



This edition's spotlight Sensory Processing



Spring is here!

In this issue:

- **SENSORY PROCESSING**
- **RESEARCH OPPORTUNITIES**
- **PUBLICATIONS**
- **SEATTLE CLUB 2019**
- **UPCOMING EVENTS**
- **MEET THE TEAM**

Welcome to our Spring Newsletter!

We know that this is a very difficult and unprecedented time and we hope you and your family are OK.

This newsletter was planned before the COVID-19 situation unfolded and thus we have included the planned topics as usual. This newsletter's 'Spotlight on' features a blog discussing sensory processing in neurodevelopmental disorders, how they can impact an individual and what we can do to help.

We also wanted to share some of our good news during these difficult times: We are fortunate to have had some new team members join, we have also obtained some new research funding and our Lab Director, Dr Jo Van Herwegen, has been awarded the Margaret Donaldson award from the British Psychological Society!

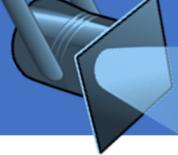
However, we are also concerned about how COVID-19 is affecting children and therefore the lab has joined forces with research centres from around the world to research the impact of COVID-19 on families. You can find more information about this research in the newsletter and we welcome you to take part!

We also hope that you have been enjoying our Maths@home games.

As always, thank you for your continued support.

Best wishes,

Brad Powell
(CDLD Research Assistant)



Sensory Processing

What do we mean by sensory processing?

By Brad Powell

MSc placement student

Sensory processing is our ability to receive and respond adaptively to sensory information (Baker et al., 2008). There are a variety of sensory inputs in our world that our brain is constantly processing, including:

- Sight: Visual patterns, colours, shapes, moving or spinning objects, bright objects or light.
- Smell: Specific smells, some people like to smell everything, whereas others are unable to detect or object to smells that other people don't notice.
- Hearing: Loud or unexpected sounds like fire alarms or blenders, singing, repetitive or specific types of noises (like finger snapping or clapping).
- Taste: Specific tastes (like spicy, sour, bitter, or minty) or textures (like crunchy, chewy or mushy), chewing or sucking on non-food objects (like shirt sleeves or collars).
- Touch: Touch from other people, touching or fiddling with objects, tight or soft clothing, certain textures or surfaces.
- Proprioception: Awareness of the position and movement of the body.
- Vestibular: Our balance, stability and spatial orientation.

However, in some cases, our brains find it difficult to process this information appropriately and individuals may not receive or respond to sensory input efficiently. For instance, sensory processing difficulties are highly prevalent within atypical populations. Research indicates up to 90% of individuals with autistic spectrum conditions have atypical sensory processing patterns (Glod, Riby, Honey & Rodgers, 2015). In addition, some research suggests that 85-95% of individuals with Williams Syndrome have auditory hypersensitivities (Donnai & Karmiloff-Smith, 2000) and up to 91% of individuals with Williams Syndrome have sensory modulation difficulties, which is the ability to regulate arousal from sensory information (John & Mervis, 2010).

Sensory processing difficulties can manifest themselves in a wide variety of ways and can be detrimental to an individual's day to day functioning. This article will briefly discuss the various ways sensory processing difficulties present themselves, the problems they can cause, and some of the ways to help.





Sensory Processing

Sensory Profiles

A widely used measure for identifying an individual's sensory processing patterns was developed by Winnie Dunn (2007), named the Sensory Profile Questionnaire. This is a survey that can be completed by parents or teachers. The responses are categorised into four main sensory profiles.

Sensory profiles are unique to everyone and scoring high on any of these profiles may impact an individual's day to day life. Some people may experience difficulties across all senses, whereas others may only experience these in one sensory domain. The profiles are:

Seeking / Seeker

An individual scoring high on this profile will seek sensory input more than others. They may:

- Find it difficult to sit still.
- Chew or fiddle with items.
- Turn the television up loudly.
- Talk loudly.
- Run instead of walk and rock when sitting.
- Like to smell things and environments filled with fragrances.
- Like to stare at fast moving objects.

