# "People think if you can't talk, you don't understand"

Scougal, Elaine

*Publication date:*
2019

**DOWN SYNDROME RESEARCH FORUM 2019**
**UNIVERSITY COLLEGE LONDON**
**16th and 17th of September**
**Torrington Place 1-19 room G12**

**10.00 – 1030 Registration**

**Coffee, tea and pastries**

**10.30 Introduction and housekeeping** **Jo Van Herwegen**

**Session 1: School age**

**10.50 Early predictors of primary school outcomes in children with Down syndrome**

Hana D'Souza[1-3], Gaia Scerif[4], Michael S. C. Thomas[3], & LonDownS Consortium
[1]Department of Psychology, University of Cambridge
[2]Newnham College, University of Cambridge
[3]Centre for Brain and Cognitive Development, Birkbeck, University of London
[4]Department of Experimental Psychology, University of Oxford
hd425@cam.ac.uk

As part of the London Down Syndrome (LonDownS) Consortium, we established a large cohort of over a hundred of infants and toddlers (3-66 months) with Down syndrome (DS). We collected a range of data to investigate individual differences in health, cognitive, neurophysiological, cellular, and genetic profiles. We will soon start a longitudinal follow up of the LonDownS cohort in order to investigate whether the individual differences observed in infancy/toddlerhood relate to variability in outcomes at primary school age. In this talk, we will introduce some of the measures we used in infancy/toddlerhood and discuss hypotheses. Building on prior work on educational outcomes in children with DS at primary school age, we seek feedback from the audience on a battery of tasks we are currently designing.

**11.10 Mediated Learning Intervention for Primary School-aged Children with Down Syndrome**

Vesna Stojanovik[1], Jo van Herwegen[2] and Vanessa Nichols[3]
[1] University of Reading; [2] University College London; [3] Breakthrough Learning
v.stojanovik@reading.ac.uk

The aim of this presentation is to give an overview of our findings following the pilot Mediated Learning intervention which included 16 children with Down syndrome aged between 6 and 10. The intervention focused on two instruments from the Instrumental Enrichment Basic programme. One instrument called 'The Organisation of Dots' which aims to develop and strengthen the children's ability to define a problem, to plan how to address the problem, to form hypothesis and use logic when making choices, as well as to be precise in visual tracking and motor performance. The second instrument is called Identifying emotions and children are encouraged to use various cues (behavioural and social) to decide what is the emotional state of a person and to relate emotional states on pictures to their own experiences. All children were assessed pre-intervention on general language

skills, general non-verbal abilities, verbal short-term memory, emotion recognition, mental rotation and planning. The pre and post-intervention tasks were divided into: core tasks (those which were directly related to the intervention instruments) which included planning, mental rotation and emotion recognition, and control tasks (those which required skills which were not directly addressed with the intervention) and which included grammatical comprehension, verbal short-term memory and general non-verbal reasoning abilities. There was a significant increase in children's scores on the core tasks post-intervention whereas the scores were mainly unchanged for the control tasks.

**11.30 School transition concerns from parents, professionals, and children with Down syndrome and Williams syndrome**

Maria Ashworth[1], Elizabeth Burchell[2], Olympia Palikara[2], & Jo Van Herwegen[1]
[1]Psychology and Human Development, UCL, Institute of Education, London, UK
[2]School of Education, University of Roehampton, London, UK.
Maria.ashworth@ucl.ac.uk

Transitioning to a new school can be an exciting time for children, but it also raises a number of social, academic and environmental challenges that can make the transition difficult. This is especially true for children with neurodevelopmental conditions with additional special educational needs. Yet, little is known about what children with Down syndrome (DS) and Williams syndrome (WS), their parents and professionals find particularly worrying about moving schools.

In this study, children with DS and WS, their parents, and professionals completed questionnaires and interviews about the transition process and any worries they may have three months before they moved to secondary school. Findings showed that all children were worried about social and environmental factors. However, there were few opportunities for the child to become suitably familiar with their new school environment and new peers, despite this being the major concern. Finally, the main areas of concern differed between the children, parents and professionals. The current study provides further insight into how to support school transitions in DS and WS.

