

2025 REFRESH VERSION PLAIN ENGLISH SUMMARY

THE GOOD LIVES FRAMEWORK: BUILDING CHANGE TOGETHER



What is this about?

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

It is a campaign that includes:

- Reports with evidence or examples from people with learning disabilities, their families and supporters.
- Examples to help organisations work on Good Lives and what matters to people with learning disabilities.
- Ideas for how people or organisations can take action locally or nationally.

Good Lives is led by what people with learning disabilities told us is most important.

It is about making change so people with learning disabilities get to live a life with choices and opportunities like other people.

The project includes all Learning Disability England members but people with learning disabilities have the final say on what Good Lives should focus on.

This work started in 2022 with the 1st **Good Lives Framework**. Since then thousands of people have read the framework or used it to help them make changes.



In 2024 more than 400 Learning Disability England members worked on the **Good Lives Manifesto**. This manifesto has been built from lots of campaigns and actions.

Good Lives is supported by Learning Disability England, the member-led national organisation which brings together people with learning disabilities, families, organisations and paid supporters.

Learning Disability England does not own Good Lives – it is there for anyone to use to make changes in their work or campaign on issues.

You can **add examples** or share stories to help others get involved in Building Good Lives and making change.



Why work on Good Lives?

It's more than 24 years since the Government created a national strategy to help improve the lives of people with learning disabilities.

The world has changed a lot in 24 years.

For many people with learning disabilities not enough has changed – many people do not get to live their Good Life.

This is because of policies by the Government or Councils or the way society works. The Reigniting Debate project has written about how people with learning disabilities lives compare to other people's. You can read about that on their website **Reigniting debate and stimulating a momentum for change: the role of research findings in engaging policy makers with current priorities for people with a learning disability.**

People with learning disabilities from minority ethnic communities are often not included when policies are made and too often do not get the same healthcare as other people. The report about that is **here**.

Sometimes having a learning disability means other important parts of people's lives are ignored and policy or services only see one part of them and their experiences. For example people's ethnicity or gender or sexuality might be ignored.

This update of Good Lives wants to make sure all people with learning disabilities can live a good life.

At the same time we know there are some really good things happening. There are ways of working that others can learn from.

Action towards Good Lives can start now if organisations learn from the good examples.

Some action might take longer as policies need changing but everyone can start working towards change now.

What is in this report

The Good Lives framework 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.
- Actions we can work on together.
- How we can use the UN Convention on the Rights of Persons with Disabilities to guide the change.
- Examples of what is good now and people want to see more of.

We have included ideas too from the Good Lives Manifesto. You can see examples of What is good now and find links to more information in the Good Lives Action collection [here](#).



How can I get involved?

We want as many people as possible to use this report or talk about Good Lives.

If you are part of a group or network, please share this with them or ask us to come and talk about it.

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 again and share again what people agree is important to do for change.

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

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

Thank you to everyone who has been part of all the work on Good Lives and shared something.

People have been generous in sharing their great work and ideas.

Any mistakes in this report are Learning Disability England's not theirs. Let us know where we went wrong or your feedback

Find out more about Learning Disability England [About Us – Learning Disability 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.
- Services should help people understand and make choices and not 'place' them in services.
- 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 there is not enough money.



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

What people said they want from home and family life is like the rights in Article 19 of the UNCRPD.

Article 19 is about people with disabilities living independently and being included in their community.

We will use Article 19 to help us think about how to make home and family life better for people with learning disabilities.

There is easy read information on Human Rights [here](#).



Actions we can work on together

1. We need to work together to make sure people with learning disabilities get the homes they want and need. This should be based on person centred planning.

Everyone can help person centred planning happen.

2. The Government needs to make sure the grant rules for social housing make it possible to build new supported housing for people with learning disabilities.

Social housing renting rules need changing so landlords can get a grant to build a house and charge the rent that is needed.

The government needs to make sure people with learning disabilities are included in the Supported Housing Act guidance and checks.

3. Local councils need to make sure there is better information on housing choices for people with learning disabilities in their area.

They also need to offer the right support to help people live good lives, be independent and feel more connected to their communities.

4. Landlords need good information on the law and tenancies if someone has a learning disability. This can help make sure people can get the right home and not have to wait.



