

Advocacy for people with a learning disability and autistic people in mental health in-patient services

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Summary

This paper sets out the case for a nationally commissioned, specialist advocacy service for people with a learning disability and autistic people in mental health in-patient services. It presents evidence that, whilst advocacy services can and should be an important resource, the quality of support is too variable and sometimes advocacy is absent altogether. It concludes that a national commissioning model would enable a higher quality advocacy service that worked more closely with family members to achieve better outcomes for people with a learning disability and autistic people in mental health in-patient services. It also recommends legislating for 'opt-out' to improve access to advocacy services.

The Department of Health and Social Care (DHSC) should:

- 1) **nationally commission a specialist advocacy service** to provide more effective and consistent support for people with a learning disability and autistic people in mental health in-patient services
- 2) **legislate for an opt-out model of advocacy provision** in its reform of the Mental Health Act 1983 (MHA) as recommended by the independent review of the MHA and supported by many other stakeholders

Background

There is widespread public concern about the experiences of people with a learning disability and autistic people in mental health in-patient services. In its report published in July 2021, the House of Commons Health and Social Care Select Committee found that “autistic people and those with learning disabilities can find themselves experiencing intolerable treatment in inpatient facilities which has included being subject to abusive restrictive practices; being detained for long periods of time in facilities that do not meet their needs; and being kept long distances away from their family and friends.”¹

Most of the over two thousand people with a learning disability and autistic people in mental health in-patient services have the right to support from an Independent Mental Health Advocate (IMHA) or other form of statutory advocacy. The MHA Code of Practice states that “IMHAs are specialist advocates who are trained specifically to work within the framework of the Act and enable patients to participate in decision-making, for example, by encouraging

¹ [Treatment of autistic people and individuals with learning disabilities \(parliament.uk\)](https://www.parliament.uk/publications/2021/10/10) p.3

patients to express their views and supporting them to communicate their views.”² The government has also proposed new responsibilities for IMHAs in future.³ However, there are well documented concerns about the quality and availability of advocacy for people with a learning disability and autistic people in mental health in-patient services which has led to DHSC and NHS England initiating a review.⁴

Current model of advocacy for people with a learning disability and autistic people

Statutory independent advocacy is an important resource for people with a learning disability and autistic people in mental health in-patient services. A recent report into independent advocacy in restricted settings found that advocates are “well placed” to support people in these settings and “make a difference in many people's lives, frequently questioning decisions, supporting people at meetings, accessing Tribunals and using safeguarding processes to protect individuals.”⁵ According to the Challenging Behaviour Foundation, independent advocacy is a “crucial resource” that “can ensure choice, well-being and enable person-centred care.”⁶

However, a recent report from the Care Quality Commission (CQC) found that:

- “Access to high-quality advocacy varied across the hospitals we visited and that the role of an advocate was not consistent.
- There was some confusion between the provider and commissioner about who the advocate was, or which organisation provided the services. This led to people being denied access to the service. In some cases, there was no evidence that advocacy had been offered to people. Even where people were allocated an advocate, they were not always engaged in decisions about the person’s care.
- There were examples of where the advocate was not informed of certain people on the ward.
- When people did have access to advocates, there were examples where advocacy was of a poor quality, where advocates were not upholding people’s rights.
- Advocates were also under pressure themselves and felt they did not have enough time to support everyone that they were responsible for. One reviewer noted: “IMHAs [Independent Mental Health Advocates] feel they are not able to have enough time to advocate fully for people at [hospital]. They have been asked to increase their input by the [clinical commissioning group] but there is no additional funding available.”⁷

Whilst there are pockets of good practice, the current model of commissioning advocacy services does not work well. A recent report into independent advocacy in restricted settings

² [Mental Health Act 1983 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/101441/mental-health-act-1983.pdf) p.54

³ [Reforming the Mental Health Act: government response \(web accessible\) \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/101441/mental-health-act-1983.pdf) p.60

⁴ [The national strategy for autistic children, young people and adults: 2021 to 2026 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/101441/mental-health-act-1983.pdf) p.33

⁵ [Independent advocacy in restricted settings for people with a learning disability and autistic people.pdf \(blackbeltadvocacy.com\)](https://www.blackbeltadvocacy.com/independent-advocacy-in-restricted-settings-for-people-with-a-learning-disability-and-autistic-people.pdf) p.5

⁶ [Advocacy-guide-for-commissioners.pdf \(challengingbehaviour.org.uk\)](https://www.challengingbehaviour.org.uk/advocacy-guide-for-commissioners.pdf) p.3

⁷ [Out of sight – who cares? \(cqc.org.uk\)](https://www.cqc.org.uk/out-of-sight-who-cares) p.18

found that “this variability in what is commissioned obviously contributes to the wide fluctuation in what can be offered - leading to the inconsistencies in people’s experiences around what support they can access.”⁸

Why introduce national commissioning of advocacy for people with a learning disability and autistic people in restricted settings?

Mental health in-patient services for people with a learning disability and autistic people present heightened risks of abuse and neglect, prolonged detention without therapeutic benefit and excessive delays to hospital discharge. To be effective in these challenging circumstances, an advocacy service needs highly skilled staff with the time to provide more intensive support and working closely with family members. This can only be achieved through a model of national commissioning which would also provide greater national accountability.

