

Northumbria Research Link

Citation: Taylor, John L. (2021) Transforming care for people with intellectual disabilities and autism in England. *The Lancet Psychiatry*, 8 (11). pp. 942-944. ISSN 2215-0366

Published by: Elsevier

URL: [https://doi.org/10.1016/S2215-0366\(21\)00349-7](https://doi.org/10.1016/S2215-0366(21)00349-7) <[https://doi.org/10.1016/S2215-0366\(21\)00349-7](https://doi.org/10.1016/S2215-0366(21)00349-7)>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/47491/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)

**Transforming Care for People with Intellectual Disabilities
and Autism in England**

John L. Taylor

Northumbria University Newcastle

The *Building the Right Support* national plan¹ was published in October 2015 in the wake of the *Winterbourne View* scandal in 2011 which involved the systematic abuse of people with intellectual disabilities in an independent sector hospital in Bristol, England. Via the *Transforming Care* programme, the national plan aimed to develop community services and close hospital beds for people with intellectual disabilities and autism in England. The plan was explicit – at a minimum 35-50% of beds would be closed by the end of March 2019. The rationale for these numbers and timescale was not made clear.

To chart the progress of the Transforming Care programme, NHS England uses ‘Assuring Transformation’ data published by *NHS Digital*. This is a monthly commissioner-based return on the number of patients with intellectual disabilities and autism in hospital. A second source of information published by NHS Digital concerning the number of people in hospital is the ‘Mental Health Services Data Set’ (MHSDS) which records monthly data from service providers. Table 1 shows Assuring Transformation data for March 2015 just prior to the plan being implemented, and for March 2019 when the programme ended. Using these like-for-like data reported by commissioners at the end of each month it can be seen that there were 135 fewer people in hospital at the end of the programme. This represents a reduction of 5.6% over a four-year period, somewhat short of the programme’s target 35-50% reduction. This shortfall was anticipated by the National Audit Office (NAO) which stated in 2017 that the programme would not deliver the required reduction in bed numbers by 2019 because of “concerns about the credibility of the [programme] Partnerships’ plans for bed closures, a lack of community infrastructure and an inability to discharge patients.”²

Building the Right Support was superseded by the *NHS Long Term Plan*³ which committed to halving the inpatient bed numbers for people with intellectual disabilities and autism over 2015 levels, but with a revised timeframe of 2023-2024. Assuring Transformation data for March 2021 (see Table

1) shows that number of people with these conditions in hospital was 2,035. This suggests that the Long Term Plan is currently no more effective than Building the Right Support in reducing the number of hospital inpatients. This lack of progress is compounded further when one considers that the MHSDS showed that there were in fact 3,310 people with intellectual disabilities and autism in hospital at the end of March 2021.⁴

To reduce the number of inpatients with intellectual disabilities and autism the number of admissions needs to decrease and the number of discharges needs to increase over time. As can be seen from Table 1, Building the Right Support and then the Long Term Plan have failed to meet these requirements to date. High quality community support is essential in preventing hospital admissions and facilitating successful discharges. The national plan said that the proposed bed closures would free-up “tens of millions of pounds which will be invested in community-based support to prevent hospital admissions.” In 2017 the NAO said that “Money is not yet being released from mental health hospitals quickly enough to help pay for extra community support.”² It appears that the situation has not improved markedly since that report. A recent Health and Social Care Committee report noted that “... the current system of community support in England is ‘broken’, ‘systematically failing’ or otherwise inadequate.”⁵

Unfortunately, rather than address the lack of investment in community services to support its Transforming Care bed number targets - or reconsider the wisdom and basis of this programme that lacks any credible analysis or evidence to support it – the government is planning to solve this conundrum using legislation. The recent *Reforming the Mental Health Act* White Paper⁶ proposes to revise the England and Wales Mental Health Act 1983 such that people with autism and intellectual disability can no longer be detained for treatment under civil sections of the Act. One stated driver for this proposed change is the government’s commitment “to reducing the reliance on specialist inpatient

services for people with a learning disability and autistic people and to developing community alternatives.”⁶

This legislative change is being pursued despite an independent review of the Act concluding “the issues arising from taking learning disabilities and autism spectrum conditions out of the Act are significant and could cause further harm.”⁷ The independent review went on to identify unintended consequences of this change including people with intellectual disabilities and autism receiving no care at all, being deliberately misdiagnosed in order to receive care, or being forced into the criminal justice system which is unable, and not intended, to meet their needs.

