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| **Newsletter Issue 2 August 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 second 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 (also called learning) disability at 12 months post randomisation and whether is this cost-effective compared to treatment as usual. **Recruitment**So far 86 participants have been randomised and 52 participants have had 4-month follow-up assessments. Three Level 4 Stepping Stones Triple P groups have been completed in the North West, one group has been completed in the North East and two in London. We would like to thank all the participants and their carers for their co-operation and putting aside some time to help with the study. We look forward to seeing you all again for the follow-up appointments in the coming months. **Staff changes**In each of our regions we will be recruiting new research assistants in the coming months as our current team move on to new opportunities. We would like to thank Hannah Cross in the north west, Matthew Unwin in the North East and Holly Wake and Miriam Ziriat in North and South London for all their hard work and commitment over the last year. We will be updating participants and families in September 2018 with the names of the new research assistants **Unblinding** We are running Stepping Stones Triple P groups in each area. 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 RAs are not unblinded to treatment allocation. | **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**

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| **Meet and Greet Sessions**A Parent meet and Greet morning will be held on 13th and 18th September 2018 from 10am-12:30pm at Contact; for families with disabled children offices * 13th September at Southwark Office - Cambridge House, 1 Addington Square, SE5 0HF
* 18th September at Lambeth Office - Weare336, 336 Brixton Road, London, SW9 7AA

Parents from South and North London sites are invited to attend. Ilham el Fenne will talk about the study and one of the therapists will be present at the event to talk about Stepping Stones Triple P and answer any questions parents may have about the intervention and the groups. Similar meet and greet events will be held at other sites as well. Please check with your local team for further details.**We are actively looking nationally for more participants** 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 please see our [information sheets](http://www.ucl.ac.uk/psychiatry/research/epidemiology/pis/hassiotis-research-portfolio/challenging-behaviour-early-intervention/participants) on the EPICC-ID website (details below) and if you decide this is the right study for you, you can ask the professionals involved in your child’s care or email us directly at epicc-id@ucl.ac.uk  |
| **Background to study**Learning disability is a lifelong condition which affects both cognitive ability and adaptive behaviours, with onset occurring in childhood. These individuals have difficulties understanding new or complex information and in performing some life skills and everyday activities independently. Children with learning disabilities are at an increased risk of developing challenging behaviours in comparison to their typically developing peers. A recent report from the Challenging Behaviour Foundation stated that at all ages, children with learning disabilities are more likely to have behaviours which challenge, estimating that this applies to 15,000 children aged between 2-6 years of age. A long-term follow-up study has shown that challenging behaviours in this population persist over time. Only 10% of participants in this study received any intervention during the study period. These figures show that a sizeable proportion of children have both a learning disability and challenging behaviour. If left untreated and unsupported, these children are at risk of developing difficulties later in life. Early intervention has been highlighted as particularly helpful and effective in bringing about change and improving longer term outcomes in children with conduct or behavioural disorders |  |
| **In the media**BBC Panorama recently met three extraordinary families who spend their lives caring for children with serious disabilities. The number of school-aged children with complex needs has doubled since 2004, but many families now struggle to secure the help their children need in the face of limited resources. The programme can be seen via the following link <https://www.bbc.co.uk/programmes/b0bc2ch6> **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 and at Evelina**Dr Eleni Paliokosta** -Child and Adolescent Psychiatrist, Tavistock and 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 Research Administrator Tommy Coyle t.coyle@ucl.ac.uk London Research assistant Miriam Ziriat m.ziriat@ucl.ac.uk London Research assistant Holly Wake h.wake@ucl.ac.ukBlackpool Research assistant Hannah Cross Hannah.Cross@bfwhospitals.nhs.uk Newcastle Research assistant Matthew Unwin Matthew.Unwin@ntw.nhs.ukSouth London Clinical Studies Officer Anastasia Papathanasiou anastasia.papathanasiou@kcl.ac.uk South London Clinical Studies Officer Melanie Ekani Melanie.Ekani@gstt.nhs.uk North London Clinical Studies Officer Rebecca Case rebecca.case@nhs.net North London Clinical Studies Officer Bianca Hinds-Walters b.hinds-walters@nhs.net Newcastle Clinical Studies Officer Emily Clare Emily.Clare@ntw.nhs.uk Newcastle Clinical Studies Officer Susan Wilson Susan.Wilson1@ntw.nhs.uk  |



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Twitter account [www.twitter.com/EPICC\_ID](http://www.twitter.com/EPICC_ID)



**Study Collaborators**



**Summer at UCL-We hope all of you are enjoying the hot summer weather!**



If you have any suggestions regarding future newsletters please email Tommy on t.coyle@ucl.ac.uk