williams
SYNDROME FOUNDATION

## The Down Syndrome Act Guidance

**We have been a part of a Department of Health and Social Care (DHSC) working group of small charities, trying to minimise the negative impact of the Down Syndrome Act guidance on the wider learning-disabled community. Our fear is that in an age of limited resources, this document will influence decision makers to direct those resources to people with DS first, creating a two-tier system which is simply not fair.**

While our advice to the DHSC has improved the document, we still feel that more can be done to include other genetic conditions and address the areas likely to impact our community.

### This consultation is our opportunity to achieve that goal – but we need your help!

Once finalised, this guidance document will be used by **ALL** service providers – health, education, social care, employment and housing. This is our **LAST CHANCE** to influence the content of this document and speak up for those with WS and other similar learning disabilities.

Please read and respond to this consultation. There is information about the full guidance document and also the easy read version.

**The Down Syndrome Act Guidance Consultation deadline is now:**

# Monday, March 30, 2026.

**PLEASE RESPOND TO THE QUESTION ON 'INCLUDING GUIDANCE ABOUT PEOPLE WITH OTHER CHROMOSOMAL CONDITIONS / LEARNING DISABILITIES'.**

**We need to make sure that people with Williams Syndrome can use this law too!**

Down Syndrome Act 2022: draft statutory guidance - GOV.UK This is the draft guidelines link.

Down Syndrome Act 2022 draft statutory guidance - Department of Health and Social Care This is the link to respond (scroll down for info about the easy read version).

**We have considered the Guidance and have shared our response below in RED:**

# Down Syndrome Act 2022 draft statutory guidance

Back

**Please tell us about any health conditions and/or learning disability that your family member (or the person you care for) has. (Optional)**

You have 100 characters remaining

Please do not include any personal information that might identify you or anyone else.

My child has Williams Syndrome – similar health, education, social care, employment and housing needs.

**If you have any further comments on the content of the guidance, please outline them here. (Optional)**

This could include any recommendations for improvement you may have. Maximum 200 words.

The real danger of these guidelines is that they are guidelines specifically for this minority group within the learning-disabled community, and people with Down syndrome will be more likely to receive the support they need of the limited resources available, through conscious or unconscious bias.

In order to help prevent this bias, the paragraph about the 1.3 million people with a learning disability who should be equally served through existing duties should be changed to bold text. Likewise, the paragraph that begins...
Importantly, the DS Act does not require and is not intended to provide enhanced or additional care and treatment for those with Down syndrome over and above other groups of disabled people or people with other conditions and/or a learning disability should be highlighted by changing the text to bold.

To give greater credence to other conditions, there should be a link within the examples of conditions with overlapping needs to a document containing all of the known overlapping conditions and a statement about those without a diagnosis who could have overlapping needs. This then will give parents of individuals with other conditions something within the document to reference should a LA authority dispute the overlap through ignorance.

**Please select which sections of the guidance you would like to provide further feedback on.**

Select all that apply. You will only be shown questions relating to the topics you've selected.

- [ ] 1. Accessible and person-centred services
- [x] 2. High-quality and holistic healthcare
- [x] 3. Independence through social care
- [x] 4. Effective education and preparation for adulthood
- [ ] 5. Meaningful employment
- [ ] 6. Appropriate housing
- [ ] 7. Where to find help and support
- [x] Inclusion of guidance about people with other chromosomal conditions, genetic conditions and/or a learning disability
- [x] The resources and examples of good practice annex

You need to tick these boxes to be able to comment on these specific chapters / resources. You may not want to comment on all of them, but please read through our suggestions highlighting the potential issues for people with WS and then select those that you wish to comment on.

**PLEASE RESPOND TO THE QUESTION ON INCLUDING GUIDANCE ABOUT PEOPLE WITH OTHER CHROMOSOMAL CONDITIONS / LEARNING DISABILITIES. We need the services to think about Williams Syndrome!**

You may wish to comment on all of them. We have written responses about the chapters that most need to change. If your views reflect those shared, you may wish to use our responses – in which case, it would be better if you could re-word them (or use AI to re-word them for you).

