

Checklist of Issues for Inclusion in the Down Syndrome Act Guidance

A Guide for Parents, Carers and Families

Dear Parents, Carers, Family Members, Friends and Advocates,

We have come a very long way together. We are now at the final and most important stage: helping to improve the statutory Guidance for the Down Syndrome Act. Your voice—and your lived experience—can directly influence what goes into the final version.

Previously, many of you shared your experiences across key areas such as Maternity and Early Years, Education, Healthcare, Employment, Housing and Social Care. Many of those needs remain unmet, and our comparison between your feedback and the current draft Guidance shows clear gaps.

One major gap is **Down syndrome-specific training** is only mentioned once. This limited reference understates the importance of having the right training in place to support both staff and students, leading to improved outcomes. Many of you told us how important it is that the people supporting your loved ones understand the unique learning profile of Down syndrome. This affects everything—from reducing diagnostic overshadowing and unconscious bias, to improving communication, inclusion, and expectations in education, healthcare, employment and social care. Yet, the current draft Guidance does **not** mention Down syndrome-specific training at all.

You may wish to highlight this throughout your consultation responses. There is also a specific consultation question on training, which is an ideal place to raise it.

Using This Guide

This resource helps you identify the key gaps that **did not** make it into the current draft Guidance.

If these issues still matter to you, please raise them in your response.

We recommend:

- Reviewing this checklist below before completing the consultation.
- Talking with your loved one with Down syndrome about the issues raised—your combined voices are powerful. We have created some easy to complete resources, that include some of the gaps that we have identified. Here is a [link](#) to those resources
- Visiting the Government's consultation website once you know what you want to say. Open tabs for both the full [consultation](#) and the [questions](#) so you can switch between both to check your replies.

- Remember: the main consultation has a 200-word limit, but the Easy Read response does **not**.
- We have suggested wording for reference, but your own experiences will be far more powerful

We have also identified some inaccuracies in the draft Guidance. For example, it states that “most” children and young people with Down syndrome have a learning disability or will “likely” require SEN support. In fact, **all** people with Down syndrome experience some degree of learning disability. We have [provided a letter you can send to your MP](#) highlighting this and other concerns.

There are 7 sections in the consultation and an Annex, where good practice is identified.

This guide will identify gaps that we have identified from our Call for Evidence where we have identified them alongside the question that is featured in the Governments consultation.

Structure of the Consultation: Gaps and Suggested Wording

Questions relating to overall views of the Guidance

Question for organisations and individuals sharing their professional views

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

The guidance meets its aim to raise awareness of the needs of people with Down syndrome by bringing together in one place everything that relevant authorities must and should already be doing to support them and meet their needs.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

Question for individuals sharing their personal views and experiences.

We would disagree.

Bringing existing duties together may raise awareness, but it falls short of the Down Syndrome Act's purpose, which is to improve outcomes. To achieve this, the guidance needs to go further by addressing the real barriers people face—such as low expectations, stereotyping, diagnostic overshadowing, and the lack of Down syndrome-specific training. It should also provide clearer direction on how needs should be met. Strengthening these areas would make the guidance far more effective in driving meaningful change.

Question for individuals sharing their personal views and experiences

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

The guidance clearly explains the help and services that people with Down syndrome can expect to receive.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

We would disagree.

The guidance could be clearer for families if it used simple, accessible language with less legal jargon and explained the practical support and services available.

The guidance brings existing duties together but does not address the issues that lead to poorer outcomes—such as low expectations, stereotyping, diagnostic overshadowing, gaps in specialist health pathways, and inconsistent educational support. It also needs stronger emphasis on Down-syndrome-specific training and the vital role of peer and community support. Strengthening these areas would make the guidance far more effective

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

The guidance will have a positive impact on people with Down syndrome and their families and/or carers.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

The guidance will have a positive impact on people with Down syndrome and their families and/or carers

We would disagree.

To have a positive impact, the guidance needs to go beyond restating existing duties and address the real issues that lead to poorer outcomes—such as low expectations, stereotyping, diagnostic overshadowing, and gaps in key health and education pathways. Greater emphasis on Down-syndrome-specific training and on the vital role of peer and community support would significantly improve its effectiveness and help it achieve the impact intended by the Act.