Scoring high on this profile may impact an individual's ability to concentrate and pay attention to instructions. They may also be seeking sensory input during class, which may distract other people. Understanding that someone is seeking input rather than trying to disrupt others can help reduce the negative impacts associated with this profile. A sensory or fidget toy can also help.

Avoiding / Avoider

An individual scoring high on this profile will avoid sensory input more than others. They may:

- Dislike being hugged, even by family.
- Be startled or frightened by unexpected sounds and bright lights.
- Hear background noise other people are unable to detect.
- Worry about being bumped in line or touched by other people while playing.
- Refuse to wear 'uncomfortable' clothes (i.e. tight, scratchy)
- Be wary of certain playground equipment.
- Prefer to be in quieter environments and avoid crowds.

When faced with a trigger, an individual may have emotional outbursts and negative reactions. This can be challenging while in the classroom or out for the day, so knowing an individual's triggers means you can take steps to minimise the impact of certain stimuli.



Sensory Processing

Sensitivity / Sensor

An individual scoring highly on this profile may detect sensory input at a greater rate than others, which can affect how an individual responds to the input. They may:

- Experience sounds louder than others.
- Have strong reactions to smells and odours
- Experience lights as brighter than others
- Have strong reactions to certain tastes.
- Appear sensitive to certain fabrics or the way clothing feels.
- Have strong reactions to painful situations.

When an individual is sensitive to certain sensations, it can be challenging for parents, caregivers, teachers and peers to understand that the individual is experiencing the senses differently to everyone else. In addition, certain sensitivities may contribute to challenges during schooling and outings. Understanding an individual's sensitivities can help identify adjustments to reduce the chance of overwhelming the senses.

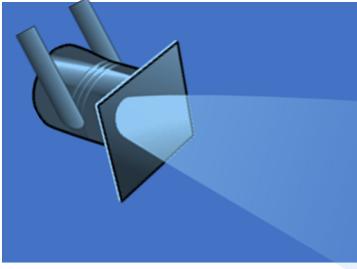
Registration / Bystander

An individual scoring high on this profile misses sensory input more than others, they may:

- Not register when their name is called.
- Appear to not feel pain.
- Take longer to respond to commands.
- Bump into things.
- May seem uninterested or in a world of their own.

When not responding to their name or instructions, it can lead to a teacher or parent viewing an individual as lazy or defiant. In addition, by not noticing when there are injuries, they may not receive the treatment that is needed to help them get better. It may be necessary to remind an individual to wipe food from their mouth as they may not feel it the same way other people do.

Individuals whose sensory processing patterns are characterised by one of these sensory profiles may experience additional challenges. For some people, sensory issues may become less severe, or even resolve as an individual ages. While they can become less severe for some, others will still experience difficulties throughout their lives. Moreover, certain difficulties can cause long term problems due to missed opportunities for socialisation and learning. Fortunately, occupational therapists can provide comprehensive assessments of an individual's sensory strengths, weaknesses and provide therapy, teach skills and recommend environmental adaptations to limit the impact of sensory issues for these individuals.



Sensory Processing

What therapies are available?

Sensory Integration Therapy (SIT) consists of a variety of sensory rich activities, that help a child appropriately respond to light, sound, touch, smells and other input. However, research indicates that SIT is not an appropriate treatment for children with autism spectrum disorders. A review of research using SIT found that out of 25 studies, only three had positive results (Lang et al., 2012).

Ayres Sensory Integration (ASI) is an individualised intervention designed to address specific underlying sensory motor issues that may be affecting performance in daily routines or activities. It consists of individual tailoring, active engagement of the child, establishment of therapeutic alliance between the child and therapist and creating sensory challenges in the context of play. A review of three studies indicates that ASI is effective and meets criteria to be considered an 'evidence-based practice' for children with autism ages 4-12 years old (Schoen et al., 2018).

