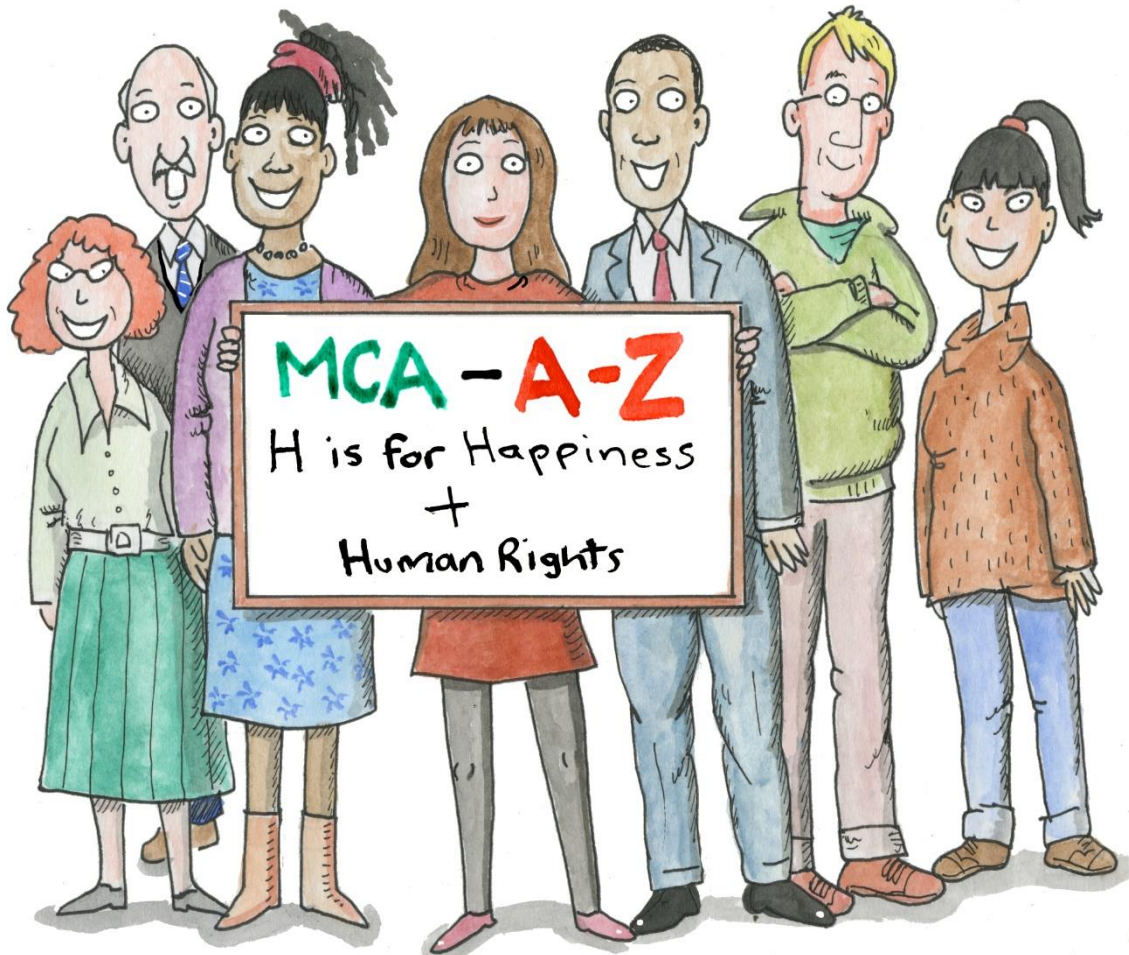


H is for Happiness and Human Rights



A compilation of easy read summaries of our work in support of the Adult Principal Social Worker Network's Mental Capacity Act Day of Action 2017

Editor Hannah Morgan

Easy Read by Rebecca Fish



The Centre for Disability Research (CeDR) is a group of researchers, educators and students at Lancaster

University whose work seeks to support the rights and aspirations of disabled people. We do this in different ways including teaching professionals about the social model of disability and independent living and doing research into issues that are important to disabled people and their families.



