

## CONSULTATION QUESTIONS

### Overall Approach

This consultation reflects a continuation and development of the Scottish Government's current approach for mental health. There is a general consensus that the broad direction is right but we want to consult on:

- The overall structure of the Strategy, which has been organised under 14 broad outcomes and whether these are the right outcomes;
- Whether there are any gaps in the key challenges identified;
- In addition to existing work, what further actions should be prioritised to help us to meet these challenges.

#### Comments

The overall structure, for the third time in 10 years, completely ignores the continued inclusion of people with disabilities within the scope of the Mental Health Act. Only because the Millan Committee and the McManus Review were prompted by submissions made by disability charities did they make mention of the possibility of future review of this situation.

Is this simply yet another rigged consultation?

### Improvement Challenge Type 1

We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes. An example of this is the implementation of the Dementia Strategy. There is a consensus that services for people with dementia are often not good enough and we already know about a range of actions that will improve outcomes. However some of these changes involve redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.

Question 1: In these situations, we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes.

#### Comments

How about implementation of national standards of care which are actually enforced, thus enabling accountability of public servants and the realisation of rights? The text above is a classic illustration of official inability and unwillingness to grasp the nature of the problems associated with dementia 'care' and other parts of the 'care' sector – where a MWC survey discovered that 75% of elderly people in care homes were being drugged

with one or more antipsychotic drugs (this was a survey of more than 1700 people residing in care homes).

## Improvement Challenge Type 2

We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes. Supporting services to improve care for people with developmental disorders or trauma are two areas where further work is needed to identify exactly what needs to happen to deliver improved outcomes.

**Question 2:** In these situations, we are keen to get your views on what needs to happen next to develop a better understanding of what changes would deliver better outcomes.

### Comments

If you constantly ignore submissions to your own consultations that do not fit with your own preconceptions, you are never going to understand how to improve service provision. Please see the main part of our submission, which does not fit into the prescriptive nature of this consultation.

**Outcome 1:** People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.

**Question 3:** Are there other actions we should be taking nationally to reduce self harm and suicide rates?

### Comments

A kinder, more compassionate society wouldn't have these problems. Stop the recategorisation of mental distress as mental 'illness', as this simply shifts the ills of society onto those who are its victims, rather than the perpetrators. A good start would be to investigate the numbers of people who die of the effects of psychotropic (psychiatric) drugs as compared to those who commit suicide. It would also be an idea to investigate how many suicides are linked to use of psychotropic drugs. Constantly brushing aside the real concerns of people and failing to take on board suggestions that would more effectively deliver improvements will take us no further forward.

**Question 4:** What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

### Comments

A kinder, more compassionate society wouldn't have these problems. Stop the recategorisation of mental distress as mental 'illness', as this simply shifts the ills of society onto those who are its victims, rather than the perpetrators. Make appropriate provision of services for people with mental disabilities, then you will see a drop in the numbers of this section of the population being incarcerated in mental institutions. Society picks up its values from the way that people are treated by those in authority. No wonder that there is hate crime against people with mental disabilities.

**Question 5: How do we build on the progress that *see me* has made in addressing stigma to address the challenges in engaging services to address discrimination?**

**Comments**

Commence a review of the Mental Health Act to remove people with disabilities from the provisions of this Act. It has no 'protective effect' for people with ASD – entirely the reverse, in fact, as psychotropic drugs are known to be particularly destructive of the health of people with ASD. No other approaches are currently used in the mental health system in Scotland, and there is no professional knowledge that is even adequate to the task of understanding and treating people with ASD, in spite of years of promises and acres of documentation. See additional information attached.

**Question 6: What other actions should we be taking to support promotion of mental wellbeing for individuals and within communities?**

**Comments** See previous comments and attached document.

**Outcome 2: Action is focused on early years and childhood to respond quickly and to improve both short and long term outcomes.**

**Question 7: What additional actions must we take to meet these challenges and improve access to CAMHS?**

**Comments**

Beware of precipitate action with children. The long-term effects of drugs like Mefhyphenidate and Risperidone on the developing brains of children are unknown, but we do at least know that they can cause diabetes and death, amongst other severe effects. There has been no programme to address the skills and knowledge deficit amongst mental health professionals of ASD, or indeed this deficit amongst any of the other professions that provide services for people with ASD, such as the teaching profession. Prevention is far better than cure, and there is no substitute for knowledge and expertise of autism if you are a Clinical Psychologist or Psychiatrist.

Question 8: What additional national support do NHS Boards need to support implementation of the HEAT target on access to specialist CAMHS?

Comments

Try providing some guidance specific to ASD and budget for autism specific training.

**Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.**

**Question 9: What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?**

**Comments**

Provide autism specific training for service providers and budgets that reflect needs.

**Question 10: What approaches do we need to encourage people to seek help when they need to?**

**Comments**

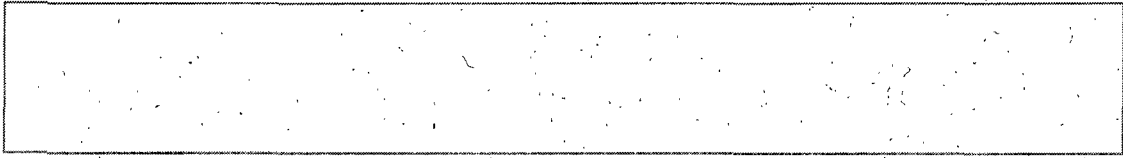
If people weren't so afraid of the nature of the mental health system (i.e. its reliance on psychotropic drugs and the risks of being trapped in it) and the known behaviours of many who work in this system, they would be much more inclined to seek help at an early stage.

**Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.**

**Question 11: What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?**

**Comments**

Beware early identification of mental health 'problems', or you will end up with Teen Screen and children as young as 18 months old being prescribed drugs for bipolar disorder, as has been happening in the USA. If a child is distressed, it is better to provide supports to the family and educational support to that child. As it is, identification, whether early or otherwise, is an irrelevance, where families with children who have ASD are constantly battling to achieve reasonable communication and adequate service provision in education.