**11.50 Anxiety and well-being in children with Downs Syndrome and Williams Syndrome**

Elizabeth Burchell[1], Jo Van Herwegen[2], Maria Ashworth[2], & Olympia Palikara[1]
[1]School of Education, University of Roehampton, London, UK
[2]Psychology and Human Development, UCL, Institute of Education, London, UK
Elizabeth.burchell@roehampton.ac.uk

There is considerable evidence to suggest that many children with neurodevelopmental disorders experience some level of anxiety. Certain groups maybe more at risk of experiencing greater anxiety with age than others. Although it is commonly thought that children with Down Syndrome (DS) experience less anxiety than other syndrome groups, there is very little research about anxiety and wellbeing in DS. Identifying the prevalence and manifestation of anxiety in this group needs greater investigation. This is especially key

since childhood anxiety can have long-term effects on mental well-being long into adulthood (Crib, Kenny & Pellicano, 2019).

The current study explored anxiety and sensory profiles in children with DS and compared them to children with Williams Syndrome (WS) in order to examine the common and syndrome specific profiles of these psychopathologies in these children. We compared parental reports of their child's anxiety, social responsiveness and professional's reports of the child's sensory processing within the school context, in 23 children at the age of 11 years.

Findings indicate that some children with DS do show significant heightened anxiety across a range of measures and that patterns converge but also divert from those with WS. The findings will be used to discuss the underlying mechanisms and relationships between anxiety and sensory processing patterns. These results provide a better understanding of mental wellbeing in DS.

**12.10 – 13.10 Lunch**

**Session 2: Number Development**

**13.10 Home Numeracy Environment of children with Down Syndrome**

Erica Ranzato [1], & Jo Van Herwegen[2]
[1] Department of Psychology, Kingston University London
[2] Psychology & Human Development, UCL, Institute of Education
e.ranzato@kingston.ac.uk

Arithmetic and number skills are very important life skills to become independent. Yet, individuals with Down syndrome (DS) fail to achieve proficiency in mathematics (Brigstocke, Hulme and Nye, 2008; Lemons et al., 2015).
Research on numeracy skills in typically developing population shows that early home numeracy experiences, including playing games, reading number books and using money have a significant impact on children's later mathematical achievement (Guberman, 2004; LeFevre et al., 2009). Many studies that investigate the development of mathematical abilities of children with DS focus on different interventions and how they support mathematical abilities, but very little is known about the home numeracy environment of these children.
The current study explored and described the findings from a web-based survey on home numeracy environment of 50 children with DS aged between 4 to 11 years old. We will compare the importance of numeracy to literacy for parents of children with DS as well as their attitudes and expectations towards their children mathematical abilities. Further, we will explore the frequency and the type of number activities occurring in the homes of children with DS as well as the use of technology in the context of learning mathematics.

**13.50 Children with Down syndrome and their parents exploring number activities during free-play**

Joanna Nye[1]
[1]Department of Psychology, University of Portsmouth, King Henry Building, King Henry I Street, Portsmouth, PO1 2DY, UK
joanna.nye@port.ac.uk

There is a growing body of evidence that informal communication about number and maths at home is important for later number skills in typically developing children. Observational work with typically developmentally children suggests that the amount of parental number talk is very low (e.g. 4.62%: Lee et al 2010), however variations in the amount of input is related to 4- & 5- olds number knowledge (e.g. Blevins-Knabe & Musun-Miller, 1996). As yet little research has been conducted on the spontaneous number related interactions of children with Down syndrome and their parents. The current study will present exploratory findings from observations of child-parent dyads engaged in free-play. Longitudinal observations were made of 22 children with Down syndrome (3-6 year olds) and 21 typically developing 2-4 year olds (matched for non-verbal mental age). Initial exploration of this data will include the proportion of time spent discussing number, the type of number activities engaged in, and the form these interactions take (following Blevins-Knabe & Musun-Millar, 1999; Durkin et al, 1986).

## Session 3: Screening and ethics

**13.50 Is there evidence to suggest that the NHS promote abortion of babies with Down's syndrome? A Critical Discourse Analysis.**