Sensory Based Activities (SBAs) range from wearing weighted vests, sitting on a therapy ball, swinging, having a weighted blanket and many more. However, these have often been prescribed without consideration of an individual's needs, and there is mixed and limited evidence of the effectiveness of SBAs (Schaaf & Case-Smith, 2014).

There is limited research in this field, which makes recommending therapies for other neurodevelopmental disorders challenging. There are, however, a range of other activities that may be useful for an individual with sensory difficulties. For example, dance, movement, music, pet and art therapies can provide an alternative avenue for an individual to communicate and express themselves. While they may not directly improve sensory processing capabilities, the activities may be highly enjoyable for individuals with sensory processing difficulties.

Strategies that may help during outings (Dunn, 2007)

The following strategies may be useful for individual with sensory processing difficulties. At times, some of these may not be possible (for instance, avoiding busy places). However, having a few strategies on stand-by may reduce the difficulties encountered during outings. Also keep a diary of what worked and what did not work as you may need more than one trick up your sleeve. The following strategies are categorised by each sensory profile:

Seeking

Touch – bring textured toys, objects and the individual could wear textured clothing.

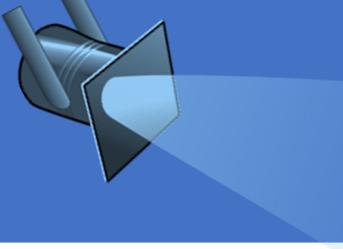
Movement – plan activities that require moving, for example, walking.

Visual – bring the individual's attention to objects in the environment.

Auditory – tell the individual what you can see, hear and smell and ask what they are noticing.

Taste/Smell – have scented lotions available for use.

Body position – have short varied trips that require an individual to move / get in and out of the car frequently.



Sensory Processing

Avoiding

Touch – try to stay away from crowded spaces.

Movement – use a stroller with upright sitting position.

Visual – wear sunglasses and create visual blinders to reduce visual input.

Auditory – schedule outings for nonpeak times.

Taste/Smell – avoid stores, aisles and places with scented products. Child may prefer a scarf over face.

Body position – the individual may benefit from wearing a backpack.

Sensitive

Touch – provide favorite blanket (or equivalent) for the individual to hold.

Movement – create typical rituals for frequent movement activities, i.e. getting in and out of the car.

Visual – give individual something to hold or focus on when moving in stroller to reduce strobe effect.

Auditory – use ear plugs or ear defenders and limit time in loud places.

Taste/Smell – be cautious about entering stores with scented products and places with scents. Reduce exposure to scents i.e. food courts. Have a pouch with preferred smell for child to smell when out.

Body position – the individual may benefit from wearing a backpack or having heavy toy on lap.

Registering

Touch – take textured objects or toys wherever you go.

Movement – take extra care when moving as individual may not notice certain objects in environment.

Visual – point out things you see.

Auditory – make sounds together, point out sounds you hear.

Taste/Smell – apply scented lotions on your own and the individuals' hands.

Body position – give individual heavy objects to carry and provide backpack for them to wear.

Want to find out more or understand your child's sensory profile?

Understanding an individual's sensory profile can help us to support people with processing difficulties to living fulfilling lives. If you have any queries about sensory profiles, then please contact bpowell@ucl.ac.uk with any queries you have.



Institute of Education

Sensory Processing

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<https://doi.org/10.1002/aur.2046>

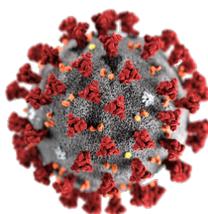


We need your help!



All our research is reliant on children, parents and practitioners contributing to our studies. We are currently recruiting for the following studies and would really appreciate any help. Equally, if you have any ideas for future studies, please get in touch!

Below 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)



TAKE PART IN A NEW STUDY ON HOW PEOPLE WITH SPECIAL NEEDS COPE WITH THE COVID-19 CRISIS

What is the study about?

