

“Good support isn’t just about ‘services’ – it’s about having a life.”

IMPACT Evidence Review- coming out of long-stay hospitals

What is the issue?



There are a **large number** of people with learning disabilities and Autistic people being admitted to hospital and **staying for a long time**.



People are **very worried** that those hospital stays are for many years with **no planned time for that person to leave**.



In the past, the UK decided to **close asylums** for people with learning disabilities from the 1960s onwards.

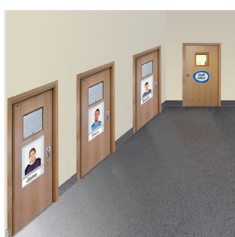


But in recent years, more people are being admitted to places called **assessment and treatment units**. This is sometimes shortened to **ATUs**.

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Some people stay in these units for **far too long**. Despite their name, there aren’t enough assessments or treatments provided that **couldn’t be done elsewhere**.



Other people live in secure units, **mental health hospitals**, or in an NHS site alongside other services.



We call all these types of places, **long-stay settings** for short.



These long stay settings are meant to have **policies** to help people leave hospital and **live in the community**. But progress is very slow.



Around **two thousand** people are living in long stay settings in England at **any time**.

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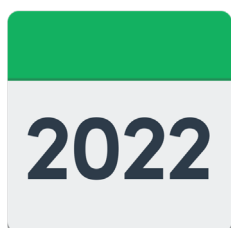


The average length of stay for people is about **five and a half years**. Around three hundred and fifty people have been in hospital for **more than ten years**.



No one thinks this is acceptable. But solving these issues has been **really difficult**.

What does this look like across the UK?



In **2022**, there was a review of previous research about **delays in leaving long-stay hospitals**.



Five national and **official reviews** from across the UK were included.

England



A review of **seclusion and restraint** in hospitals for people with learning

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disabilities was carried out by the **Care Quality Commission**.



Care Quality Commission, which is usually shorted to **CQC**, are people who look at health and care services in England.



This review looked at people's **experiences of long-term hospital stays**. It included things like;

- Segregation and seclusion.
- Discharge and transition planning.
- Barriers to people moving on.



One thing this review found was that discharge was often slowed down due to **lack of community services**. This happened for **60%** of the people they spoke to.

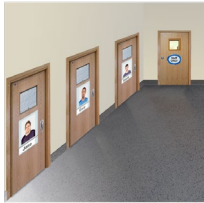
Northern Ireland



There was a **review of progress** for a programme that looked at helping

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people who are **delayed in leaving hospital**.



While there has been **some progress**, there is a lot of people still in hospital, with **only a few people** moved back into the community.



The **average stay** for people with learning disabilities in their hospital units is **just over six years**.



This average time includes **short stays of days or weeks**, which means some hospital stays must be **very long**.

Scotland



There was a review of delayed discharges called '**No Through Road.**'



This review looked at the **reasons** for **delayed discharges** from learning disability hospital wards.

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One thing this review found was that nearly **one-third of current inpatients** with a learning disability were delayed discharges.



Another review of **all long stay and out of area placements** was commissioned by the Scottish Government.



Out of area means someone is in hospital somewhere **not close** to their home or community. Some people are in hospitals **a long way from home**.

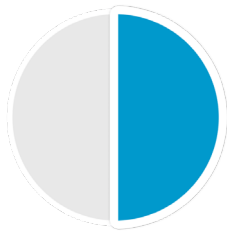


In the report, some of the findings showed that **13 people** were delayed in leaving hospital for over a year.



10 people who were delayed had placements costing over **£150,000 per year**.

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Only 51% of people in these units had **active discharge plans**.

Wales



There was a National Care Review in **Wales**. This was around the **care and treatment of people** with learning disabilities and or autism.



This review looked at how ready people were to **move out of hospital**. It also looked at whether hospital settings were **meeting their needs**.



The **average time** people in Wales were spending in long stay hospitals was **just over five years**.



This review found that a big chunk of current money **being spent on hospital stays** could be put into community services **right now**.

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This could happen if all people who are **being delayed in hospital** were helped back into their community.

Why is this a problem?



Hospitals are **not designed to support** people to lead an ordinary a life.



Even if hospitals are needed by some people for emergency help, they are **not suitable for long stays**.



Very few people would **want to live in a hospital** if they could choose not to.



