

Good Lives: Building Change Together

Plain English summary



The Good Lives Framework

What is this about?

Good Lives aims to create change that will help people with learning disabilities live good lives.

This document is the project's starting point.

It includes chapters about things that people with learning disabilities and their families have told us are important to them, for example, communication and staying connected.

In each chapter, there is information about:

- What matters to people about the issues.
- What we need to do to make change happen.
- How we can use the UN Convention on the Rights of Persons with Disabilities to guide the change.

The convention is an agreement between countries on disabled people's rights. The countries agree not to treat people unfairly or differently because they are disabled. You can read an easy read version of the convention **here**.

Inclusion Europe made a short film that explains the convention too. You can watch it **here**.

Why this project started

It's been 20 years since the Government created a national strategy to help improve the lives of people with learning disabilities.

A lot has changed in the world in 20 years. We believe it's time people had up-to-date guidance to help change things for the better for people with learning disabilities and their families.

We also hope some of the action can start now in councils or local organisations.



Who has been involved in the project so far?

Before and during the Covid-19 pandemic, we spoke to people with learning disabilities and their families.

We also talked to organisations and health and social care professionals who support people with learning disabilities.

The ideas for this come from the work of Learning Disability England members or partners – there are lots of examples of good work to build on.

We understand that today lots of people with learning disabilities still aren't being treated well. For some people that is really serious and they are stuck in bad situations. Most people tell us they experience unfair treatment in some part of their lives.

This framework is not trying to ignore the bad things. It is trying to find and share positive actions to change things for the better.

The chapters focus on what we all could do to make sure people can live their good life.

We know that Black Asian and Minority Ethnic people with learning disabilities often get left out. We want to make sure what is important to them is included in the framework.

This is a starting point. We know it can be better. Please help make this better by getting involved.

How can I get involved?

We want to hear from as many people as possible about what they think about this document, both good and bad.

If you are part of a group or network please share this with them or ask us to come and talk about it. We know Black Asian and Minority ethnic people and people with high support needs are often not included in work like this. We will work with members and partners to included their voices.

You can get involved by asking people what they think or telling us what you or your organisation think.

You can do this by emailing info@LDEngland.org.uk or calling 0300 1110444.

We will use all the feedback we receive to develop this document and share again what people agree is important to do for change.

We will use it in our work with people with learning disabilities and their families to change things for the better.

We hope this will help everyone get the change they want in their area or across England.



Chapter 1:

A home

We asked people with learning disabilities what is important to them about home and family life. They said:

- Everyone should be able to choose where they live and who they live with.
- It's wrong that some people with learning disabilities are made to live in unsafe areas.
- They are worried more people with learning disabilities will be made to live in care homes and hospitals because of a lack of money.



UN Convention on the Rights of Persons with Disabilities (UNCRPD)

What people said they want from home and family life is similar to the basic rights outlined in Article 19 of the UNCRPD. It focuses on people with disabilities living independently and being included in the community.

We will use Article 19 to guide our work on improving home and family life.

There is easy read information on Human Rights **here**.



Next steps

1. People with learning disabilities, their families and carers, housing providers and social workers need to work together to make sure people with learning disabilities get the homes they want and need.
2. The Government needs to fund more homes that are right for people with learning disabilities; reduce social housing rental costs; ensure people with learning disabilities receive enough welfare support to live in their homes.
3. Local councils need to provide better housing options for people with learning disabilities and offer financial support to help them live good lives, be independent and feel more connected to their communities.
4. People with learning disabilities need to be provided with high-quality information and support to help them access housing that's right for them.



Chapter 2:

Communication and staying connected

We asked people with learning disabilities what is important to them to stay connected with others. They said:

- They want information they can understand. And they want it quickly when they need it.
- They want to have technology that helps them stay in touch with other people and find information they are interested in.
- People want to be able to talk to other people who are having the same experiences. These people could live near them, somewhere else in the UK or in a different country.
- People with learning disabilities often don't know what support is there for them when they are finding it hard to stay connected.
- Services do not always think about the communication needs of people with learning disabilities.
- People with learning disabilities need easy-to-understand information to stay healthy, safe and well.



UN Convention on the Rights of Persons with Disabilities (UNCRPD)

What people said they want is like the rights in Article 21 of the UNCRPD.