The Transforming Care programme – which it is proposed will be underpinned by legislative changes in future – is not working and is putting people with intellectual disabilities and autism at risk.⁸ It is now time for a radical review of this policy with a view to moving to an approach to the reform of these services that is based on a serious analysis of the needs of this population with complex needs – including a realistic assessment of the number of specialist beds that are required to meet their needs safely and effectively. This should include meaningful consultation with the clinicians who are legally responsible for the care of these patients, rather than relying on NHS commissioners “sense-checking” and saying what they “believe is possible” - which is the basis of the current programme.¹ Further, careful consideration should be given to the potential consequences and possible harms that will result from the proposal to revise the mental health legislation in order to drive down hospital bed numbers. An examination of the experience of New Zealand which excluded people with intellectual disabilities from its mental health legislation and which resulted in increased numbers of people with these conditions becoming subject to compulsory detention, along with many other problems, is salutatory in this regard.^{9,10} Finally, a costed programme of real and substantial investment in an integrated system

of specialist NHS community and inpatient services is required to give this vulnerable population the parity of esteem with other mental health patients it deserves and requires.

Declaration of Interest: JLT declares no competing interests.

John L. Taylor
john.taylor@cntw.nhs.uk

Faculty of Health & Life Sciences
Coach Lane Campus-East
Northumbria University Newcastle
Newcastle upon Tyne
NE7 7XA
UK

References

1. NHS England (2015). *Building the right support: A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.*
<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf> (accessed Oct 30, 2015).
2. National Audit Office. *Local support for people with a learning disability: Report by the Comptroller and Auditor General.* London: Author, 2017.
3. Department of Health (2019). The NHS long term plan. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> (accessed Aug 20, 2019).
4. NHS Digital (2021, June). *Learning disability services monthly statistics AT: May 2021, MHSDS: March 2021 Final.* <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/may-2021-mhsds-march-2021-final/summary-report---mhsds> (accessed Aug 13, 2021).
5. House of Commons Health and Social Care Committee (2021, July). *The treatment of autistic people and people with learning disabilities. Fifth report of session 2021-22.*
<https://committees.parliament.uk/publications/6669/documents/71689/default/> (accessed July 12, 2021).
6. Secretary of State for Health and Social Care & Lord Chancellor and Secretary of State for Justice (2021). *Reforming the Mental Health Act.*
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1002920/reforming-mental-health-act-consultation-response-web-accessible.pdf (accessed March 25, 2021).

7. Department of Health and Social Care (2018). *Modernising the Mental Health Act. Increasing choice, reducing compulsion. Final report of the Independent Review of the Mental Health Act 1983.*
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778897/Modernising_the_Mental_Health_Act_increasing_choice_reducing_compulsion.pdf
(accessed Dec 5, 2018).
8. Taylor, J.L. (2019). Delivering the Transforming Care programme: A case of smoke and mirrors? *BJPsych Bulletin*, 43, 201–203. doi:10.1192/bjb.2019.3
9. Brookbanks, W. (2019). Protecting the interests of vulnerable defendants in the criminal justice system: The New Zealand experience. *The Journal of Criminal Law*, 83, 55-70.
10. Duncan, A. (2012). The Intellectual Disability (Compulsory Care and Rehabilitation) Act. In J. Dawson & K. Gledhill (Eds.). *New Zealand mental health law in practice*, pp. 353-371. Wellington: Victoria University Press.

Table 1

*Transforming Care ‘Assuring Transformation’ Data Concerning
Hospital Patients with Intellectual Disabilities and/or Autism¹*

	March 2015	March 2019	March 2021
Total inpatients ²	2,395	2,260	2,035
Admissions ³	50	100	105
Discharges ³	95	160	150
Discharges to community ³	-	115	110
Hospitals transfers/Other ³	-	45	40

Notes. ¹Data derived from NHS Digital learning disability services monthly data provided by health commissioners concerning care provided in England - and elsewhere in the UK - for patients from England (Assuring Transformation), available at: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

²These numbers are the ‘provisional’ numbers of inpatients reported to the programme by commissioners at the end of each month. ³Admissions, discharges and transfers took place during the month listed.