

# UK Down Syndrome Research Forum

## 16th-17th October 2008

### Michèle Pettinato

Down Syndrome Education International hosted the *UK Down Syndrome Research Forum*, an annual meeting of researchers interested in Down syndrome. It is an opportunity for researchers in the field to discuss ongoing work and exchange ideas. The meeting this year also included presentations which did not directly focus on Down syndrome, but were relevant to practice and research on Down syndrome.

The presentations were grouped in to themed sessions, all addressing different aspects of the needs of individuals with Down syndrome.

The theme of the first session was 'Health issues and ageing – care and basic science'. The presentations in this session reflected the work of a multi-disciplinary group of researchers and practitioners based at the University of Plymouth and Plymouth NHS who investigate issues around diagnosis and care of dementia in adults with Down syndrome.

The group's work was introduced by Judith McBrien, followed by a presentation by Andrew Merwood on the development and evaluation of the DMR, a psychological measure for identifying the onset of early dementia in people with learning difficulties. Sarah Whithwham presented a checklist which has been developed to help staff recognise the possible onset of dementia. Deirdre Ford talked about a pilot study which explored the factors determining whether a person remained at their residential home or was moved to another home once signs of dementia became evident. Lesley Goldsmith discussed the needs of people with learning difficulties when giving informed consent for healthcare interventions. She also explained ongoing research which is expected to lead to better guidelines and materials for obtaining consent.

The second session was themed around issues affecting speech, language and working memory.

Monica Bray (Leeds Metropolitan University) drew parallels between psycholinguistic and neuropsychological research on stuttering in typically developing children and the difficulties with fluency in children with Down syndrome. She argued that research in these two fields may overlap and considered the implications for intervention. Michèle Pettinato (DownsEd International) presented a new model on the interaction between speech processing and phonological short-term memory. This model emphasises the role of speech processing in short-term memory and the possible implications for future research in children with Down syndrome were discussed. Chris Jarrold (University of Bristol) presented research on the relationships between verbal short-term memory, phonological awareness and new word learning in children with Down syndrome. It was suggested that children with Down syndrome may have a relative strength in making semantic links between new words and the objects they refer to, but that they may have more difficulties in learning detailed phonological forms for words. Joni Holmes (University of York) presented a successful computer-based training programme for children with attention deficits and impaired working memory and the possibility of using this training programme with children with Down syndrome.

The session on social aspects of communication included a presentation by Kate Thorsteinsson (Portsmouth University), who talked about her thesis project investigating early interaction and emotion between babies with Down syndrome and their mothers. Sue Buckley (DownsEd International) presented a longitudinal study currently being carried out by researchers at DownsEd International. One of the aims of this study is to explore the nature and frequency of autistic-like behaviours in children with Down syndrome and whether these represent a

true form of autism or whether these are a result of developmental delay which is likely to resolve over time.

The following session consisted of talks on reading and language development. Hannah Nash (University of York) presented research which explored the nature of difficulties with reading comprehension in children with Down syndrome. The results suggested a correlation between oral language abilities and reading comprehension, and it was suggested that improving oral language may also aid reading comprehension. For the next presentation, Sue Buckley announced the award to DownsEd International and University of York of a £0.5 million lottery grant to test a reading and language teaching programme for children who have Down syndrome. She then outlined the aims and structure of the project. Silvana Mengoni (University of York) presented an evaluation of different teaching methods for vocabulary learning in typically developing children and sketched out how this study will be extended to include children with Down syndrome. Jeanette ten Brink (University of Groningen) explored opportunities and teaching strategies for foreign language learning for children with Down syndrome. Kari-Anne Naess (University of Oslo) presented an ongoing thesis project which represents the first comprehensive, longitudinal study of language development in Norwegian-speaking children with Down syndrome.

The last session sought to make links between aspects of visual development and speech development in children with Down syndrome. For vision, Mohammad Al-Bagdady (Cardiff University) gave a talk on the development of refractive errors in children with Down syndrome compared to typically developing children. Development of refractive errors in children with Down syndrome is similar to that of typically developing children, but in children with Down syndrome it

takes longer to complete and there is a wider range of errors. Caroline Newton (University College London) then presented a method which measures shifts in gaze to assess speech perception and minimises reliance on overt responses. It is thought that it may be possible to use this when investigating speech perception in children with Down syndrome. Vesna Stojanovik (University of Reading) talked about an ongoing collaboration with researchers at DownsEd International which investigates intonation abilities of children with Down syndrome in comparison to children with Williams syndrome. Finally, Sue Buckley presented preliminary data from an ongoing study which examines the links between the use of signs and the development of speech in children with Down syndrome.

Michele Pettinato is at Down Syndrome Education International

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## List of talks

- **A dementia screening programme for adults with Down's Syndrome: research and practice hand in hand**  
*Judith McBrien*; Plymouth University
- **Andrew Merwood: Diagnosing dementia in Down syndrome**  
*Judith McBrien and John Clibbens*; Plymouth University
- **Assisting carers to recognise possible dementia onset: the development of a screening checklist for adults with Down syndrome**  
*Sarah Whitwham, Judith McBrien and Wendy Mathurin*; Plymouth University
- **Predicting the capacity of residential homes to care for adults with Down syndrome and dementia**  
*Deirdre Ford, John Clibbens, Judith McBrien and Sarah Whitwham*; Plymouth University
- **Capacity, consent and people with learning disabilities**  
*Lesley Goldsmith*; Plymouth University
- **An overview of stuttering theory and therapy**  
*Monica Bray*; Leeds Metropolitan University
- **New perspectives on the interaction between short-term memory and speech processing skills – a review of current models and findings**  
*Michèle Pettinato*; Down Syndrome Education International
- **The relationships between verbal short-term memory, phonological awareness and new word learning in Down syndrome**  
*Chris Jarrold*; University of Bristol
- **Working memory training in children with ADHD and children with low working memory**  
*Joni Holmes, Susan Gathercole and D.L. Dunning*; University of York
- **Norms and longitudinal trajectories for social communicative and 'autistic' behaviours**  
*Sue Buckley and DownsEd team*; Down Syndrome Education International
- **Emotion, interaction and expression of young infants with Down syndrome**  
*Kate Thorsteinsson*; Portsmouth University
- **The gap between reading accuracy and reading comprehension in individuals with Down syndrome**  
*Hannah Nash*; University of York
- **Vocabulary learning in typically developing children: A comparison of definitions, verbal context and visual context instruction**  
**Individual variation in reading progress in preschool and school age children**  
*Sue Buckley and DownsEd team*; Down Syndrome Education International
- **Down syndrome and Foreign Language Learning**  
*Jeanette ten Brink*; University of Groningen
- **Language development in Norwegian children with Down syndrome born in 2002**  
*Kari-Anne Næss*; University of Oslo
- **The development and distribution of refractive errors in children with Down syndrome compared to typically developing children**  
*Mohammad Al-Bagdady and Margaret Woodhouse*; Cardiff University
- **Presenting spEYE – using eye-tracking to study speech perception in young children with speech difficulties**  
*Caroline Newton*; University College London
- **Intonation abilities in children with Down syndrome**  
*Vesna Stojanovik and Laura Wyllie*; University of Reading
- **The links between signing and speaking development – a longitudinal study**  
*Sue Buckley and DownsEd team*; Down Syndrome Education International