

Hospitals are not homes

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

A booklet to help you check what is happening in your local area to make things better



Longer booklet

What is in this booklet



Part 1 About this booklet

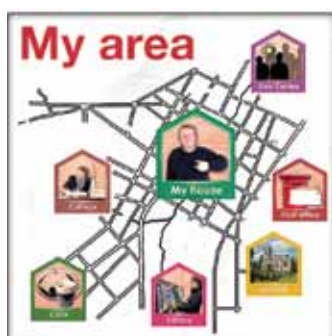
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Part 1 About this booklet



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.

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 12.



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.

Why we made this booklet



The government looked into what happened at Winterbourne View.



In 2012 they wrote a report called:
Transforming Care.

In 2015 another report came out to say that more needs to be done.

This is called:
Transforming Care for People with Learning Disabilities Next Steps.



The reports talk about really changing things so that people get better care and support.

For example, they talk about making sure:

- people do not have to go to specialist hospitals unless they really need to
- people get good care and support that is right for them in their local area instead





To make sure this happens, a new big plan was made in 2015.

It is called **Building the Right Support**.

It says what local areas should do to:



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



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

Local areas working together in this way will be called Transforming Care Partnerships.



There is an information guide called a Service Model to help local areas do this.

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

Why we made this booklet



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.



Everyone agrees that people who get health and care services or who know a lot about them should be part of this work.

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

We are working to change things.

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

Like families and people with learning disabilities and autism and others.



It is important that everyone works together on this.



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



It will tell you:

- what should be happening
- who to speak to
- what questions to ask



This booklet has lots of information in it. It is for people who want to know a lot about this work.

But there is a shorter booklet you can use instead if you want. It is on this website:

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

We hope you find it useful.

Thank you!



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

Vicki from the National Valuing Families
Forum

Why we made this booklet



Things to remember

This booklet is not about everyone with learning disabilities or autism.

It is about children and adults who have behaviour that challenges or a mental health problem.

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 or they need more support.

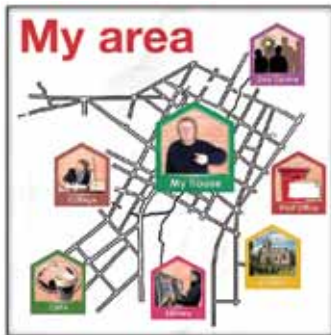


People with a mental health problem may need support with the way they think and feel.

For example, they may feel upset, scared or worried a lot. Sometimes this may mean they have behaviour that challenges.



Part 2 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.



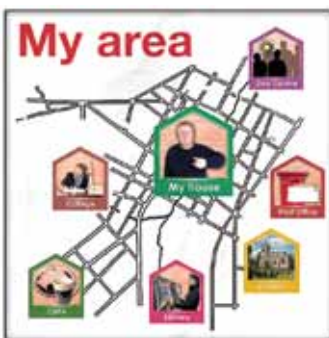
Some reports called **Transforming Care Next Steps** and **Building the Right Support** tell you more about this.

You can find out more about them on pages 45-46.

Now you can find out what the Transforming Care work is about.

Part 2 Your local area

What the Transforming Care work is about



The Transforming Care work 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 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 main people to speak to

Here are the main people to speak to about the Transforming Care work in your area.

1. The 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.



They bring together all the local people who work on health and care.

This is so they can work together and plan the right services.

Part 2 Your local area



The Health and Wellbeing Board has people like:

- doctors
- people who plan and pay for health and care services. They are called commissioners
- people from the council
- people from Healthwatch. See page 21 for more information about Healthwatch



healthwatch



2. Health and social care commissioners

They look at what health and care services people in their area need.

They plan and pay for these services.



There are different types of commissioners:

Social care commissioners



They are from the local council (also called the local authority).

They look at what care and support people need. Like support to live at home or go out and do things.

Health Commissioners



They are doctors and other health people.

They look at what health services people need.



They usually plan and pay for people to go to specialist hospitals.



Some of these people work in groups called **CCGs**. Or Clinical Commissioning Groups.

