Winterbourne View
Time is Running Out

A six month progress report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb

July 2015
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Last year, the Government did not meet its promise to support everyone with a learning disability and/or autism wrongly placed in hospital to move to community-based support.

This was supposed to happen no later than 1st June 2014.

Because of this, NHS England made a plan to speed up change.
As part of this Sir Stephen Bubb, the chief executive of the charity leaders network ACEVO, was asked to give advice for a national plan for local commissioners so they could make sure community-based support can happen.

Sir Stephen chaired the Transforming Care and Commissioning Steering Group, made up of people from the third sector, NHS and local government.

During its work, the steering group was supported by other people, such as people with learning disabilities and/or autism and their families, commissioners, organisations who work with people with learning disabilities and/or autism, people who provide care and people who study and write.
The steering group’s report – Winterbourne View: Time for Change – was published in November 2014. It gave a plan for action:

- A plan for closing in-patient care institutions;
- A Charter of Rights for people with learning disabilities and/or autism and their families;
- A ‘right to challenge’ for people with learning disabilities and their families;
• A right to ask for a personal budget;

• A set of rules for local decision-makers to follow.

• Better information collection and sharing.

• Better training and education for NHS, local government and providers of care staff;
A shared reply to this report was made by the Transforming Care programme in *Transforming Care for People with Learning Disabilities – Next Steps*.

Sir Stephen is now looking at the work of the Transforming Care programme – to make sure enough action is being taken to improve the way services for people with learning disabilities and/or autism are given.

- Money to help set up better community-based services.
This report is Sir Stephen’s six month review. (review means looking again).

The steering group came back together on 6th July 2015, and is working with those partners that have taken responsibility for acting on the plans.

Each person involved has given an update on their work, for review by Sir Stephen and the group.

This report looks at those updates and will see where we are now and where we need to be.
Everything will be reviewed or looked at again in 12 months and will involve a wide group of people.

While making ideas and plans for how NHS England should work, it is clear that any plan must go together with action from others such as local government and care providers.

Also there needs to be a stronger rights framework for people with learning disabilities and/or autism, and their families and carers.
When Winterbourne View – Time for Change was published in November 2014, still more people with learning disabilities and/or autism were going into long stay hospitals than coming out.

The report laid out a clear plan of action – commissioners are able to choose care based in the community instead of hospitals.

Care providers work in partnership together with people with learning disabilities and/or autism and their families and are at the centre of planning the care that will best meet their needs.
And they can challenge it when it does not.

Some things have got better. The number of people coming out from institutions is now more than those going in.

NHS England has made it their most important aim to make the health of people with learning disabilities better.

They are doing this by putting in place new ways of working that give care for people in their communities rather than in hospital.
The Care Act is an important piece of law, and we have had a Green Paper from the Department of Health asking if and how government can keep safe the rights of people with learning disabilities and/or autism across health and care.

But, it is disappointing that changes are happening so slowly.

Even though this has been an important job for NHS England, the Transforming Care programme has not produced much that can be seen.
This is worrying because it takes time to put in place good services in the community. Institutions can only close when there are other care services available.

The Transforming Care partners promised to do a list of actions.

I asked that my steering group met in 6 months to look at how things have moved forward and that we look seriously at actions after 12 months.
So this report is a warning call – my steering group was clear on the changes that need to take place. Where good changes have been made, I see the success. Where nothing has happened, I will point this out as a serious problem.

The Transforming Care programme has been setting up some places where services are moved away from hospitals.

These will help to show a good example of how to do this across England.
Action is happening but there hasn’t been enough working together between the Transforming Care partners and local commissioners and care service providers.

This means they are not ready for the changes because they don’t know what to do.

That is why I have set up a Provider Delivery Taskforce, alongside the Voluntary Organisations Disability Group and Housing and Support Alliance.
This will work with good providers of community-based care to make sure they can be quick and active in getting people out of institutions.

Time for Change was clear that it is very important to make sure this care in the community is available.

But there has been no move forward. This is not good and will not help the work being done in other places to make a new model of care for people with learning disabilities and/or autism. What we need is joint action.
The call for urgent action is still there, and Transforming Care still needs to keep its’ promise to provide care outside of hospitals.

I want to thank all of my colleagues on the steering group, and all those I have met or spoken to.
Introduction

Summary of this report’s main criticisms and calls to action

There are two main criticisms:

1. Lack of leadership

2. No efforts to build up community-based care to cope with closures.

1. Not having strong leaders has meant that no one knows how the changes will happen.

People have been told changes are going to happen but care providers and local services don’t know what actions and responsibilities they will be taking on.
There needs to be more communication and working together to make the changes happen quickly.

The Transforming Care programme has moved forward to see what is needed and has made some plans but action needs to happen by everyone working together in a clear way.

2. There is a promise of closing hospitals but nothing has been done to make sure that services based in the community are ready to be able to care for the people who are coming out of the hospitals.
People who are leaving hospitals may end up back there because there is no other care available for them in the community.

This is not good because the number of people with learning disabilities needing community based care over the next 10 years will rise to between 37,000 and 52,000 by 2030.

A practical plan for building up community based care needs to take place together with the closing hospitals plan.
Key Recommendations

Strengthening Rights

This report suggests that the Government brings in new laws quickly after the Green Paper talks that ended in May.

A ‘right to challenge’ needs to be put in law, so that people and their families have the power to question the care they get.
‘The Bradley Report Five Years On’ made it clear that there are still things that need to be done for people with learning disabilities and/or autism in our courts and prisons.

This report calls again for a cross-government answer, from the Ministry of Justice to Department of Health.

Without this, people with learning disabilities and/or autism will not get the support they need at all stages of the criminal justice system.
This review calls for a plan for closing hospitals to be published in October 2015.

This will need to show strong leadership and set out a clear plan for the whole country.
Making sure community based care is ready

This report says that NHS England and its partners need to make a Transition Taskforce. This would include care providers, commissioners, people with learning disabilities and/or autism and families.

The Transition Taskforce would lead on the national plan for making more community care.

Time for Change called on NHS England and the Government to make a ‘Life in the Community Fund’ to help people move out of inpatient hospitals.
This report says that the Government needs to move quickly and help the community to prepare for caring for people by putting money where it is needed.

This report says that the Care Quality Commission (CQC) should look at the way of people are treated and think about banning physical control using things like the emergency response belt.

The Government must also help the CQC have powers to check the care provided to people with learning disabilities when they are cared for in supported living.

It is really important that people with learning disabilities and/or autism are given full protection.