

## **Is “transforming care” failing people with autism?**

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### **Abstract**

Purpose – The purpose of this paper is to comment on the development and implementation of transforming care (TC) and whether it has failed people with autism.

**Design/methodology/approach – This paper is a commentary.**

Findings – The number of people with autism being admitted to assessment and treatment units is increasing despite the aims of TC. The authors argue that TC, in serving such a diverse group of people, may have failed to identify the heterogeneity of such groups or recognise the different needs of people with mental illness and people with behaviours that challenge; and that TC could be regarded as a policy that only affects people with an intellectual disability.

### **Originality/value**

Policymakers, policy implementers and health and social care staff may consider reviewing their practice to ensure that TC works for people with autism and their family and carers.

**Keywords** Autism, Commissioning, Mental illness, Intellectual disability, Transforming care, Care support services

### **Introduction**

This paper examines the government response to Winterbourne View – a scandal affecting care and treatment of adults with intellectual disabilities and or autism. Across health services it is still the case that many associate the transforming care (TC) agenda, which followed Winterbourne, specifically to adults with intellectual disability; it is therefore important to ensure that people are reminded that it also impacts on adults with autism. To this end, we examine the implementation of TC to see whether it is having the intended impact for people with autism.

### **Background**

Historically, people with autism and intellectual or other neuro disabilities have been segregated from society, kept in institutions with little access to individualised and dignified care until the advent of deinstitutionalisation (Goffman, 1961). Professor Jim Mansell in the early 1990s recognised that staff and services working with people with intellectual disabilities and autism with additional mental health difficulties and/or behaviour that challenges were not always able to meet the needs of this patient group. This was because of cost implications (community living was more expensive than residential or inpatient at the time), poor staff training (to understand the function of challenging behaviour) and the separation of health and social care services (leading to changes in the commissioning of services (Mansell, 1994). Mansell noted that whilst some people were getting good community services based on “An Ordinary Life” ((The)King’s Fund Centre, 1980) others had been left with ageing family members and were entering crisis situations. This had led to the

development of new types of accommodation, commonly referred to as assessment and treatment units (ATUs) which were initially often opened on old institution sites (Mansell, 1994). Mansell's reports in 1993 and 2007 highlighted that people with intellectual disabilities and autism with additional mental health needs and/or behaviour that challenges, were often faced with repeated placement breakdowns and crisis presentations resulting in hospital admissions into ATUs that were often located far away from their families and with a lack of community placements to be discharged back to (Mansell, 2007). Once people were moved to services out of area, the need to build specialist local community services appeared to be less of a local priority to many health providers and decisions to move people out of area became commonplace (Chaplin et al., 2010). This increase in demand for placements out of area, in part contributed to the proliferation of ATUs which resulted in more and more people being "lost" to their local NHS services and local authorities. The notion that inpatient mental health care per se is unnecessary for people with intellectual disabilities and/or autism is a viewpoint that has gained support as a result, and aggravated by unnecessary admissions to inpatient wards in the absence of local community services designed to meet their needs. Moreover, even when inpatient services are used as intended, many people experience difficult and delayed discharges and in some cases are not discharged back to their local communities. This can often result in dependence on services and/or a deterioration of their mental health.

### **Autism policy**

Recent political and social events have shaped care for people with autism, resulting in a number of key changes to legislation and policy, including Autism Act (2009) (which was the first disability specific legislation in the UK), and The National Strategy for England "Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010)". This strategy aims to ensure that people with autism can access and depend upon mainstream public health services. However, this is still largely aspirational with wide discrepancies in how both service models and provision relating to autism is provided differently across the country (McCarthy et al., 2015). The National Strategy recommendation that NICE guidelines relating to autism were produced was realised in 2012 and commented on the organisation and delivery of care (NICE, 2012). To monitor the National Strategy, autism self-assessments have been conducted leading to an update of the National Strategy Think Autism: An Update (Department of Health, 2014) in 2014 the same year as the Care Act was introduced which aimed to offer individuals more control over their lives (McCarthy et al., 2015).