Part 2 Your local area



A group called **NHS England** also plans and pays for some people to go to specialist hospitals.



For example, they may do this for some people who are sent to hospital instead of prison.



They do this through teams of people called **specialised commissioning teams**.

How to contact your local Health and Wellbeing Board or CCG (Clinical Commissioning Group)



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 local:

- Health and Wellbeing Board
- CCG (Clinical Commissioning Group).



3. Learning Disability Partnership Boards

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



Lots of people are part of the Learning Disability Partnership Board, like:

- people with learning disabilities and their families
- people who plan health and care services. They are called commissioners
- groups that give people care and support

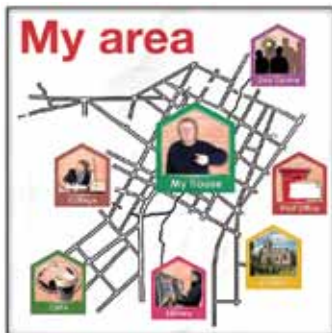


Some Learning Disability Partnership Boards work closely with the Health and Wellbeing Board.



There may be a group like this in your area for people with autism as well.

Part 2 Your local area



There is a Learning Disability Partnership Board in many local areas. But not in all areas any more.

To find out if there is one in your area go to the website for your local council.



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



4. Parent carer or family carer forums

They are parents and carers of children with a disability.



They work with groups like the council to make sure services are good enough.



This website has a list of groups:
http://www.cafamily.org.uk/media/841817/contact_lists_for_website_may_15.pdf



5. Local Healthwatch

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



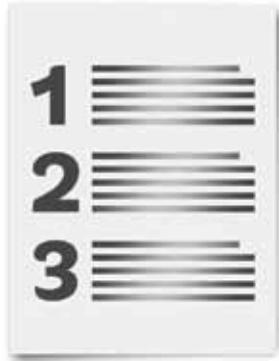
They make sure health and care groups hear what people have to say.

They are also part of the Health and Wellbeing Board.



To find your local Healthwatch group look at the map on this website:
www.healthwatch.co.uk/find-local-healthwatch

Part 3 What you can do



This part tells you:

- the big things that people in your area should be doing to make the Transforming Care work happen



- who you can talk to about each thing
- the main questions to ask



- what to do if you don't get good answers

You could speak to people about this or write them a letter.

We have made a letter to send to your Health and Wellbeing Board if you like.

It is on pages 52 to 55.





The big things that should be happening

1. Good information about people from your local area in specialist hospitals



There should be good information about:

- how many children and adults from your area are in these hospitals
- what hospitals they are in and how far away they are



Your local **health and social care commissioners** should have this information.

Part 3 What you can do

Who to speak to about this



Your Health and Wellbeing Board

Health and social care commissioners are part of this group.



Or you can go straight to the health and social care commissioners.

Or you can speak to these people. They work with the Health and Wellbeing board:

- Learning Disability Partnership Board
- Your local Healthwatch

healthwatch

You can find out who they are from pages 15 to 21.

What to ask

1. How many adults and children from this area are in specialist hospitals?

2. How many people are in specialist hospitals away from this area?

And how far away are they?



3. What is happening to bring these people back to their local area?

4. Why are these people in hospital in the first place?



Part 3 What you can do



The big things that should be happening

2. Local people working together to plan the right services for their community



Everyone with behaviour that challenges or a mental health problem should get good health, care and support in their local area.



They should get the right support for all of their life. Starting from when they are children.



Every local area should look at what services these people need and make sure they get them.

This means services like:

- health, care and support
- support to stop people going into hospital in the first place



It also means other things like housing.

There should be a plan about this.



Your local area should be working with other local areas to make the Transforming Care work happen.

They should make a big plan by April 2016 about what needs to change.



Your local area may also have its own local plan. It may be called a commissioning plan.

The plans should be about:

- making sure less people are in specialist hospitals
- making local services better



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



Your local **health and social care commissioners** should know about this work.

Part 3 What you can do

Who to speak to about this



Your Health and Wellbeing Board

Health and social care commissioners are part of this group.

Or you can go straight to the health and social care commissioners.