Article 21 is about freedom of expression and opinion, and access to information.

We will use Article 21 to help our work on communication and living well.

There is easy read information on Human Rights **here**.



Next steps

1. People who support someone with learning disabilities at home and people who support them outside of the home need to work together.

They can help people with learning disabilities who need extra help to communicate by sharing knowledge and experience.
2. We need to share examples of how technology was used during the pandemic to help people with learning disabilities connect and live well.
3. Health and social care providers need to make sure their information is easy for people with learning disabilities to find and to understand.
4. Everyone needs to work together to make sure people with learning disabilities have computers and can connect to the internet.

We also need to make sure people with learning disabilities and the people who support them get good training and support on how to use technology.

5. Local councils need to find out what communication support there is for people with higher support needs.

They need to make sure people get the support and the technology they need to communicate well. Things like speech and language therapy.

6. People with learning disabilities and their carers need to know it is their right to have the help and support they need so they can communicate well.



Chapter 3:

The right support

We asked people with learning disabilities and their families what the right support looks like to them. They said:

- Good support is about life, not services.
- It's important to be supported by the same people, so good relationships can grow.
- Relationships should be based on trust and equal power.
- People with learning disabilities feel forgotten about. The Government seems to spend more time talking about improving the lives of older people than the lives of people with learning disabilities.
- Making services better should not just be about spending money. Service providers also need to look at whether a service needs to change.



UN Convention on the Rights of Persons with Disabilities (UNCRPD)

What people said they want is like the rights in Article 26 of the UNCRPD.

Article 26 is about making sure people with disabilities get the help they need to live well and feel included.

We will use Article 26 to help with our work about people with learning disabilities and their families getting the right support.

There is easy read information on Human Rights **here**.



Next steps

1. We need to make sure people with learning disabilities and their families are the ones who decide whether a service is good at supporting them or not.
2. The Government, local councils and service providers need to work more closely with people with learning disabilities to develop services and support.

3. Support should be based on the REACH Standards.

The REACH Standards look at how people with learning disabilities can live a good, ordinary life.

4. People with learning disabilities, their families and the people who support them need to work together more.

They need to tell each other what is not working well and things they are not happy about.

For example, some overnight support workers only being paid when they are awake and not when they are sleeping.

Chapter 4:

To love and be loved

We asked people with learning disabilities and their families what is important to them about relationships, loving someone else and being loved. They said:

- Loving and sexual relationships involving people with learning disabilities are not seen as important or supported.
- People living with disabilities having sex is seen as a health issue rather than something they have a right to do.
- Support services often stop people from having full social lives.
- Keeping family relationships was not a main concern during the pandemic. This was especially the case in places where people live together but they are not related.
- Professionals often focus more on how family members support a person with learning disabilities rather than loving family relationships.
- A lack of support for families during the pandemic left them struggling with their emotions and without enough money.
- People with learning disabilities are concerned that services don't care about their relationships.
- Carers are worried what will happen to loved ones with learning disabilities when they can no longer care for them. This is because of the quality of support services.



UN Convention on the Rights of Persons with Disabilities (UNCRPD)

What people said they want about relationships and love is similar to the basic rights outlined in Article 23 of the UNCRPD.

Article 23 is called 'Respect for home and the family' and talks a lot about personal and intimate relationships.

We will use Article 23 to guide our work on home and family life.

There is easy read information on Human Rights **here**.



Next steps

1. Providers of support services need to follow the No Bedtimes guidance developed by the charity Stay Up Late.

The guide has been created to help people with learning disabilities enjoy evenings out and have a full and active social life.

2. Providers of support services need to work together to promote that people with learning disabilities have the right to love others and be loved.

3. During its inspections, the Care Quality Commission needs to check if people are receiving the support they need to express their sexuality.

A CQC inspection also needs to look at if people are getting support and education to have close relationships and maintain them if that is what they need.

4. Local councils and service providers should give people the support they need to have a good family life and relationships.

5. All social care workers need to receive training on how they can help people express their sexuality and have close relationships.

6. The REACH Standards should be met to help people with learning disabilities live a good, ordinary life.

This includes them having the freedom to choose their relationships.

