

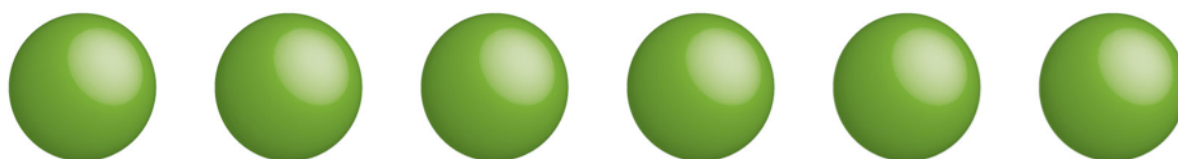


National Development Team **for inclusion**

Informing the Service Model

**A report about the experiences of
people with learning disabilities and
families**

Easy read



What this report is about



Too many people with learning disabilities get admitted to in-patient services for too long.

Sometimes this is because good community support isn't in place.



Health and social care services are working on a 'service model' that says what should be in place so people get good lives, and support.

The service model also says what should be in place if people do have to be admitted to in-patient services for a short while.



They wanted to hear from people with learning disabilities and families about their experiences of in-patient services, why people were admitted, and what happened when they left services.



This is a report about what people told us.

The information will help develop the service model.

What we did

We had four meetings with self-advocacy groups in different parts of the country.

There were meetings in Birmingham, Oxfordshire, London and Newcastle.



We had two meetings with families.



One was in Oxfordshire and one was in London with the Challenging Behaviour Foundation and Mencap.

Questions

1. What do you think about it?

☐ Good

☐ Bad

☒ Not sure

We also talked to family carers on the phone and one sent in a questionnaire.

What people with learning disabilities told us



In-patient units

It was good when:

- People felt safe and knew what to expect
- There were things to do
- There was help to get better
- People could stay in contact with their families
- Members of the self-advocacy group visited.

But – how staff talked to people in in-patient services needed to be much better.

People said that:



- Things were not explained to them
- Information was not accessible
- They were not listened to or treated with respect
- They were not included in meetings
- It could be difficult to get to classes and do things
- It was difficult for families to visit
- Hospital notes did not give a good picture of the person



Advocacy was helpful, but people weren't always told what advocates did, and some hospital advocates were more like staff.



People who were on a Ministry of Justice order could get stuck in hospital

Things that need to be in place



- Regular checks on what is happening in in-patient units
- Self-advocacy groups being involved in training staff
- Experts by Experience being part of the whole Care and Treatment Review process



Coming home

It was good when everyone worked together to make things happen.

There was a good care co-ordinator.

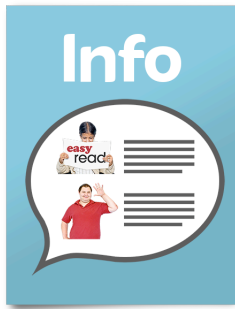


But – communication needs to be much better

Things that need to be in place



- The right support – staff who understood
- Control over their support – the right budget
- Things to do



- Good accessible information, and someone to explain it
- Self-advocacy groups who can offer friendship and support
- Friends and relationships

What families told us



Staying safe and well in the community



- Professionals did not listen
- People did not get good assessments
- Families were sometimes seen as the problem
- Services didn't talk to each other
- There was a lack of good services
- Families didn't get good information
- Things took too long
- People were given too much medication





What needs to be in place

- Person centred support and services
- Services that can help when things get difficult
- Staff who understand the law
- Services that talk to each other



In patient services

It was good when staff worked together, and supported the person and their family



But –

Families were worried about how the Mental Health Act was used



- People didn't get good support and their needs were not understood

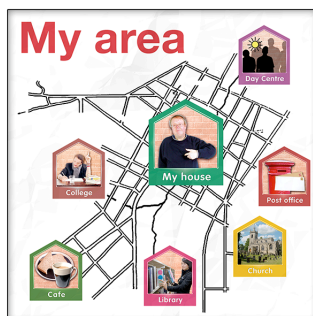
People had nothing to do

- People were given too much medication. Sometimes they were held down





- People got worse after they had been admitted
- People were not safe
- Services didn't talk to each other
- Families were not listened to
- Services were often far away from the family and home.



What needs to be in place

- Small local services that can help people
- Services that listen to families and people with learning disabilities
- Accessible information
- Better checking of services.





Coming home

It was good when there was a good staff team and good advocates

But –



- Services don't work well together and don't listen to families.
- Families are often left to sort things out

What needs to be in place



- Better planning and services working together
- Staff who have the right training.