What good might look like

Some examples that show we are on the right track. Find out more about them in the Home Action collection [here](#).

Good example 1

The Reach Standards (from Paradigm) are a guide to good support to live – they are there to help people and services make improvements

Reach Standard 1 • I choose who I live with.

Reach Standard 2 • I choose where I live.

Reach Standard 3 • I have my own home (with a tenancy or ownership).

Good example 2

Learning Disability England have made a housing guide to support [independent living](#) for everyone. It explains the concept of independent living, different housing options and how to get and maintain your own home.



Good example 3

Disabled Facilities Grant funding allocation to Councils has been increased. The grant can help people stay in their home or make a home accessible to them. This includes children and their families.

Good example 4

The Challenging Behaviour Strategy Group have worked with others on an action plan to end the misuse of specialist mental health hospitals. This includes actions on the right housing to stop people going into hospital and for those who are prevented from leaving.



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 available when they are finding it hard to stay connected.
- Services do not always think about the communication needs of people with learning disabilities so Speech and Language or other communication support can be missing.
- 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](#).



Actions we can work on together

1. People who support someone with learning disabilities at home and people who support them outside of the home can help people with learning disabilities communicate using technology by sharing knowledge and experience.
2. 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 and NHS need to make sure the communication support is there 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.



What good might look like

Some examples that show we are on the right track. You can find these examples and more information [here](#).

Good example 1

United Response has supported the creation of Easy News, the first news magazine designed to be accessible for people with learning disabilities.

It aims to encourage discussion around news stories and keep readers informed about the world around them.

Anyone can sign up to receive an online copy of the magazine.

Good example 2

The accessible information campaign group worked with British Institute of Human Rights to produce an accessible and easy to use resource on information and rights.

They also created an Easy Read Guide to the Human Rights Act.



Good example 3

The Digital Lifeline Project helped 5,500 people with learning disabilities get online by distributing a mobile or tablet, data and assistive technology.

52% of the people reported afterwards they felt less lonely because of the device.

This built on the work of self-advocacy groups and support organisations through the pandemic to support digital inclusion.

Good example 4

The Valuing People Alliance has coproduced some top tips of how health and social care services should work to make sure that people are digitally included.



Good example 5

Communication Top Tips for healthcare staff resources were coproduced by the Northeast and Cumbria Learning Disability Network and the Involving Everyone group.

The resources give healthcare professionals tips and phrases to support them when meeting and communicating with people with profound and multiple learning disability, no matter how brief their involvement may be.

Good example 6

Many self-advocacy groups are working with local partners to develop and share accessible information.

FOR EXAMPLE:

ESCC & the Involvement Matters Team develop easy read information and have just developed easy read web pages.

Involvement Matters Team have an easy read reference group where self-advocates review information and put their stamp of approval before it can be agreed and sent out.

They have supported the development of an Easy read Total Communication pack. The group has helped trial the NHS App and is co-delivering Digital Lives training.

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 is 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](#).



Actions we can work on together

1. Make sure what matters most to people with learning disabilities and their families are what decides if a service is good at supporting them or not.
2. The Government, local councils and service providers to work more closely with people with learning disabilities to develop services and support. This includes sharing power and decisions on how services work.
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. Make sure the Employment Rights Bill includes making direct support worker pay and wider terms and conditions better and that services are properly funded to do that.
5. Organisations and people work together on making the workforce strategy happen so all the staff supporting people with a learning disability are supported and trained.
6. The Association of Directors of Social Services (ADASS), Local Government Association (LGA) and NHS England (NHSE) make it important for services to make recruitment and staff should support relationship focussed. Including asking that commissioners co-design practice guidance with local people.
7. The government and local Councils make sure there is enough money for good person centred support.
8. The funding allows all the pay and conditions for the social care staff to be fair and at least the same as the same kind of NHS staff.

What good might look like

Some examples that show we are on the right track. You can find these examples and more information [here](#).

Good example 1

Flourishing Lives shares tools, resources and evidence to help supporters and organisations focus on assisting people build their good life.

They include examples of how this is happening as ‘Drops of Brilliance’.