Or you can speak to these people. They work with the Health and Wellbeing Board:

- Learning Disability Partnership Board
- your local Healthwatch

healthwatch

You can find out who they are from pages 15 to 21.

What to ask

1. Is there a plan about good local services for people with behaviour that challenges or a mental health problem and about moving people out of specialist hospitals?
2. How are you making sure that the people who give care and support have the right skills and are giving people good care and support?
3. How are you making sure people get good support for all of their lives, starting from when they are children?
4. How are you making sure people with learning disabilities or autism and their families are part of this work?



Part 3 What you can do



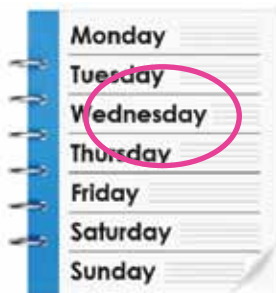
The big things that should be happening

3. Good care in hospital



People in specialist hospitals should have:

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



There should be meetings about the care people get in hospital.



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 the care and support they need in their community instead of in hospital?



People in specialist hospitals can ask for this Care and Treatment Review if they are worried about the care they are getting.



Lots of people should work with the person in hospital to make sure they get the right care and support when they leave.



This should include the people who are involved in the person's care and support after they leave hospital.

Part 3 What you can do



They should all work on:

- the person's plan for leaving hospital (discharge plan)



- the care and support they will get after they leave and their home where they will live

Who to speak to about this

Your Health and Wellbeing Board

Your local health and social care commissioners are part of this group.



Or you can go straight to the health and social care commissioners.



What to ask

1. Does everyone who is in specialist hospitals from our local area have:

- a plan and date for leaving hospital
- someone called a **care coordinator** to help them?

3. Are these Care and Treatment Reviews helping people leave hospital?



2. Are people getting the **Care and Treatment Reviews** they should get?

4. Who from our local area is working with the person in hospital to make sure they get good care and support when they leave?

Part 3 What you can do

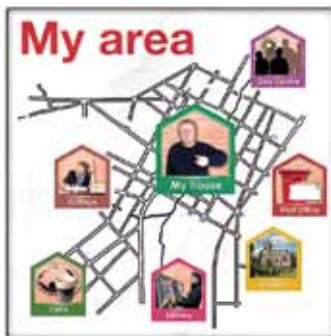


The big things that should be happening

4. Stopping people going into hospital if they don't need to



There should be a way to check if people can get the right care and support in their local area before they are sent to specialist hospitals.



People should only go to these hospitals if they cannot get the right care and support in their local area.



Health and social care commissioners should make plans about this.



They should have a list of people who may need to go to these hospitals.

This list is called a **register**.



They can use it to check if people:

- are getting good care and support
- need extra support now to stop them having to go to hospital later on



People who may have to go to specialist hospitals should also have meetings called Care and Treatment Reviews to check if they really need to go to hospital.



Local areas should use an information guide called the Service Model to make sure their local area has the right services and support for people.

Part 3 What you can do

Who to speak to about this

Your Health and Wellbeing Board

Health and social care commissioners are part of this group.



Or you can go straight to the Health and social care commissioners.



What to ask

1. How do you make sure people only go to specialist hospitals if they really need to?

3. Do you have a list of people who may need to go to these hospitals so you can check they get the right care and support?

The list is called a **register**.



2. Do people get **Care and Treatment Reviews** before they go to specialist hospitals to see what other care and support they can get?

4. How do you make sure people and their families have a say in what happens to them?

Part 3 What you can do



The big things that should be happening

5. Keeping people with learning disabilities and autism safe

Groups of people should be working to make sure:

- people with learning disabilities and autism are safe
- people don't hurt them and do bad things to them



These groups are called **Safeguarding Boards**.

Who to speak to about this



Speak to your local adult or children's Safeguarding Board.

You can find them by looking at the website for your local council.



Then type **safeguarding board** into the search box of the website.