**Outcome 5:** Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently.

**Question 12:** What support do NHS Boards and key partners need to apply service improvement approaches to reduce the amount of time spent on non-value adding activities?

**Comments**

'Evidence-based' treatment in the mental health system is something of a misnomer. As so little 'evidence' is paid for by the public purse, there is very little research into non-drug therapies.

When the 'Autism Toolbox', a supposedly specialist guidance document, has had to be partially re-written, because of a legal challenge to its description of Applied Behavioural Analysis (ABA), which dismissed the utility and effectiveness of a methodology that is approved for its effectiveness by USA's National Autism Plan, health authorities in Scotland should be wary of taking advice from a very limited pool of claimed expertise. The United States has been making provision for ASD for a very much longer period of time than has happened in Scotland. Service provision in England has also outstripped that of Scotland. Autism Rights has made its views known about the restricted membership of the ASD Reference Group, and the limitations that this is continuing to place on development of autism policy and practice.

**Question 13:** What support do NHS Boards and key partners need to put Integrated Care Pathways into practice?

**Comments**

They need to act professionally at all times. The abuses of power that Autism Rights knows are taking place would not be possible if there were official acknowledgement that these do take place – albeit this would require action on the part of government officials. Please see the submissions from Mrs. Christine MacVicar and Mrs Janette Robb for illustrations of these abuses and their associated inconsistencies.

**Outcome 6:** Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.

**Question 14: How do we continue to develop service user involvement in service design and delivery and in the care provided?**

**Comments**

Please could you supply evidence of service user involvement in service design and delivery and in the care provided for people with ASD in the mental health sector? The families we know can provide us with little in the way of positive accounts of the treatment of their sons within the mental health system, but can provide nightmarish accounts of the contempt with which their views and knowledge have been treated. Please see the attached documentation, and the various official surveys and datasets, from which it is impossible to extract any data for the numbers of people with ASD who are currently patients in the mental health system. This is in spite of numerous petitions, meetings and submissions of documentation down the years expressing concern for the failures of the mental health system in its treatment of people with ASD and in spite of the 2001 National Needs Assessment for ASD recommending the gathering of statistics on numbers of people with ASD in Scotland, in order to establish autism specific services.

**Question 15: What tools are needed to support service users, families, carers and staff to achieve mutually beneficial partnerships?**

**Comments**

Enforcement of nationally agreed Standards of service provision, where accountability of service providers is made possible and achievement of rights is not a pipe dream. That, and autism specific service provision.

**Question 16: How do we further embed and demonstrate the outcomes of person-centred and values-based approaches to providing care in mental health settings?**

**Comments**

See above

**Question 17: How do we encourage implementation of the new Scottish Recovery indicator (SRI)?**

**Comments**

Is this relevant to people with disabilities who find themselves in the mental health system because there is no appropriate service provision for them as adults?

**Question 18: How can the Scottish Recovery Network develop its effectiveness to support embedding recovery approaches across different professional groups?**

**Comments**

See above

**Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.**

**Question 19: How do we support families and carers to participate meaningfully in care and treatment?**

**Comments**

See above- ASD is ignored in this consultation.

**Question 20: What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?**

**Comments**

The collective experience of Autism Rights members is the reverse – there is a great deal that 'professionals' have to learn from families but refuse to listen or learn.

**Outcome 8: The balance of community and inpatient services is appropriate to meet the needs of the population safely, efficiently and with good outcomes.**

**Question 21: How can we capitalise on the knowledge and experience developed in those areas that have redesigned services to build up a national picture of what works to deliver better outcomes?**

**Comments**

See above and attached documentation.

**Outcome 9: The reach of mental health services is improved to give better access to minority and high risk groups and those who might not otherwise access services.**

**Question 22: How do we ensure that information is used to monitor who is using services and to improve the accessibility of services?**

**Comments**

See above, particularly comments re. The absence of statistical data on the numbers of people with ASD within the mental health system.

Question 23: How do we disseminate learning about what is important to make services accessible?

Comments

Keep it simple – there is a lot of documentation produced by the health service in Scotland that is repetitive and pointless. This does not leave room or time for meaningful and useful information – as per the absence of autism specific training and data on where the 50,000 people with ASD in Scotland (as claimed by the National Autistic Society and some government departments) are hiding. Please see latest ESAY statistics and those referenced in the attached document. From the figures available, and those I have obtained from the Health Boards through an FOI request, there are somewhere around 10,000 people in Scotland who are known to have a diagnosis of ASD. Whilst we would agree that this is very likely to be an underestimate, we doubt very much that there are five times that number of people with ASD within Scotland.

Question 24: In addition to services for older people, developmental disorders and trauma, are there other significant gaps in service provision?

Comments

If you tackle any of these 'significant gaps' as we've suggested, and further develop non-drug therapies, then we'll all be delighted. These areas are so significant that you could not be censured for concentration on these.

**Outcome 10: Mental health services work well with other services such as learning disability and substance misuse and are integrated in other settings such as prisons, care homes and general medical settings.**

Question 25: In addition to the work already in place to support the National Dementia Demonstrator sites and Learning Disability CAMHS, what else do you think we should be doing nationally to support NHS Boards and their key partners to work together to deliver person centred care?

Comments

See all comments above and attached documentation.



**Question 26:** In addition to the proposed work in acute hospitals around people with dementia and the work identified above with female prisoners, are there any other actions that you think should be national priorities over the next 4 years to meet the challenge of providing an integrated approach to mental health service delivery?

**Comments**

Given the length of time that people who are currently classed as having Learning Disabilities – this includes people with ASD – are trapped within the mental health sector, the Mental Health Act should be reviewed, with a view to taking people with Learning Disabilities and ASD out of the provisions of this Act. It offers no 'protective effect' and ensures that people with mental disabilities make up a disproportionate number of those detained in mental institutions. This will still mean that those people with ASD and LD who have mental illness (as opposed to distress at the treatment they are receiving) can still be covered by the Act – but it does not continue to act as a default setting for inadequate to non-existent care provision for people with mental disability. The creation of the Adults with Incapacity Act should have enabled progress towards a Review. If needs be, both the AWI and Mental Health Acts should be reviewed and amended.

