

I'm going to talk to you today in the main about legislation and policy that has been passed by the Scottish parliament during the past 10 years that has had a regressive effect on the human rights of people with disabilities and their families, particularly those with Autistic Spectrum Disorders.

Before any of this legislation or policy was put in place, there was considerable room for improvement to the rights of people with disabilities. It has taken until the late 20th and early 21st century for any real political thought to be applied to the rights of people with disabilities. That, in itself, is a disgrace. But what is even worse is that legislation and policy that governments have claimed are intended to create new rights for people with disabilities will actually result in their oppression.

I must also point out that much of this legislation and policy undoubtedly has the potential to be used against other sections of society – notably, but not confined to, the elderly, those with any kind of mental health problem and victims of violence.

Those of us whose political awareness was honed during the Thatcher years are very familiar with the classic Thatcherite diversionary tactic of selectively leaking information about draconian measures proposed for new legislation that are then ameliorated only by omitting the most oppressive of these measures. However, it is obvious

that the political classes, and I include the media in this, believe that we all have short memories and are not aware of these tactics.

While mental health activists were breathing a sigh of relief about their success in persuading the then Scottish Executive not to include powers to lobotomise patients under the new Scottish Mental Health Act, no-one was really challenging the basis for the Executive's inclusion of powers of compulsory treatment in the community within this legislation. As it later turned out, just before the English equivalent of this Act was passed at Westminster, the Department of Health's own research that was commissioned to look at the use of these same powers in other countries concluded that they do not improve the safety of the public or of patients.

These Community Treatment Orders are of such concern to people with ASD and their families because, under the Adults with Incapacity Act, people with learning disabilities and with ASD were reclassified as having `mental disorders`, even though ASD is internationally classified as a developmental disability. This re-classification was maintained in the Mental Health Act, thereby lumping people with disabilities in with those who are deemed to be mentally ill.

Current mental health practices revolve almost wholly around the use of psychotropic (or mind-altering) drugs.

The experience of parents who have adult sons and daughters with ASD is of a system that has comprehensively failed them – and now seeks either to label behaviours that are autistic as those of someone who is mentally ill which require control by psychotropic drugs, or to use these drugs as a means of control in the absence of any appropriate care. These experiences are not confined to people with ASD, as Mencap's report on the routine use of these drugs to control people with learning disabilities amply demonstrated.

So, we now have legislation which further consolidates the use of psychotropic drugs to control people with ASD in the absence of any standards for the limited services that are provided for them. What we have to recognise as well is that these Community Treatment Orders, or CTOs, don't just apply to adults – they also apply to children. Autism Rights made submissions to both the SIGN committee (which drew up clinical guidelines on children with ASD for all medical and educational professionals in Scotland) and the Scottish Parliament's Health and Sport Committee's inquiry into mental health services for children and young people. Our latter submission provided fully referenced information on the highly toxic and even fatal effects of the drugs that the SIGN committee recommended for the `treatment` of children with ASD (even in preference to tried and tested dietary and nutritional interventions) and the fact that the full effects on the developing brains of children are completely unknown. It should be noted here

that both of these drugs - Ritalin and Risperidone - are also recommended for the `treatment` of children with ADHD – whether you consider this a catch-all label or a diagnosis.

Research has also revealed that people with ASD often have compromised immune systems and metabolic disorders - so there are additional reasons why psychotropic drugs should not be used on people with ASD.

In 1996, the European Parliament approved the European Charter on the Rights of Persons with Autism, which was intended as an interpretation of the Human Rights Act for people with ASD. It states quite categorically that drugs should **not** be used as a means of controlling people with ASD. It is important to understand that these drugs have absolutely no therapeutic effect on ASD because it is a disability, not a disease.

All of the aforesaid wouldn't be nearly so frightening if past and current treatment of people with ASD wasn't so shoddy, going well beyond abusive control by toxic drugs. As stated, there are no standards for services specific to the needs of people with ASD. This is crucial, because ASD is quite unique in its features, from the triad of impairments (in social interaction, communication and imagination) that identify it as a disability, through to the sensory modulation problems that result in varying degrees of inability to filter out everything from background noise to the feel of fabric on the skin and to medical problems that doctors refuse to

treat.