We think it is important that everyone gets to read about what we find out in our research and teaching and so we have been producing easy read summaries of our reports and articles. We have collected together all the summaries we have produced so far

this year in support of the Adult Principal Social Worker Network's celebration of the 10th Birthday of the Mental Capacity Act.

We have called the compilation H is for Happiness and Human Rights. We chose this because the Adult Principal Social Worker Network asked people to identify their A-Z of the Mental Capacity Act. This as a way of raising awareness of different parts of the Act and the impact it has on disabled people's lives. We think the Mental Capacity Act should be used in a way that means people live the lives they want to, with the people they want to and in the places they want to. If this happens people's rights are upheld and they can be happy.



Hannah Morgan

Director, Centre for Disability Research

Our Easy Read Summaries

1. Named social workers - better social work for learning disabled people?
2. A Trade in People: The Inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder
3. Use of physical restraint on locked wards
4. The Big Bed Time Audit - Evening routines into the Community

Pictures by Change <http://www.changepeople.org/>

Each of the summaries is available on our website and there are links to more information about the research.

Named social workers – better social work for learning disabled people?

By Elaine James, Hannah Morgan and Rob Mitchell

Easy read by Rebecca Fish



This article is about people with learning disabilities having access to their own, named social worker.

The Department of Health wanted to find out if this is good thing. They asked local authorities to take part in the Named Social Worker project.



We at Calderdale Adult Social Care and Lancaster University worked together on this project.

We got help from a self-advocacy group called Lead the Way.

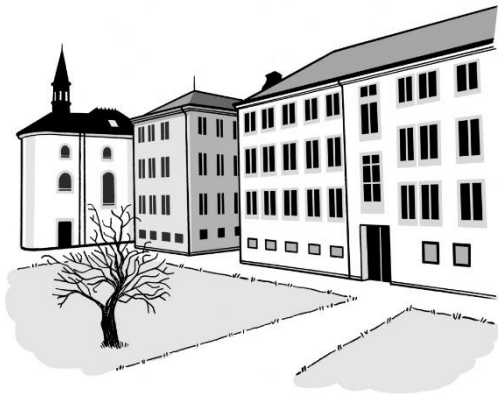


not accessible enough.

We wanted to be part of this project because we want to improve the way social workers work with people with learning disabilities.

We think that social workers control the lives of people with learning disabilities too much.

We believe in the social model of disability. The social model says that people are disabled because the world is



We think that people with learning disabilities are not treated fairly.

We are not happy that people with learning disabilities get put in long stay hospitals. This happens because staff think they are a risk to themselves or other people.



Social workers often try to protect people with learning disabilities from risk. This means that people do not get to make choices for themselves.



People with learning disabilities should be allowed to make their own decisions. Social workers and staff should not stop people making their own choices even if they disagree with them.



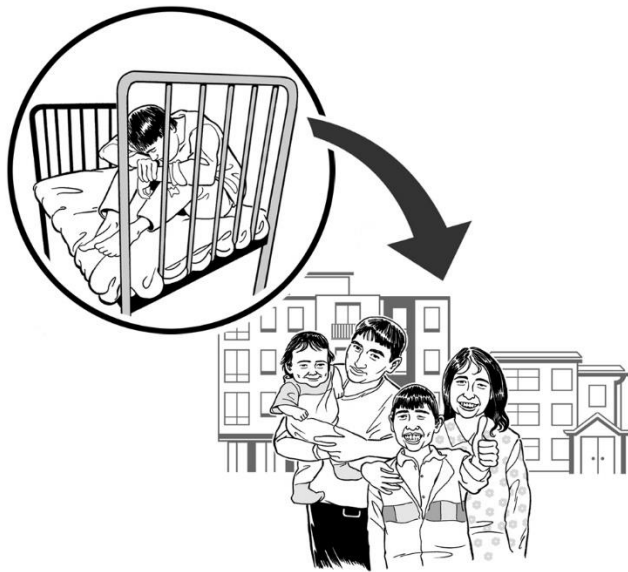
We think that people's families should be listened to better. They should be helped to get support in the community.

