Winterbourne View – time for change

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Summary

This report, commissioned by NHS England, makes a number of recommendations for how national and local organisations can work together to fulfil the government’s pledge that people with learning disabilities and/or autism and behaviour that challenges should not be inappropriately placed in hospital.

The target for achieving this by June 2014 was missed, and the report concludes that the reason why progress has been slow is not because people don’t know what needs to be done, but that systems make it hard for them to do it.

The report make a number of recommendations including:

- a charter of rights
- a mandatory commissioning framework
- closing institutions and building community capacity
- holding people to account.

LGiU associates Christine Heron and Fiona Campbell were recently commissioned by the Winterbourne View Joint Improvement Programme to write case studies of areas that had been successful in improving services. The perspective from compiling these case studies will inform this policy briefing.

Briefing in full

Background

Following the Winterbourne View abuse scandal, the Government made a pledge that people with learning disabilities and/or autism with behaviour that challenges who were inappropriately placed in hospital would be supported to move to community settings by June 2014. A large number of partners, including NHS England and the LGA, signed a Concordat committing to the pledge.
Not only was the target missed, but the number of people admitted to inpatient care in the year between September 2013 and September 2014 was greater than those discharged. In light of this, Sir Stephen Bubb, Chief Executive of the Association of Chief Executives of Voluntary Organisations (ACEVO), was asked by NHS England Chief Executive Simon Stevens to make recommendations for a national commissioning framework under which local commissioners would secure community-based support.

Bubb was supported by a steering group which included representation from NHS England, the CQC, the Department of Health, the Association of Directors of Adult Social Services (ADASS), and national organisations such as Mencap, the National Autistic Society and the Challenging Behaviour Foundation. The group decided to widen its remit beyond commissioning to include other action that would result in improvements on a national and local basis, such as a stronger rights framework.

The report does not provide a great deal of background information, so it is worth noting that people who fall within the criteria for the Winterbourne View programme have services commissioned either by CCGs or by NHS England specialised commissioning. This two-fold approach to commissioning has proved challenging for local areas, as will be discussed in this briefing.

The analysis

The review found that there is already a great deal of information about what constitutes good practice and what needs to be done to implement this. This includes the 2007 Mansell Report, and the reports produced as part of the Winterbourne View Joint Improvement Programme (JIP).

Good practice involves:
- highly personalised support, provided across the lifecourse, and designed with people with learning disabilities/autism and their families
- multi-disciplinary teams and care coordinators
- support for families, including short breaks
- independent advocacy
- crisis support when needed
- access to housing, education, work and meaningful activity
- staff trained in positive behavioural support
- inpatient care only when strictly necessary and as local as possible.

Good practice in commissioning involves:
- pooled budgets and joint commissioning
- strong local leadership
- joint strategic plans to commission a range of personalised health, care and housing services
- provider and workforce development.

The report indicates that the reason why progress has been slow is not because people don’t know what needs to be done, but that systems have made it hard for
them to do this. Areas that are getting it right are doing so in spite of the system, rather than because of it. The report considers how particular parts of the system may involve barriers.

Clinicians

Many clinicians were worried that the community support offered to people they were expected to discharge was inadequate, and could result in placement breakdown and readmission. Also, many clinicians work for providers that are financially incentivised to keep beds full. Clinicians are being asked to discharge people ‘when the people who have the expertise to suggest to them realistic community based alternatives are often unable to because they lack access to information about the individual’s needs’. It is not exactly clear what this means, but presumably it applies to people commissioned by NHS England where information has not been shared with local commissioners because of concerns about data protection. The failure to share data and work together, leading to many local authorities not having access to information about people from their areas, is one of the most frustrating aspects of the slow progress on Winterbourne View discharge.

Providers

Providers are asked to invest in community based capacity, such as staff training and accommodation, many months in advance of the new clients who would bring the income to pay for the investment. They may also not be confident that the behaviour of commissioners and clinicians will lead to predictable revenue streams. Many providers do not have the capital to make such investments.

People with learning disabilities/autism and their families

Service users and families are being asked to play a central role, but getting involved can be an ‘exhausting battle against the system’. Many others still do not know their rights, and do not have the support to express their views.

Frontline staff

Staff are asked to take on new practices such as using positive behaviour support, but often without enough support or training because the organisations they work for are not incentivised to make this a priority.

Commissioners

Commissioners are expected to collaborate and take risks across organisational boundaries to transform ‘a highly complex system’. Particular problems identified include:

- limited time and capacity to tackle the issues
- lack of expert support
- disputes about who pays and who is responsible
• lack of backing from local leaders to drive change and negotiate compromises between different organisational interests
• weak accountability and insufficient challenge
• lack of pooled budgets
• beds are already paid for through block contracts and may feel like the safe option.

Other systemic barriers include inconsistent application of rules around continuing healthcare funding, ordinary residence rules and NHS responsible commissioner rules, and difficulties engaging with specialist, secure (forensic) commissioners.

Conclusions and recommendations

The report indicates that its aims are to make it easier or mandatory for commissioners to make progress, and to make it ‘harder or impossible’ to maintain the status quo. While the focus on people who are already inpatients is necessary, attention also needs to be given to the large number of people, perhaps 24,000, who are in danger of requiring hospital admission in future.