**What changes, if any, do you think are needed to make this section (high-quality and holistic healthcare) clearer? (Optional)**

Maximum 200 words.

Healthcare aspirations, please compare with the general population when making the "more likely" comparison for people with DS, as people with WS are also at greater risk of the highlighted conditions (dementia excepted).

Mental Health Services – 60-90% of individuals with WS suffer with extreme anxiety. Please include a box with examples of conditions with overlapping needs, including Williams Syndrome, in this section.

Speech and Language Therapy is under-resourced and cannot meet demand. Many parents of children with Williams Syndrome cannot access SLT services until their child is 2-3, depending on the LA, despite the child being unable to communicat. To say SLT should start from birth and SLT services are crucial throughout the lifetime for people with DS without any recognition of the scarcity of SLT support WILL impact those with other conditions.

Occupational Therapy is also scarce and under-resourced, so multi-disciplinary approaches while great, are very difficult to set up. Please could you add a sentence with the same should be offered to children with similar global developmental delay including speech, language and motor abilities.

Transition is crucial for all – please change to "should work with young people, including those with Down syndrome, and their family…"

**What changes, if any, do you think are needed to make this section (independence through social care) clearer? (Optional)**

Maximum 200 words.

Social Care aspirations / Older adults with DS – life expectancy (and the likelihood of out-living parents) has increased for all those with learning disabilities. Local commissioners must consider this potential increased demand across the whole LD population.

People with Williams Syndrome have identical social care needs as those with DS – this list is universal, not DS specific.

There is a general lack of awareness of the social care and support available – available clear and accessible information would benefit the whole LD community.
Transition assessments / carers assessments – it must be clear that this is a MUST for all other conditions too.

"Preventative care and support for adults with DS - Under the Care Act, local authorities must provide (or arrange the provision of) services, facilities, resources or other measures, in their area, that will help to prevent, delay or reduce the support needs of adults with Down syndrome and their carers." This "must" should be re-worded to "…prevent, delay or reduce the support needs of adults, including those with DS and their carers." Forward thinking to help build skills in children and young people to enable them to contribute to society in a meaningful way will reduce social care requirements.

**What changes, if any, do you think are needed to make this section (effective education and preparation for adulthood) clearer? (Optional)**

Maximum 200 words.

We really appreciate that WS is referenced in this section, as the overlaps are so significant (the only real difference is children with WS do not tend to have the same issue with unclear speech). It would be fantastic if we could add to the sentence about what children with WS need support with to include - sensory needs, breaking tasks

down and maintaining focus. It is well documented that children with WS have sensory needs as well as issues with processing, working memory and concentration.

## Inclusion of guidance about people with other chromosomal conditions, genetic conditions and/or a learning disability

To what extent do you agree or disagree with the following statements?

**The guidance should include the needs of people with other chromosomal conditions, genetic conditions and/or a learning disability.**

- (●) Strongly agree
- ( ) Agree
- ( ) Neither agree nor disagree
- ( ) Disagree
- ( ) Strongly disagree
- ( ) Not sure

**How could the resources and examples of good practice annex be improved?**

Select all that apply.

- [x] Further case studies and/or examples of best practice could be included
- [x] Further links to additional resources could be included
- [ ] The case studies and examples of best practice could be clearer
- [x] Other
- [ ] Don't know
- [ ] No changes are needed

**Please explain your answer. (Optional)**

To give greater credence to other conditions, there should be information about other known conditions with overlapping needs and a statement about those without a diagnosis who could have overlapping needs. This then will give parents of individuals with other conditions something within the document to reference, should a LA authority dispute the overlap through ignorance.

For Williams Syndrome, we have research driven, published guidelines for Clinical Management of WS, Guidelines for Educators with pupils with WS, Guidance on managing Anxiety. It would be useful if there was a link to a webpage for each condition so that as more guidance is produced it can be added so that this guidance really does make a positive difference for people with other genetic conditions / learning disabilities.

GeNotes, a little-known NHS website, has a knowledge hub of conditions, including Williams Syndrome. https://www.genomicseducation.hee.nhs.uk/genotes/knowledge-hub/williams-syndrome/ It contains useful health information about many rare genetic conditions, so this should definitely be included within the annex.

