

# Voluntary Organisations Disability Group Representation to the Department of Health and Social Care, Reforming the Mental Health Act consultation

April 2021

## About VODG

VODG is the national infrastructure body representing organisations within the voluntary sector who work alongside disabled people. Our members' work is focused on enabling disabled people of all ages to live the lives they choose. VODG believes that an ambitious, trusted and vibrant voluntary sector that works together plays a unique role in achieving this aim. VODG members work with around a million disabled people, employ more than 85,000 staff and have a combined annual turnover in excess of £2.8 billion.

## 1. Background

There are 14.1 million disabled people in the UK, representing 21% of the population and 19% of working age adults.<sup>1</sup> In England, 21% of the population reports having a disability. The provision of essential services to disabled people in ways that promote independence, choice and control, as well as supporting their carers is a statutory obligation. The hallmark of a fair and equitable society includes fully meeting people's needs and enabling disabled people to have full choice and control over their lives, and to be included in society.

VODG welcomes the opportunity to submit this representation to the Department of Health and Social Care's *Reforming the Mental Health Act* consultation. VODG represents more than 100 voluntary sector providers of disability services, many of which provide advocacy services and/or care and support to people with learning disabilities and autistic people. VODG is, therefore, pleased about the attention given in the White Paper to the lives of people with learning disabilities and autistic people living in long-stay, in-patient units. This submission draws upon the expertise of our member organisations working in this area, as well as our long-standing interest in this issue.<sup>2</sup>

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<sup>1</sup> Department for Work and Pensions (2020) *Family Resources Survey*.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/874507/family-resources-survey-2018-19.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874507/family-resources-survey-2018-19.pdf)

<sup>2</sup> Voluntary Organisations Disability Group (2019). *A time for action: ending the reliance on long-stay in-patient units*. <https://www.vodg.org.uk/wp-content/uploads/VODG-A-time-for-action-ending-the-reliance-on-long-stay-inpatient-units-.pdf>

## 2. Introduction

VODG is pleased that the government's White Paper has taken on recommendations from the Independent Review of the Mental Health Act and welcomes the scrutiny that the White Paper brings to what is now outdated legislation. The consultation presents an opportunity to reform, update and move policy towards a more person-centred, rights-based approach to implementation of the Mental Health Act. VODG believes many of the proposals included in the White Paper represent a progressive step forward and could be transformative if implemented well. However, it is also clearly stated in the White Paper that the proposals are subject to future funding decisions, including at Spending Review 2021. This means that despite the transformative nature of the proposals, there is significant uncertainty as to whether the commitments made in the White Paper will actually be taken forward. Without funding to support the policy ambitions, the opportunities for transformation will be marginal. It is, however, also important to recognise that there are opportunities to maximise the effective use of resources in the sector.

VODG also supports consultation responses submitted by member organisations including from VoiceAbility, Royal Mencap, and Dimensions.

We use this paper to draw out those issues most relevant to disability care and support providers and the people they support. Our submission does not aim to cover the entire scope of the consultation and instead responds to key topics contained in the White Paper proposals, specifically:

### Advocacy

Independent mental health advocates (IMHAs) play a vital role in supporting people to be involved in their own care and helping them to exercise their rights. VODG strongly agrees with the proposed additional powers for IMHAs to help them carry out their functions more effectively and to provide greater support and representation to people detained under the act. Advocates provide valuable support in decision-making processes and expanding the role of IMHAs means expanding the support available to people with a learning disability and autistic people who have been detained.

Given the valuable role, IMHAs can have in supporting people, VODG believes advocacy services should be made 'opt-out' rather than the duty proposed, which states hospitals need to make people who use services, aware that advocacy services are available. It is also important to recognise the workforce training that will need to be made available about the role of IMHAs.

## People with a learning disability and autistic people

VODG welcomes 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. It is encouraging that the government acknowledges that people with a learning disability and autistic people have suffered from inappropriate detention. It is hard to imagine any other circumstances in which a British citizen could be detained indefinitely by the state, without a trial, where government has explicitly acknowledged that the conditions of their detention are for the majority inappropriate and should be ended and yet continue to detain them in precisely the same, and in some instances worse, circumstances for many years.

Currently, thousands of children and adults are locked away in long-stay, in-patient units even when they do not have a treatable mental health condition. There must be an end to the reliance on in-patient services for people with a learning disability and autistic people and the White Paper contains a set of encouraging measures to support the proposals. Through the COVID-19 pandemic we have seen a step back in progress to move people out of long-stay institutions and it is vital for government to renew its focus on ending the reliance on long-stay provision.

