

‘Right support, right care, right culture’: Does the Care Quality Commission's (CQC) new guidance encourage or inhibit improvements in the lives of people with learning disabilities and autism?

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On 8 October 2020, the Care Quality Commission (CQC) published ‘Right Support, Right Care, Right Culture’, its new guidance on the registration and regulation of services for autistic people and/or people with a learning disability. This guidance replaces its ‘Registering the Right Support’ guidance.

Those hoping for the changes called for by many in the sector will be disappointed. Before even the introduction, the CQC state that “Our policy on regulating providers that support autistic people and people with a learning disability remains unchanged from Registering the Right Support.” The new guidance is designed, the CQC say, to “clarify” how they implement the guidance.

Although the release of the guidance talks of a stronger emphasis on service user outcomes, there is little else to encourage new entrants to the sector who feel they can provide high-quality, person-centred care in a way that does not fit the CQC’s preferred model of six (or less) bed units in community settings.

In fact, reassurances in the previous guidance that the CQC does not wish to impose a ‘one size fits all’ or ‘overly prescriptive’ approach have been removed. Some providers tell us that this reflects their experiences of how the guidance was applied in any event. It seems this new guidance will do little to solve the problem of under-supply of community placements across large parts of England.

For existing providers, the guidance introduction and public message from the CQC may cause even greater concern. The CQC continues to draw a link between its preferred delivery model and the maintenance of dignity, privacy and person-centred care. It is explicit in saying that non-adherence to that model may be a consideration in whether to provide favourable inspection ratings.

It is currently unclear what effect the guidance will have on new providers taking over existing services. This was recognised as an exception in the previous guidance but that is no longer the case. One CQC case study suggests a level of flexibility for larger services with a positive inspection history.

Criticisms of the CQC’s approach

The previous guidance was subject to a substantial amount of criticism from providers of learning disability and autism services and representative bodies, such as Care England. They felt that it applied a ‘one size fits all’ approach when considering applications to open new services or expand existing ones.

It was said that this had two unintended and unfortunate consequences, namely:

1. Stifling choice for people or families that may prefer another model of care;
2. Inhibiting the drive to accelerate discharges from in-patient settings into the community by contributing to the under-supply of

Genuine choice

The CQC points to the fact that its guidance is consistent with NICE guidelines as well as the nationally-recognised 'Building the Right Support' (2015) and 'Building the Right Home' (2016) guidance documents.

It is not difficult to find broad support for the idea that the models of care set out in these documents work for many and perhaps most people. However, some providers tell us that the level of resistance from the CQC to any departure from their preferred model is reducing innovation and genuine choice.

This argument is based on the fact that people with learning disabilities and autism are as varied as any other section of society. They may wish to choose to live in more rural settings or, alternatively, in settings where a larger number of people receive care and share enhanced facilities that it may not be economical to provide otherwise. Where people can't make those choices themselves, their families may make similar choices for them. The rigid approach applied by the CQC, particularly if it now acts to reduce diversity in existing services as well, threatens to remove those options.

It is clear is that providers must show evidence that their proposed or existing services can deliver person-centred care, real choice and independence for people. That is inherent in the Fundamental Standards that all providers must meet. However, there are a wide variety of service models currently in operation, which the CQC have rated 'Good' or 'Outstanding' for many years. These providers may well be confident that they could provide evidence of positive outcomes for people. The concern is that the CQC have not been sufficiently open to considering that evidence for new services previously and may take the same approach to new and existing providers under 'Right Support, Right Care. Right Culture'.

Perhaps the pessimism expressed by some is misplaced – the 'clarification' of this guidance may lead inspectors to take at least a subtly different approach allowing a balance to be struck. However, we can see little in the guidance that suggests this. If anything, it is even less equivocal than the previous version. The CQC has repeated its existing commitment not to stick dogmatically to a limit of six beds per service but it offers no such reassurance in relation to more remote service locations even where access to local communities may be facilitated in other ways.

Supply of community placements

When 'Registering the Right Support' was published in 2017 it spoke of an estimated need for 2,400 additional community placements by March 2019. In October 2019, the Government said that 2,250 in-patients should have discharge reviews within twelve months.

