Child Development and Learning Difficulties Lab

This edition's spotlight
Mathematical abilities in Williams syndrome

Here is a picture of our new home

Hello and welcome to our Autumn Newsletter!

It's been a busy summer. We attended a number of conferences, published papers and some new researchers have joined the CDLD lab.

We organized the Down Syndrome Research Forum in September 2019 which was attended by a record 100 delegates. In this newsletter you will find a summary of the talks and discussions. We are also organizing a number of events in 2020 for parents and practitioners so check out the 'dates for the diary' section! We have been writing up our research findings about mathematical development in Williams syndrome and other developmental disorders. We have included a summary and some practical tips in this newsletter. In this newsletter you will also find more information about our latest research, our workshops and dissemination activities as well as conference presentations.

Best wishes,

Dr Jo Van Herwegen
Lab director of CDLD

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- MATHEMATICAL ABILITIES IN WILLIAMS SYNDROME
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New publications

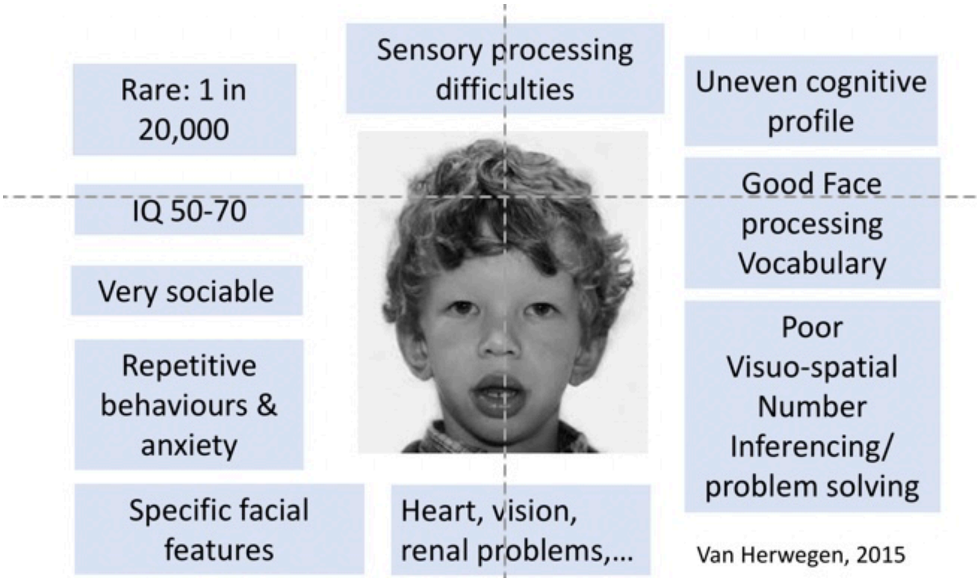
A number of publications have been published during the past few months. Most of these are freely available from the CDLD website (www.jovanherwegen.co.uk):

- Purser, H., Thomas, M.S.C. & **Van Herwegen, J**. (in press). The development of children's comprehension and appreciation of riddles. *Journal of Experimental Psychology*
- **Van Herwegen, J**., Ranzato, E., Karmiloff-Smith, A., & Simms, V. (2019). Eye movement patterns and approximate number sense task performance in Williams syndrome and Down syndrome: a developmental perspective. *Journal of Autism and Developmental Disabilities. Advance online. doi: 10.1007/s10803-019-04110-0*
- **Van Herwegen, J.,** Ashworth, A., & Palikara, O. (2019). Views of professionals about the educational needs of children with neurodevelopmental disorders. *Research in Developmental Disability, advance online. doi: 10.1016/j.ridd.2019.05.001.*
- Ross, W., Vallee-Tourangeau, F., & **Van Herwegen, J**. (2019). Mental Arithmetic and Interactivity: The Effect of Manipulating External Number Representations on Older Children's Mental Arithmetic Success. *International Journal of Science and Mathematics Education. doi. 0.1007/s10763-019-09978-z*
- **Van Herwegen, J**., Purser, H., Thomas, M.S.C. (2019). Development in Williams syndrome: Progress, prospects and challenges. *Advances in Neurodevelopmental Disorders, https://doi.org/10.1007/s41252-019-00109-x.*

Mathematical abilities in Williams syndrome: what are the difficulties and how can they be improved?

