



Pack 4

Health Services

Down Syndrome Act 2022:
draft guidance





Down Syndrome Act 2022: draft guidance

What services should do to support
people with Down syndrome



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.



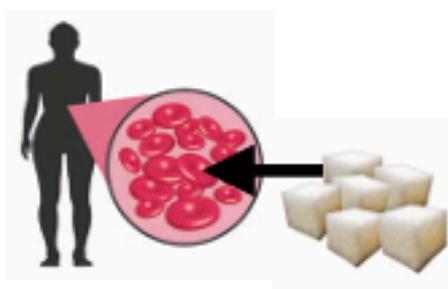
- Problems with their teeth and gums.



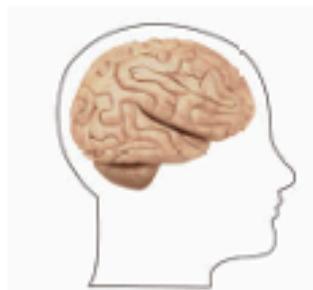
- Finding it hard to move around.



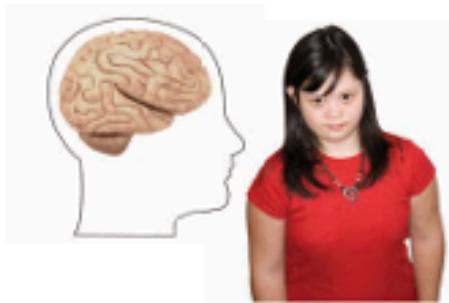
- Finding it hard to communicate and understand things.



- **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.

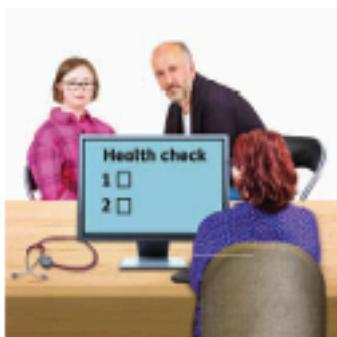


Services should make sure people have their **annual health checks**.

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



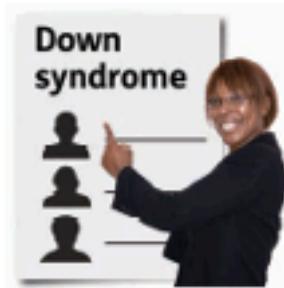
It helps to spot any health problems early. Then you can quickly get the help you need.



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.



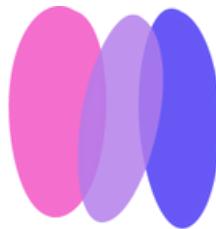
Services should have a list of people who might need extra support with their mental health.



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

National Down Syndrome Policy Group

CHANGING THE NARRATIVE



Department
of Health &
Social Care



Down Syndrome Act 2022: draft guidance

Tell us what you think



This survey is for:

- People with Down syndrome and their families and carers.
- People with similar conditions or a learning disability and their families and carers.

It is now your turn to complete the draft guidance survey Health Services.



People with Down syndrome have already said they think that it is important for all health care staff to have special training about Down syndrome.



They have said that **diagnostic overshadowing** is a problem in their lives.

Diagnostic overshadowing is when people think all health needs are caused by one condition, like Down syndrome.



Diagnostic overshadowing is not mentioned in the guidance yet.



Special training on Down syndrome will help to stop diagnostic overshadowing.



There is space at the end of this pack for you to share what you think about this.



To remind you, this is what people with Down syndrome have said before about why special training is important:



It helps make sure health needs are not missed.



People with Down syndrome should be treated fairly and have the life they choose.

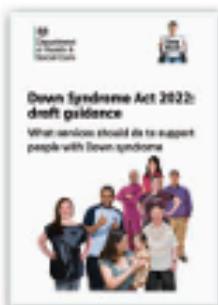


It helps people with Down syndrome to be included in their health choices.

What health services should do



Part of the draft guidance tells you what support people with Down syndrome should get from health services.



You can read about this first in the easy read draft guidance. It is on pages 11 to 18.



Question: Does the draft guidance make it clear what support people can expect to get from health services?



Yes



No



I don't know



Question: Does the draft guidance make it clear that health and care staff need to have the right skills and training to support people?



Yes



No



I don't know



Question: Do you think we need to make any changes to this part of the draft guidance?



Yes



No



I don't know



If you ticked yes, please tell us what changes we need to make. Write your answer in this box.