Good example 2

The Reach Standards (from Paradigm) are a guide to good support to live – they are there to help people and services make improvements

Some Commissioners and Providers are using this to develop local services with people and families who draw on support.



Good example 3

Changing Our Lives has been working to make sure the experiences of disabled people from minority ethnic communities are seen and heard in the disability movement and in society.

Changing Our Lives collected people's stories called Colour Between the Lines and are doing other projects to share the experiences of people with learning disabilities from minority ethnic communities.

Good example 4

Social Care Futures are bringing people together to change how Social Care works based on what people who use care say.

The Social Care Future report calls for five key changes 'To unlock an equal life'.

The changes being called for are:

Communities where everyone belongs

- Living in the place we call home.
- Leading the lives we want to live.
- More resources, better used.
- Sharing power as equals.

Good example 5

The Small Margins project worked with people with a learning disability, autistic people and their families from minority ethnic communities who either lived in their own home, lived in residential care, or were moving out of inpatient hospital settings.

It also included people who lived within the family home as data suggests less people from minority ethnic communities live in residential care or supported living when compared with white people.

The Small Margins project found out:

- Issues relating to ethnicity that affect people's day to day lives in relation to the support they receive.
- Future learning.

Good example 6

The Why are we Stuck in Hospital project was led by Researchers from Birmingham University.

The research wanted to understand the experiences of people with learning disabilities and/or autistic people in long-stay hospital settings, their families and front-line staff.

They made practice guides and training materials to support new understandings and ways of working.

Good example 7

The Sensory Projects produced a set of Core and Essential Service Standards for Supporting People with Profound and Multiple Learning Disabilities.

The document was developed by over a hundred people who all have insight into the lives of people with profound and multiple learning disabilities.



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.
- 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 and since has left them struggling with their emotions and without enough money.
- People with learning disabilities are concerned services don't care about their relationships.
- Family 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](#).



Actions we can work on together

Overall people want society and communities to respect and support people with learning disabilities' right to love and be loved – family, friends, lovers and partners as they choose on their lives. Together we can work on:

1. Providers of support services to follow the No Bedtimes guidance developed by 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 as well as community friendship and social groups. This needs to be in the standards for service contracts.

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

What good might look like

Some examples that show we are on the right track. You can find these examples and more information [here](#).

Good example 1

Supported Loving is a human rights-based network meetings, hosted by Choice Support.

The network helps people understand that people with learning disabilities and/or autism should be able to enjoy the same sexual and romantic freedoms as everyone else.

They offer information and training.

The network highlights that 3% of people with learning disabilities live as part of a couple compared to 70% of the general population.



Good example 2

Stay up Late is a charity promoting the rights of people with learning disabilities to live the lifestyle of their choosing.

It focuses on that people with learning disabilities aren't able to Stay Up Late and do the things many people, who don't need support, take for granted.

They recognised that people with learning disabilities often aren't able to lead full and active social lives because their support workers finish at 10pm.

This means lots of people with learning disabilities leave events at 9pm.

People with learning disabilities have the same right to stay up late and have fun as anyone else Stay up Late have campaigned to raise awareness of the issue, issuing a No Bedtimes guide and a Manifesto for an Ordinary Life.

Good example 3

United Pride Friends are a User Led group for LGBTQ+ people with autism and learning difficulties.

It offers a safe space that is accessible, accepting and confidential.

They have regular social events as well as being part of campaigns.



Chapter 5:

Effective voice - Self-advocacy and 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](#).



Actions we can work on together

1. 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 help achieve big changes in government policy.
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.
6. People who plan services need to use the evidence and good ideas about the difference self advocacy groups makes to support self advocacy in their area.
7. Support people from Black, Asian and minoritised ethnic communities to develop self-advocacy and make sure self advocacy make space for minoritised community voices.
8. Use models like Making it Real markers to make sure people's voice is part of deciding quality and reporting in local services
9. Make more people know about human rights by sharing the work of people with learning disabilities and Human Rights based organisations like the British Institute of Human Rights (BIHR).

What good might look like

Some examples that show we are on the right track. You can find these examples and more information [here](#).

Good example 1

My Life, My Choice and British Institute of Human Rights made an accessible resource for people with learning disabilities who have been placed in long stay hospitals either when they shouldn't have been or for too long.

