

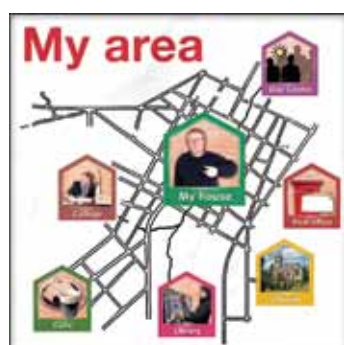
Hospitals are not homes

**Transforming Care. Better care
and support for people with learning
disabilities and autism in England
after Winterbourne View**

**An easy read booklet to help you check what is
happening in your local area to make things better**



What is in this booklet



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About this booklet



Who made this booklet?

We are called:

- The National Forum of People with Learning Disabilities
- and the National Valuing Families Forum



We are a group of people with learning disabilities and a group of families and carers.



We speak up for people with learning disabilities and their families to the government and others.



You can find out more about us on the National Forum website:

www.nationalforum.co.uk

And the National Valuing Families Forum's Facebook page.

About this booklet



Why we made this booklet

This booklet is about people who have learning disabilities or autism.

Some people may have both learning disabilities and autism.



Some people with learning disabilities or autism have to go to specialist hospitals.



Specialist hospitals are not like other hospitals.

They are for people who have behaviour that challenges or a mental health problem.



You can find out what this means on page 9.

One of these hospitals was called Winterbourne View.



There was a TV programme called Panorama.

It showed staff at Winterbourne View hurting people and treating them very badly.



Many people were upset and angry about this.



Winterbourne View closed down.

But there are still too many people in specialist hospitals and many people stay for longer than they need to.



There is work happening to look at how people with learning disabilities and autism get support. This is called Transforming Care.

To make sure this work happens a new plan was made in 2015. It is called **Building the Right Support**.

About this booklet



The plan says what local areas should do to:

- stop so many people being in specialist hospitals
- give people good support and services in their local area



It says local areas have to make a plan and work together in new ways to make the Transforming Care work happen.



There is an information guide to help local areas do this. This is called a service model.

It says what good services and support for people with behaviour that challenges should be like.



This work is about really changing things so that people get better care and support.



We really want this change to happen.

**But things are changing too slowly
at the moment.**

**So we made this booklet to show how
you can help change things as well.**



We want this booklet to help
lots of people be part of this work.



This means families, people with
learning disabilities and autism
and others.



This is because they know what
needs to change and have important
things to say.

It is important that everyone works
together on this.

About this booklet



This booklet will help you check how this work is going in your area.

It will tell you:

- what should be happening
- how you can help change things



There is also a longer booklet for people who want to know a lot more about this work.



It is on this website at:

<http://inclusionnorth.org/resources/information-packs/hospitals-not-homes/>

We hope you find this useful.

Thank you!



Karen, Craig and Kerry
from the National Forum of
People with Learning Disabilities

Vicki from the National Valuing Families
Forum



Things to remember

This booklet is not about all people with learning disabilities or autism.

It is about people who also have behaviour that challenges or a mental health problem.

This can be children or adults.

People who have behaviour that challenges.



This is when people may hurt themselves or others or damage things.

There are lots of reasons for this.

For example, people may find it hard to communicate. So it is their way of saying that something is not right for them.



People with a mental health problem may need support with the way they think and feel. For example, they may feel upset, scared or worried a lot.

Sometimes this may mean they have behaviour that challenges.

What should be happening in your local area

What should be happening in your local area



Some work called **Transforming Care** should be happening in your area.

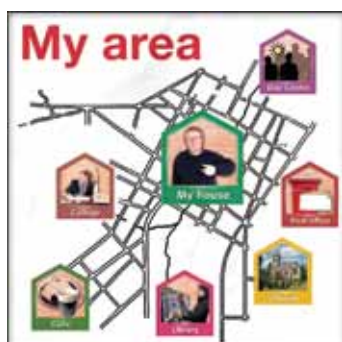
It is about really changing things for people.



What the Transforming Care work is about

It is about making sure:

- people only go to specialist hospitals if they really need to
- people do not stay in these hospitals for longer than they need to
- people can get better care and support in their community near their family and friends





- people get good care and support that is right for them
- people and their families are treated fairly and have more say about their care and support

The big things that should be happening



Local people should be working together to make the Transforming Care work happen.

This means people like the NHS, councils and others.

There are some things they should be doing.

For example, they should be making sure:

1. There is good information about the children and adults from your area in specialist hospitals.



Like how many people are in these hospitals and how far away they are.

What should be happening in your local area



2. There is a plan about the services people with behaviour that challenges or a mental health problem need and about moving people out of specialist hospitals.

Local people should work together on this.



They should make sure people can get the right health, care, support and housing in their local area.

People and their families should have a big say in this work.



