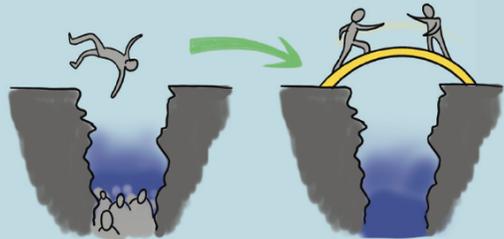
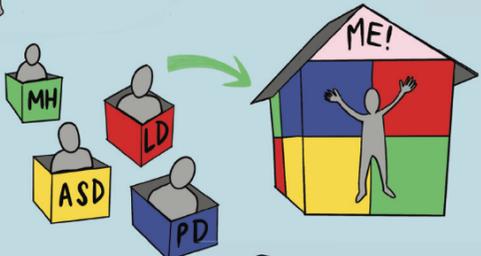
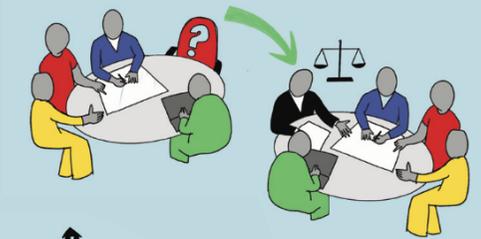
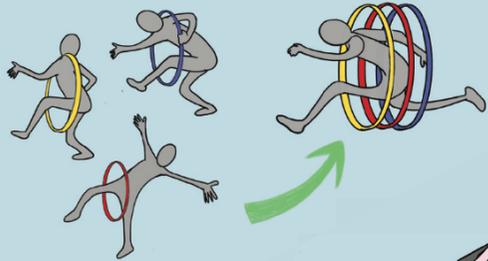


Why are we stuck in hospital?

Getting people with learning disabilities and autistic people out of long-stay hospitals. What helps and what makes it difficult?



Summary for people and families

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What did we do and how did we do it?



In the 1960s, the UK decided to close asylums for people with learning disabilities. Asylums were hospitals where people with learning disabilities were kept separate from other people. Having a learning disability or being autistic was treated like an illness or something to be kept hidden.



But in recent years, many people with learning disabilities and autistic people have been put in long-stay hospitals. Lots of people have been in hospital for many years. Lots of them have no planned date for getting out.



Around 2000 people with learning disabilities and autistic people in England live in hospitals now.

There has been lots of work done to get people out, but this has not worked.



In hospital it is hard for people to live an ordinary life.

Many hospitals are a long way away from people's families and homes.

It is expensive to keep people in hospital.

There is abuse in hospitals where staff treat people with learning disabilities and autistic people badly.



There has not been much research about why people with learning disabilities or autistic people are stuck in hospitals.

In the past, researchers have not talked to people who are stuck in hospital, their families or the staff who work with them.

We wanted to change this.



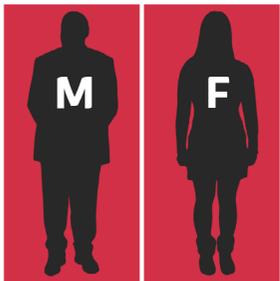
For this research, we spoke to 27 people with learning disabilities and autistic people.



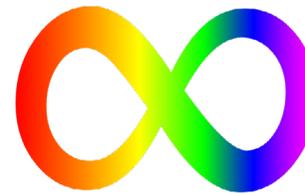
We spoke to people in 3 long-stay hospitals in England. Two of the hospitals were run by the NHS and one was run by an independent provider.



We spoke to people in a mix of different wards.



We spoke to some men and some women.



We spoke to some people with learning disabilities, some autistic people and some autistic people with learning disabilities.



We spoke to some people who had committed crime and some who had not.



We spoke to some people who had been kept away from other patients for a long time. This is called Long Term Segregation or LTS.



We also spoke to:

- Families
- Hospital staff
- Commissioners (these are professionals who pay for services and check that they are working well)
- Advocates (these are professionals who work alongside a person to help them speak up for themselves)
- Social workers
- Social care providers who work with people after they leave hospital.



