Child Development and Learning Difficulties Lab

This edition's spotlight
Moving to secondary school

Here is a picture of our new home

NEW PUBLICATIONS

SPOTLIGHT PIECE ON MOVING TO SECONDARY SCHOOL

WHAT ARE WE WORKING ON?

NEW! COLLABORATIONS

CONFERENCE PRESENTATIONS

FUTURE EVENTS

MEET THE TEAM

Hello and welcome to our Spring Newsletter!

First of all we would like to announce the fantastic news that CDLD has moved to UCL Institute of Education (IOE) in London. IOE is a world-leading centre for research and teaching in education and social science.

As before we will continue to carry out internationally excellent research in learning and development in children with learning difficulties and translate the latest findings into effective and practical assessments and interventions. This enables us to continue to provide information, advice and support to parents, carers, and professionals. We also publish our work in peer reviewed scientific journals and present our work at national and international conferences.

In this newsletter you will 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

UCL Institute of Education

Child Development and Learning Difficulties Lab

UCL Institute of Education

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!

What do you think about your child's mathematical abilities?

We are recruiting **parents** of children with **William Syndrome** or **Down Syndrome** aged between **4 and 11 years old** to complete an on-line questionnaire on Numeracy Learning Environment – follow the link below:

http://goo.gl/t4BWGh

Would you like some more info? Contact us at **e.ranzato@kingston.ac.uk**

We're Listening

We want to hear from you!

What do you think are the most pressing topics, question or issues that should be the focus of research?

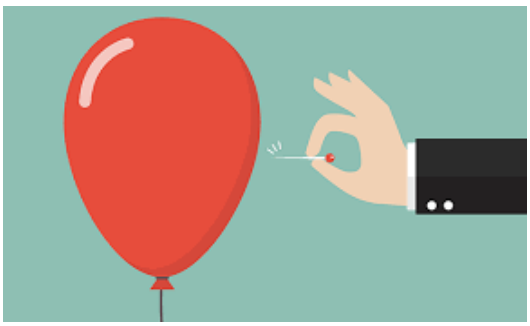
Please email us any question or suggestions you may have: j.vanherwegen@ucl.ac.uk

New publications

Comparing parental stress of children with neurodevelopmental disorders: The case of Williams Syndrome, Down Syndrome and autism spectrum disorders.

Parents of children with neurodevelopmental disorders can experience more stress compared to parents of typically developing children which can negatively impact parents' wellbeing, and be damaging to family relationships. Moreover, parents of children with rare genetic disorders, such as Williams syndrome (WS), may be at an increased risk of experiencing stress due to a lack of information about their child's syndrome. In our latest published study, we compared stress in parents of children with WS, a rare neurodevelopmental disorder, compared to parents of children with Down syndrome (DS) and autism.

Overall, the stress levels of parents with WS did not differ from those who had children with DS or autism. However, stress varied considerably within the groups; whilst some parents were very stressed about particular issues, other parents of children with the same condition were not stressed at all.



There were differences between the groups in what parents found stressful. Parents of children with WS found professionals' lack of knowledge about their child's condition more stressful compared to parents of children with DS and ASD. Considering the rarity of WS (approximately 1 in every 18, 000 live births), it is perhaps not surprising that parents find few professionals have an in-depth knowledge of WS. However, parents of children with WS found accessing a suitable educational placement was less stressful compared to parents of children with ASD. Parents of children with ASD also found it more stressful to access a professional compared to parents of children with WS and DS, perhaps due to the long waiting lists in the UK. Further results about contextual factors showed that family support and the child's age did not influence parental stress in any of the groups, but that siblings appeared to act as a buffer for parental stress in the WS and DS groups.

These findings suggest that parental stress differs for various reasons depending on the child's particular disorder. As such, clinical services and practical solutions aiming to support parents should be tailored to concerns specific to their child's neurodevelopmental disorder. For example, parents of children with WS could be provided with information packs to give to professionals working with their children to help reduce stress about professionals' lack of knowledge about WS, and parents of children with ASD could be provided with information about how they can access professional support.

