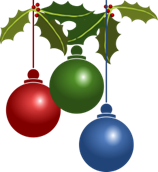
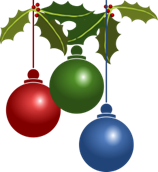
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| Newsletter Issue 3 December 2018  **EPICC-ID**  **E**valuation of **P**arent **I**ntervention for **C**hallenging Behaviour in **C**hildren with **I**ntellectual **D**isabilities |  |
| |  |  | | --- | --- | | **Prof Angela Hassiotis-Chief Investigator**  Welcome to the third EPICC-ID newsletter.  We are a national study funded to evaluate whether 9 weeks of Stepping Stones Triple P (SSTP) reduces challenging  behaviour in children with moderate to severe intellectual  disability at 12 months post randomisation and whether this  is cost-effective compared to treatment as usual.  **Recruitment**  So far 119 participants have been recruited into the study  with 79 participants having completed the 4-month follow-up assessments and 20 have already had the 12 month follow  up. Four Stepping Stones Triple P groups have been  completed in the North West, two groups have been  completed in the North East and three in London. We would like to thank all the participants and their carers for their co-operation and putting aside time to help with the study. We look forward to seeing you all again for the follow-up appointments in the coming months.  **Which treatment?**  We are trying to work out whether Stepping Stones works  and the only way to do this, is to allocate parents to the  active intervention or to usual care by chance (randomisation).  We would like to remind parents not to tell research  assistants whether they have attended any groups or not. It  is vitally important for the study that research assistants are not aware of the parent’s treatment allocation.  **We would like to wish all of the participants, families, carers, CSOs, local investigators, volunteers and support staff who have contributed so much to the study a very Merry Christmas and A Happy New Year!**  **Thank you for all of your hard work!** | **Contents**   1. **Recruitment update** 2. **Staff changes** 3. **Unblinding** 4. **Meet and Greet sessions** 5. **More Participants Needed** 6. **Background to study** 7. **In the media** 8. **EPICC-ID teams** 9. **Contact details** 10. **Study collaborators** 11. **Summer at UCL** |   Holly Wake, Matthew Unwin, Miriam Ziriat and Hannah Cross were successful in getting onto the very competitive Clinical Psychology training and have left their research assistant roles with EPICC-ID this autumn. We have recruited four new researchers to carry on the good work and who have been assessing participants in the study.  **Our new Researchers**  **Abigail Coulson-Newcastle**  Before working as a research assistant on EPICC-ID I have previously worked as an assistant psychologist in Neuropsychology, Learning Disabilities and Pediatrics. Because of my previous experience with learning disabilities and children, I have seen the challenges that families can face so this research project is of great interest to me.  **Katharine Harrison-Blackpool**  Before being a research assistant on the EPICC-ID study, I trained to be a primary school teacher, teaching in year 1 and 2. My undergraduate degree is in Psychology and my MSc is in Clinical Mental Health Sciences. I love spending time outdoors and at weekends am usually out walking my dog, running or horse riding  **Laura Paulauskaite-North and South London**  Laura has worked as a Research Assistant in the Research Team at Camden and Islington NHS Foundation Trust and was involved in several studies for people with a range of mental health disorders and intellectual disabilities. She is interested in intellectual disabilities, challenging behaviour and mental health.  **Olayinka Farris-North and South London**  Ola completed her BSc in Psychology at UCL in 2011 and a MSc in Clinical Neurodevelopmental Sciences at the IoPPN, London in 2016. She is very passionate about neurodevelopmental disorders and has been working with such client group as an assistant psychologist or research assistant for the past 7 years. Other clinical populations she has worked with includes people with brain injury, psychosis, anxiety, depression, chronic pain, substance misuse and self-harm. Ola loves tennis particularly Rafael Nadal. | C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\SLZ2L6X0\sheikh-tuhin-Christmas[1].png  **Contents**   1. **Introduction**   **-Recruitement**  **-Which treatment?**   1. **New research assistants** 2. **EPICC-ID Parent Group** 3. **Recruitment** 4. **EPICC-ID Team and Study Collaborators**   C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\SLZ2L6X0\sheikh-tuhin-Christmas[1].png  **C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\QJOJ6QKA\Christmas_Characters_by_bluesketchpad[1].jpg** |