Under-supply of services is not the only barrier to discharges but it is widely acknowledged as a major one, particularly given the need for placements to be available in a person's local area close to friends and family.

Equally, the difficulties in registering new services is not the only cause of under-supply. As with all areas of social care, funding is tight. However, at least some of the new or expanded services that the CQC have refused to register in recent years have had commissioner support. This runs contrary to one CQC argument that there is only a 'need' for services that conform to their preferred model, as commissioners will apply the same guidance as they do in choosing which services to commission.

It is not that many providers are resistant to opening services based on the CQC guidance. Some do believe that the specific people they care for require something different but for many it is simply a case of trying to find a solution that delivers the same outcomes but is also economically viable.

The CQC may well take the position that it is not their role to address all of the problems facing the system, only to regulate the quality of services by applying the guidance available to them at the time. However, those that hoped that the revised guidance would at least form part of the solution may be disappointed.

Providers' thoughts

After the publication of the guidance we sought the view of two leaders in the sector. Paul de Savary is the Managing Director of Home From Home Care, a provider of care homes in Lincolnshire for adults with special needs, learning disabilities, autism and other specialist care needs. His organisation prides itself on innovation and high-quality services, with nine of their eleven services rated 'Outstanding' by CQC. He shared his thoughts on the revised guidance:

“Appallingly, CQC’s Right Support, Right Care, Right Culture (“RRR”) ramps up discrimination against individuals with autism by continuing to treat them as a single cohort to be corralled into an ever narrower model of care. Promising the earth, the model has already failed to deliver for 2,000+ individuals incarcerated in Assessment and Treatment Units (“ATUs”), so it beggars belief that RRR’s dogma excludes input from best practice residential providers rated Outstanding or indeed from its own common sense inspectors.

RRR fails to factor operational realities, fundamental changes to property (single person apartments in place of beds), or data driven care that creates extraordinarily person centred care, transparency and real time accountability. Registering the Right Support and now RRR strangles innovation, yet ask Matt Hancock – New Models of Care are the only way forward. RRR’s dogmatic approach will inescapably prolong incarceration of individuals inappropriately condemned to an ATU and cost the taxpayer more – just as RRS before it. So where’s the learning?”

We also spoke with Dawn Berry, Chief Executive Officer of Eden Futures, to get the perspective of a leading provider of learning disability and autism services in people’s own homes. Again, Eden Futures has an enviable record of providing high-quality, person-centred care recognised by the CQC. She told us:

“The question has to be asked whether the greatest risks to high quality, person-centred care really arise from the models of delivery. There is a much wider picture to be considered. Social care funding levels limit the number of staff and the wages that can be paid by community providers to attract and retain the best people and expertise to work in the sector. Some of the worst examples of closed cultures and poor care have taken too long to come to light or have simply not been picked up by CQC inspectors. Resolving those issues is likely to do more to protect people than any controls on registration. There must be a place for a really good mix of learning disability and autism services, as varied as the people they care for. The CQC’s aspiration to register services based on need is a positive one but are they sufficiently well-equipped to understand those people’s needs where they are complex?”

So how did we get here?

‘Right Support, Right Care, Right Culture’ ultimately stems from the ‘Transforming Care’ services model, published by the Department of Health and Social Care in 2012 following the events at Winterbourne View hospital ATU, where a culture of abuse was revealed in a 2011 Panorama documentary.

The aim of the Transforming Care agenda is that fewer people will need to go into hospital for their care, resulting in the closure of hundreds of hospital beds across England. This is to be achieved by making sure that services in the community are much better. For people who do need to go into hospital the aim is to make sure that they are as close to where they live as possible.

Both iterations of the CQC’s guidance are designed to work alongside the Transforming Care programme to ensure that the large number of additional community placements that were (and still are) required “meet the needs and experiences of people with a learning disability and/or autism.”

The current state of learning disability and autism services in England

2019 and 2020 have been eventful years in this part of the sector. In May 2019, Panorama revealed abuse at Whorlton Hall hospital ATU that bore tragic similarities to Winterbourne View eight years on. This drew apologies from both the Government and the CQC. It also prompted a new impetus from Government, CQC and others to address long-term problems in the sector.

