

# People with Learning Disabilities in Surrey

What people said



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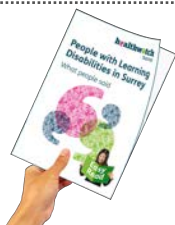
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# Introduction



Healthwatch Surrey has been talking with different people with learning disabilities and some parents and carers.



We talked with them about what it is like for someone with a learning disability to:

- Get help from local health services



- Get help from the local council's social services



We have used the things that people said in this report.

# People with a learning disability in Surrey



There are about 22,000 adults with a learning disability in Surrey.

About 4,000 adults with a learning disability get support from Surrey County Council.



People with a learning disability are living longer healthier lives. But on average they live 20 years less than other people.



Fewer people with learning disabilities in Surrey have a job now than 8 years ago.



Fewer people with a learning disability live in their own home or with their family than the average for England.



Surrey's Health and Wellbeing board want to improve the health of children with special educational needs or Autism.

# What we did



We talked with adults with learning disabilities and parents of children with special educational needs or Autism in different places:

- 12 people at a YMCA group for young adults with a learning disability



- 8 people at Active Prospects



- 2 young people who use Young Epilepsy services



- 5 parents of children who are involved with Disability Challengers and the Orpheus Centre



- Groups of people with learning disabilities who were interested in the Improving Healthcare Together Programme



# What people said



People with a learning disability are all different. They want to live different lives.



## **What matters most to people with a learning disability?**

People said that they wanted to be happy, healthy, safe and lead good lives.



Many people with learning disabilities told us they don't like change. Change can make people worried.



People often wanted to keep things as they are.



## Going to hospital

Many people with a learning disability had more than one health condition.



They often have to go to hospitals.

Hospitals can be difficult for people with a learning disability. They can be crowded, noisy and scary.



Sometimes they have to wait all alone. They don't know if the hospital staff know that they have a learning disability.



It would be better if hospital staff could use Makaton.



Sometimes the support worker can't stay with them in hospital because the support organisation does not get money for this.



People can be frightened that they may be sent away, to another hospital.

## Your local doctor (GP)



It can be difficult for someone with a learning disability to check-in by themselves at a doctor's surgery on the computer. Many people said they can't remember their date of birth.

## NHS 111



NHS 111 is a free telephone number you can phone to get help and advice about your health and access to some services.



If you phone 111, the staff don't ask you if you have a learning disability.



So the person with a learning disability has to remember to tell them.



The questions can be hard for someone with a learning disability.





## **Mental Health services**

One person told us about problems with the Community Mental Health Recovery Service.



The team were not treating him in a good way.

The team were not working in the right way.



## **Sexual health services**

One person told us about problems with a sexual health service.

You had to make your appointment online on a computer. This is very difficult.

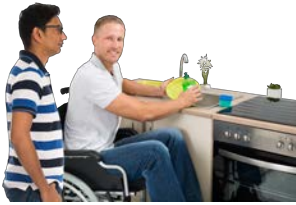


The NHS changed the company that was giving the service. The new company couldn't see the person's health records.



The person wasn't able to remember all the things about their health.

This could be dangerous. Doctors might give the wrong treatment.



## Support for living

People get support to help them to live an independent life.



The council's social worker will meet with people and work out how much support they need. The council may pay for the support.



Often you get support from a support worker who works for a care company.

Sometimes people will have an **advocate**.



An **advocate** is an independent person who will help you to speak up or speak up for you in meetings.



We heard that one person was left without any support when the care company stopped supporting them.

Another person gets no reply when he tries to phone social services.

His advocate stopped working and he is having difficulty to get the help he needs.



Another person has a physical disability as well as a learning disability. He is worried that the new social workers don't understand his needs.



A carer told us about her son who had a care plan and a key worker. The council won't pay for one of the services he needs because they say it is leisure.



## Getting a job

Some people we spoke to with a learning disability had a job.



Most have voluntary jobs that are not paid.

People say that voluntary jobs can help them learn skills and feel good about themselves.



Some of the people had jobs that are paid.



## Benefits

Some people said that it is difficult to understand what happens to your benefits if you get a job.



Many people know where to get help, but it can be very complicated.



## Travel

Disabled people used to be able to travel for free before 9:30am. Now they have to pay.



This can make it hard to get a job.



## Places to live

People often live in supported accommodation or residential care.



One man was living in supported accommodation but the money to pay for it had stopped.

He was asked to pay a lot of money and didn't understand why.



He wasn't given any information about the money for his support.



Some people with learning disabilities live in ordinary houses or flats.



They said that sometimes they don't feel safe. They are worried about bullying.



# What parents said



## Good support

Some parents told us about great support services.

Some services have great facilities and really help the young people.



These parents were good at keeping in touch with each other.



Many young people with moderate needs get a lot of support from their schools.



## Difficulties

Parents talked about the difficulties in getting good services.



Often the hardest problem is with getting the young person to school, college or the service on time.



Many parents told us that schools are always changing their minds about whether they can help a disabled child.



Some parents say they have to fight to get a good service for their child.



Some parents said they had to wait for years before meeting with a social worker to work out what services they can get.



## Very young children

Some parents said that the NHS and local council should spend more money helping children when they are very young.



A parent told us that if people with a learning disability got the right support when they are very young they will be able to do more when they are older.



Some parents said they weren't given enough information about the services that they could get.



## **Working together**

Many parents said that services should work together better.



## **Being listened to**

Some parents said that professionals don't spend enough time finding out about their children's problems.



This means that carers feel stressed. They feel that professionals don't listen to them.



## **Transition**

Transition is when a young person moves up from children's services to adult services.



Many parents said that this is a very difficult time.

# Next steps



We will share this report with:

- The people that talked to us, and helped us with this report



- Managers at local health services and the local council



- People who provide services to people with a learning disability



- Surrey Care Association

# For more information

If you need more information please contact us by:



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