Over a similar time period the Winterbourne View scandal was exposed by the BBC programme Panorama. TC: A national response to Winterbourne View Hospital: the final report (Department of Health (DH), 2012). TC and the subsequent criminal investigations revealed that despite warning signs and evidence as a result of whistleblowing, health and local authorities failed to act to protect the people in their care resulting in heinous abuse and the failure of systems to protect vulnerable people.

### **TC policy development**

TC set out a programme of action to transform services so that people with intellectual disabilities and/or autism with behaviour that challenges or mental health difficulties have the local services that are tailored to their needs and that these services are based on best practice. TC also set

out to close and reduce the numbers of old style hospital beds and ATUs and forecast for a “dramatic” reduction in available hospital placements and the closure of large hospitals (DH, 2012). In relation to bed closures, TC stipulated that all patients currently in ATUs would have their placements reviewed by 1 June 2013 and that everyone placed inappropriately would be moved to community-based living by 1 June 2014. It also provided a template for what good services should look like.

The development of TC was not made in isolation and involved families, carers, people with autism and intellectual disabilities, the NHS Commissioning Board, the Association of Directors of Adults Social Services and the Local Government Association. For example, professional associations and organisations were allocated key tasks to take forward the work of TC such as Skills for Health (2016) to deliver clinical education and training in intellectual disabilities and the Royal College of Psychiatrists Faculty of Psychiatry of Intellectual Disability (2016) to review and develop guidance on the use of psychotropic medications for challenging behaviour. However, the authors are cautious that only people with intellectual disabilities and their families and carers who have been adversely affected by ATUs appear to have been consulted and therefore a case that truly represents all viewpoints may not have been heard. Public, patient involvement, for national policy objectives often involve a narrow demographic rather than more democratic models which would empower patients or service users further (Ocloo and Matthews, 2016).

TC’s strength is that as a policy it had a clear timeline for implementation, by whom and by when (DH, 2012, Appendix B). The policy also recognised that to make real change it needed to garner power and authority through a working group to lead the transformation agenda; it achieved this through a government mandate to the NHS Commissioning Board (DH, 2012, p. 9) and the establishment of a joint improvement programme which in turn became the Transforming Care Delivery Board (TCDB). The TCDB’s role is to provide leadership and support transformation across five key organisations involved in the support, care and treatment of people with intellectual disabilities and or autism with additional difficulties. The NHS arm of the Board engaged leadership from Jane Cummings, Chief Nursing Officer and Simon Stevens, Chief Executive NHS England. This is a key achievement as it has involved leaders with significant power and political resource and brought intellectual disabilities to the forefront of the NHS agenda as opposed to on the historical side-line with limited finance, lack of structured leadership and a lack of NHS commitment (Greig, 2000). This change in emphasis can be seen through the inclusion of people with intellectual disabilities in subsequent national policy agendas such as the NHS Forward View (NHS England, 2014, p. 7) although people with autism are not mentioned: Leading Change, Adding Value (NHS England, 2016) and improved regulation and monitoring (Care Quality Commission, 2012) amongst others. Not only has TC ensured that there is a policy to transform services for people with intellectual disabilities and autism but it has also placed intellectual disability on a trajectory to parity with other fields of practice through the publication of NICE (2015) guidance for challenging behaviour and the development of a NICE (2016) guideline for the mental health needs of people with intellectual disabilities. However, it would seem that the involvement of people with autism and their family and carers is not consistent and there is compelling evidence that the voice of people with autism and their families/carers is not being heard (Larch, 2016).

