

## Declaration of interest

none declared.

- 1 Hollins S, Lodge K-M, Lomax P. The case for removing intellectual disability and autism from the Mental Health Act. *Br J Psychiatry* 2019; **215**: 633–5.
- 2 Department of Health. *Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities 'Making it Happen for Everyone'*. Department of Health, 2009.

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## Authors' reply

We welcome the responses to our editorial on removing intellectual disability and autism spectrum disorder (ASD) from the Mental Health Act (MHA)<sup>1</sup> and value the authors' contributions to this important debate. We address the key points raised.

De Villiers<sup>2</sup> questions why we seek to remove only intellectual disability and ASD from the definition of mental disorder in the MHA. The reason is simple: there is clear evidence that people with intellectual disability and/or ASD experience restrictive practices including inappropriate use of psychotropic medication, physical restraint and seclusion, and prolonged, ineffective admissions resulting in suffering, trauma and serious harm to their human rights when detained in hospital,<sup>3–5</sup> yet they are particularly vulnerable to their voices going unheard. De Villiers suggests our concern is 'stigma';<sup>2</sup> in fact, our fundamental concerns are to protect human rights and to raise the standards of mental healthcare provided to people with intellectual disability and ASD.

We agree with Courtenay<sup>6</sup> that a person with intellectual disability and/or ASD should have the same opportunities as others to avail of care that may be delivered under the MHA. Indeed, under our proposed changes if a person with intellectual disability and/or ASD also had a mental disorder, they could be detained under the MHA like anyone else. We also agree with Courtenay that aetiological factors accounting for 'behavioural challenges' can include physical health and social factors,<sup>6</sup> but we argue that the right place for these to be assessed and addressed is in the community; where mental health factors are thought to be causal, the MHA would remain an option if treatment really cannot be offered in the community.

Through our clinical experience, we have encountered MHA detentions where the underlying aetiological factor was pain because of a physical health problem. We argue that a person without intellectual disability and/or ASD would not accept being admitted to a mental health hospital because of pain arising from a physical health problem, particularly without efforts being made to elicit and treat the cause in the community. This is an example of the lazy practice and lazy diagnosis to which we refer. Watts questions the grounds for our statement on lazy diagnosis and practice.<sup>7</sup> It is based both on our opinion informed by our experience, and on evidence<sup>5</sup> including on the inappropriate prescription of psychotropic medication among people with intellectual disability and/or ASD without adequate clinical formulations.<sup>8</sup> Removing intellectual disability and ASD from the MHA would emphasise the need to elucidate and address aetiological factors in the community, clarifying that there should be a presumption against mental health hospital admission for any non-mental health crisis in people with intellectual disability and/or ASD.

Courtenay<sup>6</sup> suggests the MHA provides safeguards against 'lazy diagnosis' through Mental Health Review Tribunals. We ask what the evidence is for this. It is our experience that clinicians may misunderstand or even misconstrue distressed behaviour in a person with intellectual disability and/or ASD as a mental illness when in fact other

aetiological factors, such as environmental or sensory factors, are causal. It is our experience that professionals participating in Mental Health Review Tribunals may not always have an understanding of these factors, rendering the intended safeguards ineffective. Additionally people with intellectual disability and/or ASD face barriers to participating in their Tribunals when information about the process or their rights is not provided in an accessible format, yet it is our experience that professionals may lack the communication skills required.

Watts suggests the powers of the 'nearest relative' is another inbuilt safeguard.<sup>7</sup> In our experience, it is rare for a nearest relative to challenge the professionals who have detained their relative, and we are not aware of any published evidence on this. We wondered if this statement was the author's own opinion, and whether he had asked individuals with intellectual disability and/or ASD or their families and carers their views? Furthermore many patients who are admitted do not have involved family.

We disagree with Courtenay's assertion that using the lengths of time that people spend in hospital is not justified as an argument<sup>6</sup> – on the contrary, this is central given the negative impact on human rights to a private or family life and to live free from inhuman or degrading treatment or punishment. We agree with de Villiers that the Transforming Care programme is not working well enough.<sup>2</sup> The most recent data shows there are still 2185 people with intellectual disability and/or ASD in in-patient units with an average length of stay of 5.4 years.<sup>9</sup> Delayed discharges are usually because of lack of appropriate housing and social care.<sup>9</sup> The Transforming Care<sup>3</sup> and Building the Right Support<sup>10</sup> policies pledged to address this by investing in appropriate estate and resources in the community, including staff with the training and skills to be able to respond to a person with intellectual disability and/or ASD at times of distress, and emergency respite 'crash pads'. But this is not happening. Concerns about the impact of these failings on human rights led the Equality and Human Rights Commission to launch a legal challenge against the Secretary of State for Health and Social Care in February 2020.<sup>11</sup> Removing intellectual disability and ASD from the MHA would make it clear that it is no longer acceptable to rely on the fallback position of compelling people with intellectual disability and/or ASD to remain in hospital to cover for the failure to deliver community-based health and care services.

