Department of Health & Social Care

Down Syndrome Act 2022: call for evidence

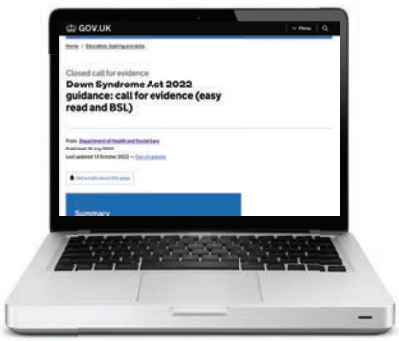
What we found out about support that people with Down syndrome get now and things that could be better

About this easy read booklet

This is an easy read of a bigger booklet called **Down Syndrome Act 2022 guidance: call for evidence - summary of findings**.

This easy read booklet tells you some of the main things people told us.

It does not tell you everything we found out.



If you want more information, you can find the bigger survey on our website:

Down Syndrome Act 2022 guidance: call for evidence (easy read and BSL)

What is in this booklet

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About the Down Syndrome Act 2022

The Down Syndrome Act is a law that was made in April 2022.

This law will help make life better for people with Down syndrome and their families and carers.

As part of the law, the government will write some **guidance**.
Guidance is like rules that organisations should follow.

This will help people with Down syndrome to get better support.

About our call for evidence

To help write the guidance, we asked people what we should put in it.
This is called a **call for evidence**.

To find out what people think, we wrote 2 questionnaires. 1 of the questionnaires was in easy read.

Over 1 thousand 5 hundred people answered our questions.

People could also tell us what they thought:

- By email

or

- By coming to an online or face to face meeting.

From July to November 2022, we heard from:

- People with Down syndrome.

- Families and carers of people with Down syndrome.

- Staff that support or work with people with Down syndrome.

- People with other conditions like a learning disability.

About our questions

We asked people questions about 4 areas:

1. Health services

These are services like your local doctor, nurse, hospital and dentist.

2. Adult social care

Social care is care and support people might need at home, in their local community or in a care home.

When people aged 18 and older need support, we call it **adult social care**.

3. Education, children and young people

Education means learning that people do. This might be at school or college.

4. Housing services

These are services that help to find homes for people.

Health services: what people told us

Support that people need in healthcare

People with Down syndrome have lots of different **physical** and **mental** health needs.

Physical health is being well in your body and **mental** health is being well in your mind.

People need support with things like:

- Eyes and hearing check ups.

- Looking after teeth and gums.

- Moving around.

- Eating and drinking.

People need good support from lots of different services to manage their health well.

This could be things like having health checks or support with communication.

People want to have staff they know and trust.

People with Down syndrome need to have **person-centred care** and support.

Person-centred care means looking at a person to see what they need. This way people get the right care and support for them.

People with Down syndrome need **reasonable adjustments**. This is when services make changes to meet a person's needs.

Reasonable adjustments are things like longer appointments or giving information in a way that people can understand.

Staff need training on how to talk to and support people with Down syndrome well.

Services need to work together to meet a person's needs.

Support from staff

Most people with Down syndrome told us they do get the health support they need.

Around half of the people felt that staff knew how to support them and talk to them.

Families and carers said this support needs to get better.

Some staff understand how to support and speak to people with Down syndrome more than others.

Just over half of staff felt their organisation supported people well.

Only 1 in 3 staff said they do know the law about supporting people with Down syndrome.

Good things that are happening

We asked people to tell us about good experiences they had with healthcare services.

People told us about some good times when:

- Health and social care staff worked together to meet the person's needs.

- Staff listened to people and involved them in making decisions about their care and treatment.

- Easy read leaflets and videos were given to people to help them understand some information.

- People had good appointment times that suited them best.

Some people did not share any experiences with us.

Adult social care: what people told us

Support that people need in social care

People need support to take part in their local communities. Things like support to travel and do activities in their local area.