When families do ask for help, their loved ones should not be sent to a care home or hospital. This is too restrictive.



We think that people are kept in hospitals and units for too long. Long term care does not help people.

We want more to be done to get people back home.



We think that social workers should always think about Human Rights. They should help people and not just tell them what to do.

Social workers should give advice and help people to access support. They should tell people what is available in the community.

We hope that this project will improve the way social workers support people with learning disabilities.

This is an easy read version of James, E. Morgan, H. & Mitchell, R. (2017) Named social workers – better social work for learning disabled people? *Disability & Society* [advanced access]

The full article is free to access at

<http://www.tandfonline.com/doi/full/10.1080/09687599.2017.1340019>

CeDR Easy Read Summary 2017:1

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



Mark Brown, Elaine James and Chris Hatton

Easy read by Rebecca Fish

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

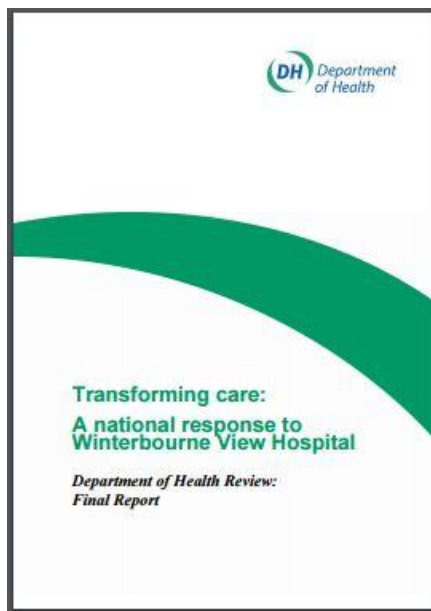
- The BBC showed how people with learning disabilities or Autism Spectrum Disorder (ASD) were abused at Winterbourne View.
- The government decided to close many long stay hospitals and move people to the community.
- In 2015, most people were still in hospital. Many private hospitals have been built.
- 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.

Introduction



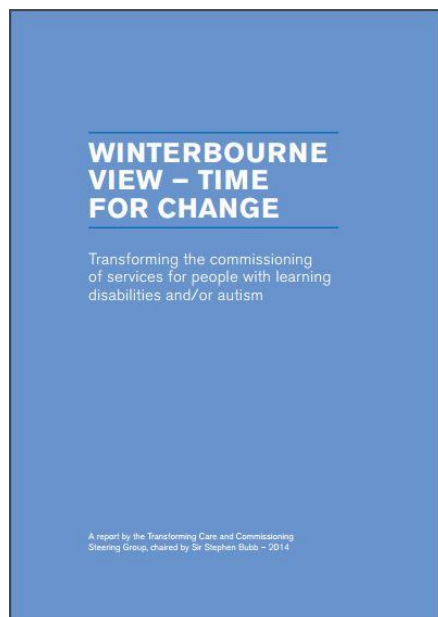
In 2011 a programme called **Undercover Care: The Abuse Exposed** was on the BBC. It showed staff abusing people with learning disabilities at Winterbourne View Hospital.

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



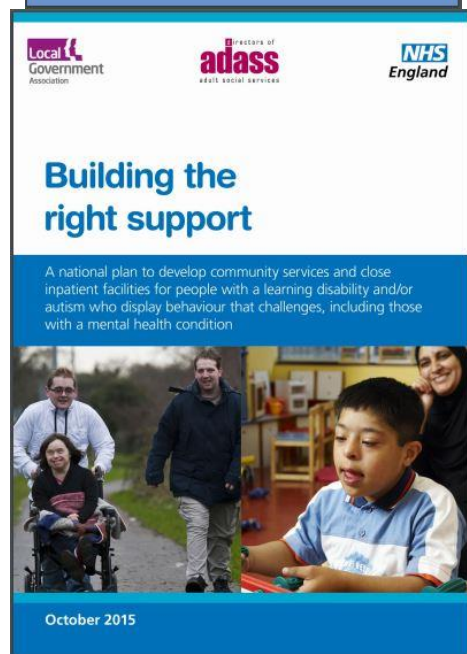
People were angry about the abuse and the government wrote a report called Transforming Care: A National Response to Winterbourne View Hospital and made an action plan to get people out of units.