The University of Birmingham did this research with Changing Our Lives. Changing Our Lives work alongside disabled people to make things fair and equal for disabled people.



We worked with a group of disabled people who checked our work and gave us advice based on their experience and expertise.

Some of them had been in long-stay hospital and some had not.

We also worked with a group of family carers, campaigners and professionals who checked our work and gave us advice.

Thank you to everyone who spoke to us or helped us.

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NIHR

The research was paid for by the National Institute for Health and Care Research (NIHR).

The words in this report are based on the people we spoke to for this research.

They gave their advice to the professionals about how to get people with learning disabilities and autistic people out of hospital.

They may not be the views of the NIHR or the government.

Tip 1: Our lives are on hold - do your jobs and get some 'oomph'



People we spoke to had been in hospital for many years. We spoke to people at the beginning of our research and then spoke to them again after one year. Many people were still in hospital after a year and were not close to getting out. People felt that their lives were kept on hold. They felt the whole system was set up to be slow.



We noticed that staff at hospitals were very busy. There were gaps when staff were off sick or changed jobs. This meant people in hospitals had to get to know lots of new staff. It also meant that things which people had planned to do got delayed or cancelled.



For people to get out there needed to be someone who believed that they could get out and helped them fight to get out.

For some people, this was a family member, an advocate or a member of care staff.



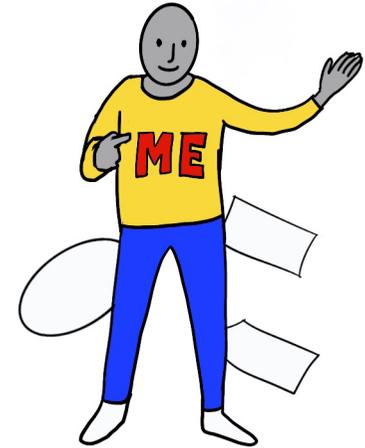
Sometimes delays happened because different teams weren't working well together. Sometimes steps that needed to be taken were not planned or done on time.



Being in hospital is often stressful and traumatic and can make someone's mental health worse.

People felt that when a person is doing well it is important for them to get out before hospital makes them ill again.

Tip 2: See the person behind the labels



People said that labels they had been given years ago stayed with them forever. A label could be a diagnosis like 'autism' or 'personality disorder'. A label could also be something that professionals use to describe a person's needs like 'challenging' or 'complex'.



Sometimes professionals made decisions about their lives because of these old labels. Some people we spoke to felt that professionals did not really know them or did not believe that they could leave hospital.



Some services have rules that say they cannot work with people who have a certain label. This rule often had nothing to do with whether the service was right for the person behind the label.



Hospitals are stressful places.

It is easy to be given new labels when you are living in a hospital where you feel unsafe and upset.

Some people 'stayed out of trouble' by being quiet and staying in their room to avoid getting more labels.