The recommendations are aimed at improving leadership and empowering individuals and their families. The report makes the point that NHS England and partners need to act quickly, but with a realistic timeline so that they do not promise another ‘false dawn’.

Strengthening rights

• The government should draw up a Charter of Rights for people with learning disabilities/autism and their families to underpin all commissioning.
• The Government should respond to the Bradley Report Five Years On (better treatment in the criminal justice system).
• People should have a ‘right to challenge’ decisions to admit them or continue keeping them in inpatient care, and be supported to exercise this right by independent advocacy.
• NHS England should extend the right to have a personal health budget (or personal health budget) to more people with learning disabilities/autism, e.g. those on the Care Programme Approach.
• The Government should explore how to protect people’s tenancies so they do not lose their home if admitted to hospital.

National commissioning framework

• The Government and NHS England should require all local commissioners to follow a mandatory commissioning framework.
• Funding and responsibility should be devolved as far as possible from NHS specialised commissioning to CCGs.
• The mandatory framework would require pooled funding of health, social care and housing budgets and long-term spending plans to build up community
services. Contracts should incentivise providers to discharge people at the earliest, safe opportunity.

- There should be a named lead commissioner in each area, working with a provider forum, service users and carers.
- Community-based providers should be given a right to propose alternatives to inpatient care
- The DH, NHS England and the LGA should support local commissioners and assure their commissioning plans, and ‘unblock systemic barriers’ such as ordinary residence rules and eligibility for continuing healthcare.

Closure of inpatient institutions

A programme of decommissioning ‘inappropriate institutional inpatient facilities’ should take place, with local closure plans and closures by NHS England where it is the lead commissioner. The CQC should operate a tougher regulatory regime, including ensuring that hospitals are not just ‘rebadged’ as care homes.

Build capacity in the community

- Workforce bodies should establish a national workforce academy for this area of work.
- A ‘life in the community’ social investment fund should be established to build community capacity, seeded with £30 million from central funding, which would leverage £200 million from other investors. The Government should also look at funding regimes to stimulate capacity such as a ‘payment for outcomes’ fund, and a ‘linked social property’ fund.

Holding people to account

There should be improved collection and publication of performance data and a monitoring framework to hold national and local commissioners to account. Local commissioners would answer to local people, e.g. through learning disability partnership boards, and to NHS England. National bodies would answer to existing governance structures such as the Transforming Care Assurance Board.

Reaction to the report

NHS England has said that it will make a detailed response in the new year, alongside other organisations responsible for action identified in the recommendations.

Care Minister Norman Lamb has said that the government will publish a Green Paper on options for legislative change to speed up the delivery of Winterbourne View commitments early in 2015. This is likely to include examining how people can have the right to challenge decisions about their care.

Developments since the report
While the June target was not met, NHS England figures for September show a clear improvement. Of 2600 inpatients, 1680 now have a date for discharge – up from 577 in June. 922 of these are due to move in a year, more than double the numbers from June. Of the 920 people without a discharge date, 691 were clinically assessed as not yet ready, down from 1614 in June. 54 percent of inpatients are in secure beds, with the rest in a mix of acute admission, rehabilitation, continuing healthcare or specialist beds. In less positive news, 404 people were admitted to hospital since June, and only 323 were discharged.

Comments

Winterbourne View was a scandal of abuse, but it also revealed a scandal of bad practice on a massive scale. There are many examples of how getting things wrong can have a devastating impact on individuals and families. Take the example of a young man who began to struggle in a previously successful community setting. Instead of intensive, in situ positive behaviour support he was taken to an out of area hospital – an unfamiliar environment filled with strangers, where, predictably, his behaviour escalated, with none of the clinical staff realising the impact of the placement.

The pledge to turn things around by June 2014 was sincere and well intentioned, but the timescale was hugely optimistic and the complexity of the problems and how progress could be measured were vastly underestimated, particularly at a time when key organisations were newly formed.

Few people would argue with the direction of this report. However, many stakeholders believe that it is short on detail and provides insufficient information about how the recommendations would work in practice. A similar point can be made about the report’s analysis which identifies the right points but often in a non specific way. For example, more detail on how policies such as ordinary residence are hampering progress would have been helpful. Also, what counts as ‘inappropriate’ inpatient care, and how can greater consistency in clinician assessment be achieved. The area of assuring commissioning plans is also not worked through. If specialised commissioning is devolved to CCGs then NHS England has a legitimate role in assurance, but is it realistic to suggest that learning disability partnership boards can really hold local partners to account?

Unless these and other problematic areas are addressed, it is doubtful that a mandatory commissioning framework will secure the step change needed.

However, the figures are now improving, and some areas are making excellent progress. Having written a number of case studies on areas that had successfully implemented their Winterbourne View programme, the common factor was senior leadership commitment from the local council and CCGs. In some areas this had been a priority for many years, and a range of support was in place so that the levels of people who fell under the Winterbourne View programme were low. Other areas
had made a concerted effort and were rapidly developing support, particularly housing options.

An effective way of encouraging progress could be for local leaders to hear the stories of people who have been inappropriately placed or held for too long in inpatient settings far from their homes.

Related policy briefings

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