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



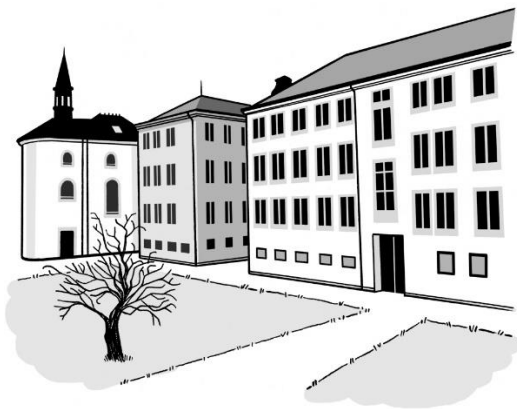
some areas have more people than others.

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.

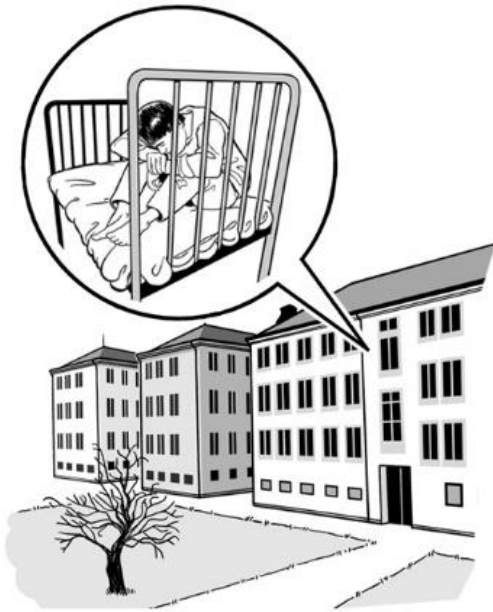
Money



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.

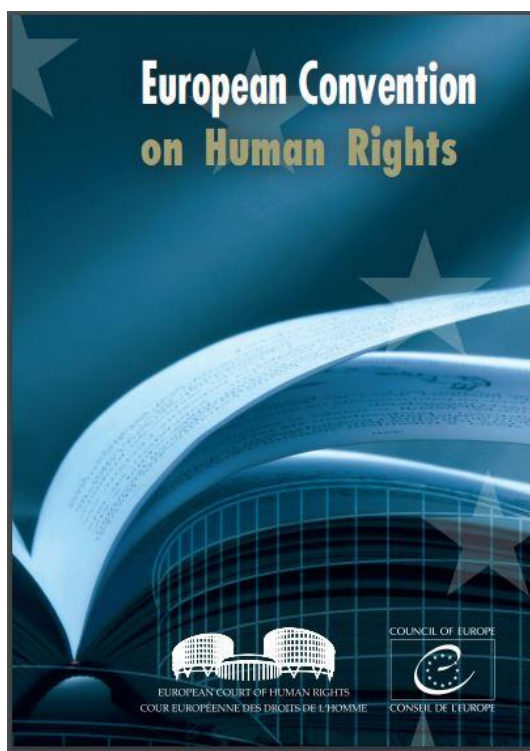
Carol said: This has hugely affected his ability to stay close, and it ruined our son's life and ours for many years. When we asked for support when he was at home, it didn't come. When we hit crisis, the local support didn't exist so he was shipped off.

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.

CeDR Easy Read Summary 2017:2

Use of physical restraint on locked wards

By Rebecca Fish and Chris Hatton

Easy read by Rebecca Fish

Physical restraint is holding somebody to stop them moving. It is done to stop harm to people or damage to property.

Staff sometimes use physical restraint to restrict someone's freedom of movement.

When people think about staying in units, they often remember being physically restrained, or seeing other people being restrained.

The **#7daysofaction** campaign (www.sevendaysofaction.net) shows stories from people with learning disabilities and their families. They say how frightening restraint is.