This study was part of the project Raising Awareness for Special Education (RASE). We would like to thank all of the participants who took part in this research as well as the Williams Syndrome Foundation for funding this project.

By Maria Ashworth

The full publication can be found here, or by searching the reference below:

Ashworth, M., Palikara, O., & Van Herwegen, J. (2019). Comparing parental stress of children with neurodevelopmental disorders: The case of Williams Syndrome, Down Syndrome and Autism Spectrum Disorders. *Journal of Applied Research in Intellectual Disabilities,* 1-11. doi: 10.1111/jar.12594

Other new publications from CDLD lab members

- Ross, W., Vallee-Tourangeau, F., & **Van Herwegen, J.** (in press). 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*
- **Van Herwegen, J**., Purser, H., Thomas, M.S.C. (in press). Development in Williams syndrome: Progress, prospects and challenges. *Advances in Neurodevelopmental Disorders*
- Lane, C., **Van Herwegen, J.,** & Freeth, M. (2019). Exploring the approximate number system in Sotos syndrome: insights from a dot comparison task. *Journal of Intellectual Disability Research.* doi.org/10.1111/jir.12604.
- Lane, C., **Van Herwegen, J**., & Freeth, M. (2019). Parent-reported communication abilities of children with Sotos syndrome: Evidence from the Children's Communication Checklist-2. *Journal of Autism and Developmental Disabilities*.

Transitions: moving to secondary school for children with neurodevelopmental disorders

Moving from primary to secondary school is an important transition for young people. It can be an exciting time as it provides opportunities for new friends, teachers and valuable new learning experiences. On the other hand the move to secondary school can be a challenge for young people and it can places social, intellectual, organisational, and emotional demands on pupils. This transition can create a number of changes which can provoke a “fear of the unknown” and anxiety about anticipating negative experiences which can be related to issues with mental wellbeing, lowered self-esteem and reduced academic progress.

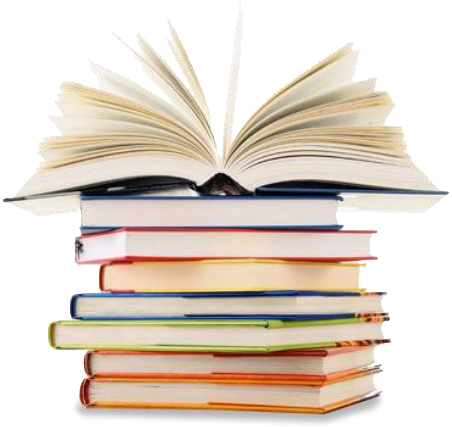
Moving from primary to secondary school generally entails a change of school campus, mixing with a new and different peer group, learning new forms of school organisation and having a number of teachers, many of whom will have very different teaching styles. Secondary schools are, for the most part, significantly physically larger than primary schools and students are often required to move to different locations throughout the day for their classes. At the same time, they need to arrive at each class on time and with the correct equipment. At secondary school, children are expected to be more independent, both in their learning and their overall care and wellbeing. New levels of organisation need to be quickly developed to manage these timetable requirements. Such challenges are a contrast to the primary school where students spend the majority of their day in the same classroom with the same teacher and the same group of peers in which all of their personal equipment is conveniently located. As such, common worries that children have about the move to secondary school include getting lost on campus, having more homework, being bullied by older students, and having stricter teachers.

Most neuro-typical children successfully cope with this move and find that many of their initial fears do not eventuate. Factors such as independence, good social skills, flexibility, self-regulation, and strong academic attainment have been shown to predict a successful move to secondary school. However, for pupils with neurodevelopmental disorders who often have areas of need in social skills, flexibility, emotion regulation, anxiety and special educational needs, the increasing demands of the curriculum and the changes in their social environment at secondary school can be particularly challenging.

