



DSUK – Full Consultation Response to DHSC

Aligned to DHSC Consultation Sections • Includes DSUK & NDSPG Recommendations

VIEWS ON DRAFT GUIDANCE

Views on the Draft Guidance as a Whole

The draft guidance reflects positive intentions but falls significantly short of the accuracy, specificity and Down syndrome–focused direction required to deliver meaningful change. A core problem throughout the document is the repeated use of vague or hedged wording such as ‘may have a learning disability’, or ‘may have speech and language delay’. These statements are factually incorrect and risk weakening professional expectations, reducing support pathways, and undermining families during crucial stages of care.

The guidance must unequivocally state that:

- **Everyone with Down syndrome has a learning disability.**
- **Everyone with Down syndrome has a delay in speech and language development.**

This is essential to ensuring appropriate support, early intervention, and the provision of reasonable adjustments in health, education and social care. Failing to state these facts clearly risks professionals using local discretion, leading to unequal access to services.

The document also fails to embed the requirement for Down syndrome–specific training, despite this being overwhelmingly emphasised in the Call for Evidence, by lived-experience groups, and by expert organisations. Generic disability training does not equip professionals with the knowledge required.

Finally, DSUK recommends explicit inclusion of the National Down Syndrome Policy Group’s (NDSPG) Advisory Group, which supports adults with Down syndrome to engage directly in policy formation. This group represents an essential lived-experience mechanism and should be recognised and signposted in guidance and the Annex. The NDSPG should also be referenced in ‘Where to Find Help and Support’ because it ensures people with Down syndrome have formal routes to influence ongoing guidance development.

Link: [National Down Syndrome Policy Group](#)





1. Accessible and Person-Centred Services

ACCESSIBLE SERVICES

Accessible and person-centred services must recognise the distinct communication, sensory and cognitive profile associated with Down syndrome. DSUK recommends mandatory Down syndrome-specific training across all relevant services, as this is essential for delivering safe, respectful, equitable support.

Professionals must use non-directive, strengths-based language, free from outdated, harmful or deficit based terminology; in maternity care avoidance of discriminatory language such as 'risk', 'abnormality' or 'defect'. Such language has a well-documented negative impact on families' mental health and contributes to stigma.

Diagnostic overshadowing remains a major barrier to safe care. The guidance must explicitly instruct professionals not to attribute symptoms to "just Down syndrome" without assessment. A proactive commitment to preventing overshadowing must be embedded across clinical pathways, care reviews, and reasonable-adjustment planning. Parents and carers need to understand diagnostic overshadowing in order to advocate effectively for their family member.

Adjustments must include:

- Extended appointment times
- Visual communication supports
- Consistent language approaches across teams
- Clinically relevant Easy Read materials
- Respect for processing time and sensory needs.

Link: [Diagnostic overshadowing](#)

2. High-Quality and Holistic Healthcare

HOLISTIC HEALTHCARE

Newborn and Early Childhood Care

The guidance must reference the DSMIG Down Syndrome Red Book insert, which provides evidence-based pathways for newborn assessments, monitoring, and follow-up schedules. This is a critical clinical tool currently omitted.

Professionals must use respectful language during assessments, avoiding uninvited discussion of antenatal screening choices. Parents consistently report these conversations as distressing and irrelevant in the newborn period.

Link: [DSMIG](#)



Feeding and Breastfeeding

Breastfeeding is conspicuously absent from the draft guidance. Babies with Down syndrome can breastfeed, and breastfeeding rates for this population increase significantly when families receive early, tailored support.

Feeding guidance must highlight:

- Babies with Down syndrome can breastfeed
- Avoidance of deficit-based assumptions
- Support for positioning, latching, pacing and stamina (evidence-based)
- Early referral to feeding specialists with Down syndrome-specific knowledge

Link: [DSUK's breastfeeding guidance](#)

Speech & Language Therapy

Everyone with Down syndrome has a developmental delay in speech and language development, which is acknowledged as a universal characteristic of the condition. Therefore, the Guidance must set clear expectations that early S< support must be identified as required and practitioners must access Down syndrome-specific training.

Children with Down syndrome have a well-evidenced, distinct communication profile that requires targeted approaches. DSUK has developed a three-part professional training programme, including modules on developing vocabulary and syntax and supporting communication and social strengths.