## **Failings**

As part of the TC agenda, *Building the Right Support* (NHS England, 2015) was published. This is a national plan to close inappropriate inpatient units, such as ATUs and develop community services for people with an intellectual disability and/or autism who display behaviour that challenges, including those with a mental health condition. While there has been some progress, there is evidence to suggest that the number of people with autism who do not have an intellectual disability in ATUs has increased (NHS Digital, 2016). Most criticism of TC and its weaknesses relate to its aim of closing or reducing the number of NHS beds for people with autism and/or intellectual disabilities with additional difficulties. Indeed, Norman Lamb, Minister of State for Care and Support at the time has been quoted as calling it “an abject failure” in this regard (Duffin, 2014) as the number of patients in these beds continued to rise (Duffin, 2014; Bubb, 2014; Cole, 2016). As the number of people with intellectual disabilities and autism with additional needs in ATUs or NHS beds continued to rise a further inquiry, the “Bubb (2014) Inquiry” was set up. In September 2016, the UK Government promised an extra £25 million to keep TC on track and whilst it is widely publicised that the number of people admitted to hospital with intellectual disability is now decreasing, for people with autism only and autism including Asperger’s, the opposite is the case with an 11.8 per cent (Autism\_only-Oct-15-n375, Aug-16, n, 425) and 4 per cent (Autism-Inc-Aspergers-Oct-15-n 240, Aug-16, n 250) rise, respectively (NHS Digital, 2016). These figures appear remarkable given there is no known evidence for any rise in the prevalence of mental health problems in people with autism and is more likely to reflect a lack of local specialist and autism friendly services. Bubb’s (2014) inquiry found that the targets for the reduction of hospital beds had been over ambitious and required more resources in the community to enable safe and effective discharges of these patients, as a result, extra funding was made available in a small number of pilot sites (NHS England, 2015).

The issue of bed and hospital closures remains pernicious with public demand to close all beds (7 Days of Action, 2016) and provide all care in local community homes high. The latest date for closures is scheduled for 2019 (ACEVO, 2016) and yet there is seemingly no voice for the continued use of ATUs despite their need being recognised within policy documents and part of recognised local mental health pathways for people with autism. Indeed, the Royal College of Psychiatrists (RCP) Faculty of Psychiatry of Intellectual Disability (2013) have published evidence of people with intellectual disabilities, family carers and paid carers who have found ATUs hugely beneficial as well as collating data from studies which evidence improved health outcomes on discharge. Furthermore, TC does not advocate that all hospital beds should be closed and both the Bubb (2014) report and the National Plan all state that such beds will continue to be needed albeit at a reduced number (pp. 28-29; NHS England, 2015 paragraph 3.13-3.14). Although it has been reported that there has been a 35 per cent reduction in numbers of in-patients, success varies widely across the country with the criticism that those easier to discharge and outside of medium security are more likely to be discharged (Glover et al., 2014). This has resulted in the closure of some ATUs and a reduction in bed number in others and funds have been diverted to create more innovative community services such as specialist enhanced intervention services for people with intellectual disabilities and autism with challenging behaviour who previously would have been inappropriately admitted to an ATU or an acute mental health ward in a crisis situation. New service models are now being developed nationally across 48 transforming care partnerships (TCPs) (NHS England, 2015); however many of these have failed to meet the requirements set out in *Building the Right Support/The National Plan* and have been returned for further work (Parish, 2016).

Moreover, people with an intellectual disability or autism with an additional mental illness may still require specialist inpatient admission and bed closures could disproportionately affect them.

## **Discussion**

The needs of people autism with or without intellectual disabilities with behaviour that challenges (who should be wholly supported in their own home) are different to the needs of those with additional mental illness; who may also require hospital treatment in the same way that the general population would according to the severity of their illness (Alexander et al., 2015). This distinction is important as people with behaviour that challenges or Autism alone should not be in hospital and it is absolutely right that we have policies that aim to end this practice, however people with intellectual disabilities or Autism with mental illness will on occasion require a specialist hospital admission in an ATU due to the relapsing and remitting nature of mental illness and the complications associated with an intellectual disability (RCP Faculty of Psychiatry of Intellectual Disability, 2013, pp. 8-9) or other neurodevelopmental condition. Although there are a number of distinct heterogeneous groups, i.e. intellectual disabilities, intellectual disabilities and autism spectrum conditions, intellectual disabilities and mental illness, intellectual disabilities and challenging behaviour, autism and challenging behaviour, autism and mental illness, autism alone, Asperger syndrome and high functioning autism, it appears that TC continues to treat these as one homogenous entity focussed mainly on the needs of people with intellectual disabilities. Although in the national plan there are nine principles outlining what a good service should look like, given the realities of current commissioning and regulations it appears there is an intrinsic lack of awareness of other sub populations such as those with autism who are subsumed into a much larger group with different needs and who require different expertise to support. Even with the advancement of autism legislation it appears that we are stuck in an historical vacuum of policy reflecting that of the early 1960s and 1970s where people with autism were indistinguishable from people with intellectual disabilities; and were treated as one group as far as policy and innovation was concerned. There is a need for policies to make a clear distinction of the needs of individuals and specific population groups when considering the implementation of TC.