One of the most important things that the health service should be doing as a national priority is setting up systems and training to identify people who cannot metabolise psychotropic drugs and for whom treatment with these drugs is dangerous to their physical and mental health. There is plenty research evidence available, especially as regards the immunological and metabolic disorders present in the ASD population, which supports a much more cautious and pro-active approach to the healthcare needs of this section of the population.

**Outcome 11:** The health and social care workforce has the skills and knowledge to undertake its duties effectively and displays appropriate attitudes and behaviours in their work with service users and carers.

**Question 27:** How do we support implementation of *Promoting Excellence* across all health and social care settings?

**Comments**

Standards that are appropriate to the needs of disability groups such as people with ASD, the Enforcement of these Standards, Accountability for those Standards by public servants and the consequent upholding of rights of people with ASD and other vulnerable groups.

Question 28: In addition to developing a survey to support NHS Boards workforce planning around the psychological therapies HEAT target – are there any other surveys that would be helpful at a national level?

**Comments**

Surveys are all very well as indicators for further investigation – what is needed are statistics that stand up to scrutiny and enable planning for services appropriate to the needs of people with ASD.



Question 29: What are the other priorities for workforce development and planning over the next 4 years? What is needed to support this?

Comments

Conflicting priorities are part of the reason that the mental health system fails many people – keep it simple and institute Standards – as described above.

Question 30: How do we ensure that we have sustainable training capacity to deliver better access to psychological therapies?

Outcome 12: We know how well the mental health system is functioning on the basis of national and local data on capacity, activity, outputs and outcomes.

Question 31: In addition to the current work to further develop national benchmarking resources, is there anything else we should be doing to enable us to meet this challenge.

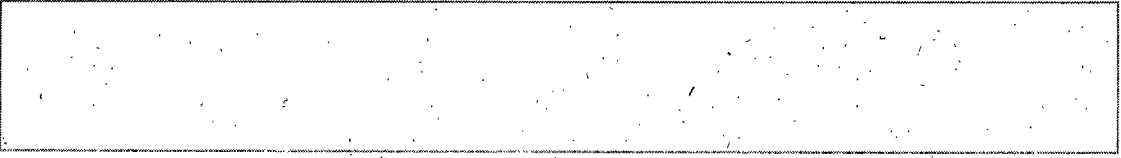
Comments

Well, you don't know how many people with ASD there are in mental institutions, nor have you any real idea how many people with ASD there are in Scotland as a whole – so there is a lot you don't know but should know, given the 2001 ASD National Needs Assessment Report recommendation that statistics on numbers of people with ASD should be compiled, in order to effectively plan and budget for services appropriate to their needs.

Question 32: What would support services locally in their work to embed clinical outcomes reporting as a routine aspect of care delivery?

Comments

Perhaps fewer conflicting priorities and less paperwork, in conjunction with disability specific standards in all aspects of service provision, particularly training?



**Outcome 13: The process of improvement is supported across all health and social care settings in the knowledge that change is complex and challenging and requires leadership, expertise and investment.**

**Question 33: Is there any other action that should be prioritised for attention in the next 4 years that would support services to meet this challenge?**

Comments

No further comment – please see above and attached documentation.

**Question 34: What specifically needs to happen nationally and locally to ensure we effectively integrate the range of improvement work in mental health?**

Comments

Please see above comments and attached documentation.

**Outcome 14: The legal framework promotes and supports a rights based model in respect of the treatment, care and protection of individuals with mental illness, learning disability and personality disorders.**

**Question 35: How do we ensure that staff are supported so that care and treatment is delivered in line with legislative requirements?**

Comments

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. As cases that have reached the Scottish media have shown, Scotland is not immune from the effects of a culture established throughout the UK, even if, in general, the Scottish health service has more resources and is less dogmatic in its political directives than its English counterpart.

## **Use of psychiatric drugs in people with an autism spectrum disorder.**

My son has Asperger's Syndrome and is high functioning. Sadly he is also diagnosed with Schizophrenia [which we dispute] and has been given many different medications over the years. In fact, at one time, over a three-year period, he had 15 changes in antipsychotic drugs. I have no way of protecting him from such treatment. Supposedly for patient protection, there are Advanced Statements. This sounds like an excellent idea but unfortunately only patients deemed well enough can complete them. My son has never been considered as having the necessary awareness required to fill in one of those statements. I have made enquiries as to whether a statement signed by psychiatrists would be acceptable, but the answer is no; it has to be the patient who completes them.

His drug prescriptions included three experiments with depot antipsychotics, which are totally unsuitable for people with an autistic condition. At a tribunal, a psychiatrist who specialises in Asperger Syndrome explained to us that depots would induce seizure activity. That is exactly what happened, though mental health staff did not recognise the symptoms. My son agreed to try this depot in my absence. [I am his named person.] When I was eventually invited to enter the review room – it was a fait accompli. An agreement to accept treatment with an unsuitable drug had been coaxed from a patient deemed not well enough to complete an advanced statement!! When I asked why he agreed to this drug, he told me the doctor said it would 'just be a little prick.' Psychiatrists can put into place mental health sections, and then effectively do what they like. On another occasion he was persuaded to accept a depot drug, it made him squawk like a peacock – 60 times an hour. [I was counting]. And wailing like a wounded animal for hours on end. These drugs should definitely never be given again to my son – but I have no means of stopping it.

Then there is Clozapine, which my son is now prescribed for the 5<sup>th</sup> time. It doesn't help. It makes him ill. But such is the faith of psychiatrists in Clozapine, they seem unable to believe that it does not suit everyone. The third time – or was it the fourth time - our son was given Clozapine – the decision once again was made in my absence. I kicked up a fuss but to no avail. Sorry - your son has agreed - I was told. I asked my son why he had agreed to Clozapine – because it will make me sleep. He had just spent months on maximum dose of a drug which caused him severe insomnia and had been spending many nights fully awake. On this occasion with Clozapine, he developed Tardive Tourettism, and started swearing at passers by. Clozapine also gives him high BP and tachycardia. [Over 1000 deaths by cardiac arrest have been reported recently in Clozapine patients.]