Our research has focused on mathematical skills in children and adults with Williams Syndrome (WS) and compared their skills to typically developing children and adults as well as those with Down Syndrome (DS). In addition, we have reviewed existing studies that have previously examined mathematical skills in WS. For more information about our work, see details below. This blog is based on our own research as well as the findings of our review.

Williams syndrome



Rare: 1 in 20,000

IQ 50-70

Very sociable

Repetitive behaviours & anxiety

Specific facial features

Sensory processing difficulties

Heart, vision, renal problems,…

Uneven cognitive profile

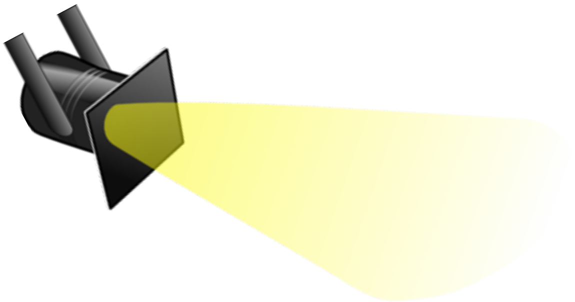
Good Face processing Vocabulary

Poor Visuo-spatial Number Inferencing/ problem solving

Van Herwegen, 2015

What do we mean by mathematics?

First of all, mathematics is a really complex subject with many components. Mathematics is made up of many different types of concepts and skills. To be successful in mathematics we must know things like being able to recognize and name digits, know the meaning of number words, understand the meaning of counting, knowing how numbers fit together in a system and realising the relationship between operations, such as that addition is the reverse of subtraction. We must also have good skills, such as being able to count accurately, carrying out addition and subtraction procedures and tackle word problem solving.



What do people with WS find difficult?

Our own research has shown that all people with WS struggle with mathematics. All verbal children and adults do learn the counting names and are able to count to 20. However, few are able to count onwards from a number different to 1 or to count backwards, due to poor working memory skills. Therefore, people with WS may “get lost” in the number word list when being asked to do something that they are not used to doing or when they get distracted. So, although we sometimes hear that people with WS are good at counting, we should put that in context: Yes, the knowledge of counting names in WS tends to be better than most children with DS, but they do struggle with numbers beyond 100 as well as counting tasks that really push working memory skills.

Secondly, many children with WS struggle to understand the meaning of counting or what counting is for: When you count items in a set, it is so that you know what size that set is. Yet, many people with WS make errors when counting. Partly, these errors can be explained by a lack of pointing when counting the items and a lack of keeping track of items that have already been counted compared to those items that have not yet been counted. However, even when asked to give a number of objects (a task that does not involve pointing or working memory), many people with WS give a random number of items showing that they struggle to understand *what* counting is for.

People with WS usually display poor visuo-spatial skills, this means that they struggle with orientation of numbers and letters and therefore digit recognition can be tricky for some, especially when double (e.g. 21) or triple digits are involved (e.g. 341). These poor visuo-spatial skills may also impact on counting skills and being able divide up counted and not-yet-counted objects.

People with WS are quite good at estimating small numbers and are able to recognize the number of objects (up to 5) quite quickly. However, their estimation of larger numbers is poor and a number of studies have now shown that their ability does not exceed that of 8-9 year old typically developing children. For example, when being shown 9 red dots and 14 blue dots, people with WS find it very difficult to say which set has more without counting. Yet, this is a task that young typically developing children find quite easy. In addition, people with WS find it difficult to understand how numbers relate to each other, or to estimate where numbers go on a number line. This all suggests that their organisation of how numbers and quantities are organized in their brain is different and might cause mathematical difficulties.