People are **often out of area**. Which means they are a long way away from their family, friends, and local communities.

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There has been a lot of **bad care scandals** in some hospital units. These came with stories of abuse, neglect, deaths and people **having their rights taken away**.



You may have seen stories like this on the news. An example of one of these stories is the scandal around **Whorlton hall**.



Hospital services can be **very expensive**. This can create something known as a vicious cycle.



This is when money is used on expensive hospital care, which means **less money for community services**. Without those services, even more people are being **admitted to long stay hospitals**.

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What do we know already?



There has been **surprisingly little research** on why people with learning disabilities and autistic people are **delayed in long stay settings**.



Past researchers **hardly ever talked directly** to people with learning disabilities and autistic people. They have also **not talked their families and front-line staff**.



As a community, we have **not often been asked** what we see as the main barriers. Or what would help more people to **leave hospital**.



Some of the solutions that are given to **help people leave hospital** are very weak and **don’t have enough detail**.



For example, someone might say we **need more community services**. But there’s not enough discussion of how many community services we already have, and **what could be done to make them better**.

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We think we won’t make more progress until we **value people’s lived experience**. We need to see people’s experiences as important, which could help us find **better ways of doing things**.



There has been recent research which tried to come up with better ways of **supporting people to come out of hospital**.



This team worked in three sites to **understand the lived experience** of people in hospital and their families. They also looked at experiences of **health and social care staff**.



They made **a free online guide** and **training video**. They also made **accessible versions** for people and their families.



Lots people with **learning disabilities and their families** have said these videos are good.

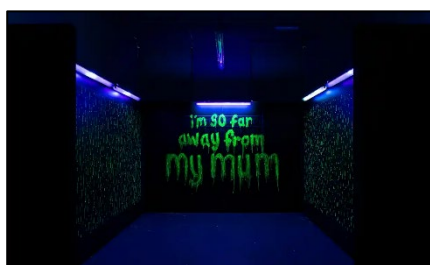
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Why are we stuck in hospital?

The guide, video and more accessible versions are available **free of charge** on these three sites:



<https://www.birmingham.ac.uk/schools/social-policy/departments/social-work-social-care/research/why-are-we-stuck-in-hospital.aspx>



<https://changingourlives.org/our-work/research/>
www.scie.org.uk/integrated-care/interventions/transfers-of-care/stuck-in-hospital



The research team also worked with an **art gallery**. They asked an artist to create an original piece of art. This was done to help **raise awareness** to the public.



It was also covered in **newspapers**, like this article here:
www.theguardian.com/society/2023/mar/14/thousands-learning-disabilities-trapped-long-stay-hospitals

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While many **health and social care staff know** all about these issues, members of the public **were really shocked** that things are like this.

Some issues from local Network co-ordinators



Local Network co-ordinators are people that help form the IMPACT Networks. They have said that it would be helpful for us to know about what they are **struggling with**.



There will be **a full report** out later this year. Examples include:



Lots of people in the study had **very traumatic** experiences, either as **children or as adults**, or both.

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People want there to be a focus on something called **trauma informed care**. This means that people are **helped to process** with what has happened to them.



Lots of families have been seeking help for **many years**. They often felt that no one listened until a major crisis occurred, and then the person was **admitted to hospital**.



People think hospitals and community services need **better relationships**. This is so they can better support people and show them what's **available in their community**.



Lots of difficult debates took place around **risk and responsibility**. People want to see hospitals do things not in policies when its in **someone’s best interest**.



Lots of people are **worried about labels**. When something is on your record it's **very hard to get rid of**.

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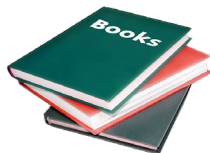
Other resources



There is also a current study looking at what helps people to stay **living independently in the community** after they come out of hospital
<https://fundingawards.nihr.ac.uk/award/PB-PG-1217-20032>



The findings of this are published on:
<https://makingpositivemoves.org/>



The rights-based organisation, **Changing Our Lives**, has published a series of '**hospital to home**' books.



They are showing what has worked for people coming out of hospital and what's possible, in spite of **any challenges**.



There website is :
<https://changingourlives.org/category/stories/hospital-to-home/>.

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We can also provide a **reference list** for our sources, please message or email if you would like this sent to you.

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