People also need support with everyday things. Things like:

- Getting dressed.

- Shopping.

- Taking medication.

- Going to appointments.

People with Down syndrome need the right support to stay safe.

Things like help to understand about road safety and healthy relationships.

People need a safe place to live and support to get a job.

People need person-centred support.

Young people need extra support when they move from children's services to adult services.

People want to have staff they know and trust.

Social care services need to make sure carers have support too.

Staff need training about how to support people with Down syndrome well.

They need to understand the law and how it says people with Down syndrome should be supported.

Support from staff

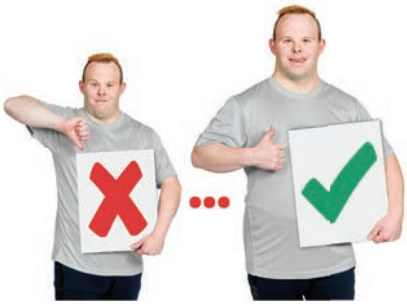
Around half of people with Down syndrome said they get the social care support they need.

Less than half of people said staff knew how to:

- Support people well

and

- Talk to people in the right way.



Families and carers said they felt like social care needs to get better.

They said social care staff do not know how to support people with Down syndrome well.

Some families and carers said they had some good experiences with staff.

Less than half of social care staff felt their organisation knew how to support people well.

Only 1 in 3 staff said they knew the law about supporting people with Down syndrome.

Good things that are happening

We asked people to tell us about good experiences they had with social care services.

People told us about some good times when:

- Social workers listened to them and supported them well.

- **Direct payments** were really useful.

  A **direct payment** is money paid straight to you from the council. You can use the money to pay for the care and support you want.

- People got the right support to live well in their home.

- Having a good **personal assistant** meant they had help and support to get out and about.

  A **personal assistant** is someone who gives you care and support.

This is not just things like washing and dressing. They can help you with things like work or college.

- Local health and social care teams supported people and families well.

- Local community groups gave people chances to join in activities and get out and about.

Lots of people did not have any experiences to share with us.

Education, children and young people: what people told us

Support that children and young people need in education

People with Down syndrome told us:

- It is really important to learn life skills. This means things like learning to cook, look after your own money and travel about.

- People needed more support to get a job or go to college.

- People wanted to be treated like an adult. They want to be involved in making decisions about their own lives.

Parents and carers told us they want care and education that meets the person's needs.

People need services to work together to meet a person's needs.

Staff said that teachers need training on how to support children and young people with Down syndrome.

Good things that are in education

We asked people to tell us about good experiences they had with education.

People told us:

- Having 1 to 1 support in the classroom is really helpful.

- Some people thought special schools were a good idea. These are schools that teach children who have extra support needs.

People said that teachers in special schools had proper training.

- **Residential** colleges are a good idea. **Residential** is when you live at the college and sleep there.

It helps people learn to do things for themselves or with some support.

- Lots of children with Down syndrome do well in regular schools.

It is really good for other children to understand the needs of children with Down syndrome too.

Good things that are happening in children's social care

People with Down syndrome said social workers have to take time to get to know them.

They need to learn to trust each other and build a good relationship.

Lots of people liked using direct payments to pay for their care and support.

Lots of people liked using **buddy services** to do activities and go to events. A **buddy** is someone who supports you to go out and about.

Community groups and activity groups have lots of things for people to do.

Good things happening with youth offending teams

Youth offending teams support children and young people who may be in trouble with the law.

Sometimes people with Down syndrome do not understand when they are breaking the law.

People said it is important to explain the law clearly to people with Down syndrome.

Police and youth offending teams need more training about Down syndrome.

Housing services: what people told us

Support that people need in housing

Some people need more support than others.

Some people need support all day every day. Other people need support with things like cooking or looking after money.

Care and housing services need to work together to meet a person's needs.

People should have choice about housing and where they want to live.

