Department of Health & Social Care

Down Syndrome Act 2022: draft guidance

Tell us what you think

This survey is for:

- People who work with people with Down syndrome and their families and carers.
- People who work with people with a similar condition or a learning disability and their families and carers.
- Other professionals who want to tell us what they think.

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About this survey

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As part of the law, the government has written some **draft guidance**.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We are asking people what they think about the draft guidance.

You will need to read the easy read draft guidance first. Then fill in this survey.

You can find the draft guidance on our website:
www.gov.uk/government/consultations/down-syndrome-act-2022-draft-statutory-guidance-easy-read

We will look at everyone's answers. This will help us to see:

- If we have the right things in the draft guidance

and

- If anything needs to change.

How to fill in the survey

We have this easy read survey online on our website. If you want to fill it in online go to:

consultations.dhsc.gov.uk/down-syndrome-act-2022-draft-statutory-guidance-easy-read

Or you can print out this survey and fill in a paper copy.

If you do not know how to print something, you might be able to get help at your local library.

If you have filled in a paper copy, please send it back to:

Neurodiversity, Disability and Learning Disability team
Department of Health and Social Care
Floor 3
39 Victoria Street
London
SW1H 0EU

Fill in the survey online or post your answers back to us by:
Monday 30 March 2026.

How we will look after the information you tell us

When you answer our questions, try not to put any personal information. Things like names, email addresses or phone numbers.

Before you send us your answers, it is important you read the privacy notice.

It tells you how we will use and look after the information you tell us.

You can read the privacy notice on our website:

www.gov.uk/government/consultations/down-syndrome-act-2022-draft-statutory-guidance-easy-read

About you or your organisation

Question: Please tell us about you or your organisation.

Tick 1 box.

☐ I am a **professional** answering for myself. I have training and experience in understanding or working with people with Down syndrome or people with a similar condition or a learning disability.

If you ticked this answer, go to page 6.

☐ I am answering for the service I work for.

If you ticked this answer, go to page 7.

Question: If you are a professional answering for yourself, tell us more about you.

You can tick more than 1 box.

☐ I work with people with Down syndrome and their families and carers.

☐ I work with people with a similar condition or a learning disability and their families and carers.

☐ Other. Please tell us. Write your answer in this box.

Question: If you are answering for an organisation, tell us who your organisation works with. **You can tick more than 1 box.**

☐ We work with people with Down syndrome and their families and carers.

☐ We work with people with a similar condition or a learning disability and their families and carers.

☐ Other. Please tell us. Write your answer in this box.

Please tell us the name of the service you work for. Write your answer in this box.

Questions about the draft guidance overall

Question: We want the draft guidance to help services to understand the needs of people with Down syndrome.

Does it tell services everything they should do to support people and meet their needs?

Yes

No

?

I don't know

Question: Will the draft guidance make things better for people with Down syndrome and their families and carers?

Yes

No

?

I don't know

Question: Do you want to tell us anything else about the things in the draft guidance? Please write your answer in this box.

Thank you for answering these questions.

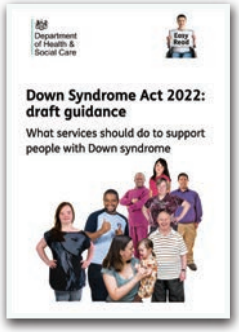
If you want to, you can finish the survey now.

If you are happy to answer more questions, please go to the next page.

You don’t have to answer all of the questions. You can stop at any time.

Things in the draft guidance for all services to do

Part of the draft guidance tells you what all services should do to support people with Down syndrome in the best way.



You can read about this first in the easy read draft guidance. It is on pages 7 to 10.

Question: Will the draft guidance help services understand what they have to do to be **accessible** and person-centred?

Accessible means services can be used by people with Down syndrome.

☐ Yes

☐ No

? ☐ I don’t know

Question: Does the draft guidance make it clear how important it is for services to communicate better with people?

Yes ☐ No ☐ ? ☐ I don't know

Question: Does the draft guidance make it clear what changes services must make? Theses changes will mean people can get the support they need.

Yes ☐ No ☐ ? ☐ I don't know

Question: Does the draft guidance help services to work together in a better way 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

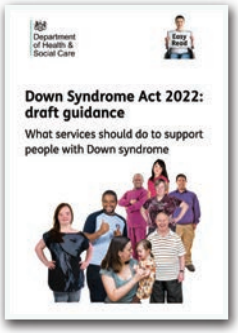
☐ No

? ☐ I don't know

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

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 clearly say what services need to do to support people's health needs in the best way?

☐

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.

What social care services should do

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

You can read about this first in the easy read draft guidance. It is on pages 19 to 24.