Georgia Zimmer
University of Leeds
georgia.zimmer@gmail.com

From 11 weeks into a pregnancy, potential mothers are offered screening tests for Down's syndrome. This regulation gives parents the option to terminate the pregnancy within the legal timeframe for abortion. The genetic tests available are seeing more advancements in terms of the level of non-invasive harm they pose to the mother, as well as efficacy in gaining accurate results. There is an issue concerning the morality of pre-natal testing, considering it aims to appraise the value of a potential life, which can be deemed unmeasurable. Nevertheless, the National Health Service (NHS) advocate the screening process. Regarding this, the present study aimed to reveal whether the NHS promote abortion of foetuses known to have Down's syndrome through their online information resource on the condition. Using Critical Discourse Analysis as the method, the NHS webpage was scanned for marginalising discourses connected to Down's syndrome, to determine if there are traces of harmful ideologies where they address this topic. This can be exemplary of the NHS' stance on this topic, as well as establish if they guide parents into abortion through representing a partisan, negative depiction. Results show agreement with theoretical predictions in that the NHS consistently appealed to a discourse of struggle when informing their readers. However, some preliminary remarks are given in terms of

how this may be disputed, as well as groundwork for future study, which will hopefully continue to lead towards social inclusion for people with disabilities.

### 14.10 Mothers experience of antenatal screening, pre and post birth diagnoses, information and support

Nicola Enoch
Founder, Ups of Downs and Positive about Down syndrome
nicola_enoch@yahoo.co.uk

This paper will present the results of a survey of mothers of babies with Down syndrome which explores their experiences of screening and diagnoses. To date 1410 responses have been received from mothers who have given birth since 2000 with the majority of responses from mothers with babies born since 2012. The survey explores how screening was presented and explained, how 'high likelihood' results were explained, how terminations were offered and how diagnoses were given pre and post birth. The implications of these findings for improving the way in which services and accurate information about growing up with Down syndrome are provided will be discussed. This is a pressing issue with the roll out of NIPT in the NHS from next year.

**14.30 – 15.10 Tea and coffee**

## Session 4: Health

### 15.10 Supporting families of children with Down syndrome with feeding and eating: Perspectives from healthcare professionals

Silvana Mengoni[1], Charlotte Hamlyn-Williams[1] & Samantha Rogers[1]
[1]University of Hertfordshire, Hatfield, United Kingdom
s.mengoni@herts.ac.uk

Infants with Down syndrome (DS) often experience feeding problems. The limited research on parents' experiences suggests that there is an unmet need for support on key issues such as breastfeeding and introduction to solid food. This study explored the experiences of key healthcare professionals who work with families of young children with DS with feeding issues.

Twelve healthcare professionals were recruited from two NHS Trusts in the East of England from the following professional groups: health visitors, speech and language therapists, occupational therapists and midwives. Participants took part in an individual semi-structured interview to explore: 1) Their experiences of supporting families of children with DS aged 0-5 years with feeding issues; 2) Care pathways; 3) Relevant training undertaken; and 4) Challenges associated with supporting feeding issues.

The interviews were transcribed and thematically analysed for themes and subthemes. Results will be presented. Early intervention is key to minimise the potential long-term impact of feeding problems. Health professionals working with young children with DS and their families are crucial to ensuring effective support for feeding problems.

This study is unique in exploring health professionals' experiences and needs with a view to informing policy and practice.

### 15.30 A physiotherapy intervention

Donna Murphy
Chartered Physiotherapist, Carn Physiotherapy, 50 Slaughtniel Road
Maghera Co Derry. BT465NJ
donna_mceld@yahoo.co.uk

My daughter Katie was born July 2015 diagnosed with Down's Syndrome shortly after birth.

My reason for this presentation is the difficulty I found when trying to facilitate the crawling movement. Katie had quite low tone and subsequently hypermobility. This enabled her to move from prone to sitting with a 90degree abduction movement of both hips "doing the splits effectively" to sit up.

This frustrated me as she was not benefitting from tummy time and I was unable to prevent her from repeating this pattern of abnormal movement. When I asked the physiotherapist about it the reply was "Oh they do that". This frustrated me further as there was an acceptance of a trait but no problem solving to address the issue. This is when I discovered the Crawling Track.

In the crawling track I could put her down and she wouldn't revert to the wide legged/splits motion and she was getting good joint sense, tactile input and proprioceptive feedback from being in prone. We could stay behind her in the crawling track with her favourite toys and a mirror in front and facilitate crawling by positioning her arms and legs and feet, which was demonstrated to me by the Family Hope Centre. Initially we had to passively position her arms and legs and lift them forward into the commando crawling pattern. Katie really had "spaghetti" legs and arms and I often wondered would she ever be able to hold herself up or push herself along. After a few weeks she started to do some of the movements actively until she was doing it all independently. It still required a lot of persuasion and motivation in the form of her favourite toy, a light up ball/mirror, her siblings at the other end of the track and various other strategies to get her to move along.