The aim of this international research project (over 10 countries are taking part so far) is to find out how individuals with special needs are coping with the Covid-19 pandemic and all its repercussions. Indeed, we are interested in learning about what is unique to their and their parents' experience of the pandemic.

Who can participate?

Parents of people (children or adults) with **Special Needs** (e.g. Autism Spectrum Disorder, Williams Syndrome, Down Syndrome, etc.).

What will you be required to do?

Answer a **questionnaire** about how you and your child are experiencing the pandemic, in terms of health issues, coping with stress and social distancing, etc. It is completely **anonymous** and will take you about **20-30 minutes** to answer.

Why is this study and your participation useful?

This study would contribute to a better understanding of the experiences and feelings of people with special needs and of their parents, thus informing the design of future interventions to improve their quality of life.

TO CONTACT US:

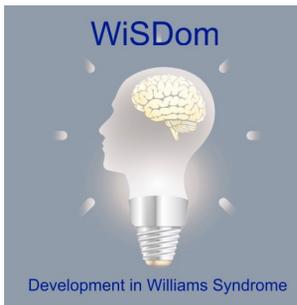
emotion@unidistance.ch

Prof. Andrea Samson & Dr. Daniel Dukes, University of Fribourg & UniDistance (CH)
Dr. Jo Van Herwegen, UCL Institute of Education (UK)

Click here to take part:

https://bit.ly/COVID-19_SN_international

We need your help



HELP US WITH THE WiSDOM study

Using a multi-lab-based approach, the WiSDom study examines development in Williams syndrome, a rare neurodevelopmental disorder from infancy to old age.

WiSDom Background questionnaire (Jo):

As part of the WiSDom study, 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

WiSDom Sensory profiles (Brad):

This study examines the development of sensory processing capabilities across the lifespan in individuals with Williams Syndrome (WS) building on from data already in the WiSDom database. However, we would like to expand the longitudinal data for sensory profiles in order to help us understand whether sensory processing is related to cognitive development and certain characteristic features of WS. We would like parents of children with WS to please complete the survey: please email Brad if you are interested: Brad Powell

b.powell@ucl.ac.uk

WS Educational Guidelines (Jess):

We have been asked by the Williams syndrome Foundation to review the existing educational guidelines and we would like **input from teachers about what information they think is missing from the guidelines** and what the new guidelines should look like. To take part in the survey please contact Jess Marshall:

https://uclioe.eu.qualtrics.com/jfe/form/SV_1H0EabtGx6Q3HPT

We need your help



SOEMO project: Socio-Emotional development in children with neurodevelopmental disorders

We have recruited over 100 people with Down syndrome but need more participants with Williams syndrome and autism. Do email emotion@unige.ch if you can help us!

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.

Recent Publication Summaries



Views of professionals about the educational needs of children with neurodevelopmental disorders

Jo Van Herwegen, Maria Ashworth, Olympia Palikara

Highlights

Teachers, teaching assistants, educational psychologists, speech and language therapists and occupational therapists all play a pivotal role in supporting children with special educational needs in schools. However, their views of working with individuals with neurodevelopmental disorders are less known.

We have gained an understanding of the views of 141 educational professionals working with individuals with Williams Syndrome (WS), Down Syndrome (DS) and Autistic Spectrum Conditions (ASC), with regards to the knowledge they have about the disorder and their views on the type of support they need to be receiving.

The research found professionals have a greater understanding of the typical difficulties faced by individuals with these neurodevelopmental disorders but are less informed to the subtle difficulties faced by these individuals.

Increasing professional's awareness of the less known difficulties faced by people with WS, DS and ASC will enhance their educational outcomes.

Why Does This Matter?

Training should be provided to educational professionals should go beyond the basic highlights of difficulties but also how these difficulties may affect learning in the classroom.

This will increase the support available to children with these neurodevelopmental conditions whilst raising confidence within professionals to meet these individuals' needs.

