



Questions for people with Down's syndrome

The government is making some new information and rules to help make life better for people with Down's syndrome in England

The new information and rules is called guidance.

Please tell us your ideas for the new guidance.



**In this document we say Down's syndrome.
But some people say Down syndrome.**



About this document

We are the government.



We made a new law in April 2022 to help make life better for people with Down's syndrome.

The new law is called the **Down Syndrome Act 2022**.



The law says that the government must make some new **guidance**.

Guidance is information.

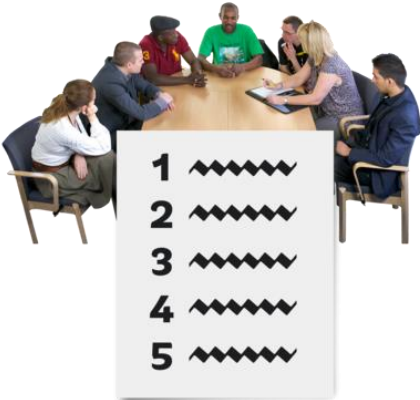
The information has rules in it that organisations must follow.

The guidance will help people with Down's syndrome to get better support.



We want people's ideas before we make the new guidance.

We want to know what people think should be in the new guidance.



We will look at what everyone says.

Then we will make the guidance.

We will share the guidance with people first to find out what they think about it.



There are some questions for you to answer in this document if you have Down's syndrome.



You can also answer the questions if you have another condition.

Like a learning disability.

We want to know if the new guidance will work for people with those conditions as well.



Please give us your answers by
11.45pm on **8 November 2022**.

You can find out how on page 28.



Why we are making the new information with rules in it

The information with rules is called
guidance.



People with Down's syndrome can have
a good life with the right support.

But many people with Down's syndrome
and their families find it hard to get
the right support.



The new guidance will help people with Down's syndrome to get better support with:

- Healthcare and mental health care. Mental health is about how you think and feel.
- Social care. This is support from staff to live at home or do other important things. Like wash, cook or do things you enjoy.
- Education.
- Housing.



The guidance will tell organisations what they must do to give people with Down's syndrome good support.

That means organisations like:

- Schools and colleges
- Councils
- the NHS and other health organisations

They will have to follow the new guidance.

The questions for you to answer

Please answer all the questions you can.

It is OK if you cannot answer all of the questions.



How are you answering these questions?

I am answering the questions about myself.

☐

I am answering the questions for someone else.

☐

Your answers should be about the person you are answering for.



I am answering the questions as part of an organisation.

☐

If so, what is the name of your organisation?



Do you or the person you are answering for have Down's syndrome?

Yes

☐

No

☐

Do you or the person you are answering for have another condition?

Like a learning disability?

Yes

☐

No

☐

Do you give care to a family member or friend with Down's syndrome? That means care that you do not get paid for?

Yes

☐

No

☐

Do you give care to a family member or friend with another condition? Like a learning disability.

That means care that you do not get paid for?

Yes

☐

No

☐

Questions about the support you need

Questions about health care

1. What support do you need to keep healthy?

That includes any health care like:

- Eye care
- Support to move around or communicate
- Mental health support if you feel sad or worried a lot





2. Do you think that health staff know how to support you and talk to you in the right way?

Health staff are people who give you health care. Like doctors, dentists or nurses.

Yes ☐ No ☐ Not sure ☐



3. Do you get all the support with your health that you need?

Yes ☐ No ☐ Not sure ☐



4. What would help you to get the right support with your health?

This is anything that you think would make your health support better.

Like better information, training for health staff or waiting less time for support.



5. Do you have any examples of good health care that you got and why it was good?

Questions about social care if you are an adult over 18



Social care is support from staff to live at home or do other important things. Like wash, cook or do things you enjoy.

Social care staff might work for your local council or another organisation.



