
TIME IS RUNNING OUT

A consultation for Sir Stephen Bubb's independent review of the Transforming Care programme for services for people with learning disabilities and/or autism

October 2015

Introduction

In 2014, Sir Stephen Bubb, chief executive of the charity leaders network ACEVO, was asked to chair a steering group to make recommendations for improving the way services for people with learning disabilities and/or autism is designed, commissioned and provided.

The steering group's report – *Winterbourne View – Time for Change* – outlined a roadmap for action:

- A closure programme for inpatient care institutions;
- A Charter of Rights for people with learning disabilities and/or autism and their families which is a clear and universally accessible document that clarifies the rights people already have, and outlines the support they have access to for using them;
- A new 'right to challenge' for people with learning disabilities and their families, which would give people and their families the right to challenge any decision that is made to change or continue a form of care;
- The right to request a personal budget;
- A mandatory framework for local decision-makers to follow that sets out who is responsible for which services and how they will be held to account;
- Improved data collection and publication, including key indicators such as admission rates, length of stay, and delayed transfers;

- Improved training and education for NHS, local government and provider staff;
- Investment to build capacity in community-based services.

After this report was published the Transforming Care programme was set up to pursue wide-ranging improvements to the care for people with learning disabilities and/or autism. This programme is made up of Association of Directors of Adult Social Services; The Care Quality Commission; The Department of Health; Health Education England; Local Government Association; NHS England.

In July 2015 Sir Stephen Bubb published a 6 month independent review of the Transforming Care programme – *Winterbourne View – Time is Running Out*. This made two particular arguments:

- A lack of communication from the Transforming Care partners is preventing local commissioners and providers from readying themselves for change, or even being aware that they will be expected to respond to a new service model.
- The Transforming Care programme has not yet delivered anything tangible in terms of new community facilities or closures. This is a concern because robust community provision will not appear overnight, yet the closure of institutions can only happen when there are sustainable alternatives built up by commissioners and providers.

Progress so far

In February 2015 Simon Stevens, CEO of NHS England, made a commitment to the Public Accounts Committee to announce a closure programme this autumn. This will draw from the five 'fast track sites' that have been established by the Transforming Care programme. These regional areas will receive support from the programme to draw up 'local transformation' plans for services for people with learning disabilities and/or autism. This includes re-designing services so that more people are able to receive care and support in the community, preventing admissions to hospitals and increasing the number of discharges from inpatient settings.

The five areas are – Greater Manchester and Lancashire; Cumbria and the North East; Arden; Herefordshire and Worcestershire; Nottinghamshire; and Hertfordshire. They have been selected for having a high number of people in hospital settings, and a variety of commissioning challenges. This will help the Transforming Care programme to develop a range of approaches across the country.

In June 2014, 2,600 people with learning disabilities and/or autism were in a hospital setting. In June 2015 this number was 2,500 people. This is according to the

data collected by NHS England, and then the Health and Social Care Information Centre.

NHS England has also established Care and Treatment Reviews which bring together commissioners, an independent clinician, an 'expert by experience,' and the individual receiving care. The stated aim of a Care and Treatment Review is to ensure that they are getting good and effective care and assessing whether their care and treatment could be provided in the community. This could provide a space for individuals to question and challenge the care that they are receiving.

Transforming Care has reported that over 1,700 reviews have taken place.

Questions

- 1. What do think about the Transforming Care strategy? How much progress do you think is being made to close institutions for people with learning disabilities and/or autism?**
- 2. What do you think of the pace of change that is being achieved?**
- 3. What more needs to be done, if anything, to make sure people with learning disabilities and/or autism have access to support in their community?**
- 4. What good practice exists already which could be scaled up to help move people out of hospitals into their community?**
- 5. What is your reaction to Sir Stephen Bubb's recommendations (please refer to those in the introduction)?**
- 6. Are Care and Treatment Reviews an effective way of making sure people can challenge their care, and request changes?**
- 7. What more needs to be done to make sure people and their families have access to the support and information they need?**

About this Consultation

This consultation looks to explore views on a range of recommendations. They are intended to strengthen or build upon existing proposals which have been set out in:

- [*Winterbourne View – Time for Change*](#) (2014)
- [*Winterbourne View – Time is Running Out*](#) (2015)

Who is this consultation for?

We are, in particular, seeking views from:

- People with learning disabilities, their families and carers;
- People with autism, their families and carers;
- Individual health and social care bodies responsible for the planning, commissioning and provision of services for people with learning disabilities and/or autism;
- Individual health and social care professionals;
- Representative local and national organisations for health and social care bodies or professionals;
- Any other party with an interest in improving the rights, health and wellbeing of people of all ages with learning disabilities and/or autism.

Consultation Period

This consultation will run until 27 November 2015.

This written consultation is accompanied by four meetings in November, where Sir Stephen Bubb will chair a discussion of all the issues raised. These will be in London, Leeds, and Manchester. If you would like more information about these meetings please include this in your response, or send a separate communication using the details below.

How to respond to this Consultation

You can respond to the consultation in the following ways:

By e-mail to: kate.brittain@acevo.org.uk

In writing to: Kate Brittain, ACEVO, Regents Wharf, 8 All Saints Street, London, N1 9RL

Responses

Responses to this consultation will inform the next report of Sir Stephen's independent review as we work to make sure transformation plans are learning from existing good practice, and focussing on the changes that need to happen. This means we can hold NHS England and its partners to account, and make genuinely innovative recommendations for how care can be designed and delivered.