Autistic persons are particularly sensitive to psychiatric drugs as they have metabolism problems. This means –

1. They can only tolerate extremely low doses of drugs – well below what normally would be regarded as a therapeutic level. Too high [for them] – and they become toxic – which will worsen psychosis if present, and their underlying spectrum predispositions will be exacerbated – anxiety, self harming, aggression and whatever other susceptibility the patient may have. In our experience, further drugs will be administered to combat these side effects, which are initially drug induced!

2. It means that withdrawal from a drug will be much more severe than in a 'normal' metaboliser. [Withdrawal / rebound psychosis] They run the risk of this being identified as an underlying mental illness – and further drugged.
3. It means that withdrawal from a drug will be much more prolonged than in a normal metaboliser –especially so in the case of depot drugs. Again – severe and prolonged withdrawal can too often be thought to be emergence of an underlying condition.

Without some kind of advanced statement our son is very vulnerable and without protection from the lack of knowledge and understanding in psychiatry, of the unusual drug reactions and metabolism problems in ASDs. The MWC can provide a second opinion but invariably they have the same lack of knowledge and understanding.

## Christie KH (Katherine)

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**From:** Fiona <fiona@autismrights.org.uk>  
**Sent:** 01 February 2012 10:15  
**To:** Mental Health Strategy  
**Subject:** submission to Mental Health Strategy  
**Attachments:** Misdiagnosis drugs in ASDs.doc; MWC extract of minutes, May 2011; Royal College of Psychiatrists recommendations, 1; Royal College of Psychiatrists recommendations, 8; Use of psychiatric drugs in people with an autism spectrum disorder.doc; Recorded Matters - from minutes of Prof. Group of MHTS; 0120638.doc

Autism Rights fully endorses and supports the submissions of Mrs. Christine MacVicar and Mrs Janette Robb to this consultation.

I attach various documents and parts thereof which contribute to an understanding of some of the issues surrounding current practices and policy affecting people with Autistic Spectrum Disorders (ASD) within the mental health system. The final attachment is our completed response form for this consultation. Our completed response form questions the nature of this consultation, which is the third review of mental health policy within 11 years, all of which have failed to address the repeated calls for review of the Mental Health Act as regards the inclusion of people with Learning Disabilities and, by implication, those with ASD, within the Act. However, both these previous reviews (the Millan Committee report and the McManus Review) did respond to the call for review by agreeing with them - so it is very strange that, yet again, there is another tightly controlled, highly circumscribed 'consultation' that omits any reference to what, to Autism Rights, is a historical anomaly that is highly damaging to the life chances of people with ASD.

There is a massive contradiction at the heart of the Mental Health Act for those with disabilities – that 'treatment' under the MHA must be likely to improve your condition or stop it getting worse. If, as we are so often told by the government, its agencies and the large autism charities, that Autistic Spectrum Disorder (ASD) is a 'lifelong disability', why is it that the only 'treatment' currently given within the health service in Scotland is medication with psychotropic drugs? ASD cannot be both an untreatable disability, but treatable with psychotropic drugs. Why is it acceptable for the SIGN clinical guidelines for children with ASD to recommend 'treatment' with stimulants and neuroleptic drugs, but to dismiss dietary or nutritional interventions, even though the effects of these drugs on the developing brain of a child are unknown?

Although government officials may claim that only those people with ASD who have a mental illness are affected by the Mental Health Act, this is plainly nonsense, as the Act itself does not qualify its inclusion of people with ASD in those terms. People with ASD are included on the basis of having a Learning Disability which is, in turn, a 'mental disorder'.

In practice, professional knowledge of ASD within the psychiatric profession is so inadequate, that behaviours that should be recognised as classically autistic or Asperger's are seen as mental illness. In addition, it is more

often the case than not that no consideration is given of the circumstances of people with ASD, such as whether or not they are receiving services appropriate to their needs and the effect that this has on their behaviour.

Given the spending levels in Scotland (which in both education and social care are substantially less for people with mental disabilities than in the rest of the UK) and the access issues that are exactly the same as those outlined in the Panorama programme on Winterbourne View (i.e. parents restricted to visiting their sons and daughters in a 'reception' area), there is nothing to stop similar abuse in Scotland. Our membership has informed us of some of this abuse. Similar access issues are encountered within the education system, although this is much worse in some local authorities compared to others, so this issue runs right the way through service provision for people with ASD.

Contrary to the view of some politicians and civil servants, the Mental Health Act does not have a 'protective effect' for those with ASD - even if they were in prison, they would not be forced to take drugs that damage their mental and physical health and their detention would be time limited. Given the aforesaid problems of absence of appropriate service provision, resulting in the mental health system providing the default setting for 'care' of many adults with ASD, and the noted ongoing problems with Mental Health Tribunals (see Herald article on this below and Mrs. Christine MacVicar's submission) it is truly absurd to make such a claim. Furthermore, our email correspondence with the Mental Welfare Commission has revealed its failure to investigate the collective experience of people with ASD within the mental health system, in spite of several complaints made to them down the years, as well as a meeting held several years ago with the then Depute Minister for Health, Frank McAveety, during which a large number of families described their nightmarish experiences of this system's 'treatment' of their adult sons. Indeed, the MWC still does not have in place any written procedures to guide their conduct in making investigations, nor does it have objective criteria for deciding which individual cases it will investigate. As a consequence, there are ongoing abuses against people with ASD in the mental health system and we see no way to stop this other than through Judicial Review.

As you will see from the weblinks supplied below, there are still no statistics available on the numbers of people with ASD who are detained under the Mental Health Act, or who are otherwise controlled by its provisions. I have tried to elicit this information from individual health boards, but have had limited success. If the government does not require them to collate statistics on numbers of people with ASD within their mental institutions, then they have no reason to do so. The 2001 NHS Health Scotland's Needs Assessment Report on Autistic Spectrum disorders recommended, for planning and budgetary reasons, that statistics on the numbers of people with ASD in Scotland should be collated. To date, there are no statistics of total numbers of people with ASD in Scotland, nor reliable statistics for any part of public services. In spite of heavy lobbying of the lead committee in the Scottish Parliament and the responsible Minister by myself and other members of Autism Rights, the chance to gather statistics of reasonable accuracy cost effectively was passed up in the 2011 Census.

