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Editorial

The case for removing intellectual disability and autism from the Mental Health Act†

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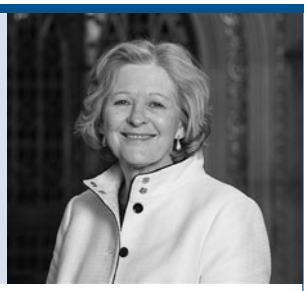

Summary

Intellectual disability (also known as learning disability in UK health services) and autism are distinct from the serious mental illnesses for which the Mental Health Act is designed to be used. Their inclusion in the definition of mental disorder is discriminatory, resulting in unjust deprivations of liberty. Intellectual disability and autism should be excluded from the Mental Health Act.

Declaration of interest

None.

Keywords

Intellectual disability; psychiatry and law; human rights.

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The place of intellectual disability in the Mental Health Act

In the last round of Mental Health Act (MHA) reform in 2007 intellectual disability (also known as learning disability in UK health services) was removed as a mental disorder. The MHA Code of Practice acknowledges that 'it shares few features with the serious mental illnesses that are the most common reason for using the Act'.[1] With the reforms 10 years ago a person could no longer be detained because of their intellectual disability. However, an exception was introduced; they could be if their intellectual disability was 'associated with abnormally aggressive or seriously irresponsible conduct'.

No definition of 'abnormally aggressive or seriously irresponsible conduct' was provided and the Code of Practice states that 'it is not possible to define exactly what kind of behaviour would fall into either category'. The Code of Practice stresses that 'bizarre or unusual behaviour' would not come under this category. The difficulty in circumscribing this exception may be seen in the Code of Practice's statement that it is not good practice to use it without an assessment by a consultant psychiatrist in intellectual disabilities and a formal specialist psychological assessment. The approved mental health professional should also have experience and skills in intellectual disability.

Clearly there was a drive to separate intellectual disability from mental disorders, but the vague exception for abnormally aggressive or seriously irresponsible behaviour meant that it was not fully removed. Only people with an intellectual disability can be detained solely because of irresponsible or aggressive behaviour. The issue was debated in the House of Lords in an attempt to remove this exception, but the amendment was unsuccessful.[2]

† The online version of this article has been updated since the original publication. A notice detailing the changes has also been published at https://doi.org/10.1192/bjp.2019.116.

Why is this a problem?

There are two broad problems with this exception.

First, it is discriminatory. Why does a person with an intellectual disability have an extra reason to be detained under the Act that does not apply to anyone else in society? If they also have a mental disorder they could be detained under the MHA like anyone else; removing intellectual disability from the MHA does not change this, nor does it change the way the Mental Capacity Act (MCA) 2005 affects those with an intellectual disability. But people with an intellectual disability have an extra condition imposed on them: they can be detained purely on grounds of behaviour that if displayed by the rest of the population would not apply. Does this really meet with the vision set out in the cross-government strategy statement for people with intellectual disabilities?

> 'That all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect.'[3]

And how does this fit with the right to liberty enshrined within the Human Rights Act 1998 that applies equally to everyone regardless of intellectual disability?

Second, it allows lazy diagnosis and lazy practice. A cause for the abnormally aggressive or seriously irresponsible behaviour does not need to be found, and a person can be detained on the grounds of their behaviour alone. We know that diagnostic overshadowing exists for people with intellectual disabilities and the exception makes it more likely that physical or mental health causes, environmental causes and communication difficulties are overlooked. It is entirely possible that somebody whose disturbed behaviour is a response to something traumatic or abusive will be overlooked, including harm perpetrated by a care provider. As the MHA stands, an individual who is simply communicating their distress may find themselves detained in hospital for prolonged periods and subjected to restrictive practices including the inappropriate use of psychotropic medication.

Autism and the MHA

Similar concerns apply to those with autism, which is considered a mental disorder under the MHA but without the exception of

'abnormally aggressive or seriously irresponsible conduct'. The Code of Practice clarifies that detaining a person with autism is rarely likely to be helpful given that this change in routine will provoke anxiety potentially resulting in more distressed behaviour. The government consultation *No Voice Unheard, No Right Ignored* heard that it was felt people with autism were being detained because of their autism-associated behaviour even when no appropriate medical treatment was available.[4]

Winterbourne View and transforming care programme

Despite concerns voiced by parliamentarians both the intellectual disability exception and autism remained in the Bill and moved into statute. However, since then there have been major developments in the provision of care for those with intellectual disabilities and/or autism.

In 2011 *Panorama* revealed abuse at Winterbourne View Care Home, and visits by the Care Quality Commission to a further 150 hospitals and homes following this scandal revealed significant concerns. The government response demanded a 'fundamental change' in how people with an intellectual disability and/or autism were cared for, promising that '… everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014'.[5] The *Winterbourne View Review: Concordat* was an agreement signed by National Health Service, statutory organisations and stakeholders committing themselves to provision of adequate services for people with an intellectual disability and/or autism including:

> 'All people with challenging behaviour in inpatient assessment and treatment services are appropriately placed and safe, and if not make alternative arrangements for them as soon as possible. We expect most cases to take less than 12 months.'[6]

Thus, began the transforming care programme, the early review of this programme by Sir Stephen Bubb after the deadline in 2014 commended the approach but found little tangible progress on the ground.[7] The National Audit Office concluded in 2015 that the transforming care programme had missed its central goal and the complexities of hitting its targets had been underestimated.[8] The programme is due to conclude in March 2019 with the job almost certainly still unfinished.