People with Down syndrome need clear information about housing and their **rights**.

Your **rights** are things you are allowed to do and how you should be treated.

It is important that people can have an **assessment** before they move to a different place.

An **assessment** means looking closely to see what support a person needs.

Housing staff need training on how to talk to and support people with Down syndrome well.

Support from housing services

Most people with Down syndrome said they didn't know what support they could get with housing.

Housing staff said that:

- Councils need to better understand the housing needs of people with Down syndrome in their area.

- Councils need to work together with health and social care services to support people's housing needs.

- Less than 1 in 3 staff felt their organisation knew how to support people with Down syndrome.

Staff said it is important to have good housing services to support people to live **independently**.

Independently means by yourself or with some support.

Staff also said it is important that the houses are near other services.

Things like being able to travel and catch a bus or train easily. Or have places to go and things to do in the local area.

Good things that are happening

We asked people to tell us about good experiences they had with housing services.

People told us about some good times when:

- Staff gave people information in a way that is best for them. Things like easy read.

- Support workers gave people really good care and advice.

- Housing staff explained things clearly.

- There was lots of choice about where to live.

Some people said that they didn't have good experiences. They had been given little or no support with housing.

Barriers to getting good services

A **barrier** is when something stops you or makes it harder for you to do something.

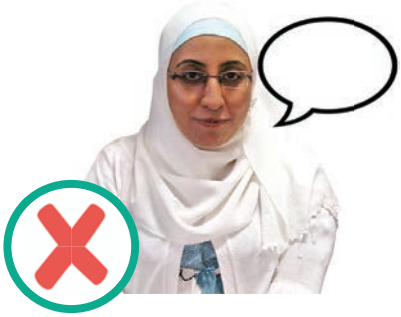
Most parents and carers told us they think there are barriers to people getting the right support.

For all of the areas we asked people about, they said the barriers were:

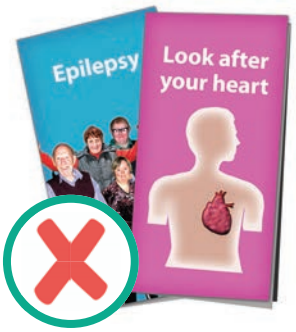
- Not enough information and advice about services.

- Not enough staff or trained staff.

- Waiting too long for care and appointments.



- Staff not talking to people or their families or keeping them updated.



- Not enough help, support and information about different health problems people can have.

Some people told us they felt the money they got in benefits was not enough to pay for their care.

This can mean families have to be **unpaid carers**.

Unpaid carers mean family and friend carers who are not paid to care for people as part of their job.

- Some people do not get the care and support they need.

- Assessments for social care are too hard.

- Services don’t work together to understand people’s needs.

What people told us about other services

People with Down syndrome should be able to live their life alongside everyone else.

People want to be listened to and have their voices heard.

People want the right support so that they can be **independent**.

Independent means being able to do things by yourself or with some support.

Getting a job and being able to travel around is important to people.

Leisure and social activities are really important to people. Things like sports, arts and crafts, meeting friends and other people.

Groups in the community are good at helping people learn new skills.
They also give people the chance to spend time together.

More people in England need to know about Down syndrome.

Staff in all services need training to understand Down syndrome.

What people said about supporting people with other conditions

People with other conditions say similar things about services to people with Down syndrome.

Some of the services for people with Down syndrome could work well for people with other conditions too.

Many people said that people with other conditions have different physical and mental health needs to people with Down syndrome.

People think services should look at a person's needs and not what condition they have.

What happens next

We looked at everything everyone told us in the call for evidence.

We have used it to write the **draft** guidance about Down syndrome.

It is called a **draft** because some things may still change in it.

We will be asking lots of people what they think about the draft guidance.

This will help us to check we have the right things in it or if we need to change anything.

This Easy Read was written by Easy Read UK.
The pictures in this easy read are from Photosymbols and ingimage.