

DOWN SYNDROME RESEARCH FORUM 2019

UNIVERSITY COLLEGE LONDON

16th and 17th of September

The Child Development and Learning Difficulties team was very pleased to host this year's Down Syndrome Research Forum at UCL. The Research Forum was attended by 100 delegates, including various professionals, parents, students and researchers. A detailed programme overview and the abstracts can be found here (<https://www.down-syndrome.org/en-us/research/forum/2019/>).

However, here are some highlights of the meeting:

Day 1:

The forum started off with 5 presentations focusing on school age. Conclusions from these talks include that:

- 1) Mediated learning can help raise young children with Down syndrome's planning abilities (Vesna Stojanovic). The team hope to get more funding to carry out a bigger study.
- 2) Using answer methods that required limited language abilities, children with DS showed that they do worry about the transition from primary to secondary school but they worry about different things (completing school work) compared to their parents and teachers (Maria Ashworth).
- 3) Elizabeth Burchell and colleagues showed that, in contrast to frequent reports that children with Down syndrome do not worry, there are a lot of individual differences and some children with Down syndrome do show very high anxiety levels. This suggest that some children with Down syndrome do need mental health support as well.

- 4) However, research by Hana D'Souza and colleagues showed that there is a lot of individual variability in the cognitive outcomes of infants with Down syndrome and we need to understand how this variability affects abilities in primary school education, in order to know better who needs what kind of support and when.
- 5) In addition, children do not just learn in school, the home environment can also stimulate and educate the child. Yet, research by Erica Ranzato and colleagues showed that parents of children with Down syndrome focused more on literacy activities and focused more on formal mathematical activities which children often find boring. This shows more information on how and what kind of informal activities can be implemented in the house need to reach parents and practitioners.



After lunch a few of the talks focused on the impact and ethics of screening for Down syndrome. Georgia Zimmer's research using discourse analysis showed how the language that is used by the NHS on their website is very negatively biased and this may guide a parents' decisions in relation to screening and abortions. In a similar vein, Nicola Enoch's project 'Positive about Down syndrome' shows that many professionals ignore the wishes of parents in relation to 1) screening for Down syndrome, or 2) the outcome of that screening test. In addition, the terminology used by professionals in relation to the screening is often very negative (e.g., bad news). At the end of the two-day meeting Nicola reported that she received an invitation from the Royal Society of Obstetrics and gynecology to discuss her

findings with them and look for ways forward to education professionals about Down syndrome.



The final session of the first day focused on health related issues and included 4 talks. The research by Silvana Mengoni and colleagues focused on the experiences of key healthcare professionals who work with families of young children with Down syndrome with feeding issues. The results from the interviews showed that professionals identified specific care pathways for children with Down syndrome who experience feeding issues and also for mums struggling with breastfeeding. These results differ from the experiences of parents reported in previous studies by the research team and therefore, this gap warrants further examination.



Next, Donna Murphy, a physiotherapist and mum of a young child with Down syndrome, introduced the audience to the importance of early motor milestones, especially the ability to crawl and the use of a Crawling Track. A lot of research in the last few years has shown how important early milestones are for development in children and thus, the crawling track shows to be a very promising tool to help children with developmental disabilities reach the important milestone of crawling. The final two talks focused on sleep issues in Down syndrome. Anna Joyce and colleagues reported that obstructive sleep apnoea (OSA) affects about half of the children with Down syndrome and OSA was found to relate to poorer working memory, emotional control and shifting. In light of this, Rina Cianfaglione and colleagues are planning a systematic review that will examine the evidence surrounding the treatments for OSA in children with Down syndrome. So far, the authors have identified 153 papers that meet the inclusion criteria for their review and they are now going through each of these papers to extract the information they need for the review. Watch this space!

The first day ended with a panel discussion reflecting on some of the issues related to Down syndrome. One of the topics of the discussion related to dissemination and it was considered to be good practice for academics to write short summaries (about 250-500 words) of the research with recommendations for daily, life, education or practice, even when the paper itself did not consider these or when there is no direct evaluation of these recommendations. There are currently very few evidence based intervention for people with Down syndrome. During the discussion ways to improve intervention research were

considered, including involving more practitioners in this research directly by providing them with the tools to evaluate the interventions and to include practitioners from the start of the intervention and research design.

Day 2:

The second day started with a number of talks that focused on recent research developments related to early development in Down syndrome, including research by Prachi Patke and colleagues that examines brain development, both cross sectionally and longitudinally in foetuses and neonates with Down syndrome and how early difference in brain development and genes link to cognitive outcomes in early life. Prachi explained the procedure of how the babies' brains are scanned and what taking part in the research entails as well as how this research can lead to early interventions.