Now at age 4 she she has an excellent pencil grip (Franzen D & Visser M 2010) , no sensory issues, great body awareness, motor planning (Huddrs-Algo 2005) proprioception and vestibular system. I feel this has all been helped by early prone positioning (Wentz, Erin 2016) followed by commando and then 4 pt crawling until 2years old. Katie commando crawled around the house for 8 months and if anyone has ever tried it you would find out how much physical effort it takes as well as coordination from left and right side which helps with bilateral integration of the brain. (DS- The importance of crawling on the stomach, Robert J.Doman and Ellen R. Doman, NACD journal 2009)

My motivation for this short presentation is to put crawling as a milestone for DS as it is not included in the DS Medical Interest Group Milestones as is seen in my experience as an unrealistic milestone even though the benefits are huge developmentally.

## 15.50 Obstructive sleep apnoea contributes to executive function impairment in young children with Down syndrome

Anna Joyce[1], Heather Elphick[2], Michael Farquhar[3], Paul Gringras[3], Hazel Evans[4], Romola S Bucks[5] Jana Kreppner[6], Ruth Kingshott[2], Jane Martin[7], Janine Reynolds[2], Carla Rush[3], Johanna Gavlak[4], & Catherine M Hill[4,8]

[1] Faculty of Humanities & Social Sciences, Regent's University
[2]Sheffield Children's Hospital NHS Foundation Trust
[3]Evelina London Children's Hospital, Guys & St Thomas's NHS Trust
[4] Southampton Children's Hospital, Southampton University NHS Trust
[5]School of Psychological Science, University of Western Australia
[6]School of Psychology, University of Southampton
[7]Southampton Biomedical Research Unit
[8]School of Clinical and Experimental Sciences, Faculty of Medicine, University of Southampton
a.joyce@ucl.ac.uk

Children with Down syndrome (DS) commonly experience difficulties with executive function (EF). They are also vulnerable to obstructive sleep apnoea (OSA). In typically developing children OSA is associated with EF deficits. We experimentally assessed sleep and EF in young children with DS, predicting that OSA would be associated with poorer EF.

Parents of 80 children with DS (50 male) aged 36 to 71 months (M = 56.90, SD = 10.19 months) completed the Behavior Rating Inventory of Executive Function - Preschool Version (BRIEF-P). Of these, 69 were successfully studied overnight with domiciliary cardiorespiratory polygraphy to diagnose OSA.

Obstructive apnoea/hypopnoea index was in the normal range (0-1.49/h) for 28 children but indicated OSA (≥1.5/h) in 41 children. Consistent with previous research, children experienced particular weaknesses in working memory, planning and organising, whilst emotional control was a relative strength. OSA was associated with poorer working memory, emotional control and shifting.

Findings suggest that known EF difficulties in DS are already evident at this young age. Children with DS already have limited cognitive reserve and can ill afford additional EF deficit associated with OSA. OSA is amenable to treatment and should be actively treated in these children to promote optimal cognitive development.

## 16.10 Treatment for Obstructive Sleep Apnoea (OSA) in children with Down syndrome (DS): a systematic review

Rina Cianfaglione[1], Beth Stuart[2], Hazel J. Evans[3], & Catherine M Hill[1,3]

[1]Clinical and Experimental Science, Faculty of Medicine, University of Southampton, UK
[2]Primary Care Population Science, Faculty of Medicine, University of Southampton, UK
[3]Southampton Children's Hospital, University Hospital Southampton NHS Trust, UK
R.Cianfaglione@soton.ac.uk

OSA involves intermittent collapse of the upper airway in sleep, causing nocturnal hypoxia and fragmented sleep with adverse health consequences. OSA affects up to 75% of children with DS and 50% have moderate-severe disease. European consensus guidelines recommend adenotonsillectomy (AT) as a treatment. AT in DS is not risk free and 50-70% of children with DS have residual OSA after surgery. The aims of this systematic review are to identify published literature on treatment outcomes for any treatment modality for OSA in children aged 0-16 years with DS.

Medical and health care (MEDLINE (OVID), EMBASE (OVID), CINAHL (EBSCO), PSYCInfo (EBSCO), Web of science and Cochrane Review) electronic databases were searched. The PRISMA statement was followed.

