

Editorial

The potential unintended consequences of Mental Health Act reforms in England and Wales on people with intellectual disability and/or autism

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Summary

The draft Mental Health Bill, which amends the Mental Health Act 1983 for England and Wales, proposes protections for people with intellectual disability and/or autism (ID/A) to prevent detention in hospital in the absence of mental illness. This editorial critically appraises the positive impact and unintended consequences of the proposed reforms for people with ID/A.

Keywords

Mental Health Act; autism; intellectual disability; mental health law; equality.

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Unique challenges facing people with ID/A requiring psychiatric hospital admission

Admission to a psychiatric hospital setting is accepted to be a measure of last resort for people with ID/A. Those who are admitted typically present with myriad social, environmental, physical and/or additional mental health factors. Furthermore, adjusting to an unfamiliar hospital environment can take time and be distressing.

Most people without ID/A in the general population present with more obvious symptoms of mental illness that are often more readily diagnosable within the major diagnostic classification systems. This can be done in a timely way. They are also frequently able to communicate and actively participate in decision-making pertaining to their care. Where relevant, judgements about capacity and insight can be made with reasonable confidence. In part, behaviour and communication changes can be quite marked, and unusual beliefs and thought processes can readily be assessed. This is rarely the case for people with ID/A, who present challenges to assessment and treatment due to the complexities of assessing their mental state, especially if cognition and communication are impaired. Furthermore, for people with ID/A at the most severe end of the spectrum, assessment requires patience and much more time to assign diagnoses and negotiate care plans safely and carefully.

The challenges of withdrawing section 3 of the MHA for people with ID/A

Section 2 of the MHA allows for detention of a person with a suspected mental disorder for assessment and treatment for up to 28 days. Presently, this can be extended to section 3 if concerns exist for either major mental illness and/or significant challenging behaviours. However, with the proposed changes, after 28 days, people with ID/A with insufficient evidence of a mental illness would need support in the community on discharge, irrespective of the risks posed to the patient themselves and/or other persons. Although clinicians endeavour to provide treatment according to

The proposed reforms to the Mental Health Act 1983 (MHA)¹ in England and Wales covering a range of recommendations also stipulate that neither intellectual disability (referred to as learning disability in the Draft Mental Health Bill) nor autism constitute mental disorders for the purpose of the MHA. Although this proposal was made in the Draft Mental Health Bill it was not made by the Independent Review of the Mental Health Act. Thus, under the proposed reforms, people with intellectual disabilities and/or autism (ID/A) should not be detained in hospital under section 3 of the MHA unless for treatment of a co-occurring mental health condition.

a biopsychosocial framework, for people with ID/A, given a lack of suitable community placements and providers providing the highly specialised psychosocial support required, this may lead to an over-reliance on psychotropic medication to mitigate significant risks.² However, it is conceivable that such overreliance could similarly occur in psychiatric in-patient settings, owing to the environmental stressors and possible comparative lack of appropriate daily activities. Thus, the focus needs to be on timely person-centred discharge to mitigate medication overreliance.

An advantage of section 3 of the MHA is the section 117 after-care framework designed to mitigate readmission by putting a statutory requirement on health and social care services to devise psychosocial care plans to support individuals in the community. The lack of access to this framework due to loss of section 3 could result in people with ID/A without obvious mental illnesses (or unrecognised mental illnesses) being discharged into the community without section 117 aftercare. Even in the absence of mental illness this aftercare framework is considered helpful and essential if care needs warrant a complex care package, and people with ID/A currently receive it, prior to the proposed reforms. This could potentially discriminate against people with ID/A, with adverse effects on support, for example on housing and travel. This could contravene the Equality Act 2010, particularly if the fabric of social care engagement is not strongly and statutorily designed.

What are the benefits of the modification of MHA section 3 for people with ID/A?

These have been well stated in the case for change by the state¹ and are in keeping with Article 14 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). A significant number of people with ID/A have had lengthy hospital stays and minimising length of stay for individuals ready for discharge from hospital is a priority. The changes to the MHA should focus care professionals and commissioners to deliver timely high-quality community care packages to meet the needs of this vulnerable cohort.