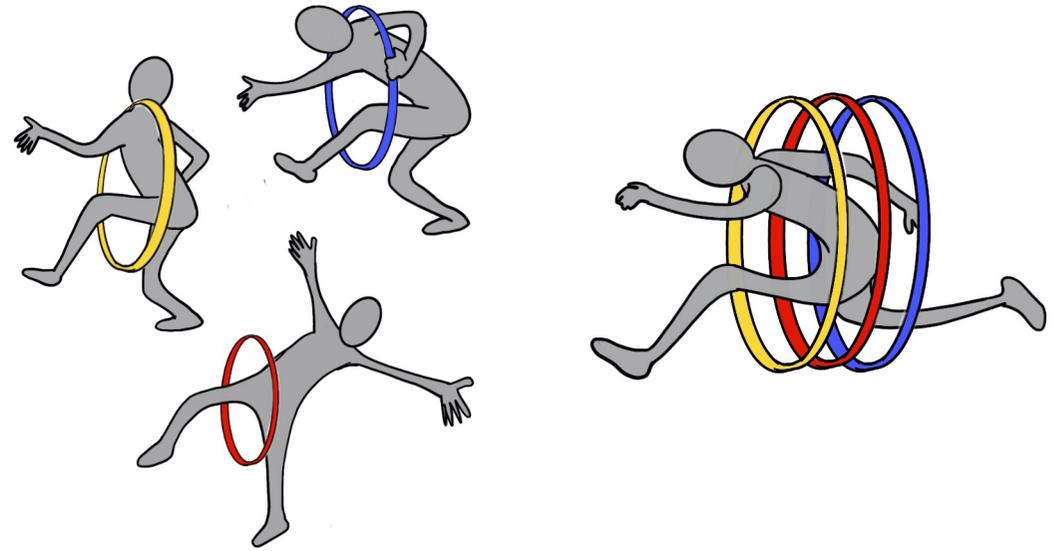


The story about why a person had been given a label was often lost or forgotten.

Some people had done things like pushing, shouting or hitting in the past when they had felt frightened or threatened.

Later on, when staff saw the person's notes, they would not know how the person had felt, they would just see that they had pushed, shouted or hit.

Tip 3: Don't make me jump through more hoops than is really needed



Some people were not clear about what they needed to do to get better and leave hospital.

If there was a plan for getting them out of hospital, some people did not know what the steps were towards getting out.



Some people felt like they had to do everything staff told them to do to prove that they were ready to come out of hospital.

People said yes to whatever staff said, even if they didn't think it was helpful for them.



Sometimes staff wanted people to prove that they could do things before they were allowed to leave.

These were not always things that they would need to be able to do in their new lives outside hospital.



This meant people stayed in hospital for longer than they needed to, learning to do things that weren't helpful for them and their plan.

Tip 4: Make sure the criminal justice system is on board when someone has committed an offence



Lots of people we spoke to had done serious crimes. This meant that the NHS and the Ministry of Justice were both in charge of their care and treatment.



Some people felt that the Ministry of Justice did not work well with the NHS. Sometimes the Ministry of Justice made decisions based on paperwork, not on knowing the person. This meant people stayed in hospital for longer or could not try new things that may help them get ready to get out.

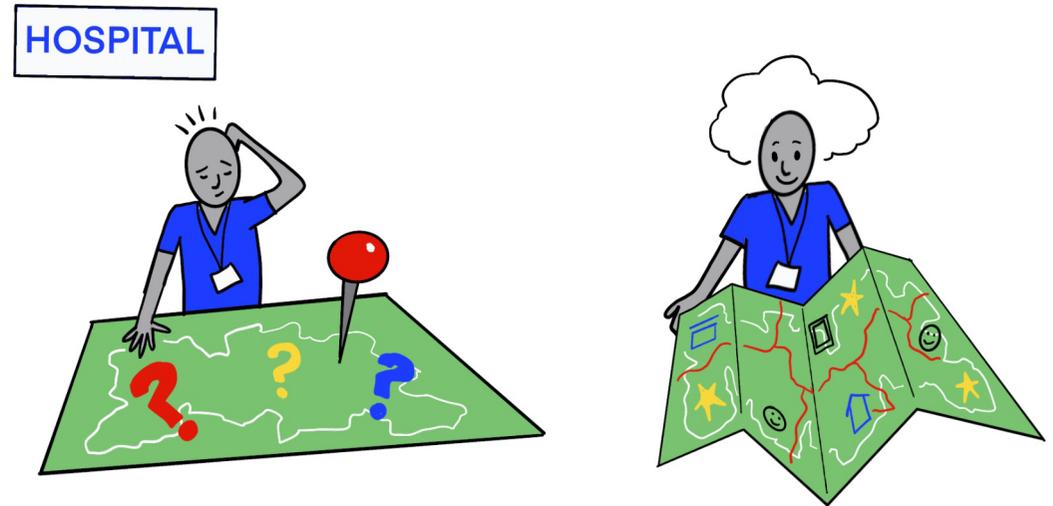


We spoke to lots of people who did not need a lot of care for their needs to do with learning disability or autism, but had done very serious crimes.



Staff who are experts in learning disabilities may not be the best people to help them. Some professionals we spoke to felt that there is a need for a new service that helps these people to stop offending when they leave hospital.

Tip 5: Help hospital staff know what's available in the community



Some staff had worked in hospital for many years. They did not know what services there are in the community and where people can go next.