Part 3 What you can do

What to ask

- 1.** What have you done to change things and keep people with learning disabilities and autism safe after what happened at Winterbourne View?
- 2.** How are you making sure that everyone whose job it is to keep people safe knows what they should be doing?
- 3.** How are you making sure that health and care staff work together and share information in the right way if they are worried someone may be unsafe?





What to do if you don't get good answers

healthwatch

1. You can speak to your local Healthwatch and ask what they can do to help you



2. You can work together with other groups of people with learning disabilities and autism in your area to see what they are doing and what you can do together



3. You can write to your local councillor.

They are people from your council.

They make big decisions about your area.

You could ask for their help with this work.



Part 3 What you can do



You can find your local councillor by looking at this website:

www.writetothem.com/

Type in your postcode to find your local councillors and their email addresses.

4. You could ask your MP for help

Your MP helps people in your local area.

They also speak up for people in your area to the government.



You can find your local MP by looking at this website:

findyourmp.parliament.uk/

Type your postcode into the search box.

Then click on **go**.



Part 4 Kayleigh's story



Kayleigh spent almost 10 years in Winterbourne View and other specialist hospitals.

They were far away from her family.



Kayleigh first went to a specialist hospital because the support she was getting in the community wasn't right for her and there was nowhere else for her to go.

It was very hard to get Kayleigh out of these hospitals once she was there.



There were many problems for Kayleigh, like:

- staff not listening to her family
- Kayleigh not being able to get the right support or housing near to where she lived
- plans not being made to move Kayleigh out of hospital as soon as possible and back to her home



Part 4 Kayleigh's story



Being in hospital made things much worse for Kayleigh.

She didn't want to be there and became very unhappy. Her behaviour changed because of this.



She tried to show how upset she was but this just made it harder to get her out of hospital.



But in 2014 her family were able to help Kayleigh buy her own home in an area that was right for her.

Kayleigh now gets support from staff who know what she needs.



Her life is much better now. She has more choices and she is learning new things and being part of the community.

Part 5 Extra information



This part has extra information.

It is there if you want to know more about what is happening in your local area.



Transforming Care and Transforming Care Next Steps.

These are reports about the work we talk about in this booklet.

You can look at these reports in easy read.



Transforming Care for People with Learning Disabilities Next Steps.

This is the main report to look at:
www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-easy-read.pdf



This one is not easy read:
www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-next-steps.pdf

Part 5 Extra information



Transforming Care

www.gov.uk/government/uploads/system/uploads/attachment_data/file/213216/easy-read-of-final-report.pdf



This one is not easy read:
www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf



Building the Right Support and the Service Model

Building the Right Support is a big plan about what local areas should do to stop so many people being in specialist hospitals and get good local services for people.



The Service Model is an information guide to help local areas do this. It says what good services and support should be like.



Building the Right support

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



This one is not easy read:
<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

The Service Model

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



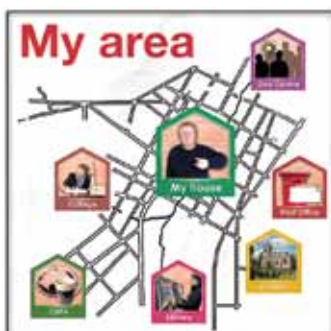
This one is not easy read:
<https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

Other plans and laws

1. The NHS Mandate.

This says that local areas should make sure:

- people with learning disabilities and autism get good care and support in their local area
- less people go to specialist hospitals
- people who provide health and care services need to work together on this



Part 5 Extra information



www.gov.uk/government/uploads/system/uploads/attachment_data/file/213132/ISL282-12-EasyRead-DH-Mandate-15Feb2013.pdf



This one is not easy read:
www.gov.uk/government/uploads/system/uploads/attachment_data/file/383495/2902896_DoH_Mandate_Accessible_v0.2.pdf



There are some other plans and laws you may want to look at:

- **The Health Education Mandate.** About better skills for health staff to work with people with learning disabilities and behaviour that challenges
- **The Adult Social Care and NHS Outcomes Framework.** The main things the government wants to happen with health and care
- **Valuing People Now.** The big government plan about people with learning disabilities
- **The Care Act law 2014.** It talks about giving people good care and support early on to stop problems happening later





- **Joint Health and Wellbeing Strategies**
A local plan about getting the right health and care services for people in the local area



- **The Joint Health and Social Care Learning Disability Self-Assessment Framework.** Where local areas have to say how they are doing on things to do with people with a learning disability



There is also some information about the people from your area in specialist hospitals.