It aims to tell them about their human rights and how to use these to challenge having to stay in hospital.

Good example 2

The Open University has worked on two research projects about self-advocacy.

The Filling in the Gaps report looks at the role of self-advocacy groups in supporting the health and wellbeing of adults with learning disabilities during the coronavirus



pandemic.

The research showed how and where self-advocacy was 'filling in the gaps' left by other services.

The Funding The Gap report looked at how self-advocacy groups are funded. This is important because lots of groups have closed because they do not have enough money, and others are struggling to survive.

The researchers wanted to know:

- How and why local authorities and Clinical Commissioning Groups fund self-advocacy in some areas, but not others.
- How groups are funded when they receive little or no funding from local authorities.
- The pros and cons of different types of funding from the perspectives of self-advocacy groups.

They came up with a series of recommendations for how to strengthen self-advocacy.

Good example 3

The Making Sense of Self Advocacy Today report talked about the state of self-advocacy in England in 2018-19 and provided suggestions for how to strengthen it.

One example was Ace Anglia's work with its local authority and clinical commissioning groups which highlighted the benefits of partnership working.

The work helped Ace Anglia get funding and local influence.

This including co-producing the Learning Disability Strategy and securing funding to support peer education in relation to Annual Health Checks.

They also successfully campaigned for Stowmarket rail station to become step free.

Good example 4

In 2022, The Henry Smith Charity launched a Strategic Grant Programme to support 15 organisations providing advocacy services across the UK.

This three-year programme was designed to support high-quality advocacy services and foster evidence-based practice.

To evaluate the programme, The Henry Smith Charity has teamed up with Social Finance as their learning and evaluation partner, and Speakup, a user-led organisation championing the voices of those with lived experience of autism and learning disabilities.

Interim report 1 Building evidence around advocacy for learning disabilities and autism was published in December 2023 and final reports February 2025.

Good example 5

The Equal Treatment project was completed over 2022.

The project worked with 3 partners and aimed to challenge racism and health inequalities through strengthening self-advocacy and peer support.

The project helped groups think about how to be more inclusive and helpful allies to tackle racism.

Good example 6

In 2022, Learning Disability England heard from some people that there is not a lot of leadership or speaking-up training that includes minority ethnic people with learning disabilities and autistic people.

People said that training about different people's experiences and anti-racist practice was not accessible to many people.

Learning Disability England learnt about this by working with people and organisations as part of the Equal Treatment and Working Together to get the job done projects.

The outcome of this work was a report called Learning to Lead.

Good example 7

The NDTi, alongside Bringing us Together, the Challenging Behaviour Foundation, People First Independent Advocacy and Speakup Self Advocacy, did a review into advocacy.

They tried to find out what was getting in the way of people getting good independent advocacy and what helps advocacy work well.

The review produced a report available in easy read, a summary, and a full version.

Good example 8

AccessAva is an online AI-driven service that makes expert legal support available 24/7 making sure people can understand their rights in health and social care and can get the help they need.



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. That could be a paid job or volunteering or being active in their community.
- 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.
- Many 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](#).



Actions we can work on together

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 and check the number is growing.
3. The Government needs to invest money so local employers can provide high-quality support that helps people with learning disabilities work. They should use the ways of working that are good and make a difference.
4. The Government needs to work with people with learning disabilities and employers to develop guidelines on providing good employment support or welfare benefits that are fair.
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.

What good might look like

Some examples that show we are on the right track. You can find these examples and more information [here](#).

Good example 1

The Disability Employment Charter calls for the government to act.

It includes a set of important actions the government can take to help more disabled people work.

By setting out clearly and simply the actions needed, it provides government with a road map for change.

The Charter has nine areas of action.



Good Example 2

Project Choice is a Specialist Post-16 programme with college and work experience as well as a supported internship programme.

It helps young adults between the ages of 16-24 with disabilities, gain work experience and improve employability and independence skills.

An example is Hft that works with DFN Project SEARCH, and other partners to run several supported internships.

Hft's role is as the Supported Employment provider.

Every intern is supported by an Employability Coach to learn new skills while on their work placement.

After the intern graduates, they receive 9 months support to seek and apply for a paid job, and ongoing support as needed once a paid job has been secured.