VODG also welcomes the White Paper's proposals to limit the scope, and make it harder, to detain people with a learning disability and/or autism under the act, including supporting the proposal that learning disability and autism are not considered mental 'disorders' warranting detention under Section 3.

However, it is essential that the availability of community alternatives is in place in order to prevent unintended consequences of this proposal. Without the provision of effective care and support in the community, the risk remains that the aims of the White Paper will not be met and people with learning disabilities and autistic people will continue to be detained via different routes. As such, robust safeguards must be developed and implemented to ensure people with learning disabilities and autistic people do not instead enter the criminal justice system and end up detained under Section 3. Furthermore, our members report concerns that a further unintended consequence may see an increase in the future numbers of people being detained under the Liberty Protection Safeguards (when implemented), which would result in fewer protections and routes to challenge detention than would be available under the Mental Health Act.

In-patient settings are often unsuitable and can trigger, rather than reduce, behaviour that challenges and create situations where deterioration justifies prolonged detention in a continual cycle".<sup>3</sup> As such, VODG also welcomes the inclusion of 'therapeutic benefit' as a measure against which treatment and detention have to be justified but that there needs to be clear definitions and consistent measures as to

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<sup>3</sup> VoiceAbility et al (2021) *Reforming the Mental Health Act - response to the public consultation*.  
[www.voiceability.org/assets/download/MHA-response-21-April-2021.pdf](http://www.voiceability.org/assets/download/MHA-response-21-April-2021.pdf)

how benefit is evaluated and how a person is evaluated as ready for discharge. What constitutes ‘therapeutic benefit’ also needs to be informed by the latest guidelines on supporting individuals with learning disabilities and autistic people.<sup>4</sup> VODG has previously reported that our members and other providers have had mixed experiences of the building the right support (transforming care) programme. At its best, it is about professionals working openly and collaboratively, putting the individual at the centre of the process and working consistently towards a positive discharge from NHS-funded care into a new life in the community.

It is imperative that across the system, professionals and the wider workforce supporting people with learning disabilities and autistic people have specialist learning disability and autism knowledge and robust government guidance is in place to support the implementation of any reforms.

The government must also acknowledge that in striving to make changes to the detention criteria to reduce admissions, people must be able to access the right support in the community and this requires a significant overhaul of local authority commissioning.

## **Community support**

Effective local authority and NHS commissioning is central to ensuring the provision of preventative, and post-discharge, community care and support. This also includes appropriate housing for people with learning disabilities and autistic people. More value and greater emphasis should be placed on early intervention and preventative services by commissioners and this needs to be fully backed by long-term funding and adequate resourcing. Alongside this, commissioners working to develop community support in this area should have the appropriate learning disability and autism knowledge and expertise in order to identify challenges and solutions, design effective preventative and post-discharge services. Furthermore, commissioners should look to the voluntary sector providers working in this area who have a history of developing person-centred, innovative services.

VODG believes that people with learning disabilities and autistic people should be cared for and supported in the least restrictive settings but this is dependent on effective community alternatives being in place. Without such provision, long-stay, in-patient units will remain the default pathway and this is simply unacceptable.

## **Regulatory monitoring**

There needs to be effective oversight of the new arrangements that will come through as a result of the White Paper. We believe the independent regulators,

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<sup>4</sup> Challenging Behaviour Foundation (2021) *Headlines for inclusion in Mental Health Act White Paper consultation response*. <https://www.challengingbehaviour.org.uk/learning-disability-assets/mhaconsultationcbfheadlines.pdf>

including the Care Quality Commission, should work together to monitor and oversee the implementation of the reform and to prepare statutory reports to parliament.

To conclude, while VODG recognises and supports the significance and importance of the reforms included in the White Paper, we remain concerned that these reforms are dependent on future funding decisions and, therefore, lack genuine commitment and impetus. The reforms must also be informed by professional expertise and the views of disabled people and their families. Without long-term funding to implement these reforms being earmarked upfront, and the voice of lived experience being at the forefront of service design, the risk is the ambitions of the White Paper will fall flat and meaningful change will not happen.

For more information or to arrange a further a discussion with VODG or our members, please contact [research.policy@vodg.org.uk](mailto:research.policy@vodg.org.uk)