible causes of ASD. We do not have any figures for the UK, but have not heard of any environmental research. Genetics is certainly an area that attracts far greater media and political attention, even though there is a huge amount of misinformation about genetics. It is wholly illogical to claim that ASD is purely genetic in origin, which is why there is official denial of any increase in the numbers of children with ASD. This official denial, usually framed in the claim that diagnosis has improved, cannot be substantiated by improvements in diagnostic training – there is no available information on this. Indeed the latest research into the best statistics in the world, those of California, has proven that improved diagnosis does not account for this increase, and that this increase is real and ongoing. It should be noted that these increases in autism diagnosis have been mirrored in the UK. Whilst we cannot presently rule out a genetic predisposition to ASD, it is clear that such increases must be triggered by environmental factors, as this is impossible.
through genetics alone.

It is simply disingenuous to deny or ignore the environmental causes of ASD, when the World Health Organisation has produced its own evidence for the neurological damage caused by environmental toxins\textsuperscript{15}, and there is international consensus amongst the scientific community as to this damage\textsuperscript{16}. Governments are now going to have to follow the lead of the United States and accept that ASD is caused by environmental factors and finance research into the factors most likely to be implicated in this.

CONCLUSION
So, through current practices, policies and legislation, the Scottish parliament has dumped people with ASD in the mental health sector, where they do not belong. We hope that the Health and Sport Committee, through their consideration of our evidence, will commence the process of disengagement from this and will recognise the consequent devastation and distress that is inflicted on children with ASD. In doing so, the committee must actively push for the adoption of service standards and a requisite increase in budgets for children with ASD. The committee must also encourage a policy shift away from the current dead end concentration on genetic research towards the exploration of epigenetic and other environmental causes for ASD, in line with best emerging international practice. Not only would such research enable the avoidance of the future use of environmental toxins that are suspected causes of ASD, but such a shift may very well make the treatment of children with ASD a possibility\textsuperscript{17}, enabling them to live with much greater independence in their adult lives.

‘EQUAL RIGHTS - NOT ENDLESS FIGHTS’
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."

www.autismrights.org.uk

\footnotesize
\begin{itemize}
\item [4] http://www.guardian.co.uk/society/2008/apr/07/mentalth.ealth.drugs
\end{itemize}

- TRANQUILLISERS PUTTING CHILDREN'S LIVES AT RISK
- ANTI-PsYCHOTICS MAY CAUSE LONG-TERM HARM, SAY CRITICS
- YOUNGSTERS UNDER 6 BEING GIVEN UNLICENSED DRUGS
- A Failed Paradigm of Care

3  http://www.ahrp.org/cms/content/view/436/28
- AHRQ No Evidence to Support Off-Label Uses of Atypical Antipsychotics Tuesday, 19 December 2006

see also: http://news.bbc.co.uk/1/hi/health/4672948.stm
Too many drugs 'not child tested' Thursday, 2 February 2006
Too many children's drugs have not been properly tested, a report says. The House of Lords said 90% of medicines for new born babies and 50% of those aimed at children are untested after collating evidence from doctors.

4  http://www.ahrp.org/cms/content/view/364/31/
http://www.fda.gov/ohrms/dockets/ac/06/briefing/2006-4210B-Index.htm
http://www.ahrp.org/cms/content/view/131/31

see also: The Oregon Drug Effectiveness Review Project
- analysed 2287 pieces of research -- virtually everyinvestigation ever done on ADHD drugs up to 2006 - to reach its conclusions:it found no evidence to support the claims about these drugs' safety, effectiveness, or the legitimacy of the ADHD diagnosis.

5  http://www.guardian.co.uk/ frontpage/story/0,,1707535,00.html
http://www.ritalinindeath.com/
6  http://www.medicalnewstoday.com/medicalnews.php?newsid=23937
- Children with autism have distinctly different immune system reactions compared to typical children 06 May 2005

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

- Latest Junk Study by Harvard Psychiatrists Drs. Biederman, Wilens

8  http://ahrp.blogspot.com/2008/10/psychiatrists-answer-questions-about.html
- Psychiatrists answer questions about drug-induced brain damage

9  http://ahrp.blogspot.com/2008/10/is-psychiatry-poised-for-economic.html
- Is Psychiatry Poised for an Economic Meltdown?

http://ahrp.blogspot.com/2008/12/expert-or-pharma-shill.html

- J & J Risperdal Documents---Biederman-Harvard

http://www.nytimes.com/2008/06/08/us/08conflicthtml?ex=1213502400&en=23737184f344c4ca&ei=5070&emc=eta1
- New York Times June 8, 2008 Child Experts Fail to Reveal Full Drug Pay

see also: http://www.medicalnewstoday.com/healthnews.php?newsid=42507
- Ex-FDA Head Under Criminal Investigation Regarding Alleged Financial Improprieties And False Statements

- Former FDA Commissioner Lester Crawford Under Criminal Investigation For
Industry Financial Ties

- FDA Does Not Have Effective Process For Monitoring Post-Market Drug Studies, GAO Report Says

- Many Authors Of Mental Health Diagnosis Guidelines Have Financial Ties To Drug Makers, Study Says


The House of Commons Select Committee on Health raises major concerns about health policy, specifically the push to create a `pill for every ill'

- Guardian front page Thursday September 28, 2006

Drug firms' lobby tactics revealed Documents show how companies try to get new medicines fast-tracked

- BMJ. 2004 July 10; 329(7457): 72. Destruction of data prompts calls for Swedish agency to investigate research misconduct

- Guardian front page Thursday September 28, 2006

11

Concern over rising use of 'chemical cosh' on disturbed youngsters The Scotsman

Wed 20 Dec 2006

EXCERPTS

‘MORE children than ever in Scotland are being prescribed drugs to treat hyperactivity, figures revealed yesterday.

