



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Down Syndrome Act 2022: draft guidance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.

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As part of the law, the government has written some **draft guidance**.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We are asking people what they think about the draft guidance.



You will need to read the easy read draft guidance first.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You can find the draft guidance on our website: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- If we have the right things in the draft guidance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:
Wednesday 28 January 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



Question: Please tell us why you are filling in this survey.

Tick 1 box.



☐ I am a person with Down syndrome.



☐ I am a family member or carer of someone with Down syndrome.



☐ I am a person who has a similar condition or a learning disability.



☐ I am a family member or carer of someone who has a similar condition or a learning disability.

☐

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



Please tell us about any other health conditions or learning disability you have.

Or tell us about any health conditions or learning disability your family member or the person you care for has.

Please do not tell us any personal information about you or anyone else. This could be things like a name or an address.

Questions about the draft guidance overall



Question: Does the draft guidance make it clear what help and services people with Down syndrome can expect to get?



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: Does the draft guidance make it clear what help and services people can expect to get?

☐

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? These 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

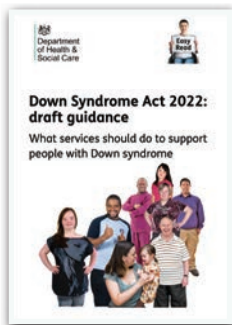


If you ticked yes, please tell us what changes we need to make. Write your answer in this box.

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 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

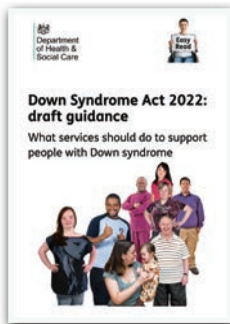


If you ticked yes, please tell us what changes we need to make. Write your answer in this box.

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 what social care support people can expect to get?



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

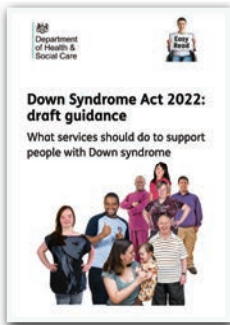


If you ticked yes, please tell us what changes we need to make. Write your answer in this box.

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 support people can expect to get from education 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 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 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

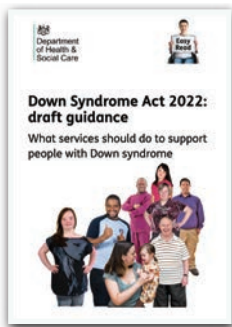


If you ticked yes, please tell us what changes we need to make. Write your answer in this box.

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 support people should expect to get from housing 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

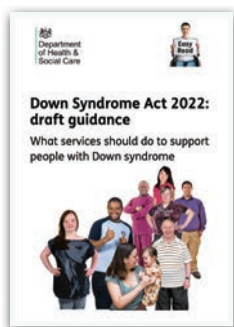


If you ticked yes, please tell us what changes we need to make. Write your answer in this box.

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: Does the draft guidance make it clear what people need to do if they are unhappy with their care and support?



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.

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 you

These questions let us know about the people we get answers from.



You don't have to answer the questions if you don't want to.



We will keep what you tell us private. No one will know who you are from the answers that you give.



If you are filling in this survey for someone else please answer these questions about them.



Question: How old are you?

Tick 1 box.

☐

Under 16

☐

16 to 24

☐

25 to 34

☐

35 to 44

☐

45 to 54

☐

55 to 64

☐

65 to 74

☐

75 or older

☐

I don't want to say





Question: What is your sex?

Tick 1 box.

☐

Male

☐

Female

☐

I don't want to say



Question: Is your gender now different to the one you were given when you were born?

☐

Yes

☐

No

☐

I don't want to say



Question: Where do you live?
Tick 1 box.

☐

England

☐

Scotland

☐

Wales

☐

Northern Ireland

☐

I live outside the UK

☐

I don't want to say



Question 19: If you live in England, tell us what part of England you live in. **Tick 1 box.**

☐

North East England

☐

North West England

☐

Yorkshire and the Humber

☐

East of England

☐

East Midlands

☐

West Midlands

☐

South East England

☐

South West England

☐

London

☐

I don't want to say





Ethnicity is your race, background and culture.

Question: What is your **ethnicity**?

Please tick 1 box.

☐

White

☐

Black, African, Caribbean or
Black British

☐

Asian or British Asian

☐

Mixed ethnic group

☐

Other ethnic group

☐

I don't want to say



Question: Do you have a disability or a **long term** illness or health condition?

Long term means it lasts for 12 months or more.

☐

Yes

☐

No

☐

I don't want to say



If you ticked **yes**, please tell us what disability or health condition you have. Write your answer in this box.



Question: If you have a condition, does it affect how you do everyday things?

Things like cleaning, shopping or making meals.

☐

Yes

☐

No

☐

I don't want
to say