

# **A consultation asking you about changing learning disability and autism services in the North West**

## **What people said**





NHS England wants to get people's ideas about locked services for people with a learning disability and/or autism.



They want to know what people think about either:

- Closing Calderstones Hospital completely
- Or keeping the newer buildings there open

Pathways spoke to 181 people about this including:

- 78 self advocates
- 14 family members
- 41 people who worked for providers
- 47 people who worked for the public sector



58 people said they or a family member had once stayed in a mental health hospital.

20 people were currently in Calderstones.



## 1. What different support do people need to live in the community?



People said...

The Care Act is making it difficult for people to get the right support.



There should be more specialist staff like learning disability nurses working in the community.



All support should be person-centred.



Different types of services should be working well together.



People should be able to use everyday health services.



There should be someone checking that people are getting really good outcomes in the community.



Self advocates and families need good emotional support.



There's a need for more mental health services based in the community. You should be able to see a mental health nurse in a GP surgery.





There is a need for more step up and step down services. People need somewhere to go that isn't a hospital when they are having a crisis.

People have gone to hospital because there is nothing else. Hospitals are noisy and are not good for people who don't like noise. It needs to be somewhere in community where people can have extra staff around them.



People need help to keep safe. When they come out of hospital they may be afraid of rejection and stigma. When they come back out into the community, neighbours might say 'we don't want your sort. Get back to the hospital. Why did they let you out?'

So people need information about hate crime and mate crime, recognising abuse and keeping safe in the house and in the community.



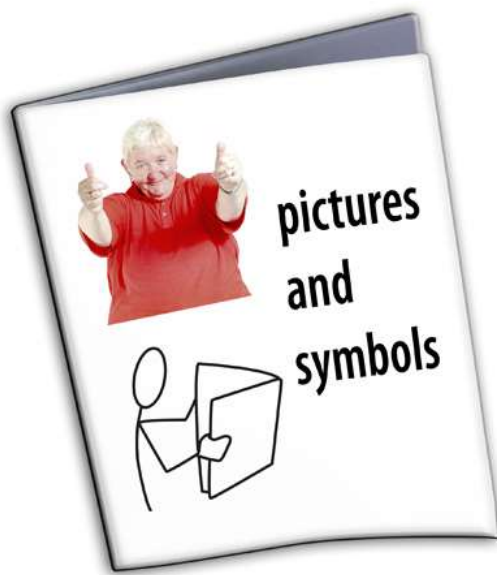
One of the things needed is learning skills. If you're in a hospital then you don't spend money because everything's provided for you. You get your food provided even though it's crap. But when you come out you need to learn this again.



Lots of people said it was important that their support workers stay the same. People get upset when their support workers change a lot. They also wanted to keep the same social worker



When people leave hospital they should not go from one institution to another in the community. Sometimes, because of funding issues, they end up in a big residential home. Some people have DoLS applied to them or there isn't enough staff to take them out. So they end locked up in a worse situation than they've come from.



People need to find appropriate and accessible information about the community to make informed choices.

There should be information on places to go to make friends, meaningful supported employment, volunteering and education including life skills training.



People might want a friend or buddy to help them move back into the community.



People need circles of support and someone to talk to.



People need independent advocacy. Not everybody needs IMHAs but they do need somebody to support them to speak up. An independent advocate doesn't have the same constraints.



People need to make friends and form relationships. They struggle with social isolation and loneliness which doesn't help their mental health.



A good short breaks service can stop people getting to the point where they need to go to hospital.



There is a need for good transition plans that cover where the person will live, what type of house, who will support them etc. It should also say what will happen if things go wrong.



It is important to have the right house that the person wants to live in and, when someone comes out of hospital, to have someone to show them the area and what's available in the community, for example self advocacy groups.





## 2. When should people go to hospital?



People said...

- When everything else has failed - as a last resort.



- When they need treatment



- When they may hurt themselves or others



- They should not go to hospital just because they don't have the right support.



**3. Some people have to live in locked places because of the Mental Health Act. What should these locked places be like?**



People said...

They should be near to where the person lives.



They should be regularly checked.

Self advocates should check that the service is well run.



They should enable people to access the local community.



They should be easy to get to with good transport links.



They should have areas that are quiet and calm.



They should make it easy for friends and family to visit.



They should look like home not a hospital.



There should be activities that people want to do.



People transferred from prison should get the same money as others.





There should be access to facilities like a swimming pool, garden, gym and cinema.



There should be opportunities to learn new skills.



There should be no big wards. People should have their own bedrooms and bathrooms.



There should be smaller, more local services.



There should be regular visits from experts by experience.



They should get people ready to leave the hospital.



They should allow people to take risks and learn from their mistakes.



They should look after people's physical health as well as their mental health.



There should be a plan in place from when they go in saying when they will leave.



There should be separate units for women and for people with Autism.



There should be a step-down service you use community services like shops, social workers and GPs. They need to see if it's going to work.



The person should be at the centre of any decisions made about them.



People should be supported to prepare meals rather than have them made for them.



Family and friends should be able to visit at any time.



#### 4. What do you think about the options proposed by NHS England?



Lots of people who came to the consultation said that the hospital should be closed altogether.



They said there is a need for a new approach with more money spent on supporting people to stay in the community.



They felt people should not be in large institutions.

Instead people should be in smaller units which are close to where they come from.



They said people have been abused there years ago.

The hospital still has bad memories and stigma for some people.

They said this is a chance to change the culture of the hospital and the staff.



Lots of other people wanted to keep the newer hospital buildings open.



They said it was a waste of money to close it as Maplewood has just been built and has good facilities.



They were worried that specialist staff would leave if the service moved to other places.



They did not want a private provider to run the services instead.

They were worried that this would lead to abuse like Winterbourne View.



They worried that 3 years is not long enough to make these changes.



They worried there may be nowhere for people with learning disabilities or Autism to get mental health treatment.



They liked the idea of running a smaller service on the site.



Lots of people said they could not decide between the 2 options.



They said there is not enough information to make a decision.



Many people said they were angry about medium secure services moving to the Ashworth site in Maghull.





They said they had not been told when the consultation was taking place.

They felt they had not had a chance to have a say.



They did not like the move because they felt Ashworth has a bad reputation.



Some people felt that the consultation document was biased towards option 1.

Some people were worried that the decision has already been made.





## 5. What did service users at Calderstones say?



We spent 3 days talking to people who currently use the hospital.



Hospital staff were in the room for most of the time.



People had lots of good things to say about the hospital.

One person said it had saved their life.



Lots of people said the staff that work there are very good.



People liked being part of the media crew and making videos.



One person said that going there had stopped them needing to go to a high secure unit.



People were also asked what is not good about the hospital

They did not like agency staff as they did not know them as well.



They said they do not get out enough.



Lots of people complained about the meals.



One person said they should not have seclusion.



Lots of people said there is a need for more members of staff. Some people had been stopped from doing things because there were not enough staff available.



Nearly everyone agreed with the 2<sup>nd</sup> option of keeping the newer buildings open.

Some people wanted all of the services to stay open on the site.