Full article: Van Herwegen, J., Ashworth, A., & Palikara, O. (2019). [Views of professionals about the educational needs of children with neurodevelopmental disorders](https://doi.org/10.1016/j.ridd.2019.05.001). *Research in Developmental Disability*, advance online. doi: 10.1016/j.ridd.2019.05.001.

Seattle Club 2019

By Jessica Marshall (Visiting student)

The Seattle Club is an annual meeting for researchers in the field of intellectual and developmental disabilities in the UK and Ireland. The first meeting was held in Birmingham in December 2001, and an annual meeting has been held ever since. The 19th Seattle Club was hosted by UCL and had been organized as a collaboration between the Child Development and Learning Difficulties Unit (CDLD) at UCL Institute of Education and UCL Centre for Intellectual and Developmental Disabilities (CIDDD).

Over 80 researcher attended, and over 50 researchers presented their work. The full abstracts of all talks can be found here:
http://seattleclubconference.org/conference_2019.html

There were truly too many interesting talks and posters to discuss but here are some of the highlights and conclusions from the meeting:

Keynotes:

Prof Patricia Howlin was one of the keynotes for the conference and focused on the ageing process in autism, specifically whether developmental trajectories improve or worsen with age. Although the jury is still out, there are some studies that suggest that some cognitive skills may be better preserved in autism than in the general population. There was a discussion of possible reasons why autism may provide a buffer against typical ageing processes. Watch this space.

Prof Dan Goodley was the second keynote and he discussed 'desire' with reference to stories where disability is present, to inspire self-advocacy of people with the label of learning disabilities. But also to make us see that we can all belong together in society and that inclusion so far has failed.

Quote from a Researcher:

"I thoroughly enjoyed giving a talk, meeting academics and learning about current research. The poster session provided a great opportunity to network and discuss projects."



Session One: Health across neurodevelopmental disorders

Research by David Mason and Colleagues found autistic people experience significant difficulties with accessing healthcare, and that many clinicians feel poorly prepared to deliver healthcare to autistic individuals. Good practice was identified by some autistic people – many elements of which could be implemented easily by clinicians at low cost, suggesting a small change in practice may have a large effect on the healthcare experience of autistic people.

A literature search also found the prevalence of type 2 diabetes is significantly greater in people with autism relative to their non-autistic peers. Accordingly, improved understanding of diabetes within this patient group will help determine appropriate resource allocation for public health measures and treatment approaches (Sam Tromans and Colleagues).

Arlene McGarty and Colleagues found parent focussed interventions could be an effective way to increase the physical activity levels of children and adolescents with intellectual disabilities.

Evangelia Petropoulou and Colleagues investigated the frequency, causes and types of injuries experienced by adults with intellectual disabilities who live with support in their own homes in Scotland. Most of the injuries occurred in the upper body. Home environment is the place that most of the injuries occurred. Fall-injuries were the commonest cause of injury in all age groups and between gender. These results may be used for the development of preventative strategies.

Similarly, Gillian S Smith and colleagues investigated rates and causes of mortality among children and young people with intellectual disabilities in Scotland: a record linkage cohort study of 800,457 school children and found the most common specific contributing causes were cerebral palsy, pneumonia, respiratory failure, and epilepsy. Deaths amenable to good care were common. Pupils with learning disabilities were much more likely to die than their peers, and had a different pattern of causes, including amenable deaths across a wide range of disease categories. Targeted improvements in care should be developed and delivered to reduce this inequality.



Seattle Club 2019

The first session finished with a presentation by Carrie Ballantyne and others, which explored Parental and adolescent perspectives of social media use in ASD, the study highlighted the importance of understanding the lived experience of the individual and the difficulties and benefits of using social media as a communication tool for those with autism and the concerns of their parents. The study highlights the need for further support as well as increased risk awareness for both autistic adolescents and their families.

