

‘Why are we stuck in hospital?’ Barriers to people with learning disabilities/autistic people leaving ‘long-stay’ hospital: a mixed methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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Plain language summary

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Plain language summary

Around 2000 people with learning disabilities and/or autistic people are living in hospital. This can be for many years. This is a real problem because hospitals:

- are not designed to help people to lead ordinary lives;
- are expensive;
- can be far away from people's homes and families;
- have had a number of abuse scandals.

Despite this, there is little research on why people remain stuck in such settings. In particular, previous research often fails to talk directly to people with learning disabilities, their families and staff. Unless we listen to these voices we will not find solutions to these problems. Too many people will therefore remain in hospital unnecessarily.

This is sensitive work. It requires skills in working:

- with people who may not communicate verbally;
- with people who might be very angry, scared and distressed;
- where there can be tensions around what is best.

We therefore included an experienced team who could carry out such in-depth work in a way that suits the needs of the individual. We also worked with a group of people with learning disabilities and/or autistic people and their families to help us do our work well.

We found that:

- lots of people are still stuck in hospital;
- they are very frustrated and distressed;
- hospital is a difficult place to be while you are waiting to leave. Once you are in it is very difficult to get out;
- health and social care staff are also very frustrated. They find it almost impossible to help people leave hospital;
- hospital staff and community services find it difficult to work with each other;
- government has promised to solve this for more than 10 years. However, there are still lots of problems.

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