Here are just some examples of Breaches of the Human Rights Act from the

testimony of our members:-

Breach of the right to Liberty – through taking evidence from health board employees, without permitting the patient or his legal representative or mother to hear this evidence (Section 2, Page 30 of BIHR 'Your Human Rights: A guide for people living with mental health problems')

[http://www.bihar.org.uk/downloads/guide/bihar\\_mental-health\\_guide.pdf](http://www.bihar.org.uk/downloads/guide/bihar_mental-health_guide.pdf)

Breach of Article 3 - the right not to be treated in an inhuman and degrading way - the BIHR classes treatment that causes severe mental or physical harm as inhuman treatment. There is undoubtedly severe mental and physical harm being caused to people with ASD who are forced to take drugs that are toxic to them and whose inevitably catastrophic reactions to these drugs then convince mental health professionals that an increase in these drugs is required, resulting in a spiral of mental and physical decline.

(Section 2, Page 13-16 of BIHR 'Your Human Rights:

A guide for people living with mental health problems')

[http://www.bihar.org.uk/downloads/guide/bihar\\_mental-health\\_guide.pdf](http://www.bihar.org.uk/downloads/guide/bihar_mental-health_guide.pdf)

## REFERENCES

Statistics and datasets

No complete data exists, and these links illustrate this.

[http://reports.mwscot.org.uk/web/FILES/Visiting\\_Monitoring/LD\\_Census\\_2010.pdf](http://reports.mwscot.org.uk/web/FILES/Visiting_Monitoring/LD_Census_2010.pdf)  
Learning Disability Census Report 2010, Mental Welfare Commission Scotland

[http://www.sclde.org.uk/sites/default/files/2010\\_esay\\_statistics\\_release\\_learning\\_disability\\_statistics\\_full\\_report\\_with\\_annexes.pdf](http://www.sclde.org.uk/sites/default/files/2010_esay_statistics_release_learning_disability_statistics_full_report_with_annexes.pdf)  
ESAY Learning Disability Statistics Release 2010

<http://www.scotland.gov.uk/Publications/2004/06/19505/38856>  
- On the Borderline? People with Learning Disabilities and/or Autistic Spectrum Disorders in Secure, Forensic and Other Specialist Settings, 2004

<http://www.isdscotland.org/Health-Topics/Mental-Health/>  
- go to Latest Publications for stats for year ending 31st March 2011  
<http://www.isdscotland.org/Health-Topics/Mental-Health/Publications/2011-12-20/2011-12-20-MentalHealth-Report.pdf>

- Published: 20 December 2011

Mental Health (Psychiatric) Hospital Activity Statistics

<http://www.isdscotland.org/Health-Topics/Mental-Health/Publications/2011-12-20/1224-Diagnosis-by-admission-Dec2011.xls>

<http://www.scotland.gov.uk/Publications/2008/03/27085247/12>  
- Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance

ANNEX E: Estimated prevalence figures by local authority area

[http://www.ohb.scot.nhs.uk/images/pdf/Autism\\_prevalence\\_across\\_Scotland\\_050411.pdf](http://www.ohb.scot.nhs.uk/images/pdf/Autism_prevalence_across_Scotland_050411.pdf)

- links for surveys and estimates of numbers of people with ASD in Scotland.



## Official reports on ASD

<http://www.scotpho.org.uk/health-wellbeing-and-disease/mental-health/data/autism>  
- Mental health: autism

Autism is the name given to a number of neurodevelopmental disorders which are characterised by an impairment in inter-personal communication and interaction.

For information on problems and issues around Autism, see NHS Health Scotland's needs assessment report on Autistic Spectrum disorders (2156Kb) and the Medical Research Council's review of Autism research: epidemiology and causes (412Kb). The National Autistic Society in Scotland has also published a number of relevant reports, including I Exist: The message from adults with autism in Scotland

[http://www.scotpho.org.uk/downloads/Autistic\\_Spectrum\\_Disorders.pdf](http://www.scotpho.org.uk/downloads/Autistic_Spectrum_Disorders.pdf)  
<http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002394>  
(broken link from Scottish Public Health Observatory webpages)

<http://guidance.nice.org.uk/CG128>

- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum

Clinical guidelines, CG128 - Issued: September 2011

NICE is recommending genetic investigation for people with ASD and the requisite biomedical interventions, where there is impaired immune or metabolic functioning

## Service provision for people with ASD

<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.

**OR, PEOPLE WITH AUTISTIC SPECTRUM DISORDERS MIXED IN WITH DRUG ADDICTS**

<http://www.heraldscotland.com:80/news/home-news/people-with-learning-disabilities-wrongly-housed-with-elderly-1.1072633>

- People with learning disabilities 'wrongly housed with elderly'

MONDAY 6 DECEMBER 2010

Almost 900 people with learning disabilities are living in care homes for the elderly, inappropriately placed to save local councils money, say campaigners.

Research by the Learning Disability Alliance Scotland (LDAS) has identified at least 869 people, the youngest aged 19, who have been placed in such homes. It says the true figure could be more than 1158.

## Protection of human rights

It's worth pointing out what happened to another BBC journalist who was working on a Panorama programme about 'care' for the elderly in South

Lanarkshire:-

<http://news.bbc.co.uk/1/hi/8187822.stm>

- Undercover care reporter arrested, Thursday, 6 August 2009

Yes, that's right, in England the police arrest the abusers, in Scotland they go for the journalist.

