

Advocacy with people with learning disabilities and autistic people, who are subject to seclusion, segregation or restraint

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Independent Advocacy is crucial to make sure a person's voice is heard and their human rights are protected. This is especially important when a person is subject to compulsory and restrictive powers.

Consistent and effective advocacy must be provided to people who most require it, whenever they require it, including to people with learning disabilities, autism or both, who are subject to long term segregation. Improvement to the delivery and commissioning of advocacy is required to achieve this.

What is needed?

Advocacy for people with learning disabilities, autism or both who are in long term segregation must be:

Accessible: People must get the advocacy support, in the first place.

Highly competent: Advocates must:

- 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.

Holistic: Support must be for all areas of a person's life and advocates must be able to act across different statutory duties so that people do not have to form working relationships with more than one advocate. Support must be available to the person at such intensity and duration as required to enable the person to move on from their current situation.

Independent and perceived to be so: Advocacy must free from conflict of interest and act solely on the instruction and in the interests of the person to whom it is provided. It ought not to be funded by the service provider. The commissioner of the service must seek to minimise, manage, and ensure transparency about any conflict of interest that they have. These may arise in cases where they are also the current or possible future funder of the hospital or community-based service for the individual.

Connecting: Advocates must work effectively and supportively in tandem with families and support the person to access expert and legal advice, and to navigate complex multi-agency professional and funding systems.

Supported: Advocacy organisations must ensure that advocates are supported to be confident, skilled, robust in their work, knowledgeable and resilient. This is ever more so when providing advocacy to people in long term segregation. It requires appropriate supervision, training and in-depth learning and development.

Joined up: People who are in long term segregation have almost invariably been through a cycle of breakdown in support arrangements. There needs to be improved access to quality advocacy support for people with learning disabilities, autism or both whose behaviour challenges, to help maintain community-based support and prevent admission. At a minimum, this ought to be triggered by Care, Education and Treatment Reviews (CETRs) or Community Care and Treatment Reviews (CTRs).

Similarly, advocacy provision needs to be enhanced for all people with learning disabilities, autism or both who are in-patients. The requirements of advocacy services noted above apply equally to advocacy support to all people with learning disabilities, autism, or both.

Commissioning

The current commissioning and funding arrangements for advocacy do not well serve people with learning disabilities, autism or both who are in segregation or who are in-patients. We believe that there are two credible commissioning options.

National commissioning of an enhanced advocacy service to people with learning disabilities, autism or both who are in-patients, or at risk of becoming in-patients. This model has a number of advantages. The model could be specified clearly, activated promptly, its delivery easily monitored, and there would be a clear line of sight on the resources. It would also enhance the separation and independence of advocacy from providers and local health and social care bodies. It may facilitate the advocacy support moving with the person as needed. These advantages would also apply should the service be solely for people who are subject to long-term segregation. National commissioning would not necessarily mean that there was just one national provider.

However, for national commissioning to be successful, the risk of further confusion and overlap with existing statutory and non-statutory advocacy provision would need to be managed. This problem is reduced if the service commissioned is available to all in-patients who have learning disabilities, autism, or both as this avoids different eligibility for those in and not in long term segregation.

Locally commissioned services would be best undertaken by the local authority within which the person is currently living. This would then align the service with most existing statutory provision. It would be a challenge to make sure that the model is consistently specified, activated promptly, sufficiently resourced and monitored, and any conflicts of interest for the local commissioner are well managed. These challenges may be heightened

by the demands on local authorities. We recommend that enhanced local commissioning is preferred only if these challenges can be overcome.

Irrespective of the commissioning arrangements, the service must be able to undertake the full range of statutory advocacy duties, rather than referring the person on and requiring that they relate to several advocates.

Recommendations

1. Advocacy for people in long term segregation must be provided on an opt-out basis

Opt-out is essential to make sure that more people in long term segregation receive the timely advocacy support and representation they need for their voice to be heard and their rights upheld. Opt-out only strengthens people's rights. A person can still make a free choice to not have the support of an advocate, but opt-out dismantles barriers that stop many people getting needed support. Opt-out is recommended by the Mental Health Act review and is already in place under the Mental Health Measure in Wales.