| **Views from the EPICC-ID Parent Group**  **Nikki Kimber from St Annes in Lancashire** is on the study's parent advisory board. Nikki cares for her 15 year old daughter who has an incredibly rare chromosome deletion that has caused her chronic developmental delays and behavioural issues. She says  "I'm not sure what most people think about when they see or hear the description 'challenging behaviour'. It's not just about the child that refuses to put their shoes on for school, or throws a bedtime tantrum. It's a world away from that. It's being kicked, bitten or punched by your child every day. Having your house trashed, being unable to join clubs, go to parties or go shopping because your child hurts others and screams at the top of their lungs. Challenging behaviour in your child is so isolating and frightening. You feel like an utter failure and the loss of control is overwhelming. It breaks families and steals self-confidence. As a parent it can be confusing and heart breaking. A research project like this one, which aims to intervene early and give parents strategies for coping with and managing behaviour is fantastic. It's so worthwhile to put time, thought and care into learning about challenging behaviour because the long term benefits of keeping families together and parents able to cope are immense. I am delighted to be involved with the project and very hopeful that the future for many families could be changed for the better." | |
| **Recruitment**  Our study is open to recruitment and we are actively looking for more participants in all 4 areas. If you can answer yes to both the questions below you can be part of our study.  -**Does your child have delays in development and challenging behaviour (e.g. screaming, hitting themselves or others, breaking and damaging things, not listening to you)?**  **-Is your child aged 3-5 years?**  To find out more see our [information sheets](http://www.ucl.ac.uk/psychiatry/research/epidemiology/pis/hassiotis-research-portfolio/challenging-behaviour-early-intervention/participants) on our website and if you decide this is the right study for you, please ask the professionals involved in your child’s care or email us directly at [epicc-id@ucl.ac.uk](mailto:epicc-id@ucl.ac.uk)      **Website**  [http://www.ucl.ac.atry/research/epidemiology/pis/hassiotis-research-  portfolio/challenging-behaviour-early-intervention](http://www.ucl.ac.atry/research/epidemiology/pis/hassiotis-research-%20# portfolio/challenging-behaviour-early-intervention)    **EPICC-ID Team**  **Chief Investigator**  **Prof Angela Hassiotis** -Professor in intellectual disability in the Division of Psychiatry at UCL and honorary consultant Psychiatrist at the Camden Learning Disability Service  **Co-applicants**  **Prof Jacqueline Barnes** -Institute for the Study of Children, Families and Social Issues, Birkbeck, University of London  **Dr Marinos Kyriakopoulos-**Consultant Child and Adolescent Psychiatrist, South London and Maudsley NHS Foundation Trust and Visiting Senior Lecturer, King's College London  **Dr Michael Absoud** -Consultant in children's neurodisability at Guys and St Thomas's NHS Foundation Trust  **Dr Eleni Paliokosta** -Child and Adolescent Psychiatrist, Tavistock & Portman NHS Foundation Trust  **Dr Kate Oulton** - Senior Research Fellow/Clinical Academic Programme Lead at the Centre for Nursing and Allied Health Research, Great Ormond Street Hospital for Children NHS Foundation Trust  **Dr Vicky Slonims** -Consultant speech and language therapist at Guys and St Thomas's NHS Foundation Trust, Evelina and honorary senior lecturer at King's College London  **Ms Rachael Hunter** -Principal Research Associate in Primary Care & Population Health at UCL Institute of Epidemiology & Health  **Prof Alastair Sutcliffe** -Professor of General Paediatrics, ICH Pop, Policy & Practice Programme and UCL, GOS Institute of Child Health  **Dr Aditya Sharma** - Consultant & Honorary Clinical Senior Lecturer in Child and Adolescent Psychiatry Newcastle University  **Mrs Una Summerson** -Head of campaigns at Contact; For families with Disabled Children  **Dr Megan Thomas** -Consultant Community Paediatrician Blackpool Teaching Hospitals NHS Trust  **Dr Gareth Ambler** -Senior lecturer in Medical Statistics at the Department of Statistical Science UCL    **Research Staff**  EPICC-ID trial manager Dr Michaela Poppe [m.poppe@ucl.ac.uk](mailto:m.poppe@ucl.ac.uk)  Research administrator Tommy Coyle [t.coyle@ucl.ac.uk](mailto:t.coyle@ucl.ac.uk)  London research assistant Laura Paulauskaite [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)London research assistant Olayinka Farris [o.farris@ucl.ac.uk](mailto:o.farris@ucl.ac.uk)  Blackpool research assistant Katharine Harrison [katharine.harrison@nhs.net](mailto:katharine.harrison@nhs.net)  Newcastle research assistant Abigail Coulson [Abigail.Coulson@ntw.nhs.uk](mailto:Abigail.Coulson@ntw.nhs.uk) | |

**Study Collaborators**



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