Sometimes hospitals were working very hard to get people out of hospital, but there were no services in the community to meet those people's needs.

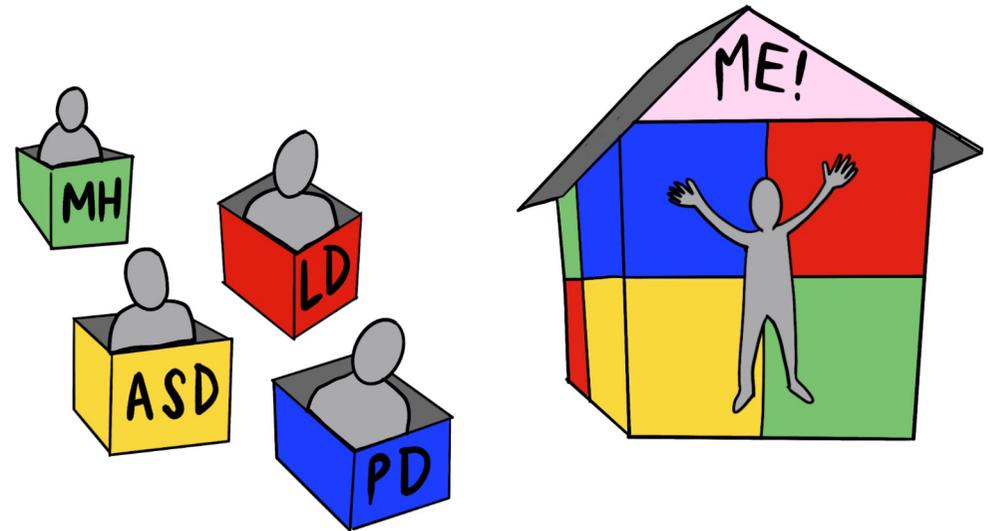


Sometimes staff in hospitals did not refer people to services in the community because they did not believe that they were able to cope with the person's needs. Sometimes staff in hospitals referred people to services in the community that were not suitable for the person's needs, just because they felt they had to refer them somewhere.



Hospitals can work with people from all over the country. Professionals who work in the community need to help hospital staff know what support there is in their area.

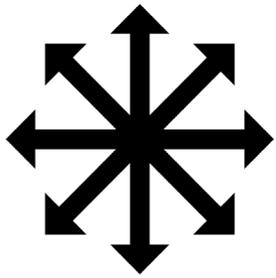
Tip 6: Don't put us into boxes or 'scatter-gun'



Everyone's needs are different. But lots of different people had very similar care packages. It seemed like people were being put into whatever services were available, not the best services to meet their needs.



Building a service around a person's needs was seen as something special or unusual. In reality, everyone should have a life that is built around them.

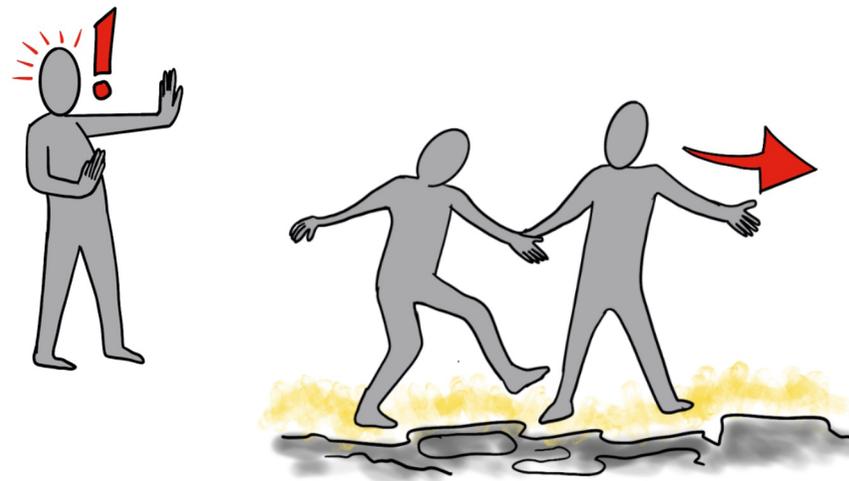


Sometimes staff were in a rush to get people out of hospital. They referred people to all the services they knew about whether they were right for the person or not. They hoped that eventually one of these services would take the person on. This led to people waiting a long time to be turned down by services that weren't right for them anyway.