[http://www.scotsman.com/news/health/nurses\\_told\\_don\\_t\\_blow\\_whistle\\_on\\_patient\\_safety\\_and\\_staff\\_numbers\\_1\\_1991167](http://www.scotsman.com/news/health/nurses_told_don_t_blow_whistle_on_patient_safety_and_staff_numbers_1_1991167)

- Nurses told don't blow whistle on patient safety and staff numbers

Published on Monday 5 December 2011, 00:00

INCREASING numbers of Scottish nurses are being told not to report their concerns about patient safety and staffing levels, according to a new survey.

A total of 37 per cent of nurses said they had been discouraged or told directly not to be whistleblowers, up from 24 per cent just two years ago.

The Royal College of Nursing (RCN), which conducted the survey, reported that with fewer nurses in Scotland, an "overwhelming majority" of its members were worried about victimisation, personal reprisals or a negative effect on their career if they made complaints.

Nurses have also lost confidence that their employer would protect them if they spoke out, dropping from 43 per cent in 2009 to 29 per cent this year.

More than half said no action was taken when they raised concerns, up from a third two years ago, and just 17 per cent of employers took immediate action, slightly lower than for the UK as a whole and down in Scotland from 24 per cent in 2009.

#### A system dependent on drugs

There is now a lot of research evidence to show that people with ASD are particularly vulnerable to the effects of antipsychotic and other psychotropic (psychiatric) drugs, because of their impaired ability to metabolise these drugs and because of their immunological problems.

<http://www.independent.co.uk/life-style/health-and-families/health-news/doctors-sued-for-creating-valium-addicts-6282542.html>

Doctors sued for creating 'Valium addicts'

Patients take legal action after being damaged by over-prescription of drugs

Nina Lakhani Thursday 29 December 2011

<http://www.heraldscotland.com/comment/herald-view/mental-health-provision-a-suitable-case-for-treatment.15276922>

Mental health provision a suitable case for treatment

Tuesday 27 September 2011

It is profoundly depressing

Scottish Government figures released yesterday reveal that 11.3% of Scots over the age of 15 are taking daily anti-depressants and in Greater Glasgow and Inverclyde the figures are even higher. Last year there were more than 4.6 million items prescribed, the highest figure ever recorded. These drugs can play a vital role in helping some patients get from one day to the next but there is now ample evidence that patients suffering from mild to moderate depression recover just as quickly without drugs. In 2007 the SNP pledged in their manifesto to reduce to zero the rise in anti-depressants and then reduce them by 10%. Instead, the figures have continued to rise and the target has now been abandoned.

<http://www.independent.co.uk/life-style/health-and-families/health-news/do-the-dangers-of-codeine-outweigh-the-benefits-2108190.html>

- Do the dangers of codeine outweigh the benefits?

By Steve Connor, Science Editor Saturday 16 October 2010

It is a well established medical fact that there will always be a section of a population that cannot tolerate particular drugs, as this article describes.

We ask you to imagine how much worse this is for people who cannot tolerate the toxic effects of the much more powerful drugs used in psychiatry.

<http://www.independent.co.uk/life-style/health-and-families/health-news/addiction-fears-prompt-tighter-monitoring-of-painkillers-6260520.html>

Addiction fears prompt tighter monitoring of painkillers

Doctors warn that abuse of prescription drugs is being hidden because statistics are not collected

Friday 11 November 2011

<http://www.heraldsotland.com/adhd-too-many-kids-on-drugs-1.839869>

- ADHD: too many kids on drugs?

Records from 2005-6 showed that the region [Fife] recorded 180 prescriptions for every 1000 5-14 year olds, compared to the Scottish average of just under 83 per 1000 children.

<http://www.psychminded.co.uk/news/news2011/june11/Ritalin-for-children-is-quick-fix-and-should-be-reviewed-demand-educational-psychologists001.html>

- Ritalin for children is "quick fix" and should be reviewed, demand educational psychologists

June 15, 2011 by Angela Hussain

<http://news.bbc.co.uk/1/hi/health/7170167.stm>

- Friday, 4 January 2008,

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.

Researchers said it was more important to address the underlying causes.

In the UK, 200,000 people with learning disabilities are given anti-psychotic drugs - even though there is a risk of side-effects, the Lancet reported.

These can include risk of weight gain, impotence and strain to the cardiovascular system.

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

- - parents have no power to stop inappropriate or even illegal drugging of their adult children, which sometimes has tragic consequences, as in the case of Harry Horne-Roberts.

<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

## Autism Misdiagnosed as mental illness

[http://www.bbc.co.uk/radio4/youandyours/yy\\_20041028.shtml](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.

## Mental illness - or a manifestation of physical ill health?

<http://www.heraldscotland.com/news/health/dna-discovery-to-help-treat-schizophrenia-1.1128671>

- DNA discovery to help treat schizophrenia

## 'Treatment' of a person with ASD with psychotropic drugs - before and after

<http://www.youtube.com/watch?v=ETHMOI4Dkcl&feature=related>

- 'Her Name is Sabine' by Sandrine Bonnaire - Trailer

Indicative of injustice for people with ASD, whose cases are more complex and who need dual legal expertise in both Mental Health and ASD.

<http://www.heraldscotland.com:80/news/health/cuts-spur-fears-for-mental-health-tribunals-1.1085548>

- Cuts spur fears for mental health tribunals

DAVID LEASK INVESTIGATIONS REPORTER 16 Feb 2011

Quotes - see final paragraph in particular:-

'There are around 4500 such tribunals every year – at which it is decided whether patients should be locked up or not. Only around 20 solicitors specialise in the field, and most are based in the Central Belt.

The Herald understands just three firms carry out three-quarters of all legal aid work for such tribunals.

Mental health solicitors currently receive £50 in legal aid per hour – and another £50 per hour in travel expenses.

Proposed savings will see travel expenses halved. That, solicitors said, means they will no longer carry out cases far from their offices.

Anyone attending a mental health tribunal has the right to a lawyer – a specialist "curator" may even be appointed to act in their interests.

Alternatives to drugs - Cognitive Behaviour Therapy is not suitable for people with ASD, so what else is available?