Potential unintended consequences of the modification of MHA section 3 for people with ID/A

First, community services in their current form cannot sufficiently manage the risks. This is related not just to a lack of services or staff, but to particularly high-risk behaviours in a minority of people with ID/A which require management in appropriately contained and safe hospital environments. These are relevant even in the absence of mental illness. Professionals need evidence-based interventions for high-risk behaviours in the absence of mental illness, and preferably without a reliance on pharmacotherapy. The use of alternative environments and building designs suited to complex sensory impairments and sensitivity to trauma for people with ID/A warrants innovation. Legislation to ensure availability of appropriate social care and behavioural supports irrespective of mental illness is necessary before discharge of such individuals from a hospital environment.

Some people with ID/A will have extreme behavioural challenges and securing a comprehensive community support package within a short time frame is not always feasible. Furthermore, 28 days is barely enough time to complete an assessment of support needs, which should inform aftercare, rather than assume that this can be done alongside assessment.² This might lead to compromises on support packages in order to facilitate prompt discharge in

compliance within the reforms (i.e. within 28 days), which could have a detrimental impact on the mental health and well-being of these vulnerable patients or lead to 'revolving door' psychiatric admissions. Furthermore, social care arrangements must be coordinated from inception if they are to be ready within 28 days. Unfortunately, appropriate therapeutic settings in the community are in short supply presently.

A principal reason for these reforms for people with ID/A is the spate of reported abuses linked to specialist psychiatric hospitals in the past few years, particularly where individuals have been incarcerated or segregated for months and sometimes years without a mental illness diagnosis but detained under section 3 of the MHA. These reforms might paradoxically perpetuate rather than reduce neglect, as the uncomfortable truth is that poor care can occur in any setting, particularly in care homes.³

It is estimated that 22% of people with ID/A in England live in registered care homes and the hospital-based cohort have significant complexities. Numerous challenges currently face service providers across settings and might result in poor care of people with ID/A. In both hospitals and care homes these include: staffing levels; staff remuneration, experience and training, supervision, management and accountability; individual care giver issues; and individual resident or patient risk issues. In care homes there might also be a lack of the legal scrutiny typical in hospitals, staff members who are not required to be clinical professionals (compared with nurses etc. as in hospitals) and failure to clearly define and oversee residents' legal and ethical rights and least restrictive practice. Nevertheless, where there is suitable time available, the potential for an in-patient to have a robust post-discharge package is optimised in most circumstances. Considering this, it could also be argued that the proposed legislative change is looking to meet an unmet need for better alternative environments and training. However, presently there is no plan for the new design to work synergistically with the old model, raising concerns regarding the possibility of a crisis due to inability to find people with ID/A a safe placement within the legislation except for prison or a forensic setting.

Another negative potential outcome of the MHA reforms would be increasing the likelihood of more people with ID/A being incarcerated in prison. Annual reduction in psychiatric bed numbers has been reported to be associated with an increase in the prison population.⁴ Although not specific to people with ID/A, this risk of 'trans-institutionalisation' is a potential concern.

Comparable legislative changes were implemented in New Zealand several decades ago, following the introduction of the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MH (CAT) Act). This act excluded people with ID/A and with no co-occurring mental illness, limiting options available for this group, who can have high-risk behaviours that do not qualify as criminal offences. This led to such individuals being sent to prison, left neglected in the community or admitted to forensic facilities as secure patients. Recognising this legislative chasm, the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 was introduced in 2004, enabling provision of compulsory care to people with ID/A who were charged or convicted of an imprisonable offence.⁵ This difficult reversal of course was a result of the unintended consequences of excluding people with ID/A from the MH (CAT) Act. As regards other comparable countries, in the USA there are various mental health laws according to the individual state concerned. In Canada, people with ID/A can be detained in hospital without the presence of a co-occurring mental illness, as both intellectual disabilities and autism would fall within their recognition of a mental disorder. In Australia, people with ID/A are not detained under their Mental Health Act. The ambiguity of how to manage people with ID/A in Australia

due to the lack of a defined legal structure has led to the use of psychotropic medication in lieu of community support, and prescribers sometimes diagnose 'mental illness' to avoid legislative requirements related to chemical restraints.⁶ This is in addition to those with 'serious behavioural problems' continuing to remain in psychiatric institutions hospitals because this is an ICD diagnosis.⁷

How to go forward?




