

A Trade in People: The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder

Easy Read Report



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This report looks at how people with learning disabilities get moved to hospitals or units that are far away from their homes. This harms people's connections with their home communities and their family relationships.

Summary

- The BBC showed how people with learning disabilities or Autism Spectrum Disorder (ASD) were abused at Winterbourne View.
- The government decided to close many long stay hospitals and move people to the community.
- In 2015, most people were still in hospital. Many private hospitals have been built.
- We found out that the government pay millions of pounds for people to stay in private hospitals. The hospitals make profits. We found that the hospitals are built where land is cheaper.
- We found that people are kept in hospital longer when there are more units in a place.
- We found that it is expensive for authorities to move people back home.
- We asked families what they think. They said that their sons or daughters were taken too far away from home. They said it was because of the cost. This caused them a lot of problems.
- Families said there is not enough local services or support.
- Their stories show how hard it is to get the right support.
- We think this is against human rights.

Contents

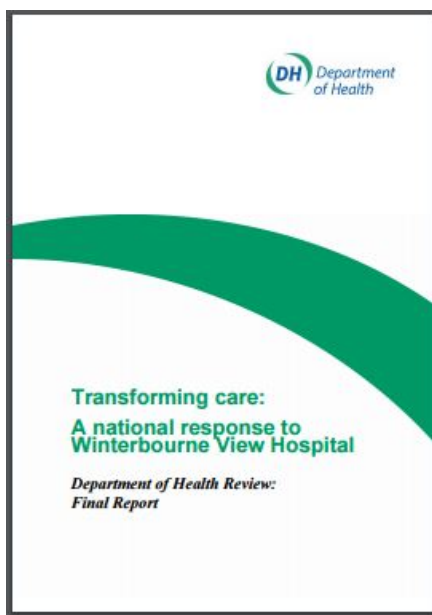
Introduction	4
How much money does it cost?	5
Inpatient rates.....	6
Length of Stay	6
Packages of Care	7
The experiences of people with learning disabilities and/or ASD.....	7
What do families think?	7
Distance from home.....	8
Money	8
Local Support	9
Conclusion	9

Introduction



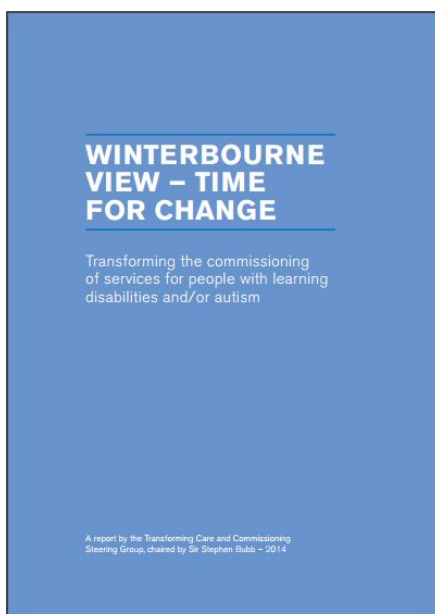
In 2011 a programme called **Undercover Care: The Abuse Exposed** was on the BBC. It showed staff abusing people with learning disabilities at Winterbourne View Hospital.

Some staff members were put in prison and the hospital was closed down.



People were angry about the abuse and the government wrote a report called **Transforming Care: A National Response to Winterbourne View Hospital** and made an action plan to get people out of units.

They wanted to find out how many people were in units because of challenging behaviour. They wanted people to have better plans and make units safer. They wanted to close down units and help people to move to the community.



In 2014 some parts of the action plan were done, but there were still many people in hospitals and units. Sir Stephen Bubb wanted to find out why.

He wrote a report called **Winterbourne View – Time for Change**. The report said that people with learning disabilities and their families should have more power and support.



The report made 11 suggestions, which were put into a plan called **Building the right support** in 2015. This was about starting good community services so people could move out of units. It set targets to cut down the amount of people in units by about half before 2019.

People who have been in hospital or units for more than 5 years should be moved to the community first, and the government will give money to help with the costs.



The **7 days of action** team put in a Freedom of Information request to NHS England to find out about Transforming Care Plans.

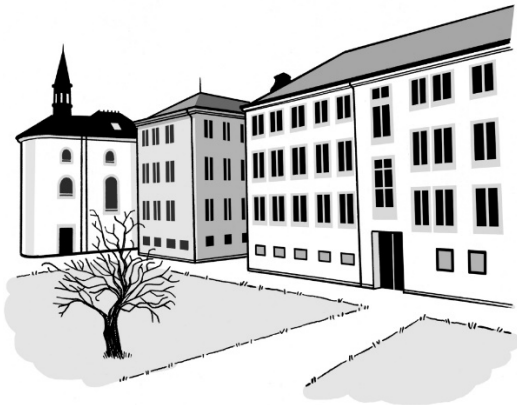
We asked the different areas how many people with learning disabilities were in hospital. We wanted to find out why some areas have more people than others.

How much money does it cost?



In 2015/16 **£ 477.4 million** was spent on keeping around 2,500 people with learning disabilities in units. About half of those units were NHS and the other half were private.

The number of units run by private businesses is going up all the time and they make a profit. The average person who has been in unit for 5 years will make nearly a million pounds in income for a private business.



People from all over the country are sent to live in these units. They should be near their families.

In this report, we look at reasons why units are in certain areas.

Inpatient rates



We looked at the **UK House Price Index**, and found that in areas where the inpatient rate is high house prices are lower. This shows that costs affect where units are built.

