

Building the Right Support: VODG Position Paper

It is an unacceptable truth that some autistic people and people with a learning disability live in settings far more secure than their needs require. Despite multiple commitments to resolve this over many years, yet another government deadline to resolve the problem passed in March 2024. Another chapter in a continuing human rights scandal.

Almost ten years ago, the NHS published its first strategyⁱ to reduce the number of people in Assessment and Treatment Units (ATUs).ⁱⁱ Subsequent deadlines to cut the numbers of autistic people and people with a learning disability living as inpatients in mental health ATUs have been missed. The latest target was to reduce the 2,905 people detained in such settings in 2015 by a half by March 2024.

Recently published figures show the reduction was instead just under 30%, with 2,045 people still living in ATUs at the end of March.ⁱⁱⁱ Of these 2,045 people, 1,380 (67%) are autistic. This denotes a 116% *increase* in the number of autistic people without a learning disability detained since March 2015.^{iv} So, within the context of an overall reduction, the number of autistic people in ATUs has sharply increased.

Nobody who has followed this story will be remotely surprised, which makes the need for urgent action even more pressing.

A Litany of Broken Promises

In 2011 BBC's Panorama exposed distressing abuse of patients by staff at Winterbourne View, a privately owned ATU. This prompted widespread condemnation, and a realisation that thousands of people were stuck needlessly in ATUs. Not because they were appropriate therapeutic environments, but because there was a lack of community support.

Several months after the Panorama documentary, the government instructed the Care Quality Commission (CQC) to inspect 150 hospitals and care homes. This uncovered wide-ranging poor practice. By the time the government instruction came through, CQC had already inspected many relevant establishments. Therefore, the subsequent programme inspected the 150 services most like Winterbourne View that had not already had an inspection informed by the Panorama revelations.

In December 2012 the government published *Transforming Care: A National Response to Winterbourne View Hospital*. The report pledged that people with a learning disability and people with autism living in ATUs would be moved to community-based care no later than 1 June 2014. This target was missed, and a subsequent report for NHS England by Sir Stephen Bubb found more people were being admitted than discharged.

In 2015, NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) published *Building the Right Support* – guidance supporting commissioners to reduce the number of people with a learning disability and autistic people in ATUs and seeking to develop community alternatives. The plan stated “35-50% of inpatient provision will be closing nationally with alternative care provided in the community by March 2019”. That target was missed.

The 2019 NHS Long-Term Plan updated the target to halving numbers by March 2024. That target has now been missed too.

New NHS priorities for 2024/25 include reducing reliance in mental health inpatient care for people with a learning disability and autistic people:

“Reduce reliance on mental health inpatient care for people with a learning disability and autistic people, to the target of no more than 30 adults or 12–15 under 18s for every 1 million population.”^v

Given the history of failure, it is reasonable to question whether this aspiration will be achieved.

When Will Things Change?

Throughout this thirteen-year period there has been no shortage of reports, papers, articles, service models and specifications published. These propose evidenced solutions, and often say much the same thing. There is not a lack of ideas about what to do. VODG has been engaged in demonstrating the practical solutions that third sector providers can offer. This combined body of member expertise underlines what we know, which is that most people currently detained in ATUs could be successfully supported in community services. Often, this support will turn out to be cheaper over time than an ATU placement. The knowledge and expertise to achieve this exists.

Three themes run throughout this sequence of events.

First is the setting of targets not met. In 2019 VODG predicted that it will take until 2030 for the ATU population to reduce by half from its 2015 level.^{vi} In March 2024 Mencap published a similar estimate.^{vii}

Second is a tendency for what might have been intended as a short-term intervention to become a stuck, long-term situation. A Mencap/ITN investigation reports the average length of stay at around five years.^{viii}

Third is a recognition that long-term stays in ATU's are very rarely appropriate for people with autism and people with a learning disability. ATUs are very likely to employ restrictive practices, including restraint, isolation and over-medication – a threat to people's safety and often in breach of their human rights. The effectiveness of any therapeutic interventions is undermined by the damage caused by these restrictive practices

Perhaps the most striking feature of all this is that almost everyone concurs. There is no need to campaign to change the Government's mind because the Government agrees. So does NHS England, CQC, most provider and membership organisations, and all user-lead organisations. And yet the problem is resilient. Why is this? To answer that we first must consider why people with a learning disability and people with autism are placed in ATUs in the first place.