6. If you need support from social care services for adults, what support do you need?



7. Do you think that social care staff know how to support you and talk to you in the right way?

Social care staff are people who give you support to do the things you want and need.

For example, social workers, housing officers and personal assistants.

Yes ☐ No ☐ Not sure ☐



8. Do you get all the social care support you need?

Yes ☐ No ☐ Not sure ☐

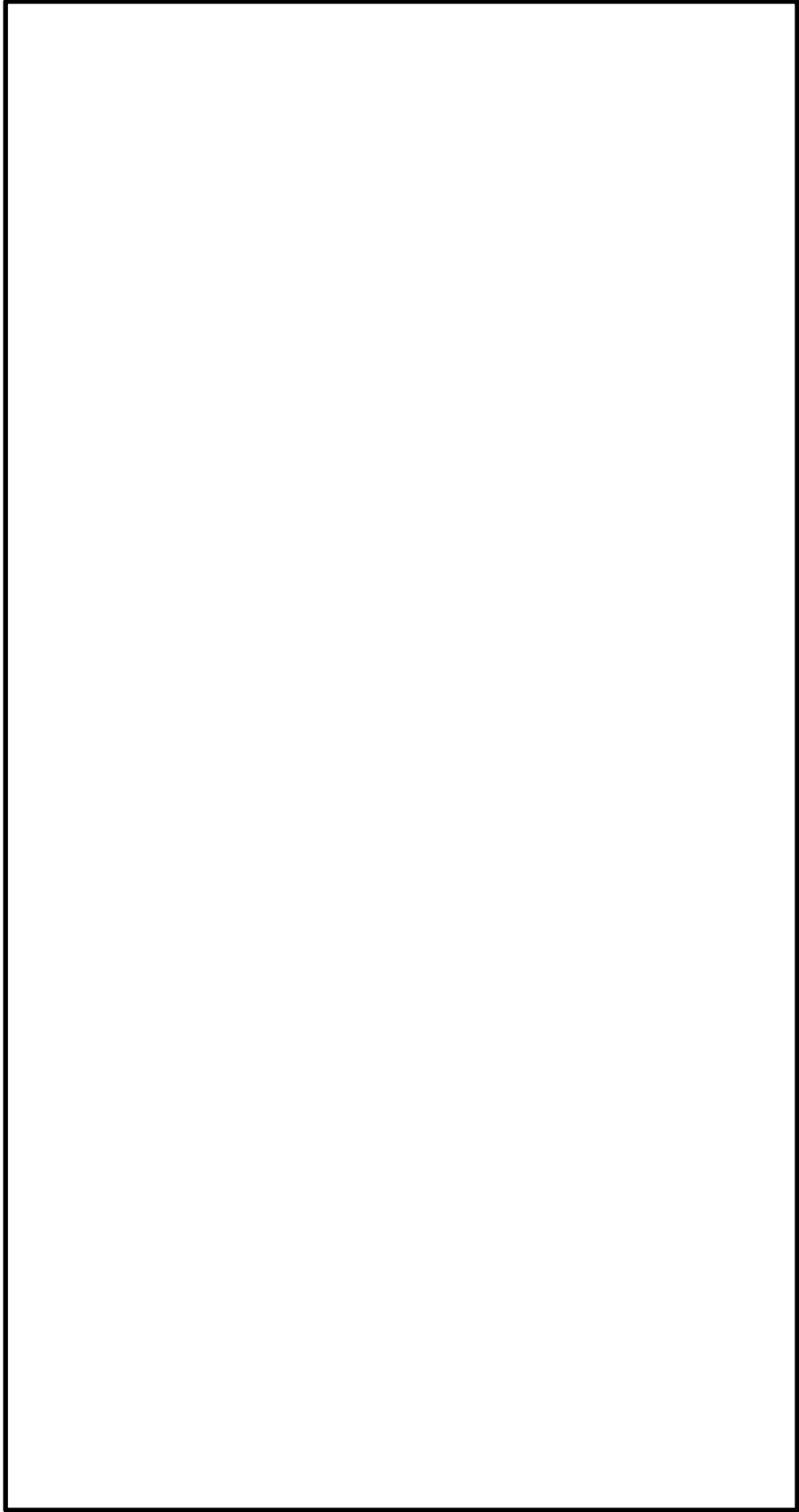


9. What would help you to get the social care support you need?

That means anything that would make your social care support better.