# Before you submit your response

We have a few questions we would like to ask to help us improve future consultations.

**How satisfied are you with the consultation process? (Optional)**

- ○ Very satisfied
- ○ Satisfied
- ◉ Dissatisfied
- ○ Very dissatisfied

**Please explain your answer. (Optional)**

I am concerned about the question asking whether this guidance will help people with Down syndrome. It is very leading and having a law and guidance for people with DS will obviously help people with Down syndrome. Given the response options, it will enable DWP to say that 90+% of respondents agreed that the guidance will be helpful for the DS community.

Where is the question about do we think that this guidance will make access to services better or worse for people with other genetic conditions / learning disabilities?

Did the DWP share the consultation questions with organisations that represent other genetic conditions / learning disabilities to get feedback on the consultation questions prior to publishing the consultation?

Department of Health & Social Care

# Down Syndrome Act 2022 draft statutory guidance (easy read)

**This the link for the Easy Read draft guidance:**
**Down Syndrome Act 2022: draft guidance (easy read) - what services should do to support people with Down syndrome**

**This is the link to a response if you are printing it out and posting it.**
**Questions for people with Down syndrome, a similar condition and/or a learning disability plus their family and carers**

**This is the online response link for the easy read version:**
**Down Syndrome Act 2022 draft statutory guidance (easy read) - Department of Health and Social Care**

**There is a really important question at the end of the questions about whether the guide should think about the needs of those with similar conditions / learning disability.**

**This is your chance to say that the guidance should think about people with similar needs, not just Down syndrome.**

**Please tell us why you are filling in this survey.**

- ○ 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 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. (Optional)**

I have Williams Syndrome

**Please tell us what disability or health condition you have.**

**Write your answer in this box. (Optional)**

Williams Syndrome

**Does your condition affect how you do everyday things?**

**Things like cleaning, shopping or making meals.**

**(Optional)**

◉ Yes

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

- (●) Yes
- ( ) No
- ( ) I don't know

**Do you want to tell us anything else about the things in the draft guidance? Please write your answer in this box. (Optional)**

**- This is an opportunity for our young people / adults to respond to the DS Act guidelines.**

**Evie's response:**

I struggle with anxiety as do lots of people with Williams Syndrome. Services should know how to support people with Williams Syndrome with our mental health and keep a list of us. I need heart checks and my tummy is causing me lots of problems as well.

I have the same needs as people with Down syndrome. I know lots of people with Down Syndrome, and we all do the same things.

I don't know what support I can get to help me.

I struggle with learning, writing and maths. I need support to help me break down activities into steps and to remind me of what I need to do.

I have hyperacusis and struggle with loud noises. I also struggle with strong smells like oranges. These make me stressed and I need help when these things upset me.

I like going to college, but they are saying that I cannot stay until 25 because of Ofsted. I don't feel I can cope with a job yet, so worry about not being able to stay at college. I don't know who will help me get a job. Can I be supported to have an apprenticeship?

I live with Mum and Dad now. I will need to move into supported living with people like me before Mum and Dad get really old. Are services planning for me to have somewhere to live with the help I need?

**Paige's response:**

I am on a long waiting list with my mental health but it would be better if I could talk to someone now not in 6 months time.

I finished my college course and then moved onto a supported internship but the jump between college and the work place was too much. I wasn't supported enough on the supported internship to make it work.

There aren't enough companies out there willing to take on someone who would be great in their company if they were given the right support. - What happens to me know that I can't do the internship and I can't go to college as I have completed the courses that they offer and I am not 25 yet, Ofsted don't want us there until we are 25!

The day services are boring and do not make us feel valued - I spent everyday there doing colouring in sheets rather then meaningful, empowering community jobs to help others but still be supported. It was quite soul destroying!

What support will I get to move into supported living when my mum and dad get too old. Social workers are not assigned to individuals so don't get to know them and their needs.


We do have some more questions we want to ask you.

Are you happy to answer more questions?

- (•) Yes
- ( ) No