The Research Briefing of the draft Mental Health Bill advises of 'an overwhelming need for a sustained programme of investment to ensure, that as far as possible, people are cared for in the community'. It asks for this to be supported by a statutory duty for health and social care providers to work together. This is a laudable sentiment, considering that community care can be substantially improved, but such investment and community-based infrastructure needs to be developed prior to such reforms.

Otherwise, there will inevitably be a period when people with ID/A are being effectively denied in-patient treatment while the specialised community care services required are simultaneously not yet available. Any legal reform regime that denies the right to avail of timely, effective treatment on an equal basis with others would be a concern.

Conclusions

Some people with ID/A can present with behaviours that put themselves and other persons at significant chronic risk, without the need for a co-occurring mental disorder to be present. There have clearly been situations in which hospital treatment of people with ID/A has been wholly unacceptable. There is no suitable legislative model internationally which can be used to give confidence on this matter. Irrespective of how intellectual disability and autism are conceptually or legally defined, there is a need, in keeping with the UNCRPD, to ensure that the reforms are not discriminatory and enable sufficient legislative flexibility to provide people with ID/A with the support they need to live fulfilling lives.

Alternative and acceptable legal frameworks need to be in place, for example possibly strengthening the Mental Capacity Act 2005 (MCA). As things stand the MCA can be used to continue the detainment of people with ID/A in hospital, but without the safeguards offered by the MHA. Further development and increasing availability of person-centred community care settings are needed. In addition, appropriate training of professional and individual care staff is necessary, for staff to have the right skills and knowledge. This requires accreditation by regulatory bodies, set up and fit for purpose. The above provisos we believe would go some way to enabling people with ID/A to lead fulfilled lives of their choosing in the community.

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References

- Secretary of State for Health and Social Care, Lord Chancellor and Secretary of State for Justice. *Reforming the Mental Health Act (CP 355)*. TSO (The Stationery Office), 2021 (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/951398/mental-health-act-white-paper-web-accessible.pdf).
- Abraham J, Purandare K, McCabe J, Wijeratne A, Eggleston E, Oak K, et al. An 8-year study of admissions and discharges to a specialist intellectual disability inpatient unit. *J Appl Res Intellect Disabil* 2022; **35**: 569–76.
- Nicolle L. Care home put in special measures following report of abuse and inadequate staff training. *Learning Disability Today* 2022: 15 Mar (<https://www.learningdisabilitytoday.co.uk/care-home-put-in-special-measures-following-report-of-abuse-and-inadequate-staff-training>).
- Wild G, Alder R, Weich S, McKinnon I, Keown P. The Penrose hypothesis in the second half of the 20th century: investigating the relationship between psychiatric bed numbers and the prison population in England between 1960 and 2018–2019. *Br J Psychiatry* 2022; **220**: 295–301.
- McCarthy J, Duff M. Services for adults with intellectual disability in Aotearoa New Zealand. *BJPsych Int* 2019; **16**: 71–3.
- Edwards N, King J, Williams K, Hair S. Chemical restraint of adults with intellectual disability and challenging behaviour in Queensland, Australia: views of statutory decision makers. *J Intellect Disabil* 2020; **24**: 194–211.
- Sainsbury M. Richmond revisited. *Medico-Legal Society of NSW Scientific Meeting, Nov 2005*. Medico-Legal Society of NSW, 2005 (<http://medicolegal.org.au/wp-content/uploads/2018/05/46.pdf>).