Session Two: Adulthood

The first talk by Mark Gallagher and Colleagues discussed parents' experiences of the transition to adulthood for their child with profound and multiple learning disabilities, which found parents are experts on their child's care and support, which continues well into adulthood. There is a need for care and support services to formally recognise the important role they play in their child's life, particularly during transition. Given the closeness of their relationship parents needs are often intertwined with their children which raises important questions about independence.

The next talk focussed on the Preliminary long-term outcomes of the Standing up for Myself (STORM) intervention designed to increase stigma resistance among people with intellectual disabilities. Outcome data and qualitative accounts from STORM group members and facilitators indicate that STORM is well received and that it potentially increases participants self-esteem, mental wellbeing and sense of social power. STORM as a public health intervention has the potential to empower members of marginalised groups by engaging them as active agents in challenging stigma (Katrina Scior and Colleagues).

Session Three: Syndromes

The first talk discussed Wiedemann-Steiner syndrome and behaviour, family life and parents' views about research priorities. Most parents reported high levels of sociability, particularly with adults, with high approach to strangers and a preference for adults and younger peers. Those with siblings often had strong emotional bonds with them. Most parents reported different behaviour at home and at school. Perceptual/ cognitive features commonly reported were impulsivity, difficulty with self-regulation, sensory sensitives and importance of routine. Based on the initial findings, further research is needed to better our understanding of behavioural features, theoretical and practical understanding.



Seattle Club 2019

The next talk discussed an Interpretative Phenomenological Analysis of the personal experience and identity of adults with Tourette's syndrome, which suggests that the experience of the participants is a multidimensional one related to self-identity threat, social withdraw, and self-stigma. Implications for clinical practice on the topic were considered (Melina Malli and Colleagues)

Session Four: Relationships

The fourth session began with a discussion of Family relationships and their associations with perceptions of family functioning in mothers of children with intellectual disability. While this was an exploratory study, the findings suggest that interventions which target the marital/partner subsystem could improve the overall functioning of the family unit (Emma Langley and Colleagues).

Next was a discussion of developmental trajectories and the relationship between fathers and their children with intellectual disabilities in a population-based cohort by Kirsty Dunn and Colleagues. The talk concluded Father-child closeness improved over time, although there was a slight dip between ages 5 and 7 years old. This dip coincided with children beginning formal schooling. Factors associated with this transition, including the fact that some children receive a diagnosis of intellectual disabilities at school, may have contributed to this dip in closeness.

Research by Kate Theodor, Daniel Foulds and others aimed to challenge stigma faced by parents with intellectual disability and to enhance training resources for health and social care professionals working with them.

The next talk looked at associations between sibling behaviours and relationships where one has an intellectual disability. The final structural model indicated that the behaviours of both the child with intellectual disability and the sibling without were associated with the outcomes measuring sibling relationships. Longitudinal analyses are required to understand these associations further (Nikita Hayden and colleagues).



Session Five: Interventions

This session started with a talk on access to early intervention for families with young children with developmental disabilities (DD) across the UK. The results indicated that several access barriers to early intervention are present for families of children with DD. Practical implications for early intervention and recommendations for future research were discussed (Suzi Scott and colleagues).

Research by Athanasios Vostanis and colleagues found that precision teaching may be beneficial for students with intellectual disabilities. It also showed that students with intellectual disabilities could perform both accurately and quickly when the instruction is appropriate. Finally, it demonstrated that students with IDD could achieve steep weekly learning rates.

Ingolf Prosetzky aimed to identify the gap between research and the needs of practice and intervention within individuals with Williams Syndrome, and suggested ideas to bridge them. The authors interviewed family members, teachers, physiotherapists, but also members of the volunteer fire brigade. They collected a data set from qualitative data (1,800-page transcript of 74 interviews) and quantitative data (N = 31) between March and December 2017 and are in the process of analysing the data.

Following this, the prevention of offending behaviour by people with intellectual disabilities was discussed with reference to a specialist childhood and adolescent early intervention, which suggested that targeted services in childhood and adolescence could play a role in reducing the offending behaviour and forensic involvement of people with ID. This has implications for the service models provided for children and adolescents with intellectual disability with challenging or offending behaviour (Verity Chester and colleagues).

