



Department  
of Health



# Winterbourne View









## What we have done in 2014

### Easy read



This is an EasyRead version of  
Winterbourne View: Transforming Care -  
Two years on.  
**January 2015**

# What is in this booklet

	Page	
	<b>What this report is about</b>	<b>1</b>
	<b>1. The right care in the right place</b>	<b>6</b>
	<b>2. Making sure organisations own up</b>	<b>14</b>
	<b>3. Doing better checks</b>	<b>18</b>
	<b>4. Getting better quality and safe care</b>	<b>24</b>
	<b>5. Checking and reporting on how we are doing</b>	<b>31</b>
	<b>6. Children and young people</b>	<b>34</b>
	<b>7. And finally</b>	<b>38</b>

There are some words in this that can be hard to understand. They are printed in **bold**, then put in easy English on **page 39**.



Department  
of Health



Public Health  
England



# What this report is about

This is a report by the:

- Department of Health
- NHS England
- Local Government Association
- Care Quality Commission
- Health and Social Care Information Centre
- Public Health England
- Association of Directors of Adult Social Services.



What happened at Winterbourne View shocked us. We said it must not happen again.



We wrote a plan to change things called **Transforming Care**. This report looks at how we have done in 2014.



We have done some of the plan:

- we know how many people are in hospitals, and who is responsible for them



- we have new ways to make sure the services are good and safe



- we have new rules on using restraint. We are looking at how to get more information about when restraint is used



- we have new ways of checking hospitals for people with learning disabilities. The teams doing this include people with learning disabilities and their families



- the Care Act 2015 is a new law. It says how important good advocacy is to support people with worries about their care.



- there has been a change in leadership in NHS England since last April



But we have not done all of the plan which is not good enough.

It is taking more time than we thought.



People with challenging behaviour have different needs and are in different types of inpatient settings so we need to make sure the right decisions are made about how they are looked after.



The views of people with challenging behaviour, their families and carers are the most important thing.



In this report, when we talk about people with challenging behaviour, this means people with:

- learning disabilities



- autism



- mental health problems who might have behaviour that challenges.



We will keep working hard to make their lives better. We are involving people with challenging behaviour and their families much more.



This will help make sure people are not left in hospitals if they are better off in the community with the right support in place.



People should only be in hospital when it is the right care for them, and only stay there for as long as this is the case.



People with challenging behaviour all deserve a good life.



# 1. The right care in the right place

This means:



- the needs of people with challenging behaviour, their families and carers are met



- the services people with challenging behaviour get are what they need, not what other people think they should have

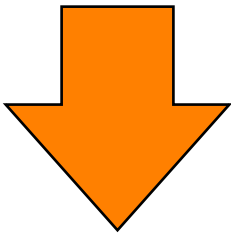


- the services provide lots of support and care for people with challenging behaviour



- people with challenging behaviour receive the support they need locally





We wanted less people with challenging behaviour to be living in hospitals by 1 June 2014.



We did not manage this. Some people were supported to leave hospital but other people keep being sent there.



Sometimes people need to be in hospital for a short time.



Some people are sent to hospital by courts or prisons. But not all of them need be there.



To bring down the number of people with challenging behaviour in hospital we have to:

- bring down the time they spend in hospital





- have better care for them in hospital and at home



- have a better life for them in hospital and at home.

We are working with lots of organisations to make this happen.



Department of Health

**NHS**



The Department of Health (DH) and NHS England had £7 million each in 2014 for people with challenging behaviour who do not need to be in hospital to support them to live in the community.



The DH's money is being used to support some people with challenging behaviour in different parts of the country to leave hospital with the support they need to live in the community.

# Getting Care and Treatment Right



NHS England set up a team called **Improving Lives** which has been checking on the lives of people who lived at Winterbourne View.



The team is made up of:

- health staff



- social care staff



- people with challenging behaviour



- families/carers of people with challenging behaviour



48 people lived at Winterbourne View at the time it was shut down. In June 2014, of these 48 people:

- 10 were still living in a hospital



- 20 were living in group homes



- 5 were in supported housing where they are the tenants



- 12 were living independently as tenants



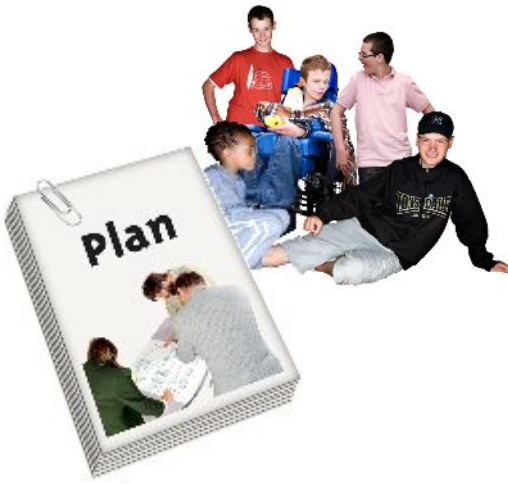
- 1 person had died.