<http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/matrix/the-psychological-therapies-matrix.aspx>

- The Psychological Therapies Matrix

Discipline: Psychology Theme: Workforce development, Mental health and learning disabilities Overview: The Psychological Therapies 'Matrix' is a guide to planning and delivering evidence-based Psychological Therapies within NHS Boards in Scotland. It provides a summary of the information on the current evidence base for various therapeutic approaches, a template to aid in the

identification of key gaps in service, and advice on important governance issues. Publication date: 10-01-2012 00:00 Format: PDF Contact: Ms Jennifer Davies Document: The Matrix 2011 6971KB

The Psychological Therapies 'Matrix' has been produced to help NHS Boards: Deliver the range, volume and quality of Psychological Therapy required to achieve the HEAT Psychological Therapies Access Target, and to meet ICP accreditation standards.

Provide evidence-based psychological interventions in other key government priority areas; by

Summarising the most up-to-date advice on evidence-based interventions;  
Providing information and advice on strategic planning issues in the delivery of efficient and effective Psychological Therapies services;  
Explaining the levels of training and supervision necessary for staff to deliver Psychological Therapies safely and effectively; and  
Describing the additional support available from Government in terms of related Mental Health initiatives-the Mental Health Quality and Efficiency Support Team (MH QuEST); Health Improvement Scotland (HIS) and the Integrated Care Pathway (ICP) process; the Information Services Division (ISD); and NHS Education for Scotland (NES)

Scottish Recovery Indicator - how does one 'recover' from autism?

<http://www.sri2.net/news-and-articles/61-the-closure-of-sri-1>

<http://www.sri2.net/32-whp-should-do-an-sri-2>

<http://www.sri2.net/31-the-sri-2-recovery-indicators-and-reflective-questions>

<http://www.sri2.net/29-sri-2-how-it-works>

<http://www.sri2.net/28-sri-2-connects-to-other-initiatives>

This email, and the attached documentation, comprises our submission to this consultation

Fiona Sinclair  
on behalf of Autism Rights  
[www.autismrights.org.uk](http://www.autismrights.org.uk)

**'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."

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Misdiagnosis in Autism and Asperger Syndrome and Inappropriate Drug use.

A huge problem lies hidden within our mental health system and it needs addressing – and it needs addressing quickly. I refer to people with autism spectrum disorders.

Psychiatric drugs are being prescribed to this section of society for a variety of reasons; sometimes in an attempt to control aggressive behaviour, hyperactivity or self-harming; or psychosis which has a medical basis, or caused by trauma. People on the autism spectrum have difficulties processing drugs – they have metabolic differences and sensitivities to toxins; often their detox pathways are faulty. Thus - on going to professionals for help, huge problems can emerge as a result of the drugs they are prescribed. People with an ASD can display side effects much sooner than people outwith the spectrum, and sometimes these side effects are very different from those seen in the neurotypical population. There is a temptation for doctors to continue prescribing additional medication to counter these side effects. This only serves to make psychiatric or autistic symptoms worse.

Because people with this condition suffer stress and anxiety, they are particularly prone to mental illness, but efforts to help are often having disastrous results. Drug side effects or toxicity are leading to young people being incarcerated for life, and / or permanently damaged, with some developing life threatening conditions even resulting in death.

<http://www.islingtontribune.com/news/2010/apr/harry-horne-roberts-parents-welcome-probe-police-autistic-son%E2%80%99s-death-while-care-home>

Harry Horne-Roberts' parents welcome probe by police into autistic son's death while in care home

In a recent radio programme 'All in the Mind', [Oct 4<sup>th</sup> 2011] Dr Alex Mitchell of Leicester University, points out that deaths in the mentally ill resulting from drug side effects, outnumber suicide deaths by 4:1. [He was not referring to people with an ASD who are particularly sensitive to psychiatric drugs.]

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

Worryingly, Dr Mitchell points out that in many cases the physical side effects are not being monitored, and when they are, they are not treated efficiently.

It seems the professionals not only lack expertise and education in diagnosis and treatment of Autism spectrum disorders, but also in the dangers of prescribing psychotropic drugs to patients with these disorders. Often the drugs given to people on the autism spectrum start with Ritalin or SSRI antidepressants, both of which can result in psychosis. These prescription drug-induced states seem to be poorly recognised within the profession and inevitably lead to the prescribing of antipsychotics, which can also cause or worsen psychosis. This problem is not new – it has been around for decades, but as the present tsunami of adolescents on the Autism spectrum hit adult psychiatry, it could now rapidly worsen unless something is done to prevent it. Apart from the obvious rising cost of care and treatment, inappropriate drugging is causing untold suffering to patients and their families.

<http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/ASDRef/ASD24Jan11>

Agenda Item 10: Criminal and forensic issues and ASD - Brief introduction - Dr Iain McClure

10.2 It is vital that people are not misdiagnosed. A significant number of people may be being criminalised (i.e. their ASD is not picked up in criminal investigations of aberrant behaviour) and / or possibly admitted to forensic psychiatry units such as Carstairs and medicated for possible 'false positive' diagnoses e.g. for schizophrenia (which has many symptoms and signs on mental state examination that overlap with ASD) when they are in fact undiagnosed autism. Such scenarios may lead to possible miscarriages of justice, as well as inappropriate clinical management approaches.

With the emergence of drug-induced psychosis – or a psychotic episode resulting from stress and anxiety, patients are mistakenly being labelled and treated as schizophrenic, or as having bipolar or some other affective disorder.

Paul Shattock in Autism File Magazine Issue 31 -  
[He is now president of World Autism Organisation]

Adolescents and Adults with Asperger's Syndrome  
"Personally, I have come across literally hundreds of adults who have been diagnosed late in life and so many of them have been misdiagnosed as suffering from bipolar or dyspraxia or Tourette's syndrome, the features of which constitute parts of the tapestry of Asperger's. Worse still, many are diagnosed at some stage as having schizophrenia and have consequently been treated with powerful drugs which are completely inappropriate for Asperger's and which can clearly make some of the symptoms worse. [And this is seen as evidence that higher doses should be given and so on...]"