When it comes to addition and subtraction, many children and adults with WS manage to solve simple sums that use single digits and do not exceed the number 16. However, we have no research about more complex sums. As we know that people with WS struggle with double digit recognition, these larger sums might be a challenge for them.

Overall, across all aspects of mathematics, except for small number estimation, people with WS may show difficulties throughout their lives.

What can you do at home?

Our review of existing research has shown that there are no intervention studies that have assessed how to improve mathematical skills in people with WS. There are no studies that have evaluated what works in the classroom in terms of mathematical practice for children with WS. So we can only make an informed guess based on what we know about mathematical abilities in typically developing children and studies that have examined what works for other children that have mathematical difficulties.

- *Improving number names*: Although the knowledge of number names is delayed, children with WS are able to learn the number names and songs can particularly help children with WS. Actually there are a number of studies that suggest that the verbal abilities might, to a certain extent, help children with WS compensate for their non-verbal mathematical difficulties.
- *Pointing*: Children with WS rarely point, especially younger ones. So try and find opportunities for children to point at things (by putting objects out of reach for example or by showing them two things one of which they really like and ask them to point to what they want). Also praise them and respond when they point. Pointing can help them when counting things later on.
- *Number line skills*: Understanding how number relate to each other is very important for solving mathematical problems. There is good evidence to suggest that playing very simple board games- like snakes and ladders, helps children understand the number line (i.e. that numbers go from 1-10, with small numbers on the left and large numbers on the right). Playing games in which children have to put numbers in right order or amounts/sets of objects from small to large may also help.
- *Set sizes*: Practicing comparing small sets of objects may help estimation skills. Share out two small sets of sweets and ask them to guess who has more! This will be motivating but also useful.
- *Cardinality*: Task a bag of toys and ask children with WS to take out a specific number of items and give them a sticker each time they give the correct number of items. As children find this very difficult it is OK to start with numbers 1 and 2.
- *Digit recognition*: As digit recognition difficulties are partly caused by visuo-spatial issues using larger font size, more space between sums (and even better just to have 1 per work sheet) as well as using colour to show how the digits go together (in 12 both numbers are blue but in 1 and 2 each number is a different colour) can help people with WS.

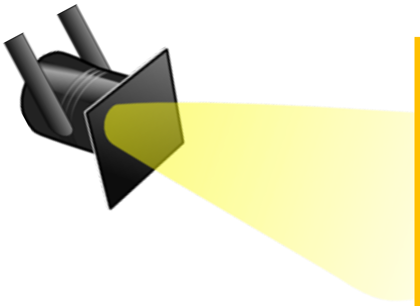
Also children with WS have working memory difficulties and will find it hard to keep track of items counted or to manipulate information in their minds only. So teaching them strategies of how to break sums down, how to keep track of items counted (line items to be counted up!) and encourage the use of fingers might really help them.

As with all learning in WS, it can take a very long time for people with WS to show true understanding and repetition is key. In addition, we know that some days people with WS can show good understanding of something and the next time it seems like they have forgotten everything (due to anxiety, lack of motivation, lack of concentration, sleep, who knows?!). Therefore, what works one day may not work on another day but luckily maths is all around us and thus, it should be easy to implement some maths activities in your daily routines. But also, motivation is key so using their favourite topic to cover some maths questions will really help them (e.g., How many people fit in that plane/train? Is that more than on the other plane/ train? How long it is the extension of that hoover? Is that longer than the other one?).

Some examples of maths in daily life:

- When driving in the car there are a lot of digit recognition games you can play: speed limits, road numbers, car registrations, they all contain different digits!
- When shopping you can talk about the amount of items in your trolley, how that compares to people around you and how much you think you need to pay. This game is good for large number estimation.
- When a child or adult with WS asks for something (sweets, money, anything to eat like three fishfingers, four beans, one potato) ask them to count out the number of items.
- If your child likes to line up toys, you could for example stick stickers with numbers or quantities (a number of dots) o =n these toys and use these and you child’s fondness of lining up toys to improve their understanding of how numbers relate to each other.