NHS England thinks these checks are good. They are using what they have learned from these to set up 'Care and Treatment Reviews' for people with challenging behaviour who are in hospital.



NHS England is also doing some work to stop people with challenging behaviour being sent to hospital, if a review shows that they can live at home with the right support.



## Local planning and commissioning

Local areas must have plans to make sure future generations of people with challenging behaviour do not go to hospital.



Everyone must work together for this to happen. Some places have done a lot of work on this. But not everywhere.



There are some things that make this hard to do all over England. Some of this is to do with how we pay for a person's care when they move.

We are looking at better ways to do this.



In the person's home area they must work on plans for each person. People with challenging behaviour need good support in their community.

## Making sure people get their rights

People did not get their rights in Winterbourne View. We have been working to change this but we think more needs to be done to support people with challenging behaviour to:



- know their rights



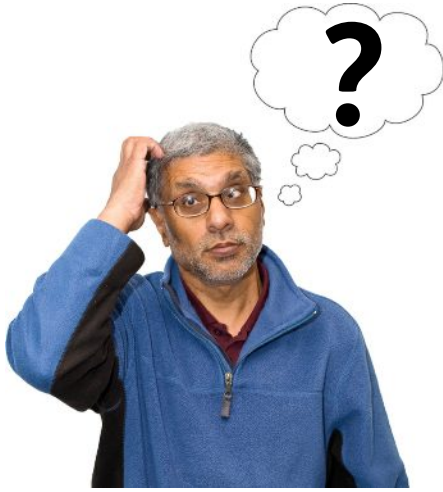
- use their rights



- have their rights respected.



We are looking at how we can make the rights people with challenging behaviour have stronger, if they need new rights and what else is needed to support people in using their rights.



## 2. Making sure organisations own up

When things go wrong, people with challenging behaviour and their families/carers often do not know who to blame.



It is important that services say when things go wrong.



There are two Government groups making sure the changes needed after Winterbourne View happen.



You can find the papers and minutes of the Transforming Care Assurance Board at <http://tinyurl.com/careboard>

And the Learning Disability Programme Board at <http://tinyurl.com/progboard>





There is a new rule for when things go wrong. Services must tell people and their families what has happened.



When they are not honest, the **Care Quality Commission (CQC)** can make them be honest. The CQC can make them keep to this rule.

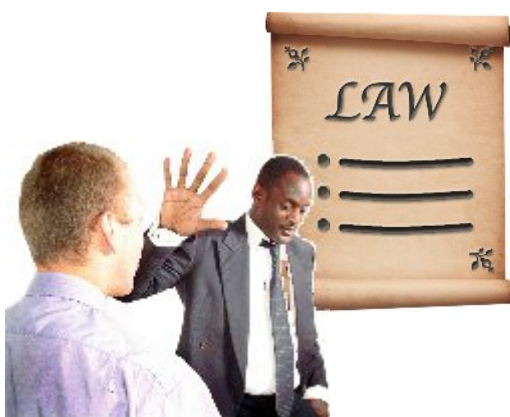


When new managers are employed the CQC can make sure they are up to the job.



## **What we still need to do about making sure organisations own up**

It is important that people who run health and care organisations are asked questions and responsible for when poor care has happened.



New laws have come in since November 2014 to help achieve this. There will also be new laws on **ill treatment and wilful neglect.**



## Quality of care and leadership boards

It is important that people who own or run health and care organisations are responsible for the quality and safety of the services they provide.



This covers:

- hiring people who work there in a safe way



- training people who work there



- clear instructions to people who work there



- making sure people have the information they need to make their own choices about their care



Disclosure &  
Barring Service

## Criminal checks

People who work in health and care organisations can now sign on with the **Disclosure and Barring Service (DBS)**.



This keeps their criminal checks up to date. When they move jobs the employer can check on them **using this**.



This is an easier way for people who work in health and care organisations to keep their criminal checks up to date.



It also helps people who own and run these organisations to check that they are not hiring people with a criminal past.

April 2014						
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### 3. Doing better checks

From April 2014 the CQC started new ways of checking hospitals for people with learning disabilities and specialist health services.



They decided on new ways to judge how well the hospitals are doing.