A highly skilled workforce with improved professional support and supervision

Advocates need to have an enhanced skill set with well-developed professional curiosity and experience of working in environments with heightened safeguarding risks. Kate Mercer Training and VoiceAbility have identified eight core competencies for effective advocacy in restricted settings. Advocates must:⁹

- be skilled to communicate effectively with people with autism and learning disabilities
- understand trauma
- understand the potential of quality community-based provision
- be able to challenge decisions in clinical and specialist setting
- be skilled in identifying, raising and escalating safeguarding issues
- understand the use and misuse of segregation and restraint
- work across legislation and advocacy roles (Mental Health Act, Mental Capacity Act, Deprivations of Liberty, and Care Act)
- be skilled in using non-instructed advocacy.

A report by the National Autistic Society also concluded that advocates need more “specific training” so they can “adjust their communication for autistic people and people with a learning disability,” including the use of non-instructed advocacy, and should also “have an in-depth knowledge of autism, learning disability, challenging behaviour and the *Transforming Care* policy.”¹⁰ The National Institute for Health and Care Excellence (NICE) guideline on learning disabilities and behaviour that challenges recommends that commissioners “ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services”.¹¹

⁸ [Independent advocacy in restricted settings for people with a learning disability and autistic people.pdf \(blackbeltadvocacy.com\)](https://blackbeltadvocacy.com) p.8

⁹ [Advocacy-with-people-with-learning-disabilities-and-autistic-people.pdf \(voiceability.org\)](https://voiceability.org) p.1

¹⁰ [Transforming Care our stories \(2\).pdf \(thirdlight.com\)](https://thirdlight.com) p.14

¹¹ [Learning disabilities and behaviour that challenges: service design and delivery \(nice.org.uk\)](https://nice.org.uk) p.15

A nationally commissioned service would enable contracted provider(s) to develop a critical mass of highly skilled and experienced advocates with more tailored professional support and supervision. It would not be possible to develop such a critical mass under the current local commissioning model where the number of people with a learning disability or autistic people in mental health in-patient services will inevitably be quite small in some local authority areas.

A service that is able to follow the person and provide more long-term support

The current commissioning landscape makes it almost impossible to provide consistent and long-term support. For example, if someone moves between local authorities, due to a change of hospital placement or transition back into the community, then the advocacy service also changes. There can be complications depending on whether someone is eligible for support from an Independent Mental Health Advocate (IMHA), Independent Mental Capacity Advocate (IMCA) or other form of advocacy.¹² The practice of many independent healthcare providers to commission and refer to their own advocacy services confuses the picture further. Ultimately, this can lead to poor outcomes with “multiple advocates ‘dipping in and out’ of a person’s life” to little effect.¹³

A nationally commissioned service can work more easily across geographical and legal boundaries. Advocates also need time to build a relationship of trust and understanding, to allow them to get to know the person and vice versa and ensure the person’s wishes are fully understood and communicated, including through a non-instructed advocacy approach if required. Capped caseloads would enable advocates to provide more intensive support, working closely with family members and legal representatives. The alternative option of DHSC and NHS England seeking to influence the commissioning arrangements across 150 local authority and 42 Integrated Care System areas is unlikely to be consistently successful and also slow to produce results. It will also never facilitate a more portable service.

Improving access to advocacy services

Around one in four people with a learning disability and autistic people in mental health in-patient services do not receive any support from an independent advocate.¹⁴ This means opportunities to empower people and provide safe spaces for people to raise concerns are being lost. The current legal duty to inform people about advocacy is weak and the CQC has “found wards where staff did not routinely refer any eligible patients to an IMHA.”¹⁵ We recommend legislating for ‘opt-out’, where people automatically get support from an advocate but can still choose to opt-out.¹⁶ This would also reinforce the independence of advocacy services. Opt-out was recommended by the independent review of the Mental Health Act and is supported by a wide range of stakeholders.¹⁷

¹² [Monitoring the Mental Health Act in 2020/21 | Care Quality Commission \(cqc.org.uk\)](#) p.26

¹³ [Independent advocacy in restricted settings for people with a learning disability and autistic people.pdf \(blackbeltadvocacy.com\)](#) p.8

¹⁴ [Learning Disability Services Statistics - NHS Digital](#)

¹⁵ [Monitoring the Mental Health Act in 2019/20 \(cqc.org.uk\)](#) p.53

¹⁶ [Briefing-Mental-Health-Act-Advocacy.pdf \(voiceability.org\)](#)

¹⁷ [VoiceAbility | Mental Health Act: Call for “unequivocal commitment”...](#)

Recommendations

A national commissioning model would enable the development of a more specialist advocacy service that would better meet the needs of people with a learning disability and autistic people in mental health in-patient services. It would also help ensure the independence of the advocacy service and provide greater national accountability for its quality and availability.

We recommend that the Department of Health and Social Care:

- 1) **nationally commission a specialist advocacy service** to provide more effective and consistent support for people with a learning disability and autistic people in mental health in-patient services
- 2) **legislate for an opt-out model of advocacy provision** in its reform of the Mental Health Act 1983 (MHA) as recommended by the independent review of the MHA and a wide range of other stakeholders