Question: Does the draft guidance make it clear that social care services should check what support people need?

☐ Yes

☐ No

? ☐ I don’t know

Question: Does the draft guidance make it clear what things social care services need to support people with?

Yes ☐ No ☐ ? I don't know ☐

Question: Does the draft guidance make it clear how social care services should support children and young people to move to adult services?

Yes ☐ No ☐ ? I don't know ☐

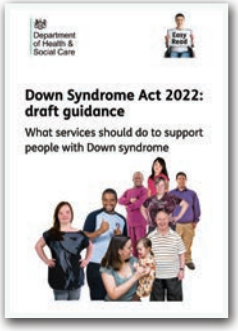
Question: Do you think we need to make any changes to this part of the draft guidance?

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.

What education services should do

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



You can read about this first in the easy read draft guidance. It is on pages 25 to 31.

Question: Does the draft guidance make it clear what education services should do to support people with their learning needs?

☐

Yes

☐

No

? ☐

I don't know

Question: Does the draft guidance clearly tell services what they should do about the things that make it hard for people to learn?

☐ 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.

What employers and other services should do

Part of the draft guidance tells you what support people with Down syndrome should get from employers and other services. Things like local councils, colleges and job services.

You can read about this first in the easy read draft guidance. It is on pages 32 to 36.

Question: Does the draft guidance make it clear what services should do to support people into work?

☐

Yes

☐

No

? ☐

I don’t know

Question: Does the draft guidance make it clear what services should do to support people to do training?

This might be things like going to college or university. Or it could be work placements and apprenticeships.

☐ Yes

☐ No

? ☐ I don’t know

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

This might be support to get into work, go to university or do training.

☐ Yes

☐ No

? ☐ I don’t know

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

☐ Yes

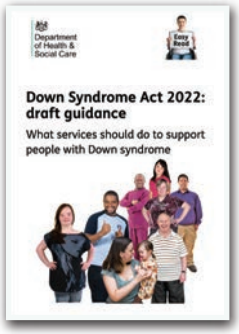
☐ No

? ☐ I don't know

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

What housing services should do

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



You can read about this first in the easy read draft guidance. It is on pages 37 to 40.

Question: Does the draft guidance make it clear what information housing services should give to people?

☐ Yes

☐ No

? ☐ I don’t know

Question: Does the draft guidance make it clear what housing services should do to support people to live more **independently**?

Independently means doing some things for yourself and some things with support.

☐ Yes

☐ No

? ☐ I don't know

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

☐ Yes

☐ No

? ☐ I don't know

Question: Will the draft guidance help services to understand what they should do to support people who are homeless or who might become homeless?

☐ Yes

☐ No

? ☐ I don't know

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

☐ Yes

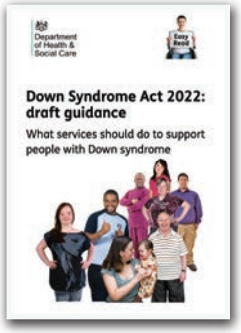
☐ No

? ☐ I don't know

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

Making sure people know where to find help and support

Part of the draft guidance tells you what people can do if they are not happy with the care and support they get.



You can read about this first in the easy read draft guidance. It is on pages 41 to 42.

Question: Are there any other ways that people can tell a service they are unhappy?

☐ Yes

☐ No

? ☐ I don’t know

If you ticked yes, please tell us what the other ways might be. Write your answer in this box.

People with similar conditions or a learning disability

Question: Should the guidance think about the needs of people with similar conditions or a learning disability?

☐ Yes ☐ No ☐ I don't know

Question: Does the guidance make it clear what services should do to support people with similar conditions or a learning disability?

☐ Yes ☐ No ☐ I don't know

More questions about your service

Question: Please tell us what kind of service you work for.

Tick 1 box.

☐ **Public sector**. These are services that are run by the government. Things like the NHS, schools, councils and the police.

☐ **Private sector**. These are services that you pay to use. This might be things like some hospitals, dentists or care services.

☐ **Not for profit**. These are groups like charities. All of the money goes on helping people.

☐ Other kind of service. Please write your answer in this box.

Question: What does the service you work for mainly support people with? This might be things like healthcare, housing, money or the law.
Please write you answer in this box.

Question: Which part of the UK does your service work in? **You can tick more than 1 box.**

- [ ] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland

- [ ] Outside the UK

- [ ] I don't want to say

Question 19: If you ticked England, tell us what part of England your service is in.

- ☐ North East England
- ☐ North West England
- ☐ Yorkshire and the Humber
- ☐ East of England
- ☐ East Midlands
- ☐ West Midlands
- ☐ South East England
- ☐ South West England
- ☐ London
- ☐ All over England