LDE
Learning Disability England

How we Survive & Thrive

How we Survive and Thrive:
The people with learning disabilities' pandemic commission



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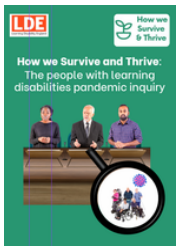
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About this report



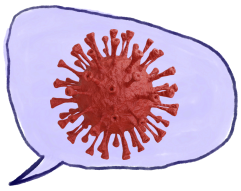
This report is about a **Commission** called ‘How We Survive and Thrive’.



A **Commission** is a project that works together to answer a question or understand something that has happened. It collects evidence and makes suggestions on things that should change.



People with learning disabilities and family members led the Commission.



We spoke to other people with learning disabilities and relatives about what life was like during the **COVID-19 Pandemic** and what needs to change.





COVID-19 Pandemic was a new illness that spread around the world and made many people very ill across the world.



In this report, we talk about people with learning disabilities.



We know some people use different words to describe themselves, like learning difficulties. This report includes them too.



What we learned from the pandemic



Things were already not fair for people with learning disabilities before the pandemic.



COVID-19 made this worse. People with learning disabilities were much more likely to die of COVID-19 than people who do not have learning disabilities.



Support stopped or was reduced when people needed it most.



This left some people feeling like they were alone and frightened. It put people at risk of harm.



Many people did not understand what was happening or what the rules were.



Often, as people with learning disabilities and families, we felt that we were ignored when important decisions were made. This made things worse.



A lot of the things people said were needed should already have been happening. This includes things that the law says must happen. But they did not happen.



We want government, councils and services to work with us to make changes so that people can live better lives.



This will help us to be better prepared if there is another pandemic.



Support is important to people

They reduced my hours with no warning from 6 hours to 2 hours!





In a crisis, people need more support. But many people got less.



Some people were left with little or no support at all. Many families had to cope on their own and were under a lot of pressure.



People with learning disabilities who do not get **social care services** were often missed.



Social care services are often arranged by the Council to help people to get on with their everyday life and stay safe.



People who arranged their own support using **Direct Payments** were also not thought about when the government made rules and guidance.



Direct Payments - money that the Council gives people so that they can arrange their own support, instead of the Council arranging it.



Day services closed and some services moved online only. This worked badly for many people.



Some people had to use new services for the first time, like food banks.



Fewer people checked if things were ok. **Inspections** of services stopped for a while and most **advocacy** moved online.



Inspections means checking whether services are good and safe, then taking action if they are not.



Advocacy- someone on your side to support you to understand information, speak out and be in control of your life.



It was hard for some people to get masks.



Children were especially badly affected. Schools closed. Many children did not have computers to use. Some children missed therapies. Parents could not get support if they got ill.



Many staff worked very hard to support people. As one person told us:



Mine went above and beyond to support me.



Family members did everything they could to help their relative when things were very difficult.



Some people felt well supported and were able to make choices about their lives.



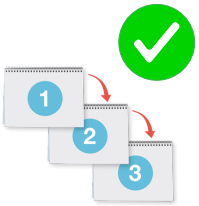
But there were big problems because people with learning disabilities had their support taken away when it was needed most.



Some people felt the government did not always understand how social care is different for people with learning disabilities than for older people.



What must change:



- Services must plan ahead for a crisis.



- Support must not stop in a **crisis**.



A **crisis** is when things go wrong. They can happen to you or can happen to everyone at the same time. Covid is an example.



- Support should increase when people need more help.



- Councils must make sure each person with learning disabilities has someone to check how they are, including people who do not get support.



Health



My **psychiatrist** phoned me.
I would just say *'I'm okay'* so they wouldn't know what was going on.



A **psychiatrist** is a doctor who helps look after your mental health.



People with learning disabilities have poorer health and often die younger than people without learning disabilities.



Things are even worse for some people. Many people from Black and Asian communities and people with high support needs had a very bad time during COVID



During the pandemic, people with learning disabilities were more likely to go to hospital or die from COVID than other people.



It became harder to get help from doctors and health services. Phone or online appointments often did not work and problems were missed.



Some people were treated unfairly. Some decisions were made about groups of people, not individuals. This put people at risk.



Some doctors filled in forms saying not to try to start a person's heart again if it stopped. It looks like they did this because the person had a learning disability.



People's **mental health** got worse.

Mental health is about how we feel and think. If our mental health is not good, our feelings or thoughts may upset us.



Mental health support for children and adults was not always good enough for people with learning disabilities.



Things improved when people with learning disabilities and people who supported them were listened to. For example, it was made easier for people with learning disabilities to get protection from COVID.

My second vaccination took place at home, which worked much better.





A **vaccination, or vaccine,** is sometimes called a jab. It is when you get an injection to stop you becoming very poorly.

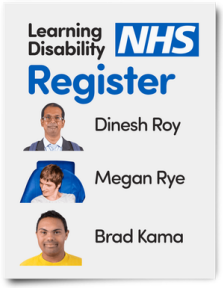
What must change:



- Health services must do the things that are known to help people with learning disabilities.



This includes making sure that people with learning disabilities are on the **GP Learning Disability Register**, so that we can get the health support we need.



GP Learning Disability Register – this is a list at a GP surgery of people with learning disabilities.

It helps people get the health care they need.