## **Conclusion**

At the start of this paper we set out four goals stipulated in TC about bed closures. The evidence has shown that this aspect of TC has failed, in that large numbers of people are still “living” in ATUs and have yet to receive a placement review and there are still large hospitals yet to close. Indeed, admissions of people with autism have risen despite there being no indication that the prevalence of mental illness in this population has increased. Newly developed TCPs have so far failed to live up to the values laid out in TC and its subsequent guidance. There is a strong voice for the continued closure of such beds yet it appears that consideration of the effects of mental illness on people’s lives may not have been fully explored. There is a risk that by clustering those with behaviour that challenges and those people with additional mental illness as one homogeneous group, the needs of each group may not be fully considered or addressed. It is not clear that people with autism and their family and carers have been consistently involved in TC and perhaps the rise in admissions of people with autism could be a warning sign that local services have not acknowledged the heterogeneity of each of the population groups that TC serves. The voice of people with autism and their family and

carers should not be lost or forgotten and policymakers, policy implementers and health and social care staff need to ensure that TC works for everyone.

## References

7 Days of Action (2016), "Life for a learning disabled person", available at: <https://theatuscandal.wordpress.com/> (accessed 6 July 2016).

ACEVO (2016), "Time for change: the challenge ahead", available at: [www.acevo.org.uk/sites/default/files/ACEVO\\_report\\_TCA\\_final\\_web.pdf](http://www.acevo.org.uk/sites/default/files/ACEVO_report_TCA_final_web.pdf) (accessed 12 July 2016).

Alexander, R., Devapriam, J., Michael, D., McCarthy, J., Chester, V., Rai, R., Naseem, A. and Roy, A. (2015), "'Why can't they be in the community?' A policy and practice analysis of transforming care for offenders with intellectual disability", *Advances in Mental Health and Intellectual Disabilities*, Vol. 9 No. 3, pp. 139-48.

Autism Act (2009), (c.15), The Stationary Office, London, available at: [www.legislation.gov.uk](http://www.legislation.gov.uk)

Bubb, S. (2014), "Winterbourne View – time for change. transforming the commissioning of services for people with learning disabilities and/or autism", NHS England, London.

Care Quality Commission (2012), "Learning disability services inspection programme. National overview", available at: [www.cqc.org.uk/sites/default/files/documents/cqc\\_ld\\_review\\_national\\_overview.pdf](http://www.cqc.org.uk/sites/default/files/documents/cqc_ld_review_national_overview.pdf) (accessed 10 July 2016).

Chaplin, E., Kelesedi, K., Emery, H., O'Hara, J., Lockett, J. and McCarthy, J. (2010), "People with learning disabilities placed out of area: the South London experience", *Journal of Learning Disabilities and Offending Behaviour*, Vol. 1 No. 3, pp. 5-14.

Cole, A. (2016), "Autism services 'let people down' people are not being well served by a system that promised them more care in the community", *Nursing Standard*, Vol. 30 No. 40, pp. 18-20.

Department of Health (DH) (2012), "Transforming care: a national response to Winterbourne View Hospital", The Stationary Office, London.

Department of Health (2014), "Think Autism: an update to the government adult autism strategy", Department of Health, London.

Duffin, C. (2014), "Inpatient transfer policy has been an 'abject failure' too many people with learning disabilities are waiting for homes in their local communities, writes Christian Duffin", *Learning Disability Practice*, Vol. 17 No. 10, pp. 10-11.