No-one spoke to us about personal budgets, individual service funds or direct payments. These are all tools that help people build their own support. We think more people should have these.

Tip 7: Give me the chance to try life outside



Some people felt that they couldn't get out of hospital until they proved they were ready. But living in hospital meant they weren't getting chances to do the things that would show they were ready to leave hospital. They felt trapped.

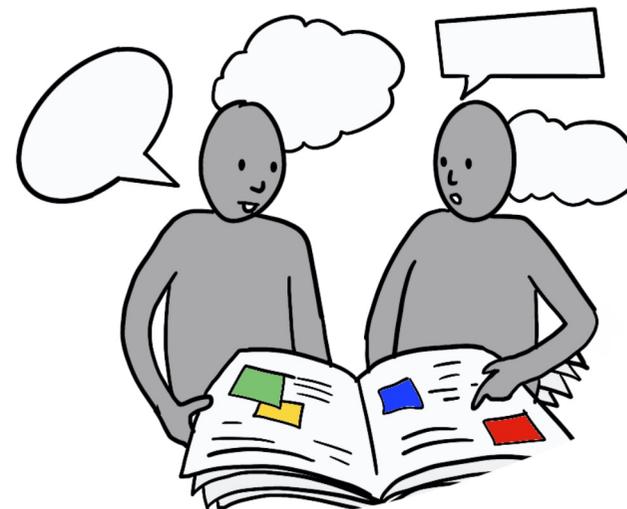


Some people felt that whenever they achieved a goal that showed they were ready to leave, a new goal was set for them that was even harder to achieve.



Some people felt that no matter how hard they tried to get better, staff would say they were only better because they were in hospital.
This meant they would never be seen as ready to leave.

Tip 8: Help me with the trauma I've experienced



Most people we spoke to had had very difficult lives. Many had been treated badly as children or as adults. Most people found being in hospital stressful too. Some people felt like hospital made their mental health worse, not better.



Trauma is a word we use to describe the effect that difficult experiences have on a person's mind. Trauma can make someone's mental health worse. It can change the way someone acts or thinks about things.



We think that all staff in hospital need to know about trauma and how it affects people. They need to work in a way that helps people cope with their trauma and heal from it.

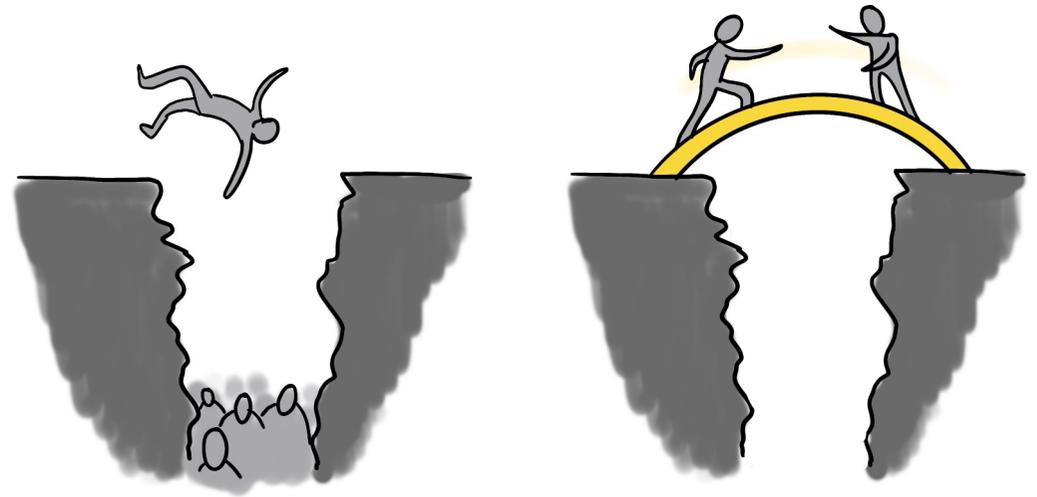


There was not enough mental health help in hospital from professionals like psychologists. Some people did not have any physical health needs, they were only in hospital for their mental health. It was not clear why these people were not getting mental health support in the community instead.



