



Down Syndrome CEN: working to support children and adults who have Down syndrome.

**OCTOBER 25  
NEWSLETTER**

## DS CEN Updates

We are pleased to introduce 3 new members of our committee:

**Katie Highway:** I am a speech and language therapist and have experience working with children and young people with Down Syndrome from pre-school to Post-16. I have worked in independent practice, but currently work for a local authority education service where I am clinical lead for Down Syndrome.

**Laura Winstone:** I am a Speech and Language Therapist specialising in working with children and young people with Down Syndrome. I am fortunate to have worked with people with Down Syndrome from infancy to early adulthood and I particularly enjoy my work facilitating social groups for teenagers and young adults.

**Katherine Storey:** I've worked with children with Down's Syndrome throughout my career in speech and language therapy. I love to help children show others how much they can do when they're well supported and motivated. I work with children at home, in school and through DS support groups. I have worked in Kent and Stockport for the NHS and spent two years working for VSO in Kenya. I'm currently based in Cambridgeshire working as an independent therapist.

We're always looking for people to join our committee – please do get in touch if you would like to get involved in the future. An overview of the roles of the committee can be viewed by clicking here: <https://tinyurl.com/DSCEN-RolesMarch22>

### Research Opportunities

#### Project CECiLiA:

Project CECiLiA is running an online survey to find out more about Care, (Education) and Treatment Reviews(C(E)TRs). We are inviting people to take part who have attended a C(E)TR in the last year, and who are from the following groups:

- Autistic adults and children
- Adults and children with a learning disability
- Family members and carers
- Health, education, and social care professionals
- C(E)TR panel members.

#### King's College London Down Syndrome and Bilingualism Study:

Who can take part?

- children and adolescents with Down syndrome aged 7 to 16 living in England
- participants can be either from English-speaking or non-English-speaking households

Please see attached flyers for further information.

## 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/jointhedsцен>

## Events and CPD

### DS CEN summer term meeting, 14<sup>th</sup> July

The Summer Term Members meeting was held on Monday 14th July. Professor Christopher Jarrold, Professor of Cognitive Development, University of Bristol, delivered a presentation on the topic of "Working memory and language in Down syndrome." The presentation covered current research detailing the working memory challenges for people with Down Syndrome, specifically in relation to verbal working memory and how this impacts on vocabulary learning and strategies which may support. Members discussed implications for their clinical practice, including how working memory challenges were accounted for when completing therapy activities. DS CEN autumn meeting.

### The following references were shared by participants:

DePaolis, R., Vihman, M. & Keren-Portnoy, T. (2011) Do production patterns influence the processing of speech in prelinguistic infants? *Infant Behavior and Development*, 34(4), 590-601, ISSN 0163-6383, <https://doi.org/10.1016/j.infbeh.2011.06.005>.

Hall, M. L. (2020). Dissociating the impact of auditory access and language access in deaf children's cognitive development. In M. Marschark & H. Knoors (Eds.), *The Oxford handbook of deaf studies in learning and cognition* (pp. 99-122). Oxford University Press.

Hall, M. & Bavelier, D. (2012) Working memory, deafness and sign language. In M. Marschark & H. Knoors (Eds.), *The Oxford Handbook of Deaf Studies, Language, and Education*, 15 (1), 104-127, 66,

Kanazawa, Y., Nakamura, K., Ishii, T., Aso, T., Yamazaki, H. & Omori, K. Phonological memory in sign language relies on the visuomotor neural system outside the left hemisphere language network. *PLOS ONE* 12(9): e0177599. <https://doi.org/10.1371/journal.pone.0177599>

Silverman., W. (2007) Down syndrome: cognitive phenotype. *Ment Retard Dev Disabil Res Rev*. 2007;13(3):228-36. doi: 10.1002/mrdd.20156. PMID: 17910084

### DS CEN peer support group

Our peer support group offers a supportive space to listen, reflect and learn from one another. The agenda is led by group members. There is space for general issues, particular themes (eg: working with narratives), and case discussion. Each question can generate a theme for reflections and discussion stretching across the lifespan. All levels of experience are welcome.

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. Please come along! We would love to see you there.



## Tell us about taking part in a Care, Education and Treatment Review (C(ET)R): Interview or Online Survey Study

### Who can take part?

You can take part if you have been part of a Care, Education and Treatment Review (C(ET)R) in the last year in England, and if you are in one of the following groups:

- Autistic adults or adults with a learning disability or autistic adults with a learning disability
- Autistic children or children with a learning disability or autistic children with a learning disability
- Family members and carers of people with autism or who have a learning disability or autistic people with a learning disability
- Members of the C(ET)R workforce
- Health, education and social care staff

### What will taking part involve?

You can take part in either:

- An online survey, or
- A Talking Mats interview.

You will answer questions about your experience of taking part in a Care, Education and Treatment Review (C(ET)R).

To find out more and take part visit:  
<https://bit.ly/42PuOdE>

or scan:



If you have questions or would like to find out more, please email:



[Cecilia@contacts.bham.ac.uk](mailto:Cecilia@contacts.bham.ac.uk)

or phone:

0121 414 3086

Thank you!



## CALLING FOR RESEARCH PARTICIPANTS



Hello! My name is Yuko, and I am a student researcher at King's College London. I am looking for children who want to take part in my study!

### Aim of the study

We would like to understand how children who have Down syndrome from various language environment, including bilingual children, develop their English skills

### Who can take part?

- Pupils with Down syndrome
- Age between 7 and 16



### What will you be asked to do?



Activities to see the child's language and cognitive skills



2-3 hours including breaks (done in 2-3 sessions)



Online parental questionnaires on the child's language environment



At your home, school or King's College Lab

Take part and get our original T-shirt and certificate



If you want to take part or have any questions...

**Yuko Matsuoka**

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REQUEST DETAIL FROM HERE