Length of Stay



We looked at how long people had been in hospital. People were more likely to stay longer in hospital if there were more hospitals in the area.

We found that people were more likely to be placed away from their family if there were less hospitals near their home. This shows that services are chosen because of cost rather than people's needs.

Packages of Care



Section 117 Packages of Care are given to a person going back to the community. They are expensive and authorities may put off people from going home because of the cost. The high costs might mean authorities send people to live in a different area.

This changed in April 2016. Now a person's home authority has to pay for their support when they leave units but decide to live in the area in which the unit is located. However, this does not apply to people who were detained in hospital before April 2016.

The experiences of people with learning disabilities and/or ASD



People in hospitals or ATUs are more likely to experience seclusion, accidents, assaults, restraint and self-harm. Patients detained in **private** units are more likely to experience an assault and more likely to be restrained than people in **NHS** Units.

What do families think?



We collected some stories from families of people who were detained in hospital. These families were involved in the **7daysofaction** campaigns. Their stories show how hard it is to get the right support. They have said we can use their stories in our report. We have changed their names.

Distance from home



Jane told us that she found it very difficult to get a home for her son Richard. They ended up finding one which was 3 hours away. She said that this had a big effect on the family.

Jane said: Richard missed out on seeing his nieces and nephews. Only having limited visits from mum and dad which he loved but caused him great stress. The anxiety of knowing we were coming was hard for him to deal with and often unsettled him for days. Then when we arrived he had difficulty in adjusting to it. Then the reverse anxiety of us having to leave. It was a huge stress.

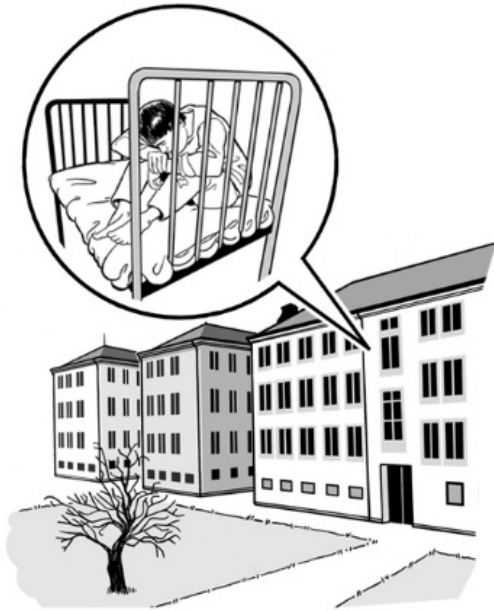
Money



Anne told us that the authority gave them the cheapest option. This meant that the placement broke down.

Anne said: It seems the LA was using the cheapest option when considering a care provider which resulted in the lack of experience and breakdown in care after 8 weeks

Local Support



Carol's son was taken away to hospital because there was no local support.

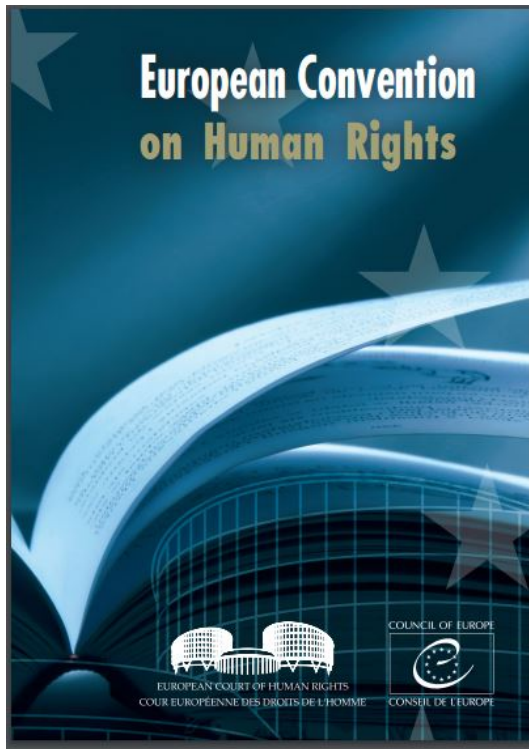
Carol said: This has hugely affected his ability to stay close, and it ruined our son's life and ours for many years. When we asked for support when he was at home, it didn't come. When we hit crisis, the local support didn't exist so he was shipped off.

Conclusion



The amount of people in hospital is affected by private units. Private companies build units in areas where house prices are lower. Also, the more units in the area means that people stay longer in the unit.

Recent governments have turned people into **costs** or **profits**. For local authorities and CCGs they are **costs** that they send to other areas and for private units they bring in millions of pounds of income or **profit**.



People and their families are finding it hard to keep relationships going. As well as having to deal with the crisis, they end up having to fight a system where the most important thing is money. We believe that this is against the human rights to of people with learning disabilities and their families.

We think that the **European Convention on Human Rights** is not being followed. Mainly Article 5, the right to liberty and Article 8, the right to a private and family life. The right to a private and family life has been torn from many families in the fight for their loved one's freedom.

My life has just been fighting to free my son and get him back near his family and siblings. It's a very sad case. What they have done to my autistic son, who should never have been locked up. I hope he can be free and get his life back and start living again.

You can see some more stories on Sevendaysofaction.net

This is an easy read version of Brown, M. James, E. and Hatton, C (2017) **A Trade in People: The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder** Lancaster: Centre for Disability Research.

It was written by Rebecca Fish and the pictures used are from CHANGE www.changepeople.org



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