



All Party Parliamentary Group on Autism

Minutes of Meeting on 25 April 2007: Mental Health

Parliamentary Attendance:

Janet Dean MP (Chair)
Rt. Hon. Rosie Winterton MP (Minister of State for Health Services)
Lord Astor of Hever
Russell Brown MP
Geoffrey Cox QC MP
Lynda Waltho MP
Betty Williams MP

Apologies:

David Amess MP	Tim Farron MP	Rt. Hon. Lord Morris of Manchester
John Austin MP	Andrew George MP	John Randall MP
Anne Begg MP	Sandra Gidley MP	Lord Rix
Tim Boswell MP	Mike Hancock MP	Lee Scott MP
Peter Bottomley MP	Oliver Heald MP	Joan Walley MP
Angela Browning MP	Stephen Hesford MP	Rudy Vis MP
Paul Burstow MP	Paul Holmes MP	Joan Walley MP
Lord Clement-Jones	Jeremy Hunt MP	Bill Wiggin MP
Sir Patrick Cormack MP	Eleanor Laing MP	Hywell Williams MP
Claire Curtis-Thomas MP	David Lepper MP	Roger Williams MP
Rt. Hon. David Davis MP	Dr Doug Naysmith MP	
Bill Etherington MP		

Speakers

Rt Hon Rosie Winterton MP is the Minister of State for Health Services and has been so since 2003. She has been MP for Doncaster Central since 1997, before which she worked in Public Relations and in various capacities for Rt. Hon. John Prescott MP. She is responsible for, amongst other things, mental health issues within the Department of Health.

Mr E is one of the carers of H.L. of the 'Bournewood' case. In 1998, the Es, the carers of HL, took a case to the European Court of Human Rights claiming that HL's rights had been infringed under article 5 and were successful in their claim. This forced the Government to review legislation to introduce a process for people who lack capacity to consent to detention to be deprived of their liberty, when it is in their best interests. We cannot publish their full names here.

Background

The Mental Health Bill is, after 8 years of deliberations, currently passing through Parliament. It will make several amendments to the Mental Health Act 1983 and the Mental Capacity Act 2005. The 1983 Act was concerned with the circumstances in which people could be detained and subjected to compulsory treatment without their consent. However, as noted above, the European Court of Human Rights found that the detention of HL amounted to a breach of the European Convention on Human Rights on the basis of deprivation of liberty and the right to have the lawfulness of detention reviewed in court.

The inclusion of autism in the definition of mental disorder was the first amendment debated by the Mental Health Bill Committee on 24 April, the day before the meeting. The amendment, presented by Angela Browning MP, would have partially excluded people with autism from the definition of 'mental disorder', unless they displayed 'abnormally aggressive or seriously irresponsible conduct'. This additional qualification is in the 1983 Act and has been retained for people with a learning disability only, but specifically not for people with autism.

Mr E spoke about his experiences. HL has profound autism and an associated learning disability. HL, then aged 48, had been living informally with carers for 3 ½ years. On the day that they were due to celebrate HL's formal discharge to their care, HL became very anxious and distressed at his day service, consequently, he was readmitted to Bournemouth hospital and detained under common law for 3 ½ months. He was in a severe behaviour unit and the Es could not visit him. He had several changes of medication. Although the Es challenged HL's admission, there was a 'clinical decision' to keep him there.

After delays, the Es took this decision to a judicial review. The appeal court ruled that his detention was illegal without being detained under the Mental Health Act. He was then detained almost immediately. HL's advocate was not present at the hearing to represent HL's views or best interests. After 2 ½ months the mental health review tribunal ruled that HL did not meet the criteria for detention and never had – as HL is not able to speak, he was not able to consent or dissent to his detention. HL was then discharged.

There were 11 changes of medication in 8 weeks during HL's detention. He lost weight, his behaviour got worse, he was covered in bruises and the Es had concerns that he was mis-treated and complained to the health ombudsman.

