



## Peer Support Group Update

Our DS CEN peer support group offers a friendly and supportive space to listen, reflect and learn from one another. We meet online, currently on the first Thursday of the month 4-5pm. The group is facilitated and co-ordinated by Jo Gawn and Zein Pereira. The agenda is led by whatever group members bring.

### Questions we reflected on this Autumn have included:

What are the parameters of enabling 'functional communication'?

A multi-pronged approach with a child who finds speech work difficult.

How to write a target in a way that explains its value and function.

How to support a child in year 5 with higher level language and social communication support needs, and an upcoming transition, given the constraints in service provision.

Supporting self-advocacy in a young person post-16.

### A quote from a DS CEN member:

*"I find the peer support group invaluable to support my clinical practice (no question is too basic) and to bounce ideas. I always learn something new and sometimes can help someone else. Everyone is very generous with sharing expertise and resources."*

We hope you can join us in the new year. Our next sessions are scheduled for **Thursday 5th March 2026 and Thursday 16th April at 4pm.**

## DS ACT Draft Statutory Guidance

As you will have seen in recent emails from the DS CEN, the DS Act draft statutory guidance is now available to view and can be found here:

<https://www.gov.uk/government/consultations/down-syndrome-act-2022-draft-statutory-guidance/down-syndrome-act-2022-draft-statutory-guidance#:~:text=This%20guidance%20brings%20together%20existing,this%20guidance%20section%20below>

There is now a consultation period where people are invited to give their views on this draft guidance issued under the Down Syndrome Act 2022: <https://www.gov.uk/government/consultations/down-syndrome-act-2022-draft-statutory-guidance>.

**Please note, the deadline for consultation is now 30th March 2026.**

As the DS CEN we feel it is important to discuss the guidance with members and consider feedback from the DS CEN, particularly around the information on speech, language and communication. The working group have met twice to discuss the DS CEN's response and have agreed the following actions:

- review the draft response with members at the Spring Term Study Day
- submit final response on 6<sup>th</sup> March 2026

## Members Meetings and Study Days

We held our Autumn Term Members' Meeting on the 24th November 2025, where we focused on Parent-child interaction. Dr Ciara O'Toole, Senior Lecturer in Speech and Language Therapy of the University College Cork, delivered a presentation on the topic of Parent-child interaction: *A customised intensive parent-child interaction therapy for children with Down syndrome: Findings from a real-world pilot effectiveness study.* (Authors Ciara O'Toole, Hannah Moloney, Chloe McCarthy, Sophie Vousden, Abby O'Sullivan, Deirdre Flynn, Susanna Stokes and Pauline Frizelle.)

The minutes from the meeting can be viewed via the Members' area of our website, along with links to the handouts and presentations: [DS CEN Autumn Term Study Day - November 2025 | Down Syndrome CEN](#)

**Our next online study is on Monday 2<sup>nd</sup> March 10am - 1pm**

Our topic will be on hearing and vision in Down syndrome and the implications for speech and language therapists. We have two excellent speakers who will be delivering the following presentations:

- The Impact of Hearing on Communication in Down Syndrome: Implications for SLT Practice. Caroline Murphy, Independent Speech and Language Therapist <https://www.carolinemurphyslt.co.uk>
- Vision in Down's syndrome: implications for SLTs Maggie Woodhouse, School of Optometry & Vision Sciences, Cardiff University <https://www.cardiff.ac.uk/downs-syndrome-vision-research-unit/about/who-we-are>

All DS CEN members will get a link so they can access this study day. We look forward to seeing as many of you as possible.

## Research updates

Silvana Mengoni and Emma Pagnamenta hosted the DS CEN Research Group meeting on Tuesday 20<sup>th</sup> January. We have been looking into existing guidelines for involvement in research and groups that are carrying out some of this work already. We presented a paper by Frankena et al. (2018) to discuss in the context of thinking about an impact project for the group: [A consensus statement on how to conduct inclusive health research - Frankena - 2019 - Journal of Intellectual Disability Research - Wiley Online Library](#).

Our next meeting will be on **14<sup>th</sup> April at 3.30pm.** Leela Baksi will be sharing her RCSLT Presentation with Sam (co-researcher with Down syndrome) on new approaches to coproduction.

## Keep in touch

Email: [dscen@letsgouk.org](mailto:dscen@letsgouk.org)

Website: [www.ds-cen.co.uk](http://www.ds-cen.co.uk)

Twitter: [@DownSynCEN](https://twitter.com/DownSynCEN)

Closed Facebook Group: Full & associate members only: [www.facebook.com/groups/5837910309557009](https://www.facebook.com/groups/5837910309557009)

Join the DS CEN: <https://www.ds-cen.co.uk/jointhedsen>