The CQC now says that all mental health hospitals are either:

- not good enough



- need to do better



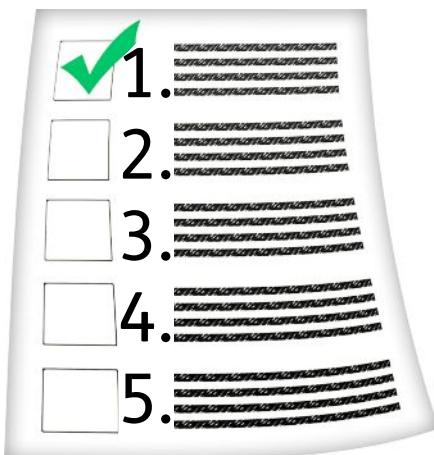
- good



- very good.



They decided on this with people with learning disabilities and their families, as well many kinds of people who work with people with challenging behaviour.



The CQC checks now have 5 main questions when they look at services.



These questions ask if the service is:

- safe



- doing a good job



- caring



- friendly and open to listening and changing



- led by good managers



The views of people with challenging behaviour, their families and carers are very important to all CQC checks.



The CQC has also worked with health and care staff, people who use services, families/carers and people who work at the CQC to produce information for checks on specialist health services for people with learning disabilities.



They might ask questions about:

- not allowing people to go out



- how they decide when a person is ready to leave hospital and what happens then



- how far people are from their home



- how their families are involved in decisions



- getting advocacy from outside the hospital.



The CQC can close a hospital where there is poor, unsafe care.





The CQC sometimes needs to share information with other organisations to stop the wrong organisations being able to provide care.



The CQC has taken action in 2014 with organisations which have not provided the right care in the right way:



- 141 actions were taken covering how people are hired in learning disability services



- 11 warnings were also made by the CQC.



## 4. Getting better quality and safe care

Organisations which provide health and care services have to make sure they provide good, safe care.



To help raise awareness, we have shared the best ways on working with people with challenging behaviour.

# NICE

National Institute for Health and Care Excellence

The National Institute for Health and Care Excellence (NICE) has written about good care for older people.

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NICE is now writing about:

- what they expect for people with learning disabilities and challenging behaviours. They will finish this in October 2015





- ways for staff to work with people with learning disabilities and challenging behaviours. They will finish this in May 2015



- ways for staff to work with people with learning disabilities who have mental health problems. They will finish this in September 2016.



## Improving safeguarding

A new law called the Care Act will start this April.

As well as doing lots of other things, it will make sure that more action is taken by the police, local authorities and NHS to protect people from abuse. Local authorities will need to make sure this happens.



## Mental Health laws

The CQC now checks that services are working to mental health law.



There is a proposed Code of Practice for the Mental Health Act 1983 which updates the old Code of Practice so that worries people have had about the Mental Health Act 1983 are picked up.



This includes a number of things like people and their families are part of all the decisions about their care and people are treated well and with respect.

## Positive Behavioural Support and restrictive practices



The DH produced new guidance in April 2014 to make it clear to staff that people with challenging behaviour should only be restrained when all other options have been taken, and only then for the shortest possible time.

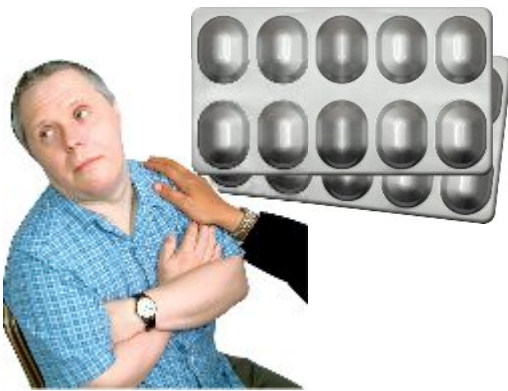


Other organisations also produced guidance on this topic.



At the moment, there is no data collected about how often restraint is used but we are working to make sure this happens and will report on this in Spring this year.

## Medicines

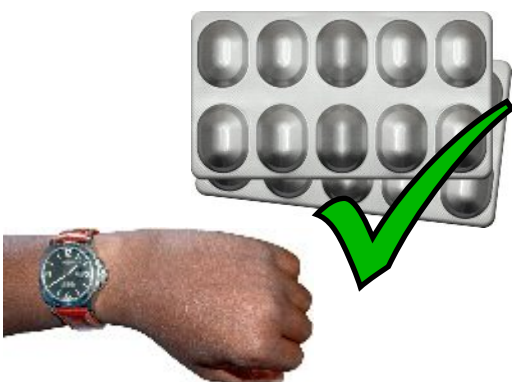


The Winterbourne Medicines Programme was set up in April 2014 and is looking at medicines for people with learning disabilities who have challenging behaviours.



