

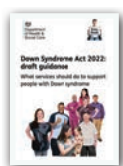


Down Syndrome Act 2022: draft guidance

What services should do to support
people with Down syndrome



What is in this booklet



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About the draft guidance



The Down Syndrome Act 2022 is a law to help make life better for people with Down syndrome and their families and carers.



As part of the law, the government has written some **draft guidance**.



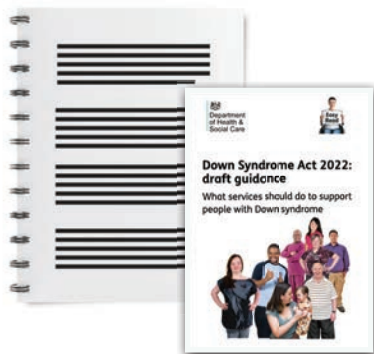
Guidance is like rules that services should follow.



Draft means that some things may still change in it.



We are asking people what they think about the draft guidance.



This is an easy read of the **Down Syndrome Act 2022: draft statutory guidance**.



It tells you about the main things in the longer guidance.



This easy read still has a lot of pages. You do not have to read it all at once. You might want to take breaks. Or you could just read the bits you want to.

Who needs to follow this guidance:



- **Healthcare services** like local doctors, nurses, hospitals and dentists.



- **Local council services.**

These services make sure towns and cities have what they need for people to live well.

Things like schools, roads and support for people who need it.



- **Social care services.**

These services give people care and support when they need it.

This might be at home, in the local community or in a care home.



- **Education services** like schools, colleges and universities.



- **Employers and job services.**

An **employer** is the place or the person someone works for.



- **Housing services** that help to find homes for people.



People with Down syndrome, their families and carers can also read these rules.

It will help them understand what support they should get from services.

People with similar conditions or a learning disability

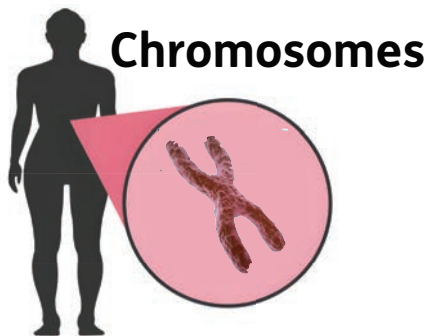


Some people have similar needs to people with Down syndrome.



This might be people who have a **chromosomal** or **genetic** condition.

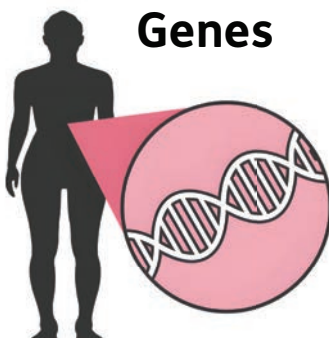
Or this might be people with a learning disability.



Chromosomes

Chromosomes are tiny parts of you that tell your body how to work.

A chromosomal condition is when you have a change in your chromosomes.



Genes

Genes are tiny parts of you that control different things about you. Things like how you grow or how different parts of your body work.

A genetic condition is when you have a change in a **gene**.



When chromosomes and genes change, it can cause health problems or a disability.



When services follow the guidance, it should help people with similar conditions or a learning disability too.

Things in the draft guidance for all services to do



Services must follow the law about treating people fairly.



Services should ask people how they like to **communicate**.

Communicate means being able to tell other people what you want and how you feel.



Services should communicate with people in a way that is best for them.



People might need support from more than 1 service. The services should work together to meet peoples needs.



Services should give information in ways that are easy for people to understand.

This might be things like easy read, braille, large print or **audio**. **Audio** is recordings of people reading out the words.



Services must follow the law about making **reasonable adjustments**.

Reasonable adjustments are when services make changes to meet a person's needs.



Things like extra time and support in appointments. Or, having a quiet place for people to wait.



Services should give people care and support that is right for them. This is called **person-centred care**.



Services should make sure people can have their say about things that affect them.



Services should make sure there is an **advocate**, if a person needs one.

An **advocate** is someone who can help you speak up for yourself or they can speak up for you.



Services should give staff training about how to support people well. This could be training about Down syndrome.



They should also have training about treating people fairly and including people.



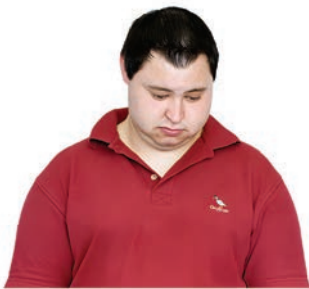
Services should support people to make their own decisions, if they need it.



Services should help to keep people safe, if they need it.



People with Down syndrome have more chance of **abuse** or **neglect**.



Abuse is when someone does or says something to hurt you or make you feel bad.



Neglect is when your needs are not met.



