Winterbourne View
Time for Change
Part one
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Foreword
After the Winterbourne View Scandal the Government said they would move all people with learning disabilities and/or autism, who should not have been placed in hospital, into Community Care by June 2014.

The Government didn’t do this and people are angry and frustrated.
Simon Stevens (CEO of NHS England) asked me (Sir Stephen Bubb) to make a plan to make sure people with learning disabilities and/or autism are moved out of institutions.

We need to make sure the right money and resources are in place in the community.

The families, individuals, health services, voluntary organisations and councils need to work together to make this happen.
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To help people live in the community and not in Institutions we need money to grow community services. We need to bring about change.

We need a strong **Charter of Rights** so that people with learning disabilities and/or autism feel empowered to demand change.

We want empowered people who have the right care and support e.g. personal budgets.

To help people live in the community and not in Institutions we need money to grow community services.
This money may come from a new fund called a ‘social finance fund’.

We hope that the Government and NHS England will start this fund.

The steering group for this report said that developing skills and a new workforce is important.
Long term care cannot be based in institutions.

Everyone must work together to bring about change.

We must close down institutions and stop bad care.

Long term care cannot be based in institutions.

This must happen alongside developing community facilities.
In 1851 a doctor called Samuel Gridley Howe wrote about how bad institutions are.

He said that we should have as few of them as possible. He said the human family is very important.

We must recognise this and close institutions.

Over the past years people with learning disabilities and/or autism have seen little action.
This report shows the plan for change.

The steering group will meet in 6 months time and again in 12 months time to review our progress.

I want to say thank you to the steering group and everyone who has been involved in this report.

Sir Stephen Bubb
About the Report
The report was produced by Sir Stephen Bubb after the Winterbourne View Scandal.

The report is about the plan to move people with learning disabilities and/or autism out of institutions into the community with support.
Sir Stephen was supported by a steering group of representatives from the voluntary sector, NHS England and local government.

The group included people with learning disabilities and their families members.

The group met with commissioners, academics, and providers.

The group said that help would be needed from local and central government, as well as NHS England.
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In the 21st Century people with learning disabilities and/or autism should not be living in institutions when they can live in the community.

Change needs to be led by government and the NHS – and also by empowered people with learning disabilities and/or autism.

People are angry and frustrated that the original pledge has not been met.

We need to act urgently but also not promise things that we cannot deliver.
The Problem
Some people with learning disabilities and/or autism will sometimes need to go to hospital.

But with better support in the community, fewer people would need to go to hospital.

When people do need to go to hospital, some of them stay in institutions for too long.
There are two steps:

1. We must make sure there is support in the community for people with learning disabilities and/or autism so they can be discharged from hospital quickly.

2. We must support people in the community so they are not sent away to hospital.

With the right support they could be discharged and live closer to their families.
People have been talking about these issues for a long time, you may ask ‘why has more not happened’?

• It's been too hard to do the right thing.

• And too easy to do wrong thing,
We want to make it easier to do the right thing, harder to do the wrong thing.

People with learning disabilities and/or autism should not have to live in institutions. Hospitals are not homes.

• We do not give enough power or support to the people who can make the change.

We want to empower and support people who want to make change.

We want to make it easier to do right thing, harder to do wrong thing.
We want to make it easier to do the right thing.

Please read Part Two to find out what we want to do.
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Time for Change

Part two - What We Want to Do
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What We Want to Do
Recommendations
The Government should create a Charter of Rights for people with learning disabilities and/or autism.

a) Strengthening Rights

- Charter of Rights

People with learning disabilities and/or autism often feel powerless.

People with learning disabilities and/or autism might not understand their rights. Sometimes their rights are ignored.

The Government should create a Charter of Rights for people with learning disabilities and/or autism.
Commissioners will have to make sure they follow the Charter of Rights and that these rights are respected when they choose what services to fund.

The Charter of Rights will clearly show the rights that people with learning disabilities and/or autism already have.

It will also tell people about the support they can use to access their rights.

Commissioners will have to make sure they follow the Charter of Rights and that these rights are respected when they choose what services to fund.

- Better treatment in the Criminal Justice System

People with learning disabilities face problems in the criminal justice system.
The government needs to make sure that the rights of people with learning disabilities and/or autism are respected in the Criminal Justice System.

- **The right to challenge decisions**

  People with learning disabilities and/or autism and their families should be able to challenge a decision to admit them to hospital, or to keep them there.

  Some people with disabilities may not feel able to challenge decisions about their care.
Community-based providers should be given a right to propose different options to care in a hospital.

Commissioners should also take responsibility for reviewing treatment and should be able to challenge admission to hospital.

**Personal budgets**

More people with disabilities should have the right to personal health budgets and the support to manage them.

This should include:

- People in hospitals or people who may be admitted to hospital.
People with learning disabilities and mental health needs.

Children and young people with learning disabilities and/or autism.

Protecting peoples’ homes

Some people with learning disabilities and/or autism who go into hospital are not able to keep their homes while they are away.

This can be very distressing for the person.
This also means that they will have to find a new home before they can come out of hospital.

The government should find ways of protecting the homes of people with learning disabilities and/or autism who are admitted to hospital.

This means they can go back to the same home when they are discharged, if they wish to.
b) Better Commissioning

Commissioning means spending money on services.

The Government and NHS England should make all local commissioners plan how to fund services in the same way.

Local commissioners should come together, share their funding and work together to improve community services.
There should be a lead commissioner in each area working with people with learning disabilities.

Community based providers should give options to people with learning disabilities who are in an institution, to help them come out of institutions.

Commissioners will have to make sure they follow the Charter of Rights and that these rights are respected when they choose what services to fund.
Commissioners should:

- Work together with people with learning disabilities and/or autism to make plans for services.

- Choose services that make information accessible and adaptable for different needs.
• Support independent advocacy services for people with learning disabilities.

• Offer personal health budgets.

• Make sure that people with learning disabilities and/or autism know their rights and how to access support.
People with learning disabilities, their families and carers must hold commissioners accountable for providing quality services.

• Provide support and options for people with disabilities to come out of institutions.

People with learning disabilities and/or autism should be employed in the health and social care system.

People with learning disabilities, their families and carers must hold commissioners accountable for providing quality services.
c) Closing Down Institutions

People with learning disabilities and/or autism, self-advocacy groups, families, and carers agree that we need a plan to close down some, if not all, institutions.

But people disagree on how fast this plan can be put in place and which institutions should be shut.
In the plan for closing down the institutions, we need to make sure that we do no harm.

People with learning disabilities and their families should take part in the planning.

NHS England should set a clear timeline for closing institutions.
We need to have high-quality, community-based support so that the institutions can be shut.

The Care Quality Commission (CQC) must get tough on registering institutions.
d) Stronger Community

Our plans rest on more high-quality community-based support services.

We need to develop the skills and expertise in the workforce.

This means care assistants, family carers, doctors and nurses, and commissioners.
Health Education England, Skills for Health and partners should develop a National Workforce Academy.

People with learning disabilities and/or autism should be employed in the Academy.

The Academy’s job would be to spread their expertise and knowledge of good practice across the workforce.

Money will be needed to help move people back into the community from institutions.

This will be called a social investment fund.
Money should be put into the fund from the Government and/or NHS England.
e) Holding Commissioners to Account

How well the plan is working should be made public and accessible so that everyone can see.

Information should be collected and then published locally and nationally.

Commissioners should have to explain to the public why things have gone wrong if the plan does not work.