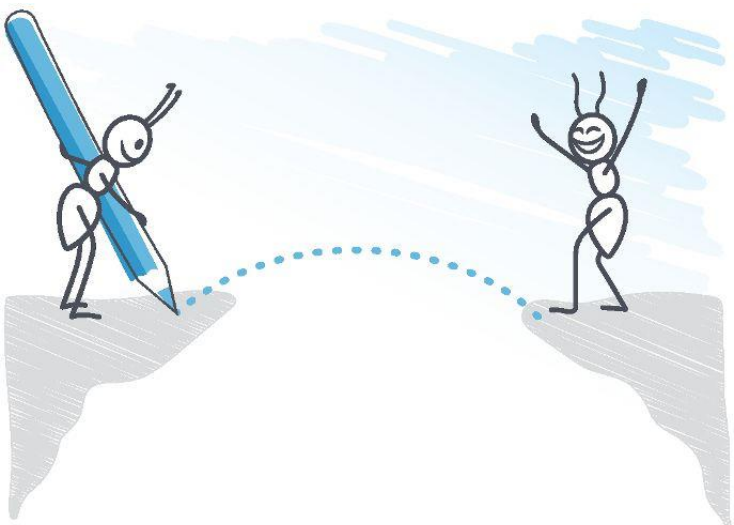
Firstly, the idea of 'change' alone can be very distressing for children with neurodevelopmental disorders because they can often have poor theory of mind which impacts their ability to predict outcomes of situations. As such, the 'fear of the unknown' related to moving to a new school can be more significant for these pupils.

Meeting new pupils can also be particularly anxiety provoking for children with neurodevelopmental disorders that have difficulties with social interaction and communication, and miscommunications between students and/or school staff could result in negative interactions. Larger and more busy, chaotic buildings and classrooms at secondary school level can pose significant problems for pupils with neurodevelopmental disorders that have sensory needs. Having to change classes can also be a real barrier for pupils with poor visuo-spatial awareness as finding their way around a building is much more difficult, if not impossible, for such children. Travelling around the school between classes can also be physically tiring because children with neurodevelopmental disorders can often have low muscle tone and poor gross motor skills. Additionally, these pupils may have to deal with changes in the structure and quantity of additional support they are receiving in school that may impact their ability to access the curriculum and achieve goals.

It should be noted that there are a range of different transitions that pupils with neurodevelopmental disorders may experience. For example, students may move from a mainstream primary school to a special secondary school, or to a mainstream secondary school with a special educational needs and disabilities unit on site. In other cases, some children will not even experience a transition to secondary school because they attend a special school that caters to their particular needs from a young age all the way to post-16 sometimes. The decision about what particular school setting and transition that a pupil experiences is unique for each pupil, and will depend on the schools available in the local area and how they can cater to the child's particular special educational needs.



Although there are a number of factors associated with neurodevelopmental disorders and special educational needs that have the potential inhibit a good transition, there are a number of points of goof practice that parents and schools employ to ensure the best possible transition to a new school. Clear, frequent and transparent communication between the primary and secondary schools and the parent and child are key to promoting a successful transition.

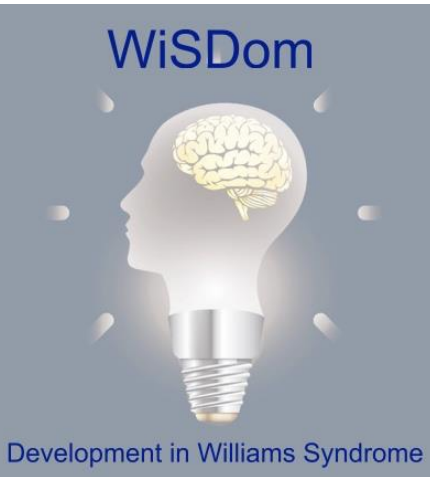


This can include meetings with the special educational needs coordinator, transition coordinator or other school staff involved in the child's transition and education that outline the child's areas of need and their strengths, the necessary provision and predicted outcomes. The role of the transition coordinator is important from the parents' perspective as they can be one member of the school staff to whom queries can be addressed, so building a good relationship early in the transition process can be very beneficial.

What are we working on?