7. A large campaign needs to be launched to raise awareness of the sexual rights of people with learning disabilities.

Chapter 5:

Advocacy and self-advocacy

We asked people with learning disabilities what is important to them about speaking up for themselves and what they care about. They said:

- We need to raise awareness of our right to have our voice heard.
- We need access to easy-to-understand information to help us speak up.
- People with learning disabilities should be listened to. Their experience is more important than the qualifications of professionals.
- People with learning disabilities may have different ideas to their families.
- Let people with learning disabilities take risks.
- Language should be used that respects people with learning disabilities.
- People with learning disabilities should be paid for the work they do and the knowledge they offer.
- We need to help people with complex disabilities have their voices heard.



UN Convention on the Rights of Persons with Disabilities (UNCRPD)

What people said they want with regards to having their voice heard is similar to the basic rights outlined in Article 5 and Article 17 of the UNCRPD.

Articles 5 and 17 focus on equality and respect for people with a disability.

We will use Articles 5 and 17 to guide our work on helping people with learning disabilities speak up for themselves and what is important to them.

There is easy read information on Human Rights **here**.



Next steps

1. We need to help self-advocacy organisations grow and get stronger so they can help more people with learning disabilities speak up for themselves.
2. The Government needs to help self-advocacy organisations connect with each other so they can achieve big changes through the Disability Strategy.
3. The Government must work with people with learning disabilities before making decisions that affect the lives of people with learning disabilities.
4. People with learning disabilities should always be asked to lead, be part of or speak at events or meetings about people with learning disabilities.
5. We need to create one online space where people can access easy-to-understand information that will help them speak up for themselves.
6. People who plan services need to share good ideas about how self-advocacy groups can earn money to help them be more independent.
7. We need a quality scheme and mark that shows people with learning disabilities have helped to create information materials or led that work.

The scheme and mark should also be used to show that people with learning disabilities have helped to create, or are delivering, a service.

Chapter 6:

Employment and contribution

We asked people with learning disabilities what is important to them about working and contributing to society. They said:

- Everyone with a learning disability should get good support to help them find, get and keep a job.
- Adjustments need to be made to jobs so they encourage more people with learning disabilities to apply for them.
- The Equality Act is not clear and employers do not always follow it.
- There are no targets for the number of people with learning disabilities who should be employed in England.
- The usual way employers recruit for jobs makes it hard for people with learning disabilities to show off their skills and talents.
- Employers don't understand how they can use the Access to Work scheme to help people with learning disabilities in their job.
- Employers are not using the helpful information available to them to make it easier for people with learning disabilities to apply for a job.
- The benefits system is confusing and people are worried about losing benefits that are hard to apply for.
- The education system does not inspire young people with learning disabilities to achieve a lot in the future, such as getting a job.
- Some young people do not get to see what it is like to have a job because they don't get the chance to do work experience at school.



UN Convention on the Rights of Persons with Disabilities (UNCRPD)

What people said they want with regards to employment and contributing to society is similar to the basic rights outlined in Article 27 of the UNCRPD.

Article 27 focuses on work and employment for people with a disability.

We will use Article 27 to guide our work on helping people find, get and keep a job or volunteer role, or contribute to society in another way.

There is easy read information on Human Rights **here**.



Next steps

1. Organisations that support people with learning disabilities must make sure everyone can contribute to society through work, volunteering or another way.
2. The Government needs to find out and tell us how many people with learning disabilities have a paid job.
3. The Government needs to invest money so local employers can provide high-quality support that helps people with learning disabilities work.
4. The Government needs to work with people with learning disabilities and employers to develop guidelines on providing good employment support.
5. The Government needs to make sure the Access to Work scheme and welfare benefits help more people with learning disabilities to work.
6. Local councils should find out how many people with learning disabilities have a paid job in their area.

This number could then be used to check if local services are giving good support to help people find, get and keep a job.

7. From an early age onwards, we must inspire and tell people with learning disabilities that they can contribute to society.

This includes telling them about their rights and sharing success stories.

Acknowledgements

We, at Disability England, say thank you to the many people with learning disabilities, their families, allies and supporters who shared ideas, time and worked to make what is in this framework.

Thank you to everyone who shared their personal stories and agreed for those to be shared here.

Thanks also goes finally to Dr Sam Smith of C-Change for writing this report.



We would love to hear from you

www.learningdisabilityengland.org.uk

info@LDEngland.org.uk

Or call our office on 0300 1110444