Database searches resulted in 2067 results, de-duplicated to 1410 in Endnote. Using Rayyan software, titles and abstracts have been screened for eligibility by 2 authors (RC and BS) and disagreements resolved by CMH.

Full texts of 153 studies are currently under review. Data extraction will be primary on benefits of the treatments for the child, level of hypopnoea index and longitudinal outcomes. In addition, effect on quality of life, behavioural and neurocognitive outcome s and risk factors for the child with DS will be reported.

**16.30 Discussion panel**

**17.00 End of Day 1**

**Dinner arrangements – Monday evening**

**Optional Dinner to give an opportunity for more networking**

**Dinner will be early – with drinks at restaurant straight after conference day ends.**

**To be held at** https://www.iguanas.co.uk/restaurants/london-brunswicksquare/menus

**Please note you pay for dinner at the restaurant – this is not part of Forum registration.**

**If you wish to come and have not yet confirmed this please let Sue know by Thursday pm (sue.buckley@dseinternational.org)**

**DAY 2: Tuesday 17th of September 2019**

**9.00 Introduction and housekeeping Jo Van Herwegen**

**Session 1: Early development**

**9.10 Early Brain Development in Down Syndrome**

Prachi Patkee[1], Olatz Ojinaga Alfageme[1,2], Ana Baburamani[1], Emily Farran[3], Michael Thomas[2] & Mary Rutherford[1].

1. Centre for the Developing Brain, School of Biomedical Engineering and Imaging Sciences, King's College London, St. Thomas' Hospital, London, SE1 7EH, UK
2. Centre of Brain and Cognitive Development, Department of Psychological Sciences, Birkbeck, University of London, London, WC1E 7HX, UK
3. School of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH, UK

prachi.patkee@kcl.ac.uk

There is now abundant evidence from mouse model, histological and neuroimaging studies confirming altered brain development, structure and functioning related to Down Syndrome. Recently, we have shown using magnetic resonance(MR) imaging of the fetus that, in humans, brain alterations such as reduced volumes of the cerebellum and cortex, occur early in development. These alterations become more pronounced as the baby grows. However as in all other aspects of Down Syndrome we have noted a wide spectrum with some measures overlapping with control fetuses. We have also demonstrated alterations in chemicals within the developing brain of neonates with Down syndrome using MR spectroscopy. It is likely that these brain abnormalities underlie the intellectual disability and delayed development present in children with DS but this needs to be demonstrated by longer term follow up of the children participating in our studies.

We will present our details of our MR examinations and techniques and how these have to be adapted to image the mobile foetus and neonate. We will also present our future plans to examine whether early MR brain biomarkers (e.g. cortical volumes, connectivity and even cortical microstructure) are predictive of later cognitive outcomes.

**9.30 Attention profiles in children with Down Syndrome and Williams Syndrome tested with the Early Child Attention Battery (ECAB)**

Janette Atkinson[1], Fleur Corbett[2], Hana D'Souza[3], Oliver Braddick[4], & Dean D'Souza[2]

[1]University College London

[2]Anglia Ruskin University

[3]University of Cambridge

[4]Oxford University

j.atkinson@ucl.ac.uk

The control of attention is key for success in everyday living. We have developed the Early Child Attention Battery (ECAB), consisting of 4-8 short subtests for selective, sustained and control of attention, to define individual profiles of abilities in children of developmental age 3-6 years (Breckenridge, Atkinson & Braddick, 2013a).

This ongoing, longitudinal project is using the new iPad-based ECAB to measure attention in children with Down (DS) and Williams (WS) syndrome, aged 9-10 years. Preliminary results indicate distinctive profiles across syndromes of the neurologically separable components of attention. Both children with DS and WS show impaired overall attention skills beyond that accounted for by their mental age (typically developing 4-6-year-olds). In particular, children with DS showed marked difficulty in inhibiting inappropriate responses, with high response rates to non-targets in the visual search and sustained attention subtests. However, consistent with earlier results (Breckenridge et al, 2013b) children with WS were more impaired in inhibiting a familiar prepotent action in the 'counterpointing' subtest, reflecting their specific impairments in visuospatial cognition.

We will discuss these findings concerning the dorsal-stream and frontal brain networks underlying these responses (Atkinson, 2017), and their implications for distinct rehabilitation and education in children with DS and WS.