HL had been detained under the common law doctrine of necessity, which would mean that it had to be in his best interests to be detained. This was agreed by the House of Lords, but it was noted that there was a gap in the law. The Es then took the case to the European Court of Human Rights, which took 6 years. The complaints team continued to investigate the abuse he is alleged to have suffered.

Mr E noted that the Government said at the time that there was no need for reform but that now there are proposals to stop the 'Bournemouth gap'. There are problems with the safeguards: Mr E believes they have still not got what is best for HL. If people with autism are taken out of their environment to somewhere unfamiliar, they will get worse – they need to be returned to their home environment.

The impact for HL has been long-lasting: he has a distrust of the medical profession – a family friend who is not dressed as a nurse takes his blood pressure. It has made the Es reticent about going out in public, due to people's intolerance and ignorance. Mr E does not think the Bournemouth safeguards are strong enough to protect HL.

Rt Hon Rosie Winterton MP initially noted that the campaign that the carers of H.L. had conducted since 1997 had impacted upon the Government's policies towards issues surrounding mental health, and that she had personally worked on some of the issues that arose from the case during the preparation of the Mental Capacity Bill during her time as Parliamentary Secretary to the Lord Chancellor's Department (now the Department for Constitutional Affairs) before 2003. She also noted that the debate on the Bill the previous day had been a very good one, and there had been a number of points raised on the subject of the inclusion or otherwise of ASD from the definition of mental disorder for the purposes of the bill. It should be noted for the record that throughout her speech the Minister was subject to a number of interventions by members of the audience.

The Minister spent much of her speech justifying the government's decision not to exclude ASD from the provisions of the bill. Several people present pointed out that ASD is not a mental illness or disorder as conventionally understood. Initially the minister attempted to justify the fact that the 1983 Act had specifically excluded learning difficulties from its provisions, but made no mention of specifically excluding ASD. She said that there had been a fear when the Act had initially been drafted that people with a learning disability might be detained under the Mental Health Act on the basis of differences in behaviour. However, in drafting the current bill, the Government had decided that it wanted to include as few exclusions to the provisions of the bill as possible on the basis that were some conditions, such as ASD, to be excluded then there was the possibility that other conditions would then have to be excluded – such as obsessive-compulsive disorder and attention deficit disorder.

The Minister stated that this may lead some vulnerable people not receiving the treatment that they may require. The Minister stated the Government's belief that it was necessary to remove barriers to people who needed treatment receiving it and that excluding more conditions, including ASD would make it more difficult to treat people.

She also stated her belief that excluding ASD from the provisions of the bill may have a negative impact on the management of offenders with ASD, as it would be better to treat some such people in hospital than imprisoning them. She said that would be the likely result, in some cases, if the qualification of 'abnormally aggressive or seriously irresponsible conduct' applied to ASD: it would be up to the courts to decide what was 'seriously irresponsible' conduct. As a result of these factors, the Minister stated that the Government had concluded that it would not be in the best interests of people with ASD to exclude their condition from the provisions of the bill.

The Minister went on to describe some of the safeguards that would be contained within the bill. She stated that under the Mental Health Act there were already very strict conditions that had to be met before people are detained under the provisions of the Act and that there are ways that people can appeal against their detention.

She also noted that new safeguards were being included within the bill, including the widening of the scope of the Court of Protection and the manner in which people will now be able to apply to represent people without capacity. The Minister also dealt with a specific point that had been raised by the carer of H.L. regarding increasing the rights of those who cared for people who lacked the sufficient capacity to make their own decisions regarding their care. The Minister stated that the reason why the Government was not willing to go too far on this issue was that there was a concern that not all carers would be able to cope with the weight of these responsibilities and because there would be some cases where an abusive relationship existed between the carer and the cared for.