There are many more examples of how you can incorporate maths teaching in daily life, without the need to sit at a table and complete some worksheets. If you have any good examples, do get in touch!



We need your help!
Do you teach children with SEND?
Please tell us how you differentiate the maths and reading curriculum for them or what you do in your classroom. Email Jo: j.vanherwegen@ucl.ac.uk if you are happy to discuss over a phone conversation

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- Van Herwegen, J., Ansari, D., & Simms, V. (under review). Mathematical development in Williams syndrome: A systematic review.
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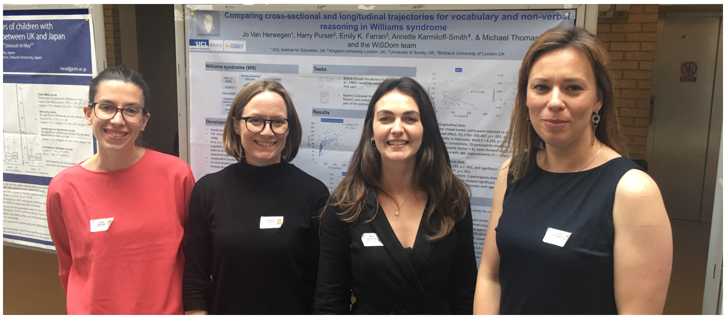
Conference Presentations

On Monday 16th of Tuesday 17th of September 2019 CDLD together with Down Syndrome Education International a two-day research forum during which speakers discussed their latest research about Down Syndrome.

The event was attended by 100 attendees including professionals (about 48%), parents (about 32%) and academics (about 10%). A summary of this 2-day event can be found below.

In addition to the Down syndrome Research Forum, the team has been very busy and presented at the following conferences:

- Jo presented data from the WiSDom project and Transcend project at the Society for Research on Child Development (SRCD) in Baltimore, USA in April 2019.
- Jo, Erica, and Maria presented work at the Neurodevelopmental disorders annual seminar (NDAS) at the university of Surrey in June 2019.
- Jo gave a keynote at the European Conference on Education (ECE), IAFOR in London in July.
- Jo presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASCIDD) in Glasgow in July.
- Erica, Maria, and Elizabeth presented at the Down syndrome research forum in London in September 2019
- Jo and Maria presented at the Williams syndrome research meeting in Durham in September 2019.



Some of the CDLD team members at NDAS2019

Elizabeth presented the TRANSCEND study at the Down Syndrome Research Forum in London

Down Syndrome Research Forum summary

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:

Mediated learning can help raise young children with Down syndrome's planning abilities (Vesna Stojanovik). The team hope to get more funding to carry out a bigger study.

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).

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.

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.

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

Dad

"The Forum was so impressive, I can't speak highly enough of it.
It has left a lasting impression on me. My only wish is that Bernie, my wife, could've attended. One of us will attend next year if at all possible."

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: Down Syndrome Research Forum

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 Patkee 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.

Clinical Psychologist

"I am really pleased to have attended the Research Forum earlier this week. It was my first experience of the Forum and it did not disappoint!! It was really interesting to hear from a range of presenters from different backgrounds and perspectives, talking about a variety of topics. It was also really useful and insightful to have the opportunity to engage in some informal conversations and discussions during the coffee and lunch breaks."

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 done!

Future events

At CDLD we don't just attend conferences, we also organise some!

- We are also organizing **Seattle Club** at UCL in December 2019. Seattle Club is a conference on research in intellectual and developmental disabilities. http://seattleclubconference.org/conferences.html

- **Open winter lecture on maths anxiety**: Do come and join us for the winter lecture at the Centre for Language, Literacy and Numeracy: Research & Practice. Jo is organizing the talk and has invited Prof Denes Szucs from the University of Cambridge to come and talk about maths anxiety in children: **Wednesday 11/12/2019 17.30-18.30.** To register click here: https://www.ucl.ac.uk/ioe/departments-and-centres/centres/centre-language-literacy-and-numeracy-research-practice

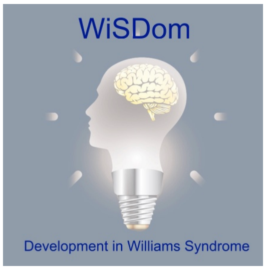
- Next conference we'll organise will be the **European Association for Learning and Instruction (EARLI):** special interest group for Special Education Needs and Inclusion (SIG15): 10/08/2020-11/08/2020. Click here for details: https://www.earli.org/node/38

- Next September there will be a professionals meeting for those professionals (teachers, SLTs, OTs, SENCOs, etc.) working with Williams Syndrome. Details to be advertised soon.