It also includes **annual health checks**, **health action plans**, **hospital passports**, and learning **disability liaison nurses** in hospital.



Annual health check - this is a health check people with learning disabilities have a right to every year.



Health Action Plan - A plan that says what someone needs to do to stay healthy and what support is needed.



Hospital Passport - Information about a person that helps the hospital to know what support is needed.



Learning disability liaison nurse - A nurse who helps people with learning disabilities get the right support and treatment in hospital.



- **Health services** must make **reasonable adjustments** so people can get the treatment they need.



Health Services – Places that help people to look after their health. It can mean places like the GP surgery and hospital.



Reasonable adjustments - changes that disabled people can ask for so that things work as well for them as they do for other people.



- **Healthcare decisions** must be made about individuals.

Healthcare decisions – understanding and making choices about your health and treatment.



Doctors and nurses and other people who work for health servicesmust not give people worse treatment because they have a learning disability.



- Health services must treat people with learning disabilities as a priority, including during a pandemic.



- **Service providers** should support people to make healthy choices in everyday life.



Service providers are organisations that give you support when you need it.

Information



Things changed all the time, and it was confusing.



During the pandemic, communication was very poor.



There was not enough accessible information for many people, for example:

- not enough **Easy Read information.**



Easy Read information is things written so that they are easier to read. Not using difficult words. Not using long sentences. Using pictures to make things clearer.



- not enough **BSL (British Sign Language)**.



BSL (British Sign Language) - a language used by many Deaf people. It uses hand signs, facial expression and body movements.



- not enough information in different languages.



Some people did not get any information at all or could not understand it. Many people did not know what was happening or what to do to stay safe.



Poor communication meant that some people found information which was wrong, especially about vaccines. This made people worried and scared.



Not everyone could use online services, so some people were left out. People must be able to get information without being online.



Voluntary groups and **self-advocacy** groups tried to make information more accessible, but this did not happen everywhere.



Voluntary group - a group or organisation that helps people in the community.



Self-advocacy group - people with learning disabilities who meet to speak up for themselves and to make change happen.



Information should be planned and properly funded.



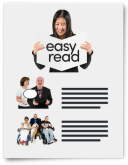
People with learning disabilities must be involved in making accessible information.



What must change:



- Information must be clear, easy to understand and given to people early.







- Information must be in ways people can use, including Easy Read, BSL and different languages. It must be given to families and support staff for when people need help to understand.



- People must be able to get information without using the internet.



- Self-advocacy organisations must be supported so they can help people understand information and speak up.



Decision-making



I don't think anyone wanted to hear what I had to say



People with learning disabilities were often not listened to during the pandemic.



Many people were not involved in decisions about their own lives, including their care and support.



Being in control and making your own choices is an important part of living a good life.



People with learning disabilities were not thought about enough when big decisions were made about plans and rules.



Some people were less likely to be heard.



This includes people from minority ethnic communities and people with higher support needs.



Self-advocacy organisations helped some people to be heard, but this did not happen everywhere.



Many people did not have enough support or advocacy to be heard.

What must change:



- People must be listened to and involved in decisions about their lives.



- People with learning disabilities must have a strong national voice so government hears our views and acts on them.



- Government and councils must involve and listen to people with learning disabilities, families and their organisations before making big decisions which affect us.



- People must have clear information and advocacy to take part in decisions. Family and trusted people should be involved if the person wants this.



- People with learning disabilities must be included and valued in planning and decisions: before, during and after a crisis.



Relationships and doing things that matter



I missed my dad and friends.



People need to spend time with family and friends and do things that matter. People need to feel part of their community.



During the pandemic, many people with learning disabilities lost their sense of purpose and connection.



Some people lost jobs or volunteering. People could not see partners, family and friends and many people felt they were alone.



Some people with learning disabilities are carers too, they often did not get extra support from social care.



Many people living in care homes and houses where staff supported them could not see the people they loved for a long time.



People could not go out to places where they usually meet other people, like community groups, day services and places of worship.



When things moved online, people who could not use them were left out.



Being online helped some people stay in touch, but not everyone could do this.



Some people were more affected than others, especially those without good support.



Children missed school and support. This affected them and their families.



Some people lost confidence and independence, and this has not always come back.



Good and trusted support made a big difference. Where people had good support, they were able to stay connected, find new ways to communicate and develop new skills and interests.



What must change:



- Councils should support self-advocacy organisations so that we can stay connected, speak up and take part in our communities.



- Service providers must help people to keep doing things that matter, including work, volunteering, and education.



- Everything possible should be done so that people can keep seeing friends and family safely.



- Service providers must help people get access to and use online tools if they want to and make sure people can take part face to face.



- Government, councils, and employers must make sure that it is easier for people with learning disabilities to get work, volunteering and education.



They must plan so that people can keep these things going even during a crisis.



Making the future better



We need to bring people together, surround them with community, and make sure everyone's voice counts.



People with learning disabilities were much worse affected by the pandemic than people who do not have learning disabilities. This must not happen again.



We know what needs to change.



People with learning disabilities and families must be listened to and involved in decisions.



Government, councils and services must act on these recommendations and show what has improved. We must be able to see what has changed as a result.



This is everyone's business.

Together, we can make sure that people with learning disabilities are included, treated fairly and able to play our full part in our communities.



Find out more about our work at:
https://www.learningdisabilityengland.org.uk/surviveandthrive

With thanks to our partners and funders:

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