Seattle Club 2019

Session Six: Social Cognition

The last session began with a talk on microexpressions in children with autism. Findings from this study demonstrated the importance of facial expression duration and that this may highlight why children with ASD experience difficulties in everyday social interactions. Implications of these findings were discussed with regards to how children with ASD would especially benefit from further training in detecting microexpressions (Elisa Back and Colleague Rashma Hirani).

The last talk discussed reports of mental health in children with Down Syndrome, Williams Syndrome and Autism in the lead up to transition from primary to secondary school, which found that some children with Downs Syndrome do show significant higher levels of anxiety across a range of measures, while parental reported and self-reported levels of worries differed and there were differences between the neurodevelopmental groups. The findings were discussed in the light of the implications they have for supporting the mental health of these children during the critical period of transition from primary to secondary school (Elizabeth Burchell and Colleagues).

We'd like to thank all of our speakers, presenters and guests for attending. A special thanks goes to our two fantastic keynote speakers Prof. Patricia Howlin and Prof. Dan Goodley, who gave up their time and travelled very inexpensively so that we could keep registration costs as low as possible. Particular thanks go to Erica Ranzato, Paulien Eijckeler and Dave Dagnan who did a large amount of work behind the scenes. It was a great two-day meeting and we look forward to seeing you next year at Seattle Club 2020!





The 15th of May 2020, the Williams Syndrome Foundation is celebrating their 40th anniversary! To celebrate and raise awareness about the condition, we will be sharing 40 facts about Williams Syndrome across our social media channels. We will be sharing a fact a day, starting from Monday 6th April and finishing on the 15th May.

Williams Syndrome is a rare genetic condition that occurs 1 in every 18,000 births. It is caused by a deletion on the long arm of chromosome 7 that can affect up to 28 deleted genes. This genetic deletion occurs sporadically and can happen to anyone.

Williams syndrome is characterized by medical problems, including cardiovascular disease, developmental delays and learning challenges. These problems occur side by side with striking abilities, such as highly social personalities and a passion for music.

At the CDLD, we are proud to have contributed many research articles on Williams Syndrome. We have looked at outcomes related to teaching, school transition, home environments, cognitive assessments and interventions for people with Williams Syndrome. In addition, we have also contributed to the development of new training methods and policies that positively impact individuals with WS.





Below our links and brief summaries of various research articles on Williams Syndrome conducted by the CDLD:

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>

- *This research highlighted the effectiveness of utilising a multi-lab-based approach when researching Williams Syndrome. It provides a cost-effective means to gather data from a larger sample of participants over an extended period. Using this approach does requires greater care and planning, for instance, standardisation of protocols across labs.*

Palikara, O., M. Ashworth & Van Herwegen, J. (2018). [Educational outcomes of children with Williams syndrome: another neglected area of research?](#) *Journal of Autism and Developmental Disabilities*

- *This research found there is limited information on the type of educational provision and academic achievements that individuals with WS obtain. It called for additional research exploring the risk and protective factors associated with the educational outcomes of these children, the perspective of the children themselves, and the development of the evidence –base about the effectiveness of education intervention programs.*

Van Herwegen, J. (2015). [Williams syndrome and its cognitive profile: the importance of eye movements.](#) *Psychology Research and Behavior Management*, 2015(8), 143-151.

- *This review evaluated eye-tracking research in relation to the uneven cognitive profile within WS. Developmental studies have shown that difficulties with saccade planning and sticky fixation influence and interact with specific cognitive developmental processes from infancy onwards. Importantly, studies have demonstrated that individuals with WS are capable of saccadic adaption, which shows they have the capacity for saccadic motor learning which may improve cognitive outcomes related to the scan paths in infancy.*



Van Herwegen, J., Aznar, A., & Tenenbaum, H. (2014). [The use of emotions in narratives in Williams syndrome](#). *Journal of Language and Communication Disorders*, 50, 1-7.