Questions

After the Minister's speech she answered several questions, both from Parliamentarians and members of the public. **Geoffrey Cox MP** expressed his belief that a person with autism was unlikely to be a danger to themselves and others, and that he couldn't imagine a situation in which they would need compulsory treatment. He asked the Minister in what circumstances it would be possible for people to be deprived of their liberty as a result of having autism. When the Minister suggested that people with ASD may be detained as a result of their behaviour, **Janet Dean MP** in the Chair noted that people with a learning disability had been excluded from the 1983 Act on this very basis. The Minister said that she believed that the issue of 'labelling' in the current Bill was less important than it had been in the 1983 Act as the Bill removed the complication of having four different 'labels' and replaced them with the singular description 'mental disorder'.

When several people, including Mr Cox and several members of the public pointed out that ASD was not a mental disorder as conventionally understood, with the inference by some that consequently ASD should not be included within the provisions of the bill, the Minister stated that arguing for the exclusion of ASD was effectively saying that it is a mental disorder.

When Mr Cox stated that ASD should be recognised as being a separate disorder, and shouldn't be equated with mental disorders, the Minister stated that the Bill doesn't give specific definitions of what constitutes a mental disorder and that doing so was the job of clinicians rather than legislators, and said that she believed that giving precise definitions within the Act could be very dangerous. In answer to previous points that had been made regarding the circumstances in which people with ASD could be detained under the Act the Minister stated that there was a high threshold contained within the Bill regarding people's behaviour and that one of the conditions of detention was that appropriate medical treatment was available.

Dr Ian Hall, a learning disability psychiatrist, said he welcomes the Government listening about learning disability and clinical discretion. He supports Angela Browning's amendment. Despite the clinical discretion, there will be pressure upon psychiatrists to section, rather than to give more appropriate treatment in the community, or social care services. The HL case sounds most relevant to this – admission is sometimes 'an easy option'.

Liza Dresner from Resources for Autism noted that the emphasis has been around the medical model, so was pleased to hear the social element. In HL's case, the people responsible for his care had messed it up. In response to Geoffrey Cox's point, Liza said that she could imagine a lot of situations where intervention was necessary, but that it was not just about medical care.

A member of the audience said that the problem is that people cannot get help when they need it, and authorities often wait until the person is in crisis. Public awareness is needed and the Disability Discrimination Act will become more important.

Mr Harris said that putting autism in the Bill could put it in the forefront of the minds of clinicians.

Robin Pemberton said that autism should not be looked at as one clinical condition or another. He said there is a need for adequate local provision: if there was not, then the person would be taken a long way.

Richard Exley of Autism Consultancy Services asked where people would be detained if beds were not available; and noted that pharmacological abuse could be disastrous and exacerbate people's problems.

Hilary Gilfoy of Autism Speaks said that there are no medical treatments for autism, and no biomedical markers – it is diagnosed only on behaviour.

Cris Bolduc spoke about her son, Piers, who was misdiagnosed with schizophrenia and presented challenging behaviour. He has spent 13 years in Broadmoor.

Helen Pearce, a learning disability psychiatrist, said that abnormally aggressive or seriously irresponsible behaviour is very rare in people with autism, but when it happens it is a big problem for the person, and gave examples. She believed the abnormally aggressive or seriously irresponsible behaviour qualification should apply to people with autism.

In response to the above points, Rosie Winterton made the following points:

- The Government were being asked to mention autism in the Bill, they were not doing it themselves.
- It is important to stress that a person should be detained only when treatment is only available in a hospital setting – detention will not be forced on clinicians.
- We should ask, if treatments are not available, whether there are treatments that we want to develop.
- Treatment must be there to meet the person's needs. There is a new appropriate treatment test, and if drugs are not appropriate treatment, they should not be prescribed.

With regard to the overall development of services, Rosie Winterton said that this cannot be done in the Bill. The Bill can only set the legal framework, and all other conditions for detention must be met before someone is detained. She recognised that services need to be developed, but that there is nothing in the Bill to lead to greater detention.