Services must work together to protect people from abuse and neglect. This is called **safeguarding**.

What health services should do



People should have good healthcare from before they are born to the end of their lives.

What people with Down syndrome need



People with Down syndrome are more likely to have health problems. This might be things like:



- Problems hearing or seeing.



- Heart, breathing and tummy problems.



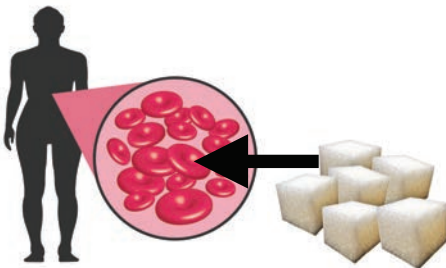
- Problems with their teeth and gums.



- Finding it hard to move around.



- Finding it hard to communicate and understand things.



- **Diabetes.** **Diabetes** is an illness that means there is too much sugar in your blood.



- **Dementia.** **Dementia** is the name for some problems that cause parts of the brain to stop working properly.



People with Down syndrome are more likely to have dementia at a younger age.



- **Mental health** problems. **Mental health** is things like your thoughts, feelings and how you cope in everyday life.

What services should do to support people with Down syndrome



Services should make a plan that says how health and care services will work together to meet people's needs.



Services should know what people's needs are in their area.



Services should think about these needs when they plan and buy services.



Services should give people, their families and carers a say about plans for services.



Services should think about what services people might need in the future.



Services should make sure staff have the right skills, knowledge and training to support people well.



Services should make sure people have their **annual health checks**.

This is when you get checked every year by your local doctor or nurse.



It helps to spot any health problems early. Then you can quickly get the help you need.



Services should know which health problems people are more likely to have.



Services should give good support and information to families of children with Down syndrome.

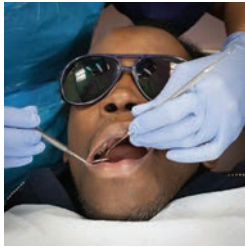


Services should keep a list of people in their area who have Down syndrome.

Services should support people to go for tests and manage their health conditions. Things like:



- Eye and hearing tests.



- Seeing the dentist.



- Heart, breathing and tummy checks.



Services should offer speech and language therapy to people who find it hard to communicate.



This can help them to tell other people what they need and understand what other people say.



Services should support young people to move from using children's services to **adult** services.

An **adult** is a person aged 18 or older.



Services should offer special dementia tests to people with Down syndrome who need them.



Services should support people at the end of their life.

Mental health hospitals and local community services



Services should know how to support people with Down syndrome.



Services should have a list of people who might need extra support with their mental health.



Services should have good plans to support people with their mental health.

What social care services should do

People should get the care and support they need to:



- Live as **independently** as possible.

Independent means doing some things for yourself or with some support.



- Live a healthy life.



- Live the life they want to live.

What people with Down syndrome need

People with Down syndrome are more likely to need support with things like:

- Cooking and cleaning the house.



- Washing and getting dressed.



- Taking part in their local community. Things like going to groups or **volunteering**.



Volunteering is when you give your time and skills to help other people.



- Filling in forms, paying their bills and managing their money.





- Planning what to do. Or making sure there is enough time to do the things they want to.



- Taking medication.



- Going shopping or to appointments.



- Getting to school, college or work.



- Staying safe. Things like help to understand road safety and staying safe online.



- Taking a short break if they need it. Things like staying in a care home for a short time. Or, having care in the daytime.

What services should do to support people with Down syndrome



Services should check what support people need. This is called an **assessment**.



Services should do assessments for carers. This helps carers to get the support they need too.



Services should support people to make **care and support plans**.

A **care and support plan** says what a person's needs are. And what support the law says they should get.



Services should support people with their **personal budget**. This is money people get from the council to pay for care and support.



Services should make sure people know what support they can get in their local area.



Services should give people early help and support. This can help to stop problems from happening or from getting worse.



Early help and support could be an alarm to help them remember things. Or a hand rail to help them when standing up.



Services should make sure people get the right services when they become adults.



Services should support people with Down syndrome who have dementia.



Services should check what people might need as they get older.

What education services should do



Education is about learning. This might be at places like nurseries, school or college.



All children and young people should have a good education.

What people with Down syndrome need

People with Down syndrome are more likely to need support with things like:

- Learning, understanding and remembering new things.
- Reading words and understanding numbers.





- Communicating.



- Being able to see information clearly. Things like small writing or busy pictures.



- Moving around. Things like sitting and walking.



- Writing and drawing.



- Being able to hear what is happening in the classroom.



- Remembering new information and following instructions.



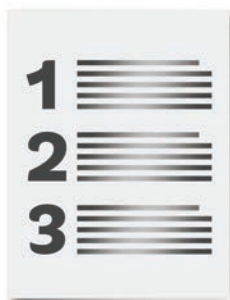
- Getting enough sleep. If children are tired, this can affect their learning.