### 9.50 Understanding face looking in infants/toddlers with Down syndrome in the context of naturalistic parent-child interaction

Hana D'Souza[1-3], Dean D'Souza[3,4], Dan Brady[5], Rosanna Hurst[1], Adelaide Mettrick[1], Stefania Cangemi[4], Veronica Capaldo[1], Annette Karmiloff-Smith[3], Mark H. Johnson[1], Michael S. C. Thomas[3], & LonDownS Consortium

[1]Department of Psychology, University of Cambridge
[2]Newnham College, University of Cambridge
[3]Centre for Brain and Cognitive Development, Birkbeck, University of London
[4]Faculty of Science and Engineering, Anglia Ruskin University
[5]School of Psychology and Clinical Language Sciences, University of Reading
hd425@cam.ac.uk

Faces are considered to play a special role in early development. In fact, a number of interventions with atypically developing or "at-risk" infants/toddlers encourage these young children to focus on others' face in order to facilitate interaction and learning. However, much of the available evidence on face looking in young children comes from tightly controlled laboratory studies or from anecdotal evidence. This talk will focus on face looking during naturalistic play in infants/toddlers with Down syndrome (DS) and their parents. The children with DS will be compared with typically developing children as well as children with a different neurodevelopmental disorder (Williams syndrome).

Face looking in the naturalistic environment is highly interactive, yet often studies only focus on the child's behaviour and the parent is omitted. To bridge this gap, we also analyse parental face looks to the child. This will enable us to understand the role of parental behaviour in face looking in DS. Furthermore, we will discuss what purpose face looking plays in parent-child interaction and whether this purpose is likely to be syndrome-specific. Finally, we will emphasize the developmental and context-dependent nature of face looking and discuss future directions for this research.

**10.10 The Power of Parents: Understanding the Significance of Parent-Child Interaction for Child Development in Down Syndrome**

Desiree Grafton-Clarke, Elizabeth Nixon, Eleanor Molloy[2,3] & Jean Quigley[1]
[1] Infant & Child Research Lab, School of Psychology, Trinity College Dublin
[2] School of Medicine, Dept of Pediatrics, Trinity College Dublin.
[3] National Children's Hospital, Tallaght University Hospital.
graftond@tcd.ie

Parent-child interaction provides the critical infrastructure for development. Very little research has been conducted on interaction in the context of Down Syndrome (DS). This research addresses this gap through detailed examination of parents in triadic and dyadic interaction with their children and will contribute to our understanding of the factors that influence the developmental profile in children with DS. Initial data will be presented from 22 children (aged 10 months – 4 years) recruited from Ireland's first dedicated Down Syndrome Clinic and within the community as part of a multidisciplinary collaboration with Children's Health Ireland. Preliminary analyses will be presented on different realms of parental influence, and how these are reciprocally related to multiple domains of development including language, cognitive, motor, social-emotional and adaptive functioning using gold standard tools. 22 parent-child dyads were video recorded while engaged in play and reading tasks.
These observational data are complemented by parent-report measures including quality of life, resilience, family impact, co-parenting and reflective functioning. Qualitative data from semi structured interviews with parents will also be presented. Our testing paradigm provides opportunities to investigate the parental role further and to understand how parents and early intervention therapists may support the development of children with DS.

**10.30 - 11.10 Tea/ coffee break**

**Session 2: co-morbidity**

**11.10 Exploring parents' experience of their child's dual-diagnosis of DS & ASD**

Katie Lambert, Kate Gleeson and Emma Williams.
University of Surrey
k.lambert@surrey.ac.uk

It was previously considered that Down's Syndrome (DS) and Autism Spectrum Disorder (ASD) could rarely co-occur. However, research indicates variable but high rates of ASD in children with DS. While research supports the concept that individuals with the dual-diagnosis of Down's Syndrome and Autism Spectrum Disorder (DS-ASD) present with features that are distinct from what one might expect from a child with DS without ASD, and despite evidence of potential emotional and practical implications of having a child with a disability, parents' experiences of DS-ASD have largely been overlooked. This study sought to explore how parents of children with DS experience and make sense of their child's additional ASD diagnosis.

Six parents of children with DS-ASD were invited to tell their stories. Transcripts were analysed using a narrative approach, focusing on how participants narrated their stories and made sense of their experiences.

Narrative themes were identified across the transcripts. A tentative model proposed a complex, non-linear process whereby parents reflect on their sense of belonging, understanding of DS-ASD and what it means to them, their identity and parental role.