The information looks at things like how many people from your area are in specialist hospitals.

It is called **Assuring Transformation Data**.



You can look at it on this website:

www.hscic.gov.uk/assuringtransformation

Part 6 Things to help you



On the next pages you can find:

- A form you can use to fill in the main people to speak to in your local area



- A letter you can use to send to your Health and Wellbeing Board



- A form about the Transforming Care work for your Learning Disability Partnership Board to fill in

- Some information about people in specialist hospitals in England at the moment



- A list of hard words and what they mean
- A checklist of the main things that should be happening

Part 6 Who to speak to form

| Group | Job title of person to speak to | Their name | Their contact details |
|--|--|-------------------|------------------------------|
| Health and Wellbeing Board | | | |
| Local council (care for adults) | | | |
| Local council (care for children) | | | |
| Local Healthwatch | | | |
| CCG (Clinical Commissioning Group) | | | |
| NHS England Specialised Commissioning | | | |

Part 6 Letter

Date....

Dear (name of the Chair 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 community

Part 6 Letter



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.



When they work together in this way it is called Transforming Care Partnerships.

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 would like 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?

3. Are you checking what happens to them?



Part 6 Letter



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)



Part 6 Letter



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)

Part 6 A form about the Transforming Care work for your Learning Disability Partnership Board to fill in

Name of area and date

The number of adults and children in specialist hospitals

Adults:

Children (under the age of 18):

The number of people in specialist hospitals that are out of this area

The number of people in specialist hospitals that have a leaving date (**transfer date**)

The number of people in specialist hospitals that have a plan about about leaving (**a discharge plan**)

Who is paying?

Number paid for by CCGs:

Number paid for by NHS England:



If you are part of a Learning Disability Partnership Board you can ask them to fill in this form each meeting with the latest information for your area.

Part 6 Some information about people in specialist hospitals in England at the moment



The number of adults and children in specialist hospitals in England:

(A small number of people may be in hospitals in other parts of the UK)



Total number of people: **2,595**

Number of adults: **2,435**



Number of children under 18: **160**



This information is called Assuring Transformation Data. It is right at this time (December 2015). But it will keep changing.

You can find out more about the Assuring Transformation Data on page 49.

Part 6 A list of hard words



| The word | What it means |
|---|--|
| Transforming Care | The work about better care and support for people with learning disabilities and autism who have behaviour that challenges or a mental health problem. |
| Transforming Care for People with Learning Disabilities Next Steps | A report about what still needs to be done for this. |
| Building the Right Support and the Service Model | A big plan and information guide about how local areas should be working together to make the Transforming Care work happen and what local services should be like. |
| Local Area | <p>This means the area that your local council gives people care and support.</p> <p>You can find your area on this website www.gov.uk/help-care-support</p> |
| Specialist Hospitals | They are hospitals for people who have behaviour that challenges or a mental health problem. Winterbourne View was a specialist hospital. They may also be called Assessment and Treatment Units. |

Part 6 A list of hard words



| The word | What it means |
|---|--|
| Care and Treatment Reviews (CTRs) | <p>Meetings with people in specialist hospitals or people who may go to one.</p> <p>The meetings look at:</p> <ul style="list-style-type: none">• what care and support someone needs• if they can get care and support in their local area instead |
| CCGs (Clinical Commissioning Groups) | <p>Groups of doctors who plan and get health services for people in their area.</p> |
| Health and Social Care Commissioners | <p>The people who plan and get health and care services for people in their area.</p> <p>They are people from CCGs, the council and NHS England.</p> |

Part 6 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 a 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

Part 6 Checklist



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

Part 6 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>



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 and people who shared their stories with us.



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Hospitals are not homes

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

A booklet to help you check what is happening in your local area to make things better



national forum
of people with
learning disabilities



Longer booklet