Support must include:

- Feeding and swallowing assessments
- Oromotor development
- Early communication, language and interaction
- Ongoing review

Link: [DSUK's Speech & Language Therapy professionals training](#)

Common Health Conditions

The guidance must include clinically relevant signposting for conditions with increased prevalence, including:

- **Constipation** – include direct link to NICE CG99 (Children and Young People)
- **Hirschsprung's Disease** – Families of children with Down syndrome affected by Hirschsprung's require Down syndrome-specific support. DSUK is the only UK charity delivering this.
- **Vision** – Guidance states routine newborn eye screening and then again at 4 to 5 years of age, but the DSMIG advises that between 18 months and 2 years, all children with Down syndrome should have formal ocular/visual assessment by an orthoptist and ophthalmologist/optometrist.
- **Thyroid, cardiac, immune and sleep-related issues** – improved clarity on monitoring expectations.



Links:

[DSMIG](#)

[NICE Constipation Guidance](#)

[DSUK Hirschsprung's Support](#)

Maternity support

Guidance must include reference to the Royal College of Midwives (RCM) training on delivering a diagnosis:

- This is a recognised national training standard and essential for improving maternity experiences and must be referenced in the Healthcare section.

3. Independence Through Social Care

SOCIAL CARE

Social care assessments must recognise the lifelong developmental profile of Down syndrome, with clear expectations for support in communication, decision-making, personal care, mobility and independence. Assessments must not rely on parental advocacy alone.

Social care support to families

Because families require rights-based navigation of the Care Act and social care entitlements, DSUK's collaboration with Access Social Care should be referenced in the Social Care section of the Guidance, to ensure families have access to expert legal, rights-based support.

Training for social care professionals must be Down syndrome-specific, as generic disability frameworks fail to equip staff with the necessary knowledge.

Link: [DSUK Social Care Guidance](#)

4. Effective Education and Preparation for Adulthood

EDUCATION & ADULTHOOD

All children with Down syndrome require structured educational support, and this must be clearly stated. The draft guidance does not sufficiently link identified learning needs to the provision required. Education staff must receive Down syndrome-specific training. Greater emphasis on importance of early intervention as per research from Prof Sue Buckley of Down Syndrome Education International.

Preparation for adulthood must begin early, embedding independence, communication and community participation into all planning.

Annex Inclusion: [DSUK Secondary Education Programme](#)



EMPLOYMENT

5. Meaningful Employment

Young people with Down syndrome must have access to meaningful work experience and supported pathways into employment. This requires coordination between Further Education, social care, job coaches and employers.

The guidance must set expectations around:

- Preparation for employment during school years
- Rights-based access to work experience
- Support for employers to make reasonable adjustments
- Supported internships and paid opportunities

6. Appropriate Housing

HOUSING

Housing planning must begin early, focusing on independence, safety, communication needs, and supported decision-making. Local authorities must offer community-based options aligned with individual preferences.

Housing officers and social care teams require Down syndrome–specific training to understand communication needs and assess risks appropriately.

7. Where to find help and support

HELP & SUPPORT

The guidance must actively signpost families and professionals to Down syndrome–specific support, including:

[DSUK](#)

[NDSPG Advisory Group](#)

[DSMIG](#)

[Access Social Care](#)

[Local Down syndrome support groups](#)

[National online early development support](#)



8. Resources and Examples of Good Practice – Annex

ANNEX

The draft Annex currently lists generic resources but does not include any Down syndrome-specific clinical tools, communication guidance, training, or specialist support organisations. In addition to the sections above where DSUK has highlighted resources that must be incorporated into the main Guidance (as they relate to the statutory duties of relevant authorities and directly shape clinical, educational or social care practice), we also highlight below a number of resources that could appropriately sit within the Annex, provided the Guidance itself clearly references the underlying Down syndrome-specific needs.

8a. DSUK Secondary Education Programme

This is a good practice example of Down syndrome-specific educational training and resources.



It sits appropriately in the Annex as long as the main Guidance:

- Recognises that all children with Down syndrome require educational support.
- Specifies the need for Down syndrome-specific training for teachers and SEN staff.

Link: [DSUK Secondary Education Programme](#)

8b. Additional Down syndrome-specific good-practice resources

Once the main expectations are placed in the Guidance, the Annex can include:

- [Down syndrome-informed infant feeding examples](#)
- [Down syndrome-specific S< training](#)
- [Clinical supplements \(growth charts, health pathways\)](#)
- [Parent-facing early intervention programme](#)