They are making sure which medicine is:

- safe



- the right one at the right time



- the best for that person.



NHS England asked the CQC to do a check on medicines. Some medicines need two doctors to agree they are the right medicines.

CQC are checking when they are used.



NHS England wanted to know about medicines for mental health problems. They found out what medicines were given to people with learning disabilities by their doctor.



We will use this information to make sure the best medicines for people with challenging behaviour are used.



## Better information, advocacy and advice

**Advocacy** is very important. The DH is committed to working with **advocacy** groups to improve how they do their jobs.

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From April 2015 people will have to be given an advocate when:

- they find it hard to understand what is happening in planning their care
- there is no one else to support them



In 2014 there was a conference called 3 Lives. This was about 3 people with challenging behaviour who were let down by services.



One of the things they needed was legal advice. They did not get it. We are looking at what to do about this.



## Staff

At Winterbourne View the staff were not trained in how to support people with challenging behaviour.



From April 2015 there will be a new certificate for health and care support staff across England. This will help them to understand more about what good support looks like and how to give this.



We have also made courses that staff can do over the internet. The courses look at giving care that is:

- kind and thoughtful



- with good attitudes.



## 5. Checking and reporting how we are doing



We now know more about how many people with learning disabilities use health and care services. And we know more about what happens to them.



This information is called the Learning Disability Census. It helps us check how things are going.



We know how many people with learning disabilities:

- are in hospital



- have been in hospital for over a year



- have plans for them to move out of hospital



- have had advocates



- may be hurt by other people with learning disabilities



- may hurt themselves.



And also how medicine is being used.



Local partnership boards check how general hospitals are doing for people with learning disabilities.



This has been done well. But they do not know enough about how many people with learning disabilities:

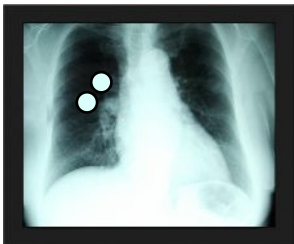
- use services like dentists and the eye hospital



- are in prison and what health needs they have



- have epilepsy



- have cancer



- have diabetes



- what people die from.



All this is very important. Sometimes poor health and pain can cause challenging behaviour.

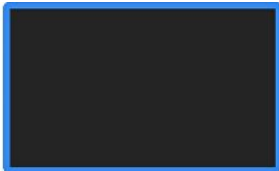


## 6. Children and young people

The right care for children and young people must take their age into account from when people with challenging behaviour are small and when young people with challenging behaviour move to adults services.



There is now a new way for planning for children with learning disabilities. Everyone involved with them needs to be part of this planning.



The plan will carry on until the young person is 25 and take in:

- education
- health





- social care.



The plan needs to make a real difference to the child's life. It is very important that the child and their family are involved.



## Mental health

NHS England looked at services for children with mental health problems. Sometimes children need quick help when their mental health suddenly gets very bad.



In some areas there are not enough places for children with emergency mental health problems.



Mental health care must carry on as children move to adult services. The young people must not be lost as they move. The Government has a group looking at how to do this well.



## Local areas

Children and young people with challenging behaviour must be included in local plans.



Work we are doing to make sure this happens includes:

- getting managers to think about how plans for a child need to carry on through life



- meetings to share good ideas



- making sure that services for children are included in all plans and checks



- supporting personal health budgets for children and young people who need a lot of care.



We know there will be more to do in future.

## 7. And finally



It is two years since the first Winterbourne View report. We have done some things. But not enough.



We must go faster. We need to make sure that people with challenging behaviour only go to hospital when they really need to.



That is why we are looking at whether the law needs changing.



We are also developing new plans working across all the different organisations involved.

We will keep a check that the plans work.



We will do everything with people with challenging behaviour and their families. They are the people who matter the most.



## Hard words

**Advocacy** is help to support you to get the care and support you need. An advocate will speak up for you.

**Care Quality Commission (CQC)** checks how good care is in hospitals and group homes.

**Commissioning** is planning and buying the services needed

**Disclosure and Barring Service (DBS)** checks if people have a criminal record. Can stop carers with criminal records working with people with learning disabilities.

**Ill treatment** is treating a person badly. For example not letting them go swimming when it is a treat.

**Personal budgets** is when money needed for a person's care is given to that person and their family. They spend it in the best possible way for the person.

**Wilful neglect** is ignoring what a person needs on purpose. For example not letting a person have a shower or bath.

The full version of this report has some stories from people, their families and carers. At the end of the report, it also says what has happened on all the actions from Transforming Care.



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Prepared by Inspired Services for Williams Lea