Good example 3

Nationally there are supported employment projects are effectively helping people secure and keep jobs. An example of this is Strawberry Fields in Liverpool.

NDTi have resources and examples to support the growth of Employment Support for disabled people.



Chapter 7:

Health for a Good Life

The BILD for the Future group worked on what should be included in this chapter. Sessions were held at the London and Leeds Learning Disability England conferences to get feedback from people on what mattered to them.

There was also an online survey and online meetings with professionals that work in health. There were also online meetings for people with learning disabilities and family members.

We asked people what is important to them about health for a Good Life. They said:

- Health is about more than clinical checks.
- There are bigger barriers to good health for some people who cannot speak up for themselves.
- People with learning disabilities, families and support workers feel they are not listened to or respected by all health services.
- People want to be able to eat well but:
 - Limited access to affordable good food (even harder for people with dysphagia).
 - Not having good information and help on eating well.
 - Lack of accessible support to lose weight or change diet.
 - Real choice on good food in shared support settings.
- People know exercise is important but:
 - Gyms are expensive and supports costs not covered.
 - Lack of accessible information and support on exercise and different options.
 - Many support staff not confident or trained in talking about exercise and health.
 - Not having local park / open spaces.

- Many people feel isolated or lonely:
 - There is a lack of affordable places to meet others.
 - Many people do not have support or transport to go out.
 - Often social care services do not value friendships and family.
- Access to health services can be hard:
 - There are very few mental health services that offer accessible services for all.
 - Many people cannot get dentists, mental health support or accessible optician appointments.
 - There are many barriers to booking appointments or managing health advice as it is often inaccessible.
 - People 'get lost' on waiting lists within complicated systems.
 - There is a lack of reasonable adjustments that help people access health services.
 - Diagnostic overshadowing or poor attitudes to people's worth.
 - Lack of preparation, poor experience or follow up for Annual Health Checks.
 - Families and support workers feel they are often not listened to when they raise concerns about someone.



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

Article 25 of the UNCRPD is about disabled people getting the same health care as non-disabled people.

There should be action taken by the government to make it possible to access health services of all kinds including dental care and mental health services.

It says disabled people should get specialist healthcare when they need it too. You can find out more [here](#).



Actions we can work on together

- Help people understand and ask for their right to reasonable adjustments to be made to make it easier to use health care.
- Invest in community services that support people to exercise, meet other people and learn new skills.
- Make it possible for people to work or do voluntary work.
- GPs to invest in doing quality Annual Health Checks and Health Action plans.
- All parts of the NHS and Social Care to follow the Accessible Information standard so people get information they can understand and use.
- Make sure health services understand people with learning disabilities and listen to them and their families and supporters.
- Make it easier to understand the information on medication.

What good might look like

Some examples that show we are on the right track. You can see these examples and more information [here](#).

Good example 1

The VIP Red Bag is a project that helps people with learning disabilities and autistic individuals during medical appointments and hospital admissions. The VIP Red Bag holds all important health and support information.

The project has been successful by helping make sure that important information is available to healthcare professionals, allowing them to provide better, more personalised care.

Good example 2

Changing Our Lives worked with Simple Stuff works to develop 'Got your Back' information and resources on Postural Care including a Postural Care passport and resources for nurses. They help everyone think about posture and protecting body shape for those who might need it most.



Good example 3

The Josephine and Jack Project uses life-size, anatomically accurate cloth figures named Josephine and Jack as part of sessions with adults and young people with learning disabilities. These sessions talk about a range of topics, including health, well-being, relationships, sex, and sexuality.

Good example 4

The Downs Syndrome Association offers resources and activities to support the health and well-being of people with Downs syndrome. This includes the DSEngage program, free, online sessions that cater to both children and adults with Downs syndrome.

Good example 5

Hospital Trusts can find people with learning disabilities on waiting lists for treatment and take action to make sure they get treatment. Calderdale and Huddersfield NHS Foundation Trust did this as part of their work to make sure people get fair treatment.

Good example 6

Menopause Cafés are gatherings where people come together to talk about menopause over tea and cake. These events aim to break the taboo surrounding menopause, help people learn about it and share experiences.



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