Statistics show prescriptions for treating attention-deficit hyperactivity disorder (ADHD) increased by almost 16 per cent in 2005-6, with 49,528 handed out by doctors.’

‘A spokeswoman for the Scottish Executive said: "New mental health treatment services for children have been developed across Scotland over the last year, and this has led to an increase in awareness of ADHD. "There is no evidence to suggest that the prevalence of ADHD has increased, but awareness of the condition and compliance with Scottish Intercollegiate Guidelines Network guidance has, and this explains a rise in prescriptions in the last year. "We would not expect to see a similar rise year-on-year over the next few years in the prescribing of these drugs."

But, unfortunately, there was:

- Herald, 17th Dec. 2008 - ‘ADHD Drug Prescriptions up 12%’

latest figure – 66,756 prescriptions 15.4% increase in cost of prescriptions – to £2.88m

The SIGN guidelines on ASD will definitely cause an increase in the prescription of these drugs, and consequent damage to children with ASD.
Healthcare costs will undoubtedly skyrocket. This next reference shows that the bulk of healthcare costs for children with ASD in the US are the result of the use of psychotropic drugs:-


A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan.

QUOTE `excess costs were largely explained by the increased use of psychotherapeutic medications.`

12 http://www.i-sis.org.uk/fromGenomicsToEpigenomics.php

The term epigenetics describes heritable changes in genome function that occur without a change in the DNA nucleotide sequence. The basis of epigenetics lies in the control of gene expression. This article goes some way to explaining why there is such confusion and misinformation about the role of genetics in research.

13 Parliamentary Question – Scottish Parliament
S2W-26127 - Rosemary Byrne (South of Scotland) (SSP) (Date Lodged Monday, May 22, 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 (Thursday, June 01, 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.


and

http://www.medicalnewstoday.com/articles/134717.php

- UC Davis M.I.N.D. Institute Study Shows California's Autism Increase Not Due To Better Counting, Diagnosis

Main Category: Autism Article Date: 08 Jan 2009

It should be noted that one of the statistical measures used in this study was data from the United States Census Bureau. The 2011 UK Census has a question on the nature of a person's disability, but it is not possible to identify ASD in the response required, in spite of the out fact that children with ASD now outnumber all other major childhood disabilities put together.
The UK and Scottish Governments must ensure that the numbers of people with ASD can be identified through the Census, or their continued excuses about the lack of statistics on numbers of people with ASD will be seen for what it is – a policy of avoiding needed expenditure on ASD.

15 Principles for Evaluating Health Risks in Children Associated with Exposure to Chemicals

Environmental Health Criteria 237
The peer-reviewed report highlights the fact that in children, the stage in their development when exposure to a threat occurs may be just as important as the magnitude of the exposure.

16 [http://www.pptox.dk/](http://www.pptox.dk/)
- International Conference on Fetal Programming and Developmental Toxicity
  Executive Summary: [http://www.iceh.org/pdfs/LDDI/LDDIExecSummary.pdf](http://www.iceh.org/pdfs/LDDI/LDDIExecSummary.pdf)

The Collaborative on Health and the Environment (http://www.healthandenvironment.org/) - Learning and Developmental Disabilities Initiative (LDDI) has published the "Scientific Consensus Statement on Environmental Agents Associated with Neurodevelopmental Disorders."

- Review of the evidence: Pesticides could poison our children’s brains
  In October 2008, Dr. Philippe Grandjean of the Harvard School of Public Health and the University of Southern Denmark co-published an extensive review of the evidence that certain pesticides have a neurotoxic effect. The paper, titled “Potential developmental neurotoxicity of pesticides used in Europe” shows that pesticides can be toxic to the developing brain. But brain toxicity is not routinely included in the tests for approved pesticides. Dr. Grandjean, renowned researcher and authority on the subject, urges the European Union to take these warnings seriously and tighten restrictions on pesticides.

- [http://environment.guardian.co.uk/waste/story/0,,1943058,00.html](http://environment.guardian.co.uk/waste/story/0,,1943058,00.html)
- [http://www.guardian.co.uk/uk_news/story/0,,2006552,00.html](http://www.guardian.co.uk/uk_news/story/0,,2006552,00.html)

- The Boston Globe
  Under suspicion - By Carey Goldberg, Globe Staff   August 13, 2007

  Researchers now believe that autism can be caused by genes in combination with environmental triggers. The question is, what are those triggers?

  “Herbert, the Harvard neuroscientist, argues that environmental exposures might not only help trigger autism, they may also continue to influence an autistic child's health and mental state, creating "striking good hair days and bad hair days." The mechanism may involve the immune system or brain chemistry or the body's metabolism -- or all three. If continued exposure is part of the problem, she says, perhaps such ongoing effects could be treatable, even reversible.”