- Feeling things in a different way. Things like bright lights, sounds and being touched.

This might make some people feel very stressed.

What services should do to support people with Down syndrome



Services should have a list of children and young people in their area who might need extra support to learn.



Services should make sure people know what support they can get in their local area.



Services should work together with young people and families and carers to plan support services.



Families and carers should have their say about what the best support looks like.



Schools should have plans and rules for supporting children and young people with **SEN**.



We say children who need extra support to learn have **special educational needs**. We call it **SEN** for short. We say it like this: **sen**



Schools should have someone who makes sure that young people with SEN get support at school.



Schools should work together with young people and their families and carers to make an **education, health and care** plan, if needed. It is called **EHC** for short.



An EHC plan says what help a young person needs. It lists:

- A child or young person's education, health and care needs.



- How these needs will be met.



- How to support them in the best way when they go to school or college



An EHC should be checked every year to make sure it is working well.



- Make sure children and young people learn about sex and healthy relationships.



Colleges should support young people with SEN to think about their future. This might be things like:



- Doing more learning.



- Living independently.



- Being healthy.



- Taking part in their local community.



Universities must treat young people fairly.

Youth justice teams



Youth justice teams work with children and young people who are in trouble with the law.



They must make sure that children and young people still have support for their SEN.

What employers and other services should do



Services like local councils, colleges and job services can help people to find a job and get into work.



People with Down syndrome should be able to get a job and work, if they want to.

What people with Down syndrome need

People need help with:

- Finding work that is right for them.
- Doing training and learning.





- Doing **work placements**.
This is when a person has a job for a short amount of time.
They can learn about the job and get new skills.



- Writing **CVs** and getting ready for interviews. A **CV** is a list of skills and work a person has done.

What services should do to support people with Down syndrome

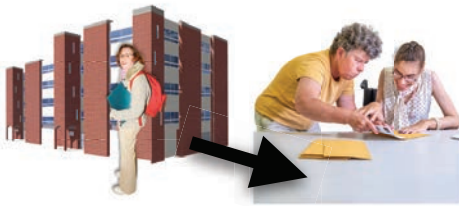


Schools, councils and employers should work together to support people to work.

This might be things like getting jobs and work placements.



Schools and colleges should help young people to start thinking about their future. This should happen when they are 13 or 14 years old.



Young people should have a plan to support them to move from college into work.



The plan might have things in it like:

- How to help people use things like computers and laptops.
- Training to help young people to travel by themselves. Things like getting a bus, train or taxi.
- Training to help young people talk to and get along with other people.





Young people with Down syndrome should be supported to have special training called an **apprenticeship**.

This training means they can learn while they work.



The government supports employers to give jobs to more people.



The government gives people help to do their job. This is called **Access to Work**.

Things like:



- Money to help with travelling to work.



- Things to help people do their job. This might be laptops and things that can read out any writing for them.



- Money to pay for a support worker to help someone at work.



The government gives people money if they cannot work. This money is called **benefits**.



It helps to pay for extra things you might need because of a disability or health condition.



The government supports people to get the help they need to go to university or start a job.

What housing services should do



People should have good homes that meet their needs.

What people with Down syndrome need



- Lots of choice about housing and where they want to live.



- Good and safe homes.



- Support to live as independently as possible.



- Clear information about housing and their **rights**. Your **rights** are things you are allowed to do and how you should be treated.

What services should do to support people with Down syndrome



Services should think about the needs of people when they plan and build housing.



Services should think about what housing and support people might need in the future.



Services should give housing to people who need it the most.



People with Down syndrome might need housing sooner than other people.

This might be because of a medical problem or disability or to keep them safe.



Services should make sure people have a say about where they live and who they live with.



Services should give people homes that are near to their family and friends, jobs and other services.

Places like shops, the library and bus stops.



Services should make sure people have good information about support and different kinds of housing they can get.



Services should help people to make changes to their homes if they need too.



The changes might help people to live more independently. Things like putting in handrails or changing bathrooms.



Services should support people who are homeless. And support people who may become homeless.

Making sure people know where to find help and support



Sometimes people may not get the care and support they expect from a service.



If this happens, people should know how to **complain**.

Complain means telling a service you are unhappy about something.



Services should make it clear how people can complain.

They should tell people what to do and what will happen next.



Some people might need support to complain. Services should tell people where they can get an **advocate**.



An **advocate** is someone who can help you speak up for yourself or they can speak up for you.

If people are unhappy with how the service has dealt with their complaint, they can complain to an **ombudsman**.

An **ombudsman** looks into complaints about a service.



They make sure the service has looked at the complaint properly.



If people think a service has broken the law, they can speak to a **lawyer**.

A **lawyer** is someone who has special training and knows a lot about the law.