Janet Atkinson and colleagues presented data from a new testing battery, Early Child Attention Battery (ECAB), that can be administrated on an iPad and measures a number of different attention abilities. The preliminary data from children with Down syndrome and Williams syndrome suggested that children with Down syndrome, in particular, showed marked difficulty in inhibiting inappropriate responses, with high response rates to non-targets in the visual search and sustained attention subtests.

Hana D'Souza and colleagues reminded us that the context in which we research abilities really matters and that a lot of the research thus far has been carried out in the lab with very controlled environments. In her latest research project, Hana and colleagues analysed the looking behaviour of young children with Down syndrome during free play sessions with their mothers. The preliminary data showed that parents look at the faces of the child to see if the child is paying attention and whilst children mainly keep looking at objects. However, there were more mutual looks between the children with Down syndrome and their parent than in the TD dyads and this could explain some of the social strengths in individuals with Down syndrome. In a similar vein, Desiree Grafton-Clarke and colleagues examined the use of child directed speech and attention in parent-child interactions. This study showed that, although most parents had very realistic expectations about their child's language delay, the study also showed that parents may over-simplify language, and miss opportunities to support learning.

Katie Lambert and colleagues discussed the difficulties that parents of children with a dual-diagnosis of autism and Down syndrome experience, especially the feelings of not belonging to either support group and not being able to find an appropriate type of school for their child. Her findings from a thematic analysis clearly show that more support for these parents is required. Jenny Glennon and colleagues examined the eye movements of children with Down syndrome and those with Fragile X during a very simple and short looking task, named GEOPreftask. In this task children are shown a 60 second video with children as well as moving geometrical shapes. Previous studies have shown that children with autism look more at the geometrical shapes compared to typically developing children. The results showed that children with a dual diagnosis of Down syndrome and autism had different looking behaviours that those with just Down syndrome or Autism alone. This shows the clinical complexity of children with a dual diagnosis that may impact on clinical (e.g., diagnosis) and educational practice.

Focusing on adults with Down syndrome, Wendy Uttley showed the challenges and solutions of getting young adults into work placements. The experience showed that not only the young adults with Down syndrome benefitted from this work experience (such as learning how to deal with money, independent travel and do some shopping) but that the companies and employers reported a number of benefits, including having a nicer and more sociable workplace.



The final talks all focused on a range of speech and language abilities in people with DS. Nicola Hart reported on how they are implementing The See and Learning programme in preschool setting in Ireland. However, Nicola discussed how it is not always easy to measure language improvements in young children or to take into account practical difficulties with implementation in the results of intervention studies. Elaine Scougal, examined the difficulties parents of children with Down syndrome experience when communicating with their child with Down syndrome and how the parents think other people perceive their difficulties. Almost all parents reported a lack of SLT support with many children being signed off from SLT support at a young age. In addition, many parents relied mainly on signing to communicate with their child. However, the use of signing means that parents then become translators for their child outside of the home. Elaine therefore suggested that parents should be educated on the use of other alternative augmentative and alternative communication (AAC) options in order to ensure that children with Down syndrome can become independent communicators and reach their full potential.

Becky Baxter and colleagues examined the type of speech errors made by 50 children with Down syndrome aged 5-10 years old using longitudinal data collected 21 months apart. Though there was considerable variability in the sample, children's speech was characterised by high levels of articulation errors and the speech articulation difficulties persisted over time.

Alex Perovic examined found in their study that adults with Down Syndrome showed exceptionally poor performance on all sentence types, even on actives of actional verbs. It is currently unclear whether this performance can be explained by any cognitive decline and thus further studies are required. However, both studies show that continued speech and language therapy is required for people with Down syndrome. With this in mind, Vesna Stojanovik and colleagues are evaluating a parent-delivered shared attention intervention for young children with Down syndrome as delivered by NHS Speech and Language Therapy services. The outcomes of this feasibility study will hopefully lead to a RCT that is feasible within NHS speech and language services and will provide much-needed evidence for early intervention to improve language and school readiness for children with Down syndrome. The Down Syndrome Research Forum ended with a short discussion that reminded us all that development is complex and that we should also consider how small changes early in

development can have an impact later on in development (see for example, the ability to crawl will allow children to explore toys more and learn language). However, we have very little research that focuses on this complexity and thus more work is to be done!