The **Mental Health Act** says that restraint should be used as a last resort. This means that staff should talk to people and try to calm them down before restraining them. Staff should also explain that the person will be restrained if they don't calm down.

The Department of Health says that in some services, physical restraint is used too much and in harmful ways.

What do people with learning disabilities think?

In some research work, Rebecca Fish asked people about being restrained. She spoke to 16 women with learning disabilities who were in locked wards. They agreed that she could write what they said.

- The women said being restrained makes them even more angry.
- They said that they think restraint is not always used as a last resort.
- Sometimes, they said that they were restrained for self-injuring.
- Some women said there is no warning that they will be restrained.



Being restrained made some of the women remember bad experiences and abuse from the past. This is worse when male staff restrain women.

When there are bank staff working, they might not know people very well. This means that restraint might be used too often. People might feel like they are being punished when they are restrained.

Rebecca also spoke to 10 staff. They told her that they did not like restraining people but they said they had no choice. The staff said that they use restraint as a last resort.

What needs to change?

- Services need to work with families better.

- Staff should talk to people to let them explain why they are angry.
- Men should not restrain women.
- Staff should talk to people calmly and caringly while restraining.



Services should help staff to make good relationships with service users. When relationships are good, restraint is not needed.

Staff need to protect service users from harm. Also, staff need to protect themselves from harm. If staff have more time to spend with people, they will be able to talk to people about what is making them angry. This might help staff and service-users to understand each other better.

This is an easy read version of Fish, R and Hatton C. (2017) 'Gendered experiences of physical restraint on locked wards for women' *Disability & Society* 21 (6) pp.780-809.

The full article is available open access here:

<http://www.tandfonline.com/doi/full/10.1080/09687599.2017.1329711>

The Big Bed Time Audit – Evening routines into the Community

By Elaine James, Mark Harvey and Rob Mitchell

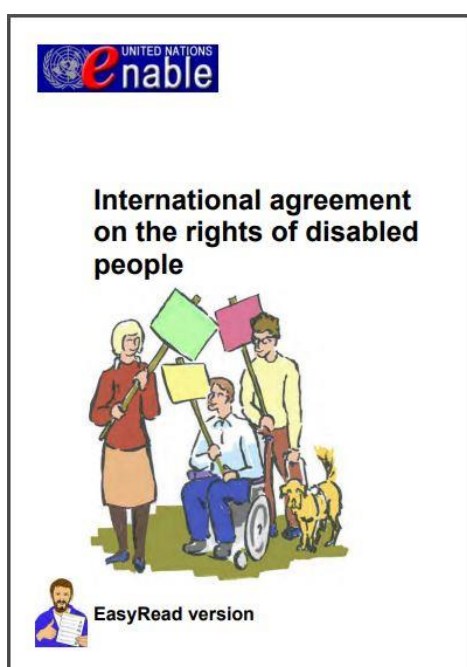
Easy read by Rebecca Fish



An NHS England report called Building the right support was published in 2015. The report set targets to cut down the amount of people in units by about half before 2019.

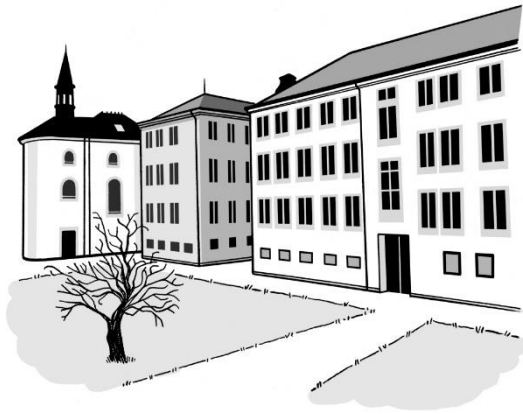
The report asked for better services for people with learning disabilities in the community. This was so people could move out of units.

The Government want people with learning disabilities to have better choices about where to live. They want people to feel included in their local area. They want less people living in hospitals and units.



The Convention on the rights of persons with disabilities (CRPD) says that disabled people have the right to live in the community. They have the right to choose where they live.