When there was not enough mental health help, hospitals felt like places to keep people waiting. If people had help with their mental health every day they may be ready to get out of hospital quicker.

Tip 9: Don't let us fall through the cracks



Many people had lots of different teams involved in their care. These could be health or social care teams, teams inside hospital or in the community, or teams across the UK.

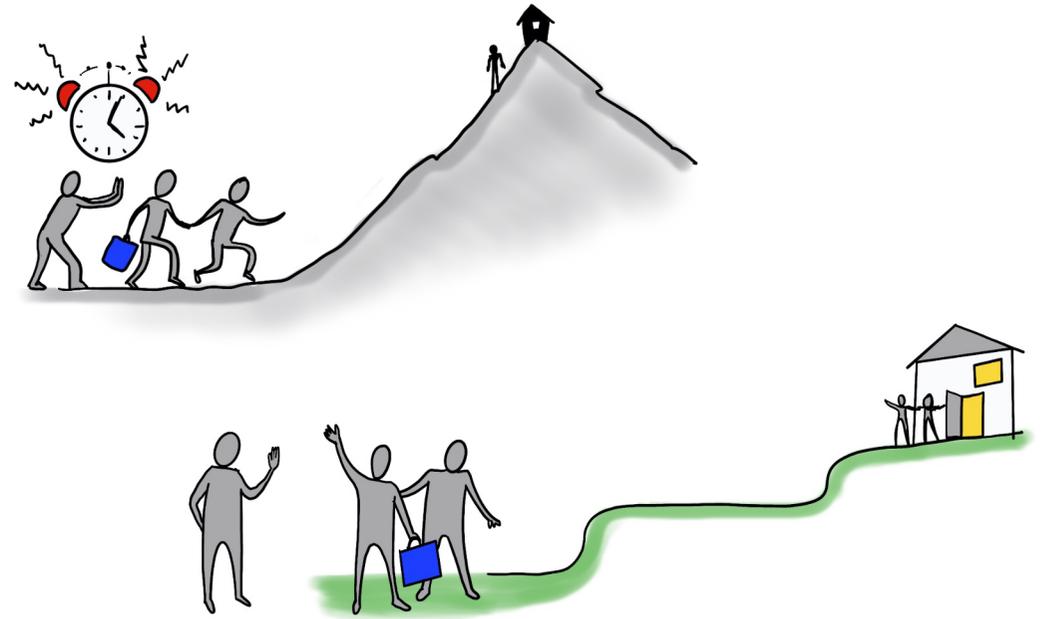


Sometimes these teams could not agree who should be in charge of the person's care or who should pay for their care. A person's case could be sent from team to team to find out who needed to help them.



To the professionals this felt like moving paperwork from one service to another.
To the person, this felt like they were being moved from one service to another.
Some people felt that no-one wanted to help them.
It made some people feel that they were the problem, or were too difficult to support.

Tip 10: Don't set us up to fail



Getting out of hospital was very slow for most people. Even so, some people felt under pressure from senior professionals to get out of hospital quickly.



These professionals sometimes set deadlines that were not possible for the person. This meant there was a rush to get the person better or move them out before they were ready. People felt like they had failed if things went wrong.



People felt that it was important to work at the speed of the person to get them ready to leave hospital.
This is not the same as not doing any work for years and years and leaving someone stuck in hospital.

Where can I find out more about the project?



You can find out more about our research by going to this link:
www.birmingham.ac.uk/schools/social-policy/departments/social-work-social-care/research/why-are-we-stuck-in-hospital.aspx



There is a policy guide for professionals and a full research report that go with this Easy Read Version.
These will be on the NIHR website and SCIE website.



To read stories about people who have come out of long-stay hospitals read the Hospital to Home book series visit the Changing Our Lives website www.changingourlives.org

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