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

WiSDom study (Dr Jo Van Herwegen)



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.

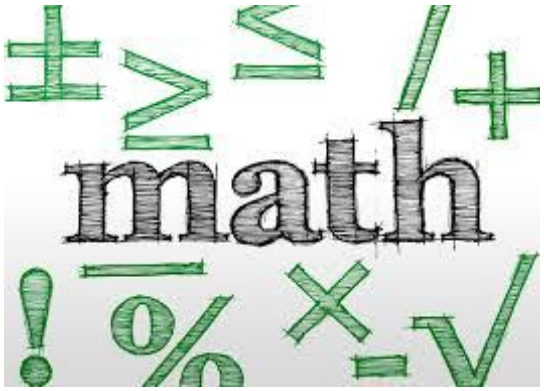
We are still analyzing the data but we have managed to get data on language and non-verbal tasks for over 200 people with WS (which is great seeing WS is rare, 1 in 20,000 births)! And for some tasks we have data for the same individual with WS from 6 different time points. This means we can really study development as well as individual differences in WS because not all people with WS are the same.

We will report further about the outcomes of this study in the next CDLD newsletter but you can also get more information from our website:
http://www.jovanherwegen.co.uk/index.php/blog/wisdom-study

What are we working on?

Maths at home (Erica Ranzato; e.ranzato@kingston.ac.uk)

Number skills are impaired in children and adults with Williams syndrome (WS) and Down Syndrome (DS). Research has shown that early home numeracy experiences, including playing games, reading number books and using money have a significant impact on children's later mathematical achievement. However, there is very little research in neurodevelopmental disorders. This study explores the Home Numeracy Environment of children with WS and DS. We are still looking for more parents to take part, please contact us if you are interested in this study.



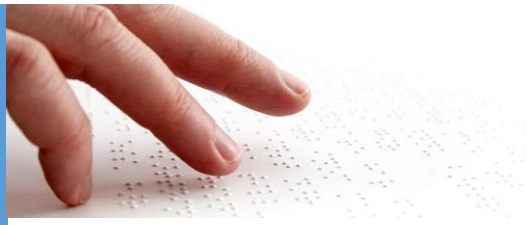
Math Autism (Erica Ranzato; e.ranzato@kingston.ac.uk)

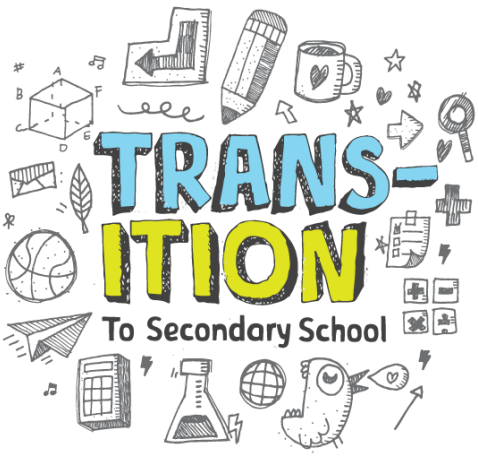
Autism Spectrum Disorders (ASD) have often been associated with superior mathematical abilities. However, clinical practice, teachers and therapists often consider mathematics as one of the difficult subjects for children with ASD. Moreover, there is a lack of understanding about which children with ASD excel and which ones have mathematical difficulties. In this study we examine whether mathematical abilities are a relative strength for individuals with ASD or not. This will allow for more precise recommendations for educational interventions to support either a specific math impairment or a more advanced mathematical programme for children with ASD.

What are we working on?

Mathematical abilities in visually impaired children (Dr Jo Van Herwegen)

This study examines the development of mathematical abilities in children with visual impairment. We are still looking for some participants to take part. If you/ your child or any of the children you work with can help out, please get in touch and we will send you more information.





Transcend study (Maria Ashworth & Dr Jo Van Herwegen)

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

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/

Emotions (Dr Jo Van Herwegen & Maria Ashworth)

This project is a cross-cultural study across Switzerland and the UK in collaboration with 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 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.