1. Accessible and Person-Centred Services

Question in the consultation:

Questions for everyone

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

The guidance will have a positive impact on people with Down syndrome and their families and/or carers.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

If you have any further comments on the content of the guidance, please outline them here. This could include any recommendations for improvement you may have.
(Optional, maximum 200 words)

Gap Identified:

- Down syndrome-specific training

Please draw on your own personal experience

Suggested wording:

There is currently no requirement for professionals to receive specialist, evidence-based training on Down syndrome. Such training is essential to reduce diagnostic

overshadowing, challenge unconscious bias, raise expectations, and improve inclusion in all settings.

2. High-Quality, Holistic Healthcare

Question for individuals sharing their personal views and experiences

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

The guidance provides clear information about the healthcare support available to people with Down syndrome.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

Gaps Identified:

- Down syndrome-specific training
- Limited reference to:
 - Gastrointestinal care
 - Thyroid screening
 - Constipation
 - Obstructive sleep apnoea
 - Dementia

Please draw on your own personal experience

Suggested wording:

There is a clear absence of any requirement for healthcare professionals to receive evidence-based training on Down syndrome. Without this training, professionals cannot accurately recognise health needs or prevent diagnostic overshadowing. Mandatory training is necessary to ensure safe, consistent, and effective healthcare.

Many common health needs, including thyroid conditions, sleep apnoea, SLT needs, mental health and dental care, are referenced without clear responsibility or referral pathways. Clearer guidance on screening, SLT provision, multidisciplinary working into adulthood and Down syndrome-specific training is needed to support timely, preventative care and better outcomes. Families also report that diagnoses are often communicated in a medicalised, deficit-focused way, underscoring the need for balanced, evidence-based, equality-driven communication supported by appropriate training.

3. Independence Through Social Care

Question in the consultation:

Question for individuals sharing their personal views and experiences

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

The guidance clearly explains what social care support people with Down syndrome expect to receive.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

Question for everyone

What changes, if any, do you think are needed to make this section (independence through social care) clearer? (Optional, maximum 200 words)

Gaps Identified:

- Respite care
- Transition to adulthood timescales
- Navigating benefits and welfare
- Down syndrome-specific training

Please draw on your own personal experience

Suggested wording:

There is currently no requirement for social care professionals to receive specialist, evidence-based training on Down syndrome. This lack of training leads to unmet needs, inconsistent support, and lowered expectations. Mandatory Down syndrome-specific training would equip staff with the knowledge and skills needed to provide high-quality, person-centred support and ensure individuals receive the standard of care they are entitled to

4. Effective Education and Preparation for Adulthood

Question in the consultation:

Question for individuals sharing their personal views and experiences

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

The guidance clearly explains the support people with Down syndrome and their families and/or carers can expect to receive from relevant authorities in meeting their learning needs.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

Question for everyone

What changes, if any, do you think are needed to make this section (effective education and preparation for adulthood) clearer? (Optional, maximum 200 words)

Gaps Identified:

- Early intervention
- Reading approaches
- Importance of differentiation and adapted resources
- Additional support for social interaction
- Transport

Please draw on your own personal experience

Suggested wording:

There is currently no requirement for educators to receive specialist, evidence-based training on Down syndrome. Early intervention is critical, yet without condition-specific training, teaching staff cannot reliably identify needs or provide appropriate support. Mandatory training would strengthen early intervention, remove preventable barriers, and significantly improve outcomes and inclusion in education.

5. Meaningful Employment

Question in the consultation:

Questions for everyone

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

The guidance clearly explains the legal duties regarding reasonable adjustments that organisations must make to support people with Down syndrome with regard to higher education and employment.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure

What changes, if any, do you think are needed to make this section (meaningful employment) clearer? (Optional, maximum 200 words)

Gap Identified:

- Lack of work experience
- Down syndrome-specific training for employers

Please draw on your own personal experience

Suggested wording:

It is vital that employers understand the unique learning profile of people with Down syndrome. Access to specialist, evidence-based training would help employers provide appropriate support, recognise strengths, and create inclusive, productive workplaces. 5.6% of people with LD are in paid employment

6. Appropriate Housing

From the call for evidence, no major gaps were identified in this section.

Please draw on your own personal experience

7. Where to Find Help and Support

Please draw on your own experience and include examples of local support groups or national bodies that have helped you.

We would encourage you to share the NDSPG Advisory Group as a support network for Adults with Down syndrome (<https://ndspg.org/advisory-group/>)

Annex: Case Studies

Please suggest or share examples of good practice that demonstrate what effective support looks like.

Don't forget you can also post your replies to the following address:

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

Thank you for taking the time to complete the consultation.

Your voice matters, and together we can help shape better services and fairer futures for people with Down syndrome.