- *In this study, 19 children with WS and 20 typically developing children matched for chronological age told a story from a wordless picture book. The results found participants with WS produced a similar amount of emotion words to their typically developing peers. However, individuals with WS produced more words about sadness, highlighting that emotion word use in WS is atypical. Therefore, future research should investigate emotion word production in relation to establishing and maintaining friendships to contribute to the development of appropriate social intervention programmes for people with WS.*

Van Herwegen, J., Dimitriou, D., & Rundblad, G. (2013). [Performance on verbal and low-verbal false belief tasks in children with Williams syndrome](#). *Journal of Language and Communication Disorders*, 45, 440-448.

- *It is unclear whether verbal abilities aid or hinder Theory of Mind ability in WS. To address this, the study investigated the relationship between performance on Theory of Mind tasks and verbal abilities. 30 children with WS and 30 typically developing peers, who were matched for vocabulary comprehension scores were included in the study. Individuals with WS performed poorer across all tasks, however, performance was not predicted by vocabulary or grammatical ability scores. This suggests Theory of Mind ability is not hindered by delayed language abilities in WS but by the task at hand.*

Thank you to everyone who has participated in our research! We couldn't do it without you!

GET INVOLVED! Like and share the facts we post throughout April and May.

If you'd like to find out more about our research or the Williams Syndrome Foundation, please follow these links:

<http://www.jovanherwegen.co.uk/index.php/blog/wisdom-study>

<https://williams-syndrome.org.uk/>

Awards



In March 2020 Jo was awarded the **Margaret Donaldson Early Careers prize** from the Developmental Section from the British Psychology Society. This is in recognition of her contribution to developmental research and public engagement, especially in relation to neurodevelopmental disorders and how children with neurodevelopmental disorders can be supported at home and in the classroom. As part of the award, Jo will give an Award Talk at the [Section Conference](#) to be held in Sheffield from the 8th – 10th September 2021. We will post pictures in the autumn newsletter. For more information see: <https://www.bps.org.uk/>

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

Researchers

Paulien Eijckeler

Dr Elizabeth Burchell

PhD-students

Erica Ranzato

Yi Wang

Tugce Cetiner

Research Students

Silvia Gini

Mizuki Tojo

Brad Powell

Jess Marshall

For more information about us or to apply to become a volunteer researcher, please see: <http://www.jovanherwegen.co.uk/>

Meet the researcher!

Brad Powell

My name is Brad and I'm interested in researching neurodevelopmental and psychiatric disorders. My passion to make a difference in the lives of people with these conditions was sparked while volunteering in Sri Lanka.



I'm currently studying MSc Developmental Psychology at the University of Surrey and I am a placement Research Assistant at the CDLD two days a week. I am also a Mental Health Act Panellist for Dorset HealthCare NHS Trust. This role entails reviewing whether service users detained under the Mental Health Act meet the criteria for legal detention under the Act, and discharging the service users when necessary. I have also spent time working in a low-security hospital and a Learning Disability service.

Prior to my MSc, I studied BSc Psychology at Bournemouth University, and my undergraduate dissertation utilised electroencephalogram and eye-tracking to explore endophenotypes of schizophrenia and schizotypal traits. Upon completion of my studies, I was elected as the Vice President Welfare of the Students' Union at Bournemouth University, the key representative in University affairs. During this role I also volunteered for Dorset Parent Infant Partnership and secured a grant to fund their service development project.

I am currently working on a project within the CDLD that is investigating the stability of sensory profiles in Williams Syndrome, and whether these are related to anxiety and repetitive behaviours. We aim to use the findings of this research in future assessment and interventions. After my MSc, I will be applying for a position as an Assistant Psychologist and the Doctorate in Clinical Psychology.

If you want to get in touch;
Email: b.powell@ucl.ac.uk
Twitter: @PositivePowell

Thanks for reading!



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

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>

twitter 



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/>