The findings demonstrate the challenging nature and complexity of what it means to parent a child with DS-ASD and how parents make sense of this. While further research is required to gather a broader range of parental experiences, the findings provide some evidence for support specifically for parents of children with DS-ASD, ideas for which, and how this could facilitate future research opportunities are discussed.

**11.30 Visual perception as a window into the nature of autistic-like trait expressions in children with Down syndrome**

Jennifer M. Glennon[1], Hana D'Souza[1-3], Luke Mason, Annette Karmiloff-Smith† & Michael S. C. Thomas[1]
[1]School of Psychology, Birkbeck, University of London, London, UK
[2]Department of Psychology, University of Cambridge
[3]Newnham College, University of Cambridge
jglenn01@mail.bbk.ac.uk

Children with fragile X syndrome (FXS) and Down syndrome (DS) are at increased risk of autism relative to the general population, yet debate is ongoing with regard to the precise nature of these comorbidities. There is research to suggest that children with isolated autism (i.e., that which presents in the absence of a genetic syndrome) show a visual preference for non-social information. Here, we examined whether autistic-like traits in children with FXS and DS varied in rate and severity according to eye-tracking indices of social attention. This was a cross-syndrome study of social attention according to performance on the GeoPref eye-tracking task. Children with isolated ASD (n=16), FXS (n=7) and DS (n=15) took part in this study; groups were matched according to chronological age and non-verbal intellectual ability. Our findings are consistent with the notion of distinct profiles of autistic-like trait expression in children with FXS and DS with implications for clinical diagnostic and intervention practices. The results of this study illustrate the value of progressing beyond questionnaire-based measures of performance to examine, in a more fine-grained way, the neurocognitive features underpinning expressions of autistic-like difficulty in these genetic syndrome groups.

## Session 3: Post school intervention

**11.50 'I can work'**

Wendy Uttley
Down Syndrome Training & Support Service Ltd
office@downsyndromebradford.co.uk

In October 2018 we launched a pilot project called 'I can work' with the aim of securing local work placements for 3 young adults with Down syndrome.

The presentation will detail our difficulties and our successes.

- how we went about finding the placements,
- what measures we put in place to ensure the work place met the needs of a young person with Down syndrome,
- how we selected, assessed and matched the young person to a placement
- how we have, and still are, supporting 3 young adults with Down syndrome to grow in many areas of development:
  Time and money skills, appropriate greetings, independent travel, independent shopping, appropriate conversations, dress sense and all of the many work related everyday skills we take for granted.

**Session 5: Speech and language**

**12.10 Evaluating a language intervention in the field**

Nicola Hart and Gavin McDonnell
SLT, Head of Member Services, Down Syndrome Ireland
Nicola@downsyndrome.ie

Over the last few years, the Irish government has increased investment in early childhood education, providing initially one, and now two free preschool years for all children. This is delivered primarily through private sector preschools for 3.5 hours per day, during school term time. In order to encourage mainstream placements for children with disabilities, there is an Access and Inclusion Model (AIM) which allows for supports ranging from specialist training and equipment to an additional member of staff to improve adult child ratios.

Down Syndrome Ireland (DSI) initially attempted to get the See and Learn programme added to the equipment and training list for AIM, but it was rejected, as the focus of the preschool curriculum is child-directed, experiential, play-based learning.

DSI believe that children with Down syndrome need additional adult directed activities to support their language development and learning, so we have decided to make the programme the focus of our major fundraising campaign.

We have the following goals:

- Develop a hands-on training programme
- Supply materials all preschools in Ireland who attend training and have a child with Down syndrome in their group.
- Gather data on real life delivery of the programme
- Evaluate the language outcomes
- Use the outcomes to campaign for the programme to be government funded in the future

We will discuss the challenges to the evaluation and welcome suggestions.

**12.30-13.30 Lunch**

**13.30 "People think if you can't talk, you don't understand": A qualitative insight into the factors underlying the communication experience of parents of children with Down's syndrome.**

Elaine Scougal, Nick Hopkins, & Annalu Waller.
University of Dundee
e.scougal@dundee.ac.uk

As a mother of twins with Down's syndrome and MSc student in augmentative and alternative communication (AAC), I am currently exploring the factors underlying the communication experience of parents of children with Down's syndrome. A qualitative approach was selected to give parents the opportunity to openly share their insights regarding their experience of communicating with their child. One-to-one semi-structured interviews were conducted with 13 parents (7 mothers, 6 fathers; mean child age = 6.9 years) and thematic analysis is currently being used to identify common themes across the data. Whilst still a work in progress, several issues were reported by most parents - 1) speech and language provision and support, 2) AAC provision and support (all used signing) and 3) public awareness of communication challenges. Combined, the issues are resulting in some children currently not reaching their verbal potential due to lack of service provision but also being restricted as to who they can independently communicate with due to dependency on a communication partner having signing ability. As such, the effectiveness of using signing as a sole form of AAC is called into question.