Collaborations

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

Centre for Educational Neuroscience (CEN): The CEN combines the expertise of researchers in child development, neuroscience, and education at three world leading universities, Birkbeck, UCL Institute of Education, and University College London. http://www.educationalneuroscience.org.uk/

Centre for Language, Literacy and Numeracy: Research & Practice (LL&NRP): The LL&NRP centre is a cross-departmental unit within the UCL Institute of Education that supports theoretical and applied research in the areas of spoken and written language and developing and understanding between language, literacy and numeracy. https://www.ucl.ac.uk/ioe/departments-and-centres/centres/centre-language-literacy-and-numeracy-research-practice

Centre for research in Autism and Education (CRAE): The CRAE is a partnership between the UCL Institute of Education (IOE) and Ambitious about Autism, the national charity for children and young people with autism. The CRAE's mission is to help enhance the lives of autistic people and their families. Researchers at the CRAE conduct ground-breaking scientific research to enhance knowledge about interventions, education and outcomes for autistic children, young people and adults. http://crae.ioe.ac.uk/

We also have some international collaborations with research labs abroad. For our newest project we work together with Dr Andrea Samson and colleagues from the Institute of Special Education at the University of Fribourg in Switzerland to do a cross-cultural study in sociability in Williams syndrome and Down syndrome across Switzerland and the UK.

In addition, our research wouldn't be possible without the help of a number of individual collaborators: Dr Elisa Back (Kingston University), Dr Dagmara Dimitriou (Institute of Education, UCL), Prof. Chris Donlan (University of London), Dr Emily Farran (University of Surrey), Dr Andrew Manches (University of Edinbrugh), Prof Maria Chiara Passolunghi (University of Trieste, Italy), Dr Olympia Palikara (University of Roehampton), Dr Vesna Stojanovik (University of Reading), Dr Harriet Tenenbaum (University of Surrey), Prof Michael Thomas (Birkbeck, University of London), and Dr Victoria Simms (university of Ulster)…to name a few!

Conferences

At CDLD we attend and present our work at a number of conferences. Here is an overview.

Girls with Autism – Many Voices Conference on 2nd April, 2019

by Paulien Eijckeler

Autism in girls is under-researched and under-recognized. The 'Girls With Autism – Many Voices' conference set out to give a voice to these girls and women, who often go unnoticed. *Key note speakers were Professor Barry Carpenter CBE, Professor Francesca Happé, Carrie Grant, and the girls of Limpsfield Grange School.*

The conference provided a setting for the launch of the book 'Girls and Autism. Educational, Family and Personal Perspectives' (eds. Barry Carpenter, Francesca Happé and Jo Egerton).

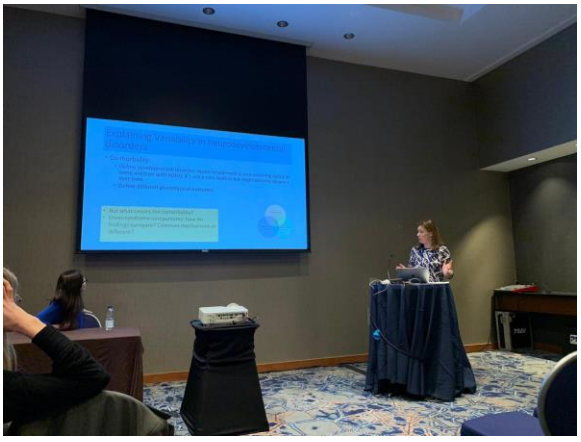
Workshops gave insight into the difficulties autistic girls experience in – amongst others – schools, BAME (black, Asian and other minority ethnics) communities, in adolescence and sexuality, and in friendships, and how these difficulties are often obscured by persisting gender stereotypical assumptions on autism.