To stay up-to-date with our events: follow us on Twitter @CDLDlab or see our facebook page: https://www.facebook.com/CDLD-Unit-Research-Group-238269226640000/

What are we working on?

This is an overview of some of the current studies that are running within the lab. If you would like more information, please contact the lead researcher (in brackets)



WiSDom study (Jo): This study examined cognitive growth and development across the life span, from childhood into late adulthood, in Williams syndrome (WS) using existing and new data on a number of standardized intelligence tasks. We are still analyzing the data but we have managed to get data on language and non-verbal tasks for over 200 people with WS (which is great seeing WS is rare, 1 in 20,000 births)! And for some tasks we have data for the same individual with WS from 6 different time points. This means we can really study development as well as individual differences in WS because not all people with WS are the same. However, in order to understand this variability more we need as many people with WS to complete our background questionnaire: https://uclioe.eu.qualtrics.com/jfe/form/SV_eQHP5QiYY7W5Brv

Transcend study (Elizabeth): Moving from primary to secondary school can be a challenging time, and this may be particularly true for pupils with neurodevelopmental disorders. This research uses a cross-syndrome comparison involving children identified with an Autism Spectrum Disorder (ASD), and children with Down syndrome and Williams syndrome to identify factors that aid transition from primary to secondary school. By considering the views from parents, professionals and the children themselves, this research will provide a unique insight into good practice with children with neurodevelopmental disorders moving to secondary school. http://www.jovanherwegen.co.uk/index.php/blog/transend-study/

Maths at home study (ERICA): This project examines the games and activities that children do in relation to maths and reading. We are still looking for typically developing children as well as children with Williams and Down syndrome (ages 4 to 11 years old) to take part: Please take the 30 minute survey and click on the link: Maths at Home Survey

SOEMO project (Jo): This questionnaire project is a cross-cultural study with our Swiss collaborators Dr Andrea Samson and colleagues from the Institute of Special Education at the University of Fribourg in Switzerland. In this project we aim to examine social and emotional strengths and difficulties in Williams syndrome, Down syndrome and Autism in the UK and Switzerland. There is very little cross-cultural research in neurodevelopmental disorders. This study will provide better insight into how cultural stable social and communicative profiles are within these neurodevelopmental disorders. We will be recruiting participants to complete questionnaires for this study soon!

Who are we?

Founded in 2014, the CDLD unit is a research group consisting of academics, PhD students and researchers with a broad range of interests and expertise in how children learn and develop.

Lab director:
Dr Jo Van Herwegen

PhD-students
Erica Ranzato
Yi Wang

Researchers
Maria Ashworth
Paulien Eijckeler
Elizabeth Burchell

Research Students
Silvia Gini
Mizuki Tojo

At CDLD we work together with a number of other UCL based labs and centres.

- Centre for Educational Neuroscience (CEN): http://www.educationalneuroscience.org.uk/
- Centre for research in Autism and Education (CRAE): http://crae.ioe.ac.uk/
- Centre for Language, Literacy and Numeracy: Research & Practice (LL&NRP): https://www.ucl.ac.uk/ioe/departments-and-centres/centres/centre-language-literacy-and-numeracy-research-practice

We welcome applications for volunteer researchers looking to gain valuable experience

Do you have any questions about our activities? Or any questions about children's development you would like some answer to? or are you interested in any CPD events for staff at your school or organization? Then please contact Jo on j.vanherwegen@ucl.ac.uk