**13.50 The nature of speech articulation difficulties in children with Down syndrome and relationships with language and reading ability**

Rebecca Baxter [1], Kelly Burgoyne[2], Sue Buckley[3]
[1]University College London, UK
[2]University of Manchester, UK
[3]Down Syndrome Education International, UK
rbaxter@letsgouk.org

Children with Down syndrome experience specific difficulties with speech intelligibility (Kent & Vorperian, 2013). This study aims to further investigate the extent of the articulation difficulties of this population, how these speech skills relate to other cognitive domains and how they develop over time. This study examines the articulation skills of 50 children with Down syndrome (aged 5-10) over a 21 month period. Children also completed measures of non-verbal IQ, reading and language. Though there was considerable variability in the sample, children's speech was characterised by high levels of articulation errors with evidence of a complex and broad range of developmental and atypical processes. There were no effects of gender, hearing status, or non-verbal IQ on articulation accuracy. Speech articulation was significantly related to age, and to concurrent measures of language and reading ability. There was no significant change in speech articulation accuracy over time. Children with Down syndrome experience significant and complex speech articulation difficulties which are likely to persist over time. Further large-scale longitudinal studies are needed to evaluate speech intervention programmes.

**14.10 The effect of age on grammar comprehension in adults with Down syndrome**

Alexandra Perovic[1] & Ken Wexler[2]
[1]University College London
[2]Massachusetts Institute of Technology
a.perovic@ucl.ac.uk

Adults with Down syndrome are known to be at increased risk of cognitive decline due to earlier onset of Alzheimer's dementia, however, it is not clear how aging affects comprehension of complex grammatical structures in this population.

In an attempt to better understand how linguistic deficits in individuals with intellectual disabilities can be teased apart from effects of general language delays, chronological age, and overall intellectual impairment, we compare comprehension of passives in English-speaking adults with Down syndrome (DS) (mean age: 38) and Williams syndrome (WS) (mean age: 30). Passives are known to develop late in typical development, especially passives of psychological verbs (see, remember), compared to actional verbs (kiss, hold).

Our results reveal divergent patterns of performance: adults with WS performed no different from younger typical controls, while adults with DS showed an exceptionally poor performance on all sentence types, even on actives of actional verbs. While the good performance of adults with WS might be due to individual variation, rather than continuous language development, we argue that the poor performance of participants with DS is due to an age-related decline of cognitive and language abilities, possibly linked to Alzheimer's type dementia.

**14.50 Evaluating an early social communication intervention for young children with Down syndrome: a feasibility study**

Vesna Stojanovik[1], Emma Pagnamenta[1], Victoria Joffe[2], Sarah Rae[3]
[1]University of Reading
[2]City, University of London
[3]Oxford Health NHS Foundation Trust
v.stojanovik@reading.ac.uk

Despite evidence that early intervention may be effective with children with different developmental disorders, there is limited evidence for early intervention for children with Down Syndrome under the age of two years. Preliminary findings suggest that an early intervention focussing on developing the foundation skills for language through the early social communication skill of shared attention benefits language outcomes for children with DS (Seager et al., 2017). Furthermore how well the child responds to the parent/caregiver's bids for shared attention has been found to be a unique predictor of later language outcomes in children with DS (Sigman et al 1999; Mason-Apps et al 2018). This NIHR-funded Research for Patient Benefit study aims to test the feasibility of a future randomised controlled trial (RCT) of a parent-delivered shared attention intervention for young children with DS as delivered by NHS Speech and Language Therapy services. The outcomes of this feasibility study will determine whether it will be viable to progress to a full RCT and whether adjustments need to be made to the procedures, data collection methods, delivery and intensity of the intervention. This will ultimately 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 DS.

**15.10 Discussion and conclusions**

**15.30 Tea/coffee**

**16.00 Depart**