



Questions for family and carers

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.

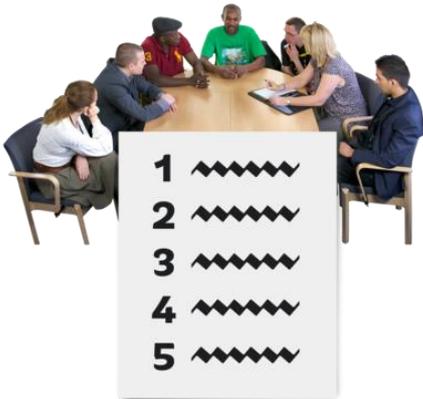
The information has rules in it that organisations must follow.

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.

The questions are for family and carers of people with 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 36.



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 support for people with Down's syndrome

Questions about health care



1. What support do you think that people with Down's syndrome need with their health?

That includes mental health.



2. Do you think that health staff know how to support people with Down's syndrome and talk to them in the right way?

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

Yes No Not sure



3. Are there problems with health services that stop people with Down's syndrome getting the support they need?

That includes mental health services.

Yes No Not sure



If there are problems, can you tell us more about them here?

Please say if the problems are about health care services or mental health services.



4. Is it easy to get information and advice about healthcare services in your local area?

Yes No Not sure



5. Do you have any examples of good health care for people with Down's syndrome. And why it was good?

That includes mental health care.



6. Do you think that health services for people with Down's syndrome could also be helpful for people with other conditions?

Like a learning disability?

Yes No Not sure



7. If health services for people with Down's syndrome can also help people with other conditions, please tell us what the other conditions are.



8. Do people with other conditions like a learning disability need different health support to people with Down's syndrome?

Yes No Not sure



9. Do people with other conditions like a learning disability need different mental health support to people with Down's syndrome?

Yes No Not sure

Questions about social care for adults 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.



10. What social care support do you think that adults with Down's syndrome need?



11. Do you think that social care staff know how to support people with Down's syndrome and talk to them 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



12. Are there problems with social care services that stop people with Down's syndrome getting the support they need?

Yes No Not sure



If there are problems, can you tell us more about them here?



13. Is it easy to get information and advice about social care services for adults in your local area?

Yes No Not sure



14. Do you have any examples of good social care for adults with Down's syndrome. And why it was good?



15. Do you think that adult social care services for people with Down's syndrome could also be helpful for people with other conditions?

Like learning disability?

Yes No Not sure



16. If social care services for adults with Down's syndrome can also help people with other conditions, please tell us what the other conditions are.



17. Do adults with other conditions like a learning disability need different social care support to adults with Down's syndrome?

Yes No Not sure

Questions about support with housing

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



18. Do you know what support your local council could give people with Down's syndrome to live in their own home?

Yes No Not sure



19. What support might someone with Down's syndrome need to live in their own home?



20. Are there problems with housing services that stop people with Down's syndrome getting the support they need?

Yes No Not sure

If there are problems, can you tell us more about them here?



21. Is it easy to get information and advice from your local council about housing support in your area?

Yes No Not sure



22. Do you have any examples of good housing support for people with Down's syndrome. And why it was good?



23. Do you think that housing support for people with Down's syndrome could also be helpful for people with other conditions?

Like learning disability?

Yes No Not sure



24. If housing support for people with Down's syndrome can also help people with other conditions, please tell us what the other conditions are.



25. Do people with other conditions like a learning disability need different housing support to people with Down's syndrome?

Yes No Not sure

Questions about support for children and young people with Down's syndrome

Like education, social care and support for young people who get in trouble with the police.



26. Do you have any examples of good education for children and young people with Down's syndrome. And why it was good?



27. What support would 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.



28. Do you have any examples of good social care support for children and young people with Down's syndrome?

Or support for young people who get in trouble with the police?

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

Please tell us which kind of support it is in your answers.



Questions about the new guidance that the government is making

Guidance is information that has rules in it for organisations to follow.

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



The guidance will already be for organisations that work in:

- Health and mental health
- Social care for adults and young people
- Education
- Housing





29. What other public services should the guidance be for?

Please tell us why you think that if you can.



30. Do you have any examples of other public services that are working well for people with Down's syndrome. And why they are working well?



31. Is there more that can be done to support staff from organisations to understand what people with Down's syndrome need?

A large, empty rectangular box with a black border, intended for a response to the question above.

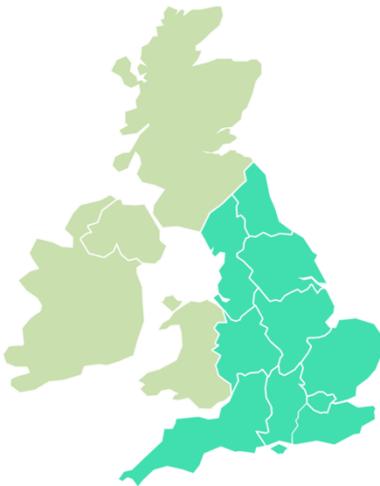
Some more questions about you



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