For its part, the CQC commissioned two reviews of its regulation of Whorlton Hall, which have formed the basis for a program to address closed cultures including revised guidance for inspectors. A review is ongoing into the use of segregation at in-patient learning disability and autism services. Its interim report highlighted continuing issues of placements far from home and a lack of discharge plans, both exacerbated by a lack of community placements. It concluded that “[T]he ‘current system of care ... has failed people whose care pathway has ended with them being segregated in a hospital. The system is not fit for purpose.”

In 2019 an expert panel was put together to inform that review. It was spelled out from the outset that the panel’s purpose was not to recommend changes to existing guidance, including Registering the Right Support. However, its recommendations did include encouraging those planning discharges into the community to be more innovative rather than looking for the ‘perfect’ solution.

In late 2019 the Joint Committee on Human Rights published a scathing report on the detention of young people with learning disabilities and/or autism, strongly criticising the CQC and stating that they had no confidence that targets to reduce hospital admissions would be met. They too identified a lack of high-quality community placements as a key barrier.

In response the Government announced in November 2019 its intention to greatly accelerate the discharge of people into the community with all learning disability and autism in-patients to receive discharge reviews by November 2020 and a reduction of around 400 placements by March 2020.

In February 2020, the Equality and Human Rights Commission threatened the Government with legal action arguing that the Government has breached the European Convention of Human Rights by failing to meet the targets set in the Transforming Care program and Building the Right Support program, including moving patients from inappropriate inpatient care to community-based settings, and reducing the reliance on inpatient care. They went on to say that they were not satisfied that new deadlines set in the NHS Long Term Plan and Planning Guidance will be met.

In June 2020, the Joint Committee on Human Rights revisited these issues when considering Coronavirus and the Human Rights of young people who are autistic or have learning disabilities and are detained in hospitals. This report identified the fact that impacts of inappropriately in-patient placements have been exacerbated by the responses to the pandemic. It also said that, even before coronavirus, the Government's plan to move people from hospital to live in the community was not working.

Previous challenges to the CQC

There have been a number of appeals against CQC decisions under the previous guidance. It is impossible to know how many were resolved before final hearings. Anecdotally, we are aware that there have been examples of the CQC being persuaded to change its decisions. However, of the small number for which judgments are available, we are aware of only one that resulted in the CQC decision being overturned. This is perhaps unsurprising, given that Registering the Right Support's status as statutory guidance means that it must be 'taken into account' in the making of any CQC decision, and by extension in any appeal.

Nonetheless, Centurion Health Care's successful appeal may give a vision of how a well-prepared application and appeal may persuade a Tribunal. The CQC were found to have failed to consider that application holistically, including the track record of the provider and the specific characteristics of the people the service was designed for. The Tribunal held that whether there was a local need for services was a matter of fact and not theory and observed that some people needing support may prefer more isolated locations, particularly where the service offered support to travel to local communities. They specifically disapproved of a 'one size fits all' approach.

There is a concern that the CQC's new guidance is designed as much to render appeals like Centurion's more difficult to bring as it is to address any concerns that have been raised by providers. The removal of some of the phrases seized upon by the Tribunal, including the specific promise of no 'one size fits all' approach, may suggest that those concerns have some foundation.

So what next?

For providers looking to design or expand learning disability and autism services, we continue to strongly advise the most thorough of preparation. Engage closely with commissioners, local Transforming Care Partnerships and/or NHS England before approaching the CQC for early registration advice. Where relevant, detailed consultation with people already using the service and their families is vital. Where you have a track record of providing good outcomes, make sure that you can demonstrate this clearly.

We will continue to provide updates on how the CQC implements Right Support, Right Care, Right Culture and on any challenges to its decisions that attract Tribunal decisions. If you are considering an application, do get in touch to see if Browne Jacobson can help you build the most compelling case.

In the meantime, the focus for increasing the availability of community placements turns to funding solutions, encouraging sector investment and, perhaps, to the longer-term prospect of changing the guidance on which the CQC's approach is based.

Contact

Carl May-Smith

Barrister (Partner)

carl.may-smith@brownejacobson.com

+44 (0)115 934 2024

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