A quote from Tony Attwood –

[http://www.tonvattwood.com.au/index.php?optibn=com\\_content&view=article&id=120:adults-with-asperger-disorder-misdiagnosed-as-schizophrenic&catid=48:diagnosis-and-assessment&Itemid=473](http://www.tonvattwood.com.au/index.php?optibn=com_content&view=article&id=120:adults-with-asperger-disorder-misdiagnosed-as-schizophrenic&catid=48:diagnosis-and-assessment&Itemid=473)

"Individuals who were not diagnosed with pervasive developmental disorders in childhood may subsequently be misdiagnosed as chronic, undifferentiated schizophrenics."

There is little evidence that SSRIs can help and children may suffer serious adverse effects as a result of taking the drugs.

<http://www.physorg.com/news200226527.html>

Benzodiazepines are effective in the short term but cannot or should not be used long-term. Wendy Lawson advocates their short-term use in acute states.

Back in 2002, there was to be public viewing of a TV programme called Frontline Scotland, which centred round a young man called Euan Johnston. Despite Euan eventually being diagnosed with Asperger syndrome, and despite a report from expert Professor Terry Brugha, doctors refused to explore the possibility of misdiagnosis and alter treatment. A local authority took out an injunction and screening was stopped.

<http://bit.ly/tcDSH9>

Cancellation of this programme led to some media publicity at the time.

[http://www.scotsman.com/news/health/autistic\\_adults\\_locked\\_up\\_after\\_false\\_diagnosis\\_11359567](http://www.scotsman.com/news/health/autistic_adults_locked_up_after_false_diagnosis_11359567)

"Shattock added: "There is no doubt that this has been going on for a long time and there may well be some individuals who have been misdiagnosed and treated inappropriately for up to 30 years. These patients are given medication appropriate for schizophrenia, which makes them worse, and they are given more and more medication as a result."

Dr Ken Aitken – consultant clinical neuro-psychologist said –

"There has to be a systematic review to find out how many people fall into this category. There may well be a large number of people who were given a particular mental health label which was appropriate for that time but whose diagnosis has not been revisited. I know it has happened and it is probably still happening."

[http://archive.disabilitynow.org.uk/search/z02\\_07\\_Jv/scottish.shtml](http://archive.disabilitynow.org.uk/search/z02_07_Jv/scottish.shtml)  
Scottish drugs scandal

<http://www.telegraph.co.uk/news/uknews/1445688/Scandal-of-asylums-that-lock-up-the-sane.html>  
Scandal of asylums that lock up the sane

<http://www.independent.co.uk/news/uk/crime/50000-psychiatric-cases-may-face-review-after-court-ruling-535126.html>  
50,000 psychiatric cases may face review after court ruling

But here we are – almost a decade later, and little has changed. In fact it has worsened. I think, or at least hope, that many of us were shocked at the Channel 4 investigation by Victoria McDonald [November 9<sup>th</sup> 2011] to learn that use of antipsychotic medication in children had doubled in the last ten years.

<http://www.channel4.com/news/numbers-of-children-on-antipsychotic-drugs-doubles>  
Number of children on antipsychotic drugs has doubled in a decade.

I have been in touch with parents of people with an ASD, and also some adults with the condition, who *have* been successfully medicated. But they tell me level of drug that works for them is tiny– maybe 1/8 or even 1/10 of the 'recommended therapeutic' dose. I think I can understand what is happening here. Medical professionals are anxious to alleviate symptoms, so they prescribe and raise the dose quickly to what they are trained to believe, is a therapeutic level. And the patient gets worse. Then the dose is raised again. But in their haste to help, they miss what could be a therapeutic window at very low levels.

**It's the Dose that Makes the Poison!**

I'm not advocating drug use for a condition which in many cases, could be improved by diet, removal of anxiety triggers, behavioural and biomedical interventions, but just trying to stress that if medication must be used, it seems it should be minimal.

We desperately need psychiatry to be educated in, or at least alerted to these possible dangers.

And most importantly- genetic testing should take place before prescribing, to check the patient's ability to metabolise drugs. Autism spectrum aside, 1 in 10 of the population is a poor metaboliser.

[http://www.lgc.co.uk/our\\_science/pharmacogenetics.aspx](http://www.lgc.co.uk/our_science/pharmacogenetics.aspx)



Constant supervision should alert physicians to emerging side effects

Regular checks should take place to pinpoint physical side effects – eg diabetes, cardiac problems, Lipid abnormalities, liver function tests, and cholesterol levels. When detected, they should be properly addressed!

It is terrifying that we cannot trust the profession in charge of autism spectrum disorders to handle this section of our society in a safe and informed manner.

### **ADDITIONAL ARTICLES**

[from press or Internet]

June 2000 - Sean Honeysett

<http://news.bbc.co.uk/1/hi/health/787526.stm>

Nov 2002 - Wendy Lawson - 25 years of pain.

<http://www.mugsv.org/wendy/wrongdx.htm>

Nov 2003 - Piers is not a criminal and he's not insane: so why is he in Broadmoor?

<http://www.telegraph.co.uk/news/uknews/1445689/Piers-is-not-a-criminal-and-hes-not-insane-so-why-is-he-in-Broadmoor.html>

Nov. 2003 - Julie Eldred

<http://psychrights.org/stories/TelegraphdoctorsturnedJulieintotwitchingwreck.htm>

June 2004 - Private Eye Asperger's - It's a Syn-drome. Piers Bolduc, Nick Priechenfried, Matthew Thomas.

<http://www.pamshouse.pwp.bluevonder.co.uk/asperger.htm>

Sept 2004 – Angela Browning House of Commons

<http://www.publications.parliament.uk/pa/cm200304/cmhansrd/vo040908/halltext/40908h04.htm>

May 2005 - Debbie's story - Informal group

[http://www.pamshouse.pwp.bluevonder.co.uk/a\\_tragic\\_story\\_of\\_mis.htm](http://www.pamshouse.pwp.bluevonder.co.uk/a_tragic_story_of_mis.htm)

May 2007

[http://www.salon.com/2007/05/18/autism\\_misdiagnosis/](http://www.salon.com/2007/05/18/autism_misdiagnosis/)

Ann Bauer