The only educational provision for most children with ASD is a placement in a mainstream school where they will be lucky to have even a classroom assistant to help them to `cope` - contrary to provision for children with behavioural problems, who are more likely to receive attention. There is no specialist teaching qualification in ASD and the most that most teachers have, even in the very few supposedly specialist units that exist, is a day or two's training. Those parents who have experienced the effects that such provision has on their children know that it is *designed to fail* – and that's exactly what happens with many autistic children. Exclusions, in spite of disability discrimination legislation, are commonplace. `Secret exclusions`, where the parents reach an agreement with the local authority to keep their child at home because the emotional damage being done to their child is too great are common, as is part-time educational provision. Not many people will be aware that local authorities can actually fine a parent of a child that they have excluded for non-attendance at school. That gives a certain amount of leverage to a local authority.

But the real pressure applied to parents to force them to accommodate the refusal to make appropriate provision either for health or education has filtered down from a theory put forward by an eminent member of the medical profession, Professor Sir Roy Meadow. It doesn't apparently matter that this theory is now widely discredited in the

public's eyes because of the criminal trials of Sally Clark, Trupti Patel and Angela Cannings, it doesn't matter that the good doctor shredded his research data, it doesn't matter that the working group set up by the government, ostensibly to investigate the scientific validity of Meadow's Munchausen's Syndrome by Proxy, metamorphosed into a committee which drew up clinical guidelines to enable professionals to detect it. The promised review of the cases of the **thousands** of parents who have had children taken away from them has not happened – only a few cases have been looked at, one has to conclude because then the government could claim that they had conducted a review. We don't know how many autistic children were taken from their parents as a consequence of MSBP accusations made through the Family Courts and Children's Panel, but we know they were disproportionate in number. The features of MSBP overlap with the internationally agreed clinical criteria for ASD. Initially, such accusations were made against parents who blamed the MMR vaccine for their child's autism. It is now routine to accuse parents of children with ASD of causing their child's problems if they don't put up and shut up with the services on offer.

Sometimes other parents are accused – the parents of a visually impaired girl recently waived their right to anonymity to reveal that an FOI application made by them on records held by Argyll and Bute Council had uncovered the council's plans to prevent their placement request for their daughter to attend the Royal Blind School by accusing

the parents of `emotional abuse`. Camilla Cavendish, who was the joint winner of the 2008 Paul Foot award for investigative journalism, pointed out in her award-winning articles that the proportion of Family Court referrals made on the grounds of the vaguely defined `emotional abuse` have skyrocketed over the past few years. Emotional abuse is a cover-all term that certainly includes MSBP. In the spirit of name changes a la Calder Hall / Windscale / Sellafield, MSBP is no longer the preferred term. Factitious and Induced Illness (FII) is now the main term, with Reactive Attachment Disorder also proving popular.

Now, while I don't have the inside track on MSBP possessed by Lisa Blakemore-Brown, who is speaking today at the Convention's main event in London on behalf of Autism Rights, I have read widely on MSBP and have conducted my own research, via the Autism Rights questionnaire on school education and through several years contact with other families. It is no exaggeration to say that we now believe that the whole MSBP / FII phenomenon is the tip of an iceberg that is being kept afloat in order to deny our children the services that they need.

Services, even during these past `boom` years, have been rigorously kept to the bare minimum. It should therefore be unsurprising that we are determined that the considerable amounts of public money that is wasted on services that are devoid of standards and bureaucrats who are devoid of basic morality should be re-directed to the provision of

appropriate services for our children. That's not going to come from datasets that conflate `children in need` with `children at risk`, nor is it going to come from service inspections that destroy doctor-patient confidentiality and it's certainly not going to be provided by data sharing or integrating services when those services don't exist in the first place.

In concluding, I must warn that the inspiration provided by MSBP to our government's bureaucracy has spread to adult services and it is this that has the greatest potential to directly affect the human rights of the entire population at some point in their lives. The Adult Support and Protection Act must surely win any and all prizes for the most ironically titled legislation around. Under this legislation, local authorities have the power to force a `vulnerable` person out of their home, without even informing them that such a decision is under consideration, without giving them a right of appeal and with the power to imprison any family member who tries to prevent such a blatant abuse of human rights. As service providers, councils will now be in a classic poacher / gamekeeper role. The fact that these councils give no respite to families and have no appropriate care provision for adults with autism will not be open to scrutiny.

Inclusion Scotland's Policy Officer, Bill Scott, has written an article for a special issue of the Scottish Legal Action Group's journal which is a thorough analysis of the impact

Speech to Convention on Modern Liberty Glasgow event, Saturday 28th February 2009

of this legislation on people without learning disabilities or ASD. I recommend that anyone interested takes a look.