When people with these support needs (and maybe other needs, too) become distressed, they may pose a risk to themselves or others. Usually, people in this situation do not need inpatient treatment. But when people reach a crisis point, ATUs often look like the only option. The reasons for this are many and complex, and include:

- A long-term failure to invest in appropriate community support focused on early intervention and prevention.
- A failure to engage third sector providers, including deaf and disabled people's organisations, in actively investing in delivering re-provision at scale and pace.
- A lack of suitable community-based housing. Community based services often require expensive specialist housing. Providers, (especially not-for-profit providers), are reluctant to invest in acquiring and preparing properties when discharge plans often change or fail.
- A Mental Health Act in need of reform, including the removal of having a learning disability or autism as a reason for detention.
- The need for a more nuanced approach to risk management

The points that explain how people often needlessly end up in ATUs, also partly explain why they stay for so long. Particularly a lack of appropriate housing and community-based support. There are other factors that point to why people get stuck:

- Often, people are placed in ATUs against their will, long distances from their families, communities and friends. This causes further distress and despair,

which often prompts a further deterioration in behaviour. This deterioration becomes, in turn, a rationale for continuing to contain people as inpatients. What started as a supposed short-term intervention to make things better, becomes a long-stay placement for someone deemed unmanageable in the community.

- The tendency for ATUs to be geographically distant from the home means that discharge – when it comes – often fails, because of a disconnect with local support infrastructure and provision.
- A confusing range of commissioning and procurement arrangements and funding protocols, and varying levels of cooperation and between local authority and NHS commissioners.
- The time required to build a trained and skilled support team for discharge, in tension with discharge schedules.

Another reason why short-term placements become long-stay is money. Inpatient placements in ATUs are expensive. Mencap research suggests an average cost of £237,000 a year. In 2019, VODG research indicated that much of the market for this type of provision was controlled by companies supported by overseas – usually American – investment.^{ix} It follows, then, that companies running such facilities have a vested interest in maintaining the considerable income made from long-stay care. Successfully ‘treating’ people and discharging them quickly is bad for business.

What should be done?

Re-think procurement

The money is in the wrong place.

National commissioning guidelines for integrated care boards (ICBs)^x state that an in-patient stay “should be for the minimum time possible, for assessment and/or treatment which can only be provided in hospital”.

Achieving this depends on a vibrant care and support market that can work with people when they leave hospital – or prevent them being admitted in the first place. Yet the market for support providers has been over-looked nationally.

There is an urgent need to build social care provider capability and capacity to deliver community-based services for people needing complex support. Good commissioning should invest to save over the longer term – resourcing prevention by partnering with community providers and housing suppliers. It should draw on the insight of people with lived experience and their families, who articulate consistently what they need – well-managed transitions between services, investment in community-based services close to families and friends, skilled staff.

A significant stumbling block to the development of community-based provision is the availability of suitable housing. Much can be achieved when NHS and local authority commissioners work in partnership with third sector providers on capital investment programmes that enable the right kinds of accommodation to be secured. But this good practice is far from mainstream.

We see little evidence that ICBs have strategic plans to avoid admission and enable discharge. Some providers have been able to develop effective community-based services that provide an alternative to inpatient provision, but demand for such support outstrips supply.

Speaking together and being heard

There is a large and strong coalition of user-led, special interest and third sector provider and membership bodies who want to see the end of inappropriate detention of autistic people and people with a learning disability. We are ready and willing to work with statutory providers to co-develop and deliver solutions, but the issue must be a political priority to drive the change needed.

Examples of the lobbying potential of this coalition include:

- VODG working with the Challenging Behaviour Foundation, Mencap and others, writing to all political leaders urging them to protect the human rights of autistic people and people with a learning disability. This included a suggested commitment for inclusion in election manifestos as below:



Investing in prevention and community services to deliver better support to individuals in their community and end the disgrace of inappropriate and costly inpatient placements for people with learning disabilities and autistic people.

- VoiceAbility launching a petition urging the Secretary of State for Health and Social Care to use the new power in the Health and Social Care Act 2022 to direct NHS England to urgently reduce the number of people with a learning disability and autistic people in ATUs.^{xi}
- The Challenging Behaviour Foundation co-producing a set of actions for policymakers, which build on the years of evidence and collective wisdom contained in reports, research projects and proposals.^{xii}
- Mencap and ITV News partnering on a news broadcast exposing the human and financial cost of detaining people with a learning disability and autistic people in ATUs.^{xiii}
- The British Association of Social Workers (BASW) Homes not Hospitals campaign.^{xiv}

As well as VODG-led activity (Appendix 1), we stand with all these initiatives and others, which indicate a shared strength of belief and purpose. Our efforts to drive change are more successful when we work together. We should further co-ordinate collective action to bring pressure to bear on the Government.

Challenge registration and ratings

ATUs not only fail to deliver effective services for individuals. Often they fail on their own terms and do not deliver on their core registered purpose. Services that are meant to be for assessment, treatment and then discharge, end up detaining people for years on end. Since 2019 VODG has asserted that such services should not be rated 'Good' by CQC. Yet many still are.