2. The provision of advocacy must be on a continuous, frequent, and regular basis until the person is settled in appropriate community-based provision

This contrasts with much existing provision which is episodic and focused on specific issues. The fact that a person is in long-term segregation is self-evidently an issue which requires attention until it is resolved. The advocate must be able to work flexibly with the person and not be restricted by the types of issues they can support with.

3. Service specifications for advocacy provision must incorporate the capabilities and approaches noted above: accessible, highly competent, independent, holistic, connecting, supported and joined up.

4. Enhanced access to advocacy of the nature outlined in this paper ought to be provided to people with learning disabilities, autism or both

- who are in-patients – not solely those in long-term segregation
- who are at risk of becoming in-patients, in order to help pre-empt and prevent admission and the use of long-term segregation

5. Resources need to be identified and allocated. Advocacy of this nature, intensity and duration is necessarily more costly to provide than other types of advocacy. The current nature of contracting makes it very difficult to ensure the level of service required because it is based on working with someone for few hours.

6. There should be national agreement on the most appropriate form of commissioning of advocacy for people with learning disabilities, autism or both who are in long term segregation, and for the wider population of people who are in-patients.

7. Additional support for families must be made available. The advocacy service must work closely and effectively with family members, other than in the rare event that the person does not wish this to happen. Additionally, support should be made

available specifically to family members, based on what families want and need. This may include advocacy provision specifically for relatives.

- 8. Monitoring the provision of advocacy should be reviewed and improved.** There is no nationally available reliable data on the uptake of advocacy. This must be addressed. Clear data is vital to assessing the extent to which this essential safeguard to people's human rights is in place across the country and to inform action.

Appendix: Who has an advocate and who commissions it?

Who has an advocate?

A person who is detained under the Mental Health Act 1983 is entitled to access an Independent Mental Health Advocate (IMHA)¹ whose role is to support the person's participation in decisions affecting their mental health care and treatment. This includes most people who are in long term segregation.

Some people will be entitled to an Independent Mental Capacity Advocate or an advocate under the Care Act.

Advocacy funded by providers sometimes includes IMHA and sometimes excludes all statutory provision.

We are not aware of data specifically about advocacy for people in long term segregation.

Who funds advocacy?

The duty to commission the IMHA and IMCA services is held by the Local Authority where the service is. Additionally, advocacy is contracted for and funded by several providers, including both the NHS and independent sector.

Where provision is funded by the hospital, it may exclude advocacy required by law (IMHA, IMCA and advocacy under the Care Act), resulting some people having to relate to more than one advocate and to confusion.

It is not unusual for there to be several advocacy providers working in a single hospital ward with different remits. This causes confusion and makes it more difficult for people to get support.

We believe that the NHS standard specifications and contracts with providers may make it more likely that providers commission advocacy². This should be reviewed to ensure specifications better reflect desired commissioning practice.

¹ Excluding people held under the short term holding or emergency powers (sections 4, 5, 135 and 136)

² The NHS Standard specification for providers of low and medium secure services require that:

An independent Advocacy service including IMHA must be provided for patients in the service and commissioned independently to ensure individual rights are safeguarded <https://www.england.nhs.uk/wp-content/uploads/2018/03/adult-low-secure-service-specification-v3.pdf> and <https://www.england.nhs.uk/wp-content/uploads/2018/03/adult-medium-secure-service-specification-v3.pdf>.

Whilst the specifications state that advocacy will be independently commissioned, the inclusion of this requirement in a service specification may suggest otherwise. We do not believe that this is clear enough about who should commission the advocacy service.

The standard contract for high secure services clearly locates responsibility with the provider, stating:

An Independent Mental Health Advocacy (IMHA) service will be provided to ensure individual rights are safeguarded. <https://www.england.nhs.uk/wp-content/uploads/2018/08/Mental-health-high-secure-services-adult.pdf>