

DS CEN Updates

Down Syndrome CEN Committee

Many of the DS CEN committee are coming to the end of their 3 year term. Therefore now is a great time to consider getting more involved. Read more about the committee and roles here: <https://www.ds-cen.co.uk/jointhedsccencommittee>

Events and CPD

DS CEN Summer Term Members' Online Meeting 8th July 2024

The topic for this meeting was 'Working with peers'. Dr Susan Foster-Cohen delivered a presentation covering "The language of inclusion: conversations between friends with and without Down syndrome." Visit the members' area to view the presentations and handouts: <https://www.ds-cen.co.uk/prev-study-days>

DS CEN Autumn Term Members' Online Meeting 14th Oct 2024 1-3pm

Dr Kelly Burgoyne will present the PACT-DS project. Find out more about the project here: <https://sites.manchester.ac.uk/pct/pact-ds/>

DS CEN Peer Supervision Groups

Our group is open access, with regulars and others who come on an 'as and when' basis. It offers regular contact with a network of peers and specialists working with individuals with DS. The agenda is led by attendees and although we may have a theme, we often begin by asking if anyone has a case to discuss then exchange information, share ideas and opinions, and collectively respond to clinical queries. Issues are discussed confidentially. The next three peer support group dates will be:

- 08 October 24 16:00-17:00
- 05 November 24 16:00-17:00
- 03 December 24 16:00-17:00

DS CEN Research Groups

The topic of the July meeting was 'Shape Research Change Lives project summary' <https://www.surrey.ac.uk/research-projects/shape-research-change-lives-setting-priorities-genetic-syndrome-research>.

We discussed the importance of engaging in research directly with the community to understand what the "real challenges" are for people with Down syndrome and their families, and for SLTs working with this population, and what "notable improvements" would look like.

Monday 18th Nov 2024 4-5pm

Our next meeting topics Participatory research methods. We would love you to come along.

Resources



Beyond Words Book Clubs take place across the UK and bring together people with learning disabilities to read word-free picture books as a group. Books Beyond Words is a co-created series of more than 50 picture books about daily lives.

<https://booksbeyondwords.co.uk>

Research updates

Perspectives of Speech and Language Therapists: AAC for children and young people with Down syndrome

Elaine Scougal is seeking the views and experiences of UK SLTs who support, or have recently supported, children and young people with Down syndrome (3-18 years) to find out about experiences and perceptions of unaided and aided AAC. Visit: <https://app.onlinesurveys.jisc.ac.uk/s/dundee/aac-slt-perspectives>

Babble App Project

This project is now recruiting 7-15 month old babies with Down syndrome to explore whether a new app helps babies to vocalise more. Families can take part from anywhere in the UK. Contact:

babbleds-project@york.ac.uk



Retrieval Practice Study

Dr Kelly Burgoyne, Dr Laura Boundy and Emily Croft have found that children with Down syndrome benefit from retrieving (producing) words during learning as children were able to more accurately recall words in a retrieval learning condition compared to restudy. For more information visit:

https://www.downs-syndrome.org.uk/wp-content/uploads/2024/07/Retrieval-project_research-summaryJULY24.pdf

Making Positive Moves

The University of Hertfordshire has produced an animation of their research findings: https://www.youtube.com/watch?v=Oy_bJreYte8 The project involved interviewing people with learning disabilities about their experiences of life after discharge from a mental health hospital. The video shares insights into what is needed to support people with learning disabilities to live their best lives.

Down Syndrome Research Forum

The Down Syndrome Research Forum was held online on Thursday 25th and Friday 26th April 2024, hosted by Down Syndrome Education International Down Syndrome Research Forum (down-syndrome.org). Next year, the Forum will be held on 17th, 18th, 19th March, 2025: <https://www.down-syndrome.org/en-gb/research/forum/>

Keep in touch

Email: dscen@letsgouk.org

Website: www.ds-cen.co.uk

Twitter: @DownSynCEN

Closed Facebook Group: Full & associate members only:

www.facebook.com/groups/5837910309557009

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