We are continuing to call on the Secretary of State to instruct CQC to:

- Rate all ATUs as 'Requires improvement' if anyone has been living there for more than 12 months
- Downgrade to 'Inadequate' any ATUs that detain anyone for more than 24 months
- Halt all admissions in 'Requires improvement' and 'Inadequate' services until the rating returns to 'Good'.

Conclusion

In 2019 VODG said that the time had gone for further reviews. That assertion holds. This is now a time to act – to act differently and to invest differently.

There are more than 2,000 British citizens detained in NHS-funded accommodation, against their wishes and against the wishes of their families. Often for years, and with no clear release date. This is the Government's responsibility. Apart from very rare occasions in the criminal justice system, it is hard to imagine any other circumstances where somebody can be detained indefinitely by the state. This continuing situation becomes even more baffling when the Government itself repeatedly and explicitly states that for most people, the conditions of their detention are inappropriate, damaging and should end.

This is a national scandal that should become a national priority. We need a Government willing to act, not just agree.

Appendix 1

VODG's illustrative engagement timeline

2011 *Another way: transforming people's lives through good practice in adult social care* (case study report).

2015 Letter to Rt Hon Alistair Burt MP, Minister of State for Community and Social Care.

2017 Email to Sarah Wollaston (Dr), Chair, Health Committee, House of Commons.

2018 *Transforming care – the challenges and solutions* (report).

2019 *A time for action: ending the reliance on long-stay inpatient units* (report and open letter to The Rt Hon Matthew Hancock MP, Secretary of State for Health and Social Care).

2020 Letter to Chris Wormald, Permanent Secretary, Department of Health and Social Care.

2023 *West Midlands Regional Demonstrator: Engaging Care Providers to Support People with a learning disability and/or Autism with Forensic Backgrounds* (report).

2024 – Further work commissioned by NHS England has begun looking at relevant commissioning guidance.

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Voluntary Organisations Disability Group (VODG)

VODG is a national charity that represents over 100 leading not-for-profit organisations who provide services to disabled people. We work on behalf of members to inform and influence the development of policy and practice which enables disabled people of all ages to live the lives they choose.

www.vodg.org.uk | research.policy@vodg.org.uk

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- ⁱ NHS England (2015) *Building the right support* www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf
- ⁱⁱ Since 2011 a feature of this debate has been the use of multiple terms to describe the facilities in which people are detailed – including inpatient units, assessment and treatment units (ATUs), hospitals, and mental health hospitals etc. In this paper we prefer ATUs.
- ⁱⁱⁱ NHS England (2024) *Learning Disability Services Statistics* www.digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics
- ^{iv} National Autistic Society *Missed target to reduce number of autistic people detained in mental health hospitals* www.autism.org.uk/what-we-do/news/missed-target-to-reduce-number-of-autistic-people
- ^v NHS England (2024) *Priorities and operational planning guidance 2024/25* www.england.nhs.uk/publication/priorities-and-operational-planning-guidance-2024-25/
- ^{vi} VODG (2019) *A time for action: ending the reliance on long stay inpatient units*
- ^{vii} Mencap (2024) *Government wastes half a BILLION pounds a year on the wrong treatment for people with a learning disability and autistic people.* www.mencap.org.uk/blog/government-wastes-half-billion-pounds-year-wrong-treatment-people-learning-disability-and
- ^{viii} Mencap (2024) *Government wastes half a BILLION pounds a year on the wrong treatment for people with a learning disability and autistic people* www.mencap.org.uk/blog/government-wastes-half-billion-pounds-year-wrong-treatment-people-learning-disability-and
- ^{ix} VODG (2019) *A time for action: ending the reliance on long stay inpatient units*
- ^x NHS England (2023) *National guidance to support integrated care boards to commission acute mental health inpatient services for adults with a learning disability and autistic adults* www.england.nhs.uk/long-read/national-guidance-to-support-integrated-care-boards-to-commission-acute-mental-health-inpatient-services-for-adults-with-a-learning-disability-and-autistic-adults/
- ^{xi} VoiceAbility (2024) *Use Your Power! Stop the detention of people with a learning disability & autistic people* www.change.org/p/use-your-power-stop-the-detention-of-people-with-a-learning-disability-autistic-people
- ^{xii} Challenging Behaviour Foundation (2024) *Actions for Policy Makers* www.challengingbehaviour.org.uk/action-plan/for-policy-makers/
- ^{xiii} Mencap (2024) *Government wastes half a BILLION pounds a year on the wrong treatment for people with a learning disability and autistic people* www.mencap.org.uk/blog/government-wastes-half-billion-pounds-year-wrong-treatment-people-learning-disability-and
- ^{xiv} BASW (2019) *Homes not Hospitals* new.basw.co.uk/about-basw/social-work-around-uk/basw-england/campaigns/homes-not-hospitals