Legislative changes

Changes in the law are not able to transform practice on their own, for example, with many seeing the introduction of deprivation of liberty safeguards as merely adding bureaucracy without changing the care for those it applied to.[9] However, given the direction of change in the last MHA review and the drive to change practice since, it seems the time is appropriate for the complete removal of both intellectual disability and autism spectrum disorder as named disorders from the MHA. This will shift the focus away from viewing behaviours that professionals find challenging in people with an intellectual disability and/or autism, and too frequently as something to be medicated and something that requires removal to a hospital, towards understanding behaviour as a communication that can only be addressed in the person's home environment.

This is not a radical idea but a continuation of an ongoing process. The issue has been explored in the consultation *No Voice Unheard, No Right Ignored*;[4] 77% of respondents wanted a change in the way intellectual disability and autism was treated under the MHA; however, there was no clear consensus on the precise nature of this change. The government response to the consultation acknowledged that 'some stakeholders, especially individuals, their families and supporters, and the voluntary and community sector were keen on the principle that some sort of change was needed' it highlighted that 'far fewer expressed a strong preference for any of the options put forward' and as such 'will require much more exploratory work before moving on to any form of legislative change'.[10] The recent Independent Review of the MHA pointed out that recommendations it made to reform the wider Mental Health Act may have an impact on people with intellectual disabilities or autism but concluded that 'our Review was not established to consider the best approach in law to be taken in relation to the care and support of people with learning disabilities and autism. That would be a much wider task'.[11] The report asked the government to take into account the review of the law in Scotland that is currently underway. The scoping exercise for the Scottish review has already stated

> 'Given the almost unanimous agreement among those who took part in this study that [learning disability and autism] should not be defined as "mental disorders", the main aim of the review would therefore be to consider what kind of legislation is needed to support people with learning disabilities and autism to become empowered citizens.'[12]

The exercise highlighted developments in human rights standards as well as the United Nations Convention on the Rights of Persons with Disabilities that have changed the landscape in which mental health law now sits.

For people who have an intellectual disability and/or autism but do not have a coexisting mental illness the right place to find solutions to their behavioural challenges is in their own environment not in a strange hospital for prolonged periods. The MCA can provide frameworks where interventions can be made. It is clearly acknowledged that intellectual disability and autism represent something different from mental illness. For those who have a coexisting mental illness that requires treatment in hospital the MHA would still enable this. We see no reason it should also compel those without a mental illness to be detained for prolonged periods.

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psychiatry in literature

Bartholomew the Englishman: *On the Properties of Things* – Wikipedia of the Middle Ages

Greg Wilkinson

Bartholomaeus Anglicus, a 13th-century Franciscan, wrote the encyclopaedic *De proprietatibus rerum* (*On the Properties of Things*) between 1220 and 1240. It became one of the most widely read books in medieval times, spreading knowledge and shaping attitudes and behaviour, with 17 editions in the 15th century and 200 original copies extant today. Nineteen books encompass heaven and earth, with over 100 sources, from Adamantius to Zoroaster. Trevisa (1397) and Batman (1582) produced English translations; and Steele abridged extracts in 1893.

Book 5 links brain, feelings and behaviour: 'In the formost cell and wombe imagination is conformed and made, in the middle, reason: in the hindermost, recordation & minde […] If the braine be let [*injured*], all that is in the body is let: And if the braine be well, all that is in the bodye is the better disposed'.

Book 7 comprises 70 medical conditions, including frenzy and madness – severe disorders requiring humane treatment.

> 5. 'These be the signs of frenzy, woodness [*insanity*] and continual waking, moving and casting about the eyes, raging, stretching, and casting out of hands, moving and wagging of the head, grinding and gnashing together of the teeth; always they will arise out of their bed, now they sing, now they weep, and they bite gladly and rend [*tear with force*] their keeper and their leech: seldom be they still, but cry much. And these be most perilously sick, and yet they wot [*know*] not then that they be sick. Then they must be soon holpen [*helped*] lest they perish, and that both in diet and in medicine. The diet shall be full scarce, as crumbs of bread, which must many times be wet in water. […] All that be about him shall be commanded to be still and in silence; men shall not answer to his nice [*foolish*] words. […] Over all things, with ointments and balming men shall labour to bring him sleep. […] If after these medicines are laid thus to, the woodness dureth three days without sleep, there is no hope of recovery.'

> 6. 'Madness [*Batman specifies melancholy and mania*] cometh sometime of passions of the soul, as of business and of great thoughts of sorrow and of too great study, and of dread: sometime of the biting of a wood hound, or some other venomous beast: sometime of melancholy meats, and sometime of drink of strong wine. And as the causes be diverse, the tokens and signs be diverse. For some cry and leap and hurt and wound themselves and other men, and darken and hide themselves in privy and secret places [*Batman says: "of whose disposition & difference it is rehearsed before in the fifth booke, where it is treated of the passion of y^e^ braine"*]. The medicine of them is, that they be bound, that they hurt not themselves and other men. And namely, such shall be refreshed, and comforted, and withdrawn from cause and matter of dread and busy thoughts. And they must be gladded with instruments of music, and somedeal [*someway*] be occupied.'

À la recherche du temps perdu!

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