Social workers should protect people's rights to be included in their community.



Before the 1980s many people with learning disabilities had to live in hospitals or institutions.

They lived very limited lives in hospitals. Staff told them what to do, like when to eat meals and when to go to bed.

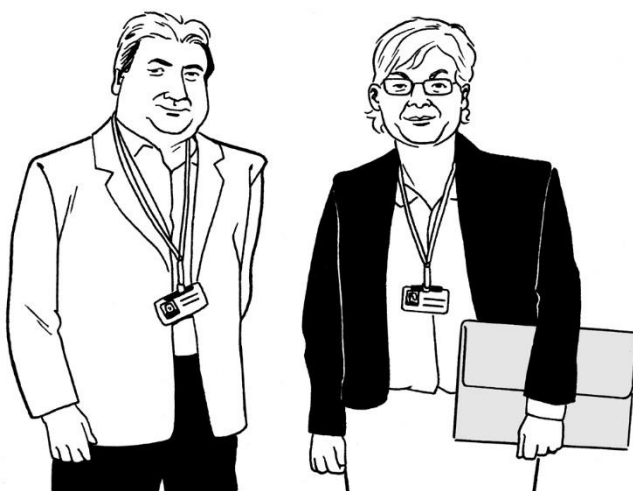


Now that people live in the community, they should be able to choose when to go to bed.

The Stay up Late Campaign was started by self advocates in 2012. They think that people with learning disabilities should be able to choose how to spend their evenings.

Their website is **www.stayuplate.org**

What is the Big Bedtime Audit?



We sent two social work teams to find out what was happening at 8 o'clock in the evening in the homes of people with learning disabilities.

The homes were all in the community. We visited supported tenancies, supported living houses, residential care homes and nursing homes.

The homes were in two different local authorities. They visited people in one area on a Thursday evening and people in another area on a Friday evening. Altogether they visited 263 people. They visited again after six months.



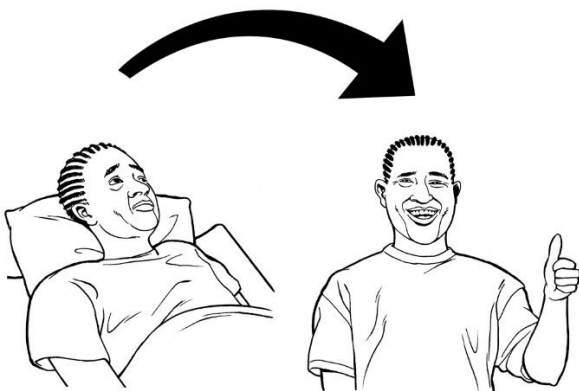
This is what people were doing at 8 o'clock in the evening:

Most people were getting ready for bed or in bed.

Only a small amount of people had gone out for the evening.

Less than a quarter were at home and not ready for bed.

Some people were already asleep in bed.