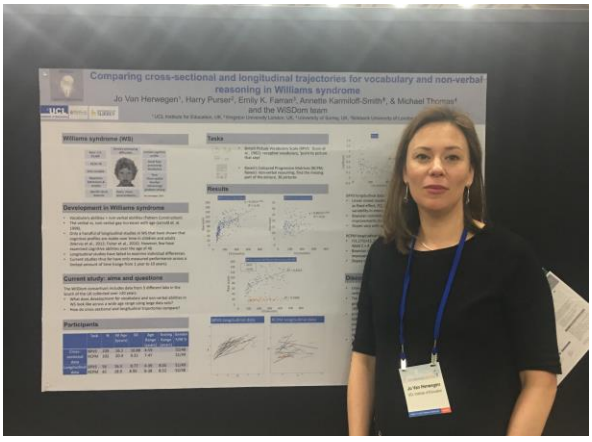
Dame Philippa Russell, Professor Dame Uta Frith and Dr Judy Gould discussed topics such as the value of diagnosis and the difficulty and need of correct diagnostics in girls. The girls of Limpsfield Grange School gave an insight in their lives as autistic girls. They want the world to know that vaccines do not cause autism, that girls can have autism, and that girls can be autistic and have friends. As Sofie Walker so beautifully stated in her Preface of the book, "Female does not equal not-male. Autistic female does not equal not-autistic."

For parents and for people working with children, in schools, research, medical situations, and so forth, it is a reminder to keep an open view and not let our judgements and expectations be clouded by the old gender stereotypes about girls and boys and autism.

Conferences

From 20th to 25th March, 2019 Jo flew to Baltimore, USA to present some of our work at the Society for Research in Child Development (SRCD) Conference, including a poster on the WiSDom findings and a discussion about variability in neurodevelopmental disorders. SRCD is one of the largest conferences on child development in the world.





In the next few months we'll be presenting our research at the following conferences:

- 20th – 21st June, 2019, Surrey: **Neurodevelopmental Disorders Annual Seminar (NDAS)**
- 9-12th of July 2019, BASEL: **International Annual Conference of the International School Psychology Association (ISPA)**
- 6-9th August, 2019, Glasgow: **The World Congress Of The International Association For The Scientific Study Of Intellectual And Developmental Disabilities (IASCIDD)**
- 18th – 19th September, 2019, Durham: **Williams Syndrome Researchers Meeting**

Past CPD events

- Improving mathematical abilities at home and in the classroom (26/02/2019)

This CPD event took place at UCL and focused on mathematical development in young children (under 5) and how parents and preschool providers can help children achieve their full mathematical potential through play and guided activities. It was a small event but it allowed attendees to get really involved and ask any questions they had.

- Understanding language development in children with visual impairments (5/04/2019)

This CPD event was requested by Linden Lodge School, a specialist school for children with visual and sensory impairments. We shared some findings from research and discussed how visual impairments can impact on all aspects of language development, including social relationships.

CDLD assessment clinic

At CDLD we always write a report for children that take part in our research. Since the introduction of EHCPs we have received a number of requests from parents for help with their child's EHCP applications and to date, we have written over 80 reports for children with special educational needs, especially those with Williams syndrome, to help their EHCP application process.

Please note that we are not a diagnostic unit, but carry out basic research into developmental disorders. We do, however, provide reports to help establish the educational and medical needs that we believe emanate from our testing of each individual child.

If you have any questions about your child's EHCP or need some help, feel free to get in touch with us.

Future events

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

This year we are organising the **Down Syndrome Research Forum** on the **16th – 17th September 2019** at UCL.

Details will follow in May 2019 on this website: https://www.down-syndrome.org/en-us/research/forum/.

We are also organizing **Seattle Club** at UCL in **December 2019**.

Seattle Club is a conference on **research in intellectual and developmental disabilities**.

More details to follow in our summer newsletter edition and on http://seattleclubconference.org/conferences.html

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.

http://www.jovanherwegen.co.uk

Lab director:
Dr Jo Van Herwegen

Researchers
Maria Ashworth
Paulien Eijckeler

PhD-students
Erica Ranzato

Research Students
Tak Hei
Silvia Gini
Farahin Ahmad Fahmy

We welcome applications for researchers looking to gain valuable experience. Email Jo for further information!

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