We agree this is a complex issue and changes to the MHA could not be made in isolation. Courtenay,<sup>6</sup> Watts<sup>7</sup> and Khan<sup>12</sup> raise concerns that removing intellectual disability and ASD from the MHA would lead to a risk of people being processed by the criminal justice system. We argue that we can learn from the New Zealand experience, and agree with Khan<sup>12</sup> that careful work is needed around how best to fuse changes to mental health legislation with changes to criminal justice system and mental capacity legislation to ensure people with intellectual disability and/or ASD in the criminal justice system have equitable access to thorough assessment, evidence-based treatment and relevant support from mental health services when this is needed, including forensic community support.

Since the publication of our editorial, the final report of the Independent Review of Learning Disability and Autism in the Mental Health Act in Scotland has concluded that intellectual disability and ASD should be removed from the definition of mental disorder.<sup>13</sup> The report states:

'...to comply with duties in international human rights law, our law must be set up to ensure that autistic people and people with intellectual disability can get access to the support, care and treatment that they need to be mentally healthy, through choice and in their own communities. Our current mental health law does not enforce the protection and promotion of positive rights that are required to achieve all of this.'<sup>13</sup>

The report suggests legislative changes to strengthen the human rights protections of people with intellectual disability and/or

ASD would be required prior to MHA changes to provide the legal structure to ensure people with intellectual disability and/or ASD receive effective care and support,<sup>13</sup> addressing a concern raised by Courtenay.<sup>6</sup> A progressive rights-based approach, in which professionals would be required to consider the potential impact of their decisions on the human rights of the individual with intellectual disability and/or ASD, is advocated.<sup>13</sup> Importantly, the report proposes that people with intellectual disability and/or ASD and their families and unpaid carers should play a key role in developing, implementing and monitoring laws and policies that support a commitment to complying with the United Nations Convention on the Rights of Persons with Disabilities.<sup>13,14</sup> We argue that it is time for mental health legislation in England and Wales to catch up, and for proper attention to be given to providing sufficient and effective care in the community.

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none declared.

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### The case for removing intellectual disability and autism from the Mental Health Act – further debate required

We thank Hollins and colleagues<sup>1</sup> for raising some interesting points in their article regarding intellectual disability and autism spectrum disorder in the Mental Health Act 1983. However, there are a number of issues with which we disagree or require further discussion and clarification. The authors state that intellectual disability has been removed from the amended Act, but this is not the case. In paragraph 2.14 of the Code for the Act, there is an unequivocal statement refuting this: ‘Learning disabilities and autistic spectrum disorders are forms of mental disorder defined in the Act’.<sup>2</sup>

Making it impossible for patients with intellectual disability and autism spectrum disorder to be detained, unless they have comorbid mental disorders, as the authors propose, could deny such patients the right to have a legal framework for treatment. For example, a patient in the criminal justice system would not have the opportunity to be diverted into hospital using Part IV of the Act, a point considered by Earl Howe in the Lords debate regarding the bill (3, column 68),<sup>3</sup> and more recently in the review of the Mental Health Act.<sup>4</sup>

The authors assert that continuing to require the additional criteria of abnormally aggressive or seriously irresponsible conduct results in ‘lazy diagnosis and lazy practice’, as a cause for this behaviour is not required.<sup>1</sup> We wondered if this was the opinion of the authors, or whether this was based on evidence. We would welcome a clarification for this strongly worded statement.

Although recommending the removal of autism spectrum disorder and intellectual disability from the Act, the authors acknowledge that there is no consensus regarding what this change should look like.<sup>1</sup> Our worry is that if the authors’ recommended change is implemented, patients may be assigned additional permitted mental disorder diagnoses with the sole aim of detention, based on flimsy clinical evidence. This potential unforeseen consequence was also debated in the House of Lords by Lord Hunt (3, column 69).<sup>3</sup> Why not propose a consultation on change, rather than the removal?

The implication from the authors in the article is that the Act is always stigmatising, and should be avoided if possible. Our experience is that the Act can be helpful to an individual, such as section 117 aftercare resulting in extra resource allocation to support a care package. The Act also has inbuilt safeguards such as reviews of detentions by independent bodies, and the powers of the nearest relative. We therefore contest this implication, but recognise it may hold true for some patients.

It is clear to us that further debate is required, and we thank Professor Hollins and her colleagues for encouraging this.

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