Glover, G., Brown, I. and Hatton, C. (2014), "How psychiatric in-patient care for people with learning disabilities is transforming after winterbourne view", *Tizard Learning Disability Review*, Vol. 19 No. 3, pp. 146-9.

Goffman, E. (1961), *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, Anchor Books, Doubleday.

Greig, R. (2000), "Public policy and organizational priority for specialist learning disability health services", *Journal of Learning Disabilities*, Vol. 4 No. 4, pp. 307-20.

(The)King's Fund Centre (1980), *An Ordinary Life: Comprehensively Locally Based Residential Services for Mentally Handicapped People*, King Edwards Hospital Fund, London.

Larch, S. (2016), "Autism, mental health and offending behaviour: a mother's quest for healthcare", *Advances in Autism*, Vol. 2 No. 4, pp. 210-14, available at: <http://dx.doi.org/10.1108/AIA-05-2016-0011>

McCarthy, J., Chaplin, E. and Underwood, L. (2015), "An English perspective on policy for adults with autism", *Advances in Autism*, Vol. 1 No. 2, pp. 61-5, available at: <http://dx.doi.org/10.1108/AIA-08-2015-0011>

Mansell, J. (1994), "Challenging behaviour: the prospect for change 1", *British Journal of Learning Disabilities*, Vol. 22 No. 1, pp. 2-5.

Mansell, J. (2007), "Services for people with learning disability and challenging behaviour or mental health needs", Department of Health, London.

NHS Digital (2016), "Learning disability services monthly statistics England commissioner census (assuring transformation) – August 2016 experimental statistics", available at: <http://content.digital.nhs.uk/article/6468/Reports-from-the-Learning-Disability-Census-collections>; <http://content.digital.nhs.uk/catalogue/PUB21668> (accessed 12 September 2016).

NHS England (2014), "Five year forward view", NHS England, London.

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", NHS England, Local Government Association, London.

NHS England (2016), "Leading change, adding value: a framework for nursing, midwifery and care staff", NHS England Publications Gateway Approval Number 05247, NHS England, London.

NICE (2012), "Autism spectrum disorder in adults: diagnosis and management Clinical guideline (CG142)", NICE.

NICE (2015), "Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges", NICE guidelines (NG11), London, May.

NICE (2016), "Mental health problems in people with learning disabilities", NICE (NG54) in development (GID-CGWAVE0684)

Ocloo, J. and Matthews, R. (2016), "From tokenism to empowerment: progressing patient and public involvement in healthcare improvement", *BMJ Quality and Safety*, pp. 1-7, doi: 10.1136/bmjqs-2015-004839.

Parish, C. (2016), "Plans to move clients into community need revision: NHS England says ideas 'lack ambition' for care and treatment of those with learning disabilities", Learning Disability Practice, Vol. 19 No. 4, p. 7.

Royal College of Psychiatrists (RCP) Faculty of Psychiatry of Intellectual Disability (2013), "People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services", Royal College of Psychiatrists, London.

Royal College of Psychiatrists Faculty of Psychiatry of Intellectual Disability (2016), "Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines", Royal College of Psychiatrists, London.

Skills for Health (2016), "Learning disabilities core skills education and training framework", Skills for Health, Bristol, May, available at: [www.skillsforhealth.org.uk/services/item/331-learning-disabilities-core-skillseducation-and-training-framework?highlight=WyJsZWYybmluZyIsIldsZWYybmluZyIsImxIYXJuaW5nJyIsImRpc2FiaWxpdkHkiLCJsZWYybmluZyBkaXNhYmlsaXR5IiI0](http://www.skillsforhealth.org.uk/services/item/331-learning-disabilities-core-skillseducation-and-training-framework?highlight=WyJsZWYybmluZyIsIldsZWYybmluZyIsImxIYXJuaW5nJyIsImRpc2FiaWxpdkHkiLCJsZWYybmluZyBkaXNhYmlsaXR5IiI0) (accessed 28 June 2016).