Like better information, training for staff or waiting less time for support.

You can answer on the next page.





10. Do you have any examples of good social care support that you got and why it was good?

Questions about support with housing

Housing is where you live or where you want to live.



11. Do you live on your own in your own home? Or do you plan to live on your own in the future?

Yes ☐ No ☐ Not sure ☐



12. If you need support to live by yourself in your own home, what support do you need?



13. Do you know what support there is in your local area to help you live in your own home?

Yes ☐ No ☐ Not sure ☐



14. Do you have any examples of good support that you got with housing and why it was good?

Questions about education and support for young people



15. Do you have any examples of good support that you got at school or college and why it was good?



16. What could help young people with Down's syndrome to get ready for life as an adult?

That includes support to get work or go to college.



17. Do you have any examples of good social care support for children and young people with Down's syndrome. And why it was good?



18. Do you have any examples of good support for young people who get in trouble with the police?

The support comes from people called **youth offending teams**.



Questions about the new information and rules that the government is making

The new information and rules is called **guidance**.



19. What would you like to see in the new guidance?

For example, what do you think that organisations must do to give people with Down's syndrome good support?



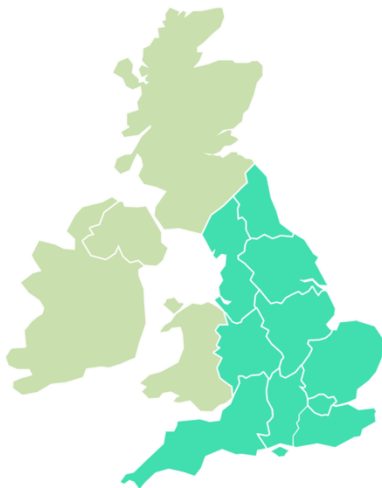
20. Is there anything else you want to say about making support better for people with Down's syndrome?

Some more questions about you



What is your age?

I don't want to say

☐

If you live in England, which part do you live in?

North East England

☐

Yorkshire and the Humber

☐

East Midlands

☐

West Midlands

☐

South West England

☐

North West England

☐

East of England

☐

South East England

☐

London

☐

I don't want to say

☐



Are you

Female

☐

Male

☐

Other

☐

I don't want to say

☐

What ethnic group are you from?

This is about things like where you and your family are from and the language you speak.

Choose one group that feels most right for you.

White

☐

More than one ethnic group

☐

Asian or British Asian

☐

Black, African, Caribbean or
Black British

☐

Another ethnic group

☐

I don't want to say

☐



Do you have any health conditions or disabilities that will last for more than a year?

That also includes mental health conditions.

Yes ☐

No ☐



If you said yes, do the health conditions or disabilities make it hard for you to do things every day?

Yes a lot ☐

Yes a bit ☐

Not at all ☐



Would you like to give us your email address so we can contact you?

That means we can:

- Get in touch with you if we have more questions for you



We will not share your email address with anyone else.

You can tell us your email address or the email address of your organisation below.

But only if you want to.



How to give us your answers

Please give us your answers by 11:45pm on **8 November 2022**.



To give us your answers you can:

1. **Print and scan** this document to your computer using a scanner.

Then email it to:

DSActguidance@dhsc.gov.uk



2. Or print and **post** this document with your answers to:

Down Syndrome Act call for evidence
Department of Health and Social Care
2NEB Quarry House
Quarry Hill
Leeds
LS2 7UE



Thank you