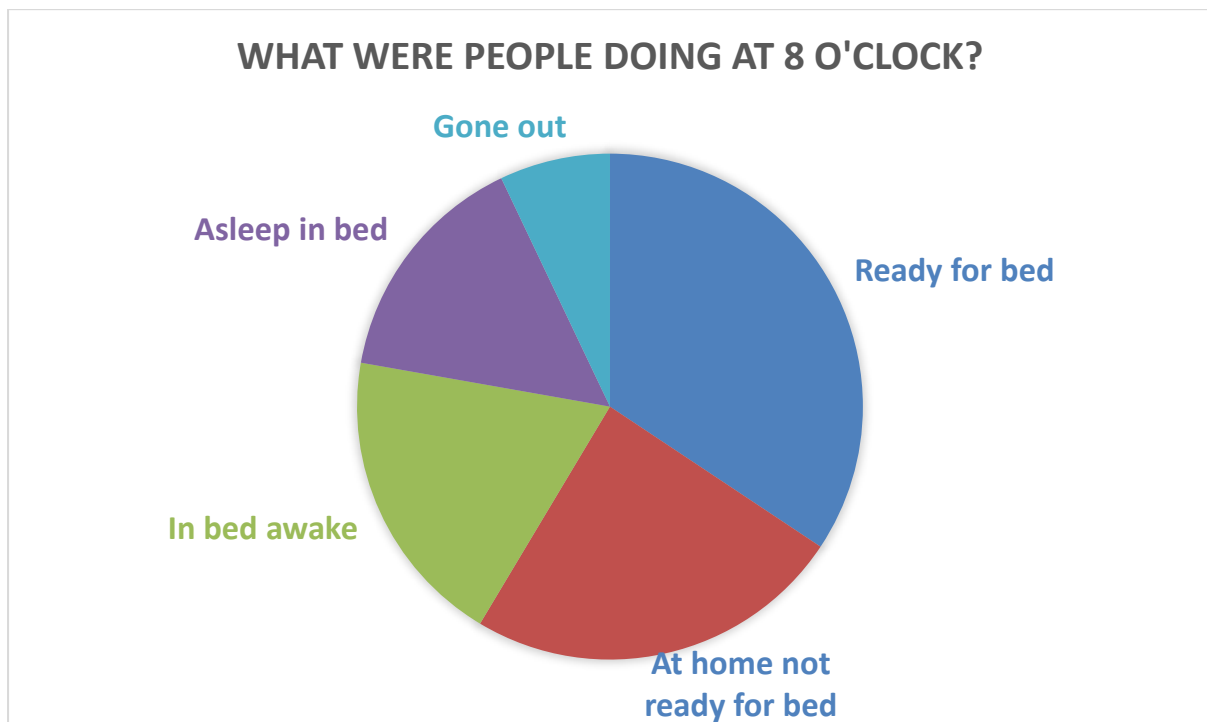


People in residential and nursing homes were more likely to be in bed.

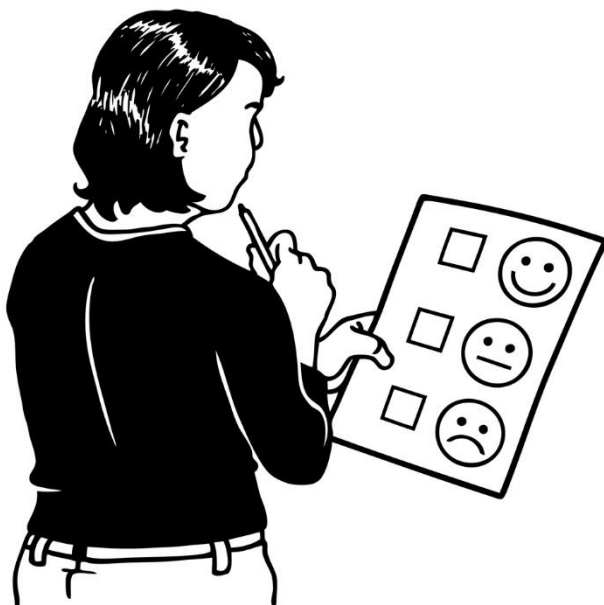
Nearly half of staff said that the person was in bed because it was their choice.

People in supported tenancies were less likely to be ready for bed.

This pie chart shows the amounts of people doing different things:



What do we think about this?



We think that early bedtimes are like hospital habits. People should be able to choose their bedtime.

When social workers plan support for people with learning disabilities, they should make sure they can make choices.

This is an easy read version of James, E. Harvey, M & Mitchell, R. (2017) An Inquiry by Social Workers into Evening Routines in Community Living Settings for Adults with Learning Disabilities *Practice Social Work in Action* [advance access]

The article abstract is available at:

<http://dx.doi.org/10.1080/09503153.2017.1342791>

If you would like a copy of the full article please contact Elaine James

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CeDR Easy Read Summary 2017:4

The Centre for Disability Research (CeDR) is a specialist research grouping that promotes and conducts high quality interdisciplinary research and research-led teaching about disability. CeDR publishes a range of working, briefing and position papers as well as research reports, summaries and other resources



<http://wp.lancs.ac.uk/cedr>

Cover image: Harry Venning