3. People get good care in hospital and can leave as soon as possible

People in specialist hospitals should have:

- a plan for leaving the hospital (a discharge plan)
- a date when they should leave hospital (a transfer date)
- someone to work with them to make sure this happens (a care coordinator)





There should be meetings about the care and support people get.

They are called
Care and Treatment Reviews.

They look at:

- what care and support does someone need?
- do they really need to be in hospital?
- can they get care and support in their local area instead?



People in specialist hospitals can ask for this meeting if they are worried about their care.

4. People only go to specialist hospitals if they really need to

There should be a way to check if people can get the right care and support in their local area instead of hospital.

People should get support to stop them going into hospital in the first place.



What you can do to help

1. Write or speak to your local Health and Wellbeing Board



There is a Health and Wellbeing Board in every local area.



They plan how to make people's health and care better.



Local health and care people are part of this group.

They should know about the work in this booklet.



We have made a letter you can use to write to the Health and Wellbeing Board if you like. It is on page 18.

It has the main questions to ask them about how this work is going.

Or you can ask to speak to them.



2. Work with other people

There may be other people in your area who can help.



For example, there may be a group called a **Learning Disability Partnership Board**.

They work to make life better for people with learning disabilities.

There may be a group like this for people with autism too.



You could find out what they are doing and what you can do together.

What you can do to help

3. Share ideas and stories



You could help people share their stories.

This means people who have behaviour that challenges or a mental health problem and their families.



You could help them talk to health and care people doing the Transforming Care work.

They could tell the health and care people about their lives and what they need.

Your Health and Wellbeing Board may be able to help you with this.



4. Talk to your local Healthwatch

Healthwatch listen to what people say about their health and care services.

They make sure health and care groups hear what people have to say.

You can ask them what they can do to help.



How to find these people



1. Your local Health and Wellbeing Board

Look at the map on this website:
www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map



Click on the coloured dot near to where you live.

This will bring up information about the website for the Health and Wellbeing Board.

2. Learning Disability Partnership Boards



To see if there is a group like this in your area go to the website for your local council.

Type **learning disability partnership board** into the search box on the website.



3. Your local Healthwatch

To find your local Healthwatch group look at the map on this website:

www.healthwatch.co.uk/find-local-healthwatch

What you can do to help

The Letter

Date....

Dear (name of the
Health and Wellbeing Board)



I am writing to you about the
Transforming Care work you are doing.

This is the work that started after the
abuse of people with learning disabilities
at Winterbourne View hospital.



Transforming Care is about making
things better for people with learning
disabilities and autism who have
behaviour that challenges or a mental
health problem.

It is about:

- better care and support for people
in their local area so that less people
go to specialist hospitals





- people working together to move people from these hospitals back to their local area.



This is in a plan called
Building the Right Support.

It says local areas should be working together in new ways to make the Transforming Care work happen.



They should make a plan about what they will do by April 2016.

Please can you tell us what you are doing about this work.



We want to know:

1. Are there plans to get good health, care and support services for people in their local area?

Is there a plan we can see?



2. How many adults and children are in specialist hospitals in this area and in other areas?

What you can do to help

The Letter



3. Are you checking what happens to them?
4. How are you making sure people only go to these hospitals if they really need to?



5. Do people have **Care and Treatment Reviews** before they go to these hospitals?

This is to see if people can get care and support in their local area instead?

Is this helping people get care and support in their local area instead of hospital?



6. How many children and adults in these hospitals have:

- a plan about leaving (a discharge plan)
- a date for leaving (a transfer date)
- someone to help with this (a care coordinator)





7. How are you all working together to make sure people get good care and support now and in the future?



8. How are you making sure people and their families are part of this work?



Please give us this information in easy read or in an easy to understand way.

Thank you for your help.
We look forward to hearing from you.

Thank you

(your name or group)

What you can do to help

Checklist – the main things that should be happening



Local people are working together to plan good health, care, support and housing for people

☐

There is a plan about how this change will happen

☐

People are getting meetings called **Care and Treatment Reviews**

☐

There are good ways to stop people going to specialist hospitals unless they need to

☐

There is list called a **register** to help with this

☐

This is a list of people who may need to go to these hospitals. It can help staff make sure these people get the right care and support



People in these hospitals have a leaving plan and date

☐

People leave hospitals when they should

☐

People and their families have a say in what happens

☐

How to find out more



A plan called **Building the Right Support** tells you more about the work in this booklet.

It is on this website in easy read:



<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-net-plan-er.pdf>

There is a longer booklet like this. It is for people who want to know a lot more about this work.



You can find it on this website:

<http://inclusionnorth.org/resources/information-packs/hospitals-not-homes/>



You can also go to the website for the National Forum of People with Learning Disabilities

www.nationalforum.co.uk

Or the National Valuing Families Forum's Facebook page.



Thank you to everyone who helped write this booklet.



Pictures by Photosymbols and Crockstock images

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