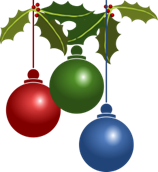
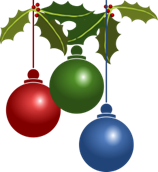
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| Newsletter Issue 5, December 2019  **EPICC-ID**  **E**valuation of **P**arent **I**ntervention for **C**hallenging Behaviour in **C**hildren with **I**ntellectual **D**isabilities (**EPICC-ID**) |  |
| |  |  | | --- | --- | | **Prof Angela Hassiotis-Chief Investigator**  Welcome to this year’s EPICC-ID Christmas 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 as compared to treatment as usual.  **Current study numbers**  The study has been recruiting for 25 months. So far 190 participants have been recruited:157 participants have completed the 4-month followup assessment and 95 have already have had their final twelve month followup!. There have been 19 Stepping Stones Triple P groups completed in total. We would like to thank all the participants and their carers for their co-operation and putting aside time to take part in the study. We look forward to seeing you all again for the follow-up appointments in the coming months.  **Reminder to Parents**  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 (this is called 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 arm allocation.  **C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\QJOJ6QKA\Christmas_Characters_by_bluesketchpad[1].jpg**  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** |   **New staff**  **Gemma Brown** has joined the EPICC-ID team in Blackpool. She has been a Research Nurse for 4 years and has an interest in children with challenging behaviour. Originally from London, she moved to Blackpool in 2006. Being by the seaside and watching the sunset is her favourite past time.  Congratulations and welcome to Gemma!  **Recruitment**  Our main site in Blackpool in North West of England is now closed to further recruitment, but they continue to see participants for follow ups. The three other sites as well as several Participant Identification Centres are open and recruiting to the study still. We need 258 to be able to tell for sure if SSTP works for those families whose children with moderate to severe learning/developmental disabilities display behaviours of concern. We have completed a social media advertising campaign on Facebook, [@epiccid](https://www.facebook.com/epiccid/?modal=media_composer&ref=page_homepage_panel) to help with recruitment in the last few months. We have also produced a formal set of questions and advice so that our research assistants can engage parents in a consistent and organised manner when trying to recruit them to the study.    If you can answer yes to both the questions below you can be part of our study.   1. **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)?** 2. **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) | C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\SLZ2L6X0\sheikh-tuhin-Christmas[1].png  **Contents**   1. **Introduction** 2. **Current study numbers** 3. **Reminder to parents** 4. **Christmas wishes** 5. **New staff** 6. **Recruitment** 7. **What Families are saying** 8. **EPICC-ID Team and Study Collaborators**   **Christmas Carol singing at UCL**    C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\SLZ2L6X0\sheikh-tuhin-Christmas[1].png    **Here is a word cloud of parents views**    C:\Users\rejutco\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\SLZ2L6X0\sheikh-tuhin-Christmas[1].png |
| **What Families are saying -Questions about the study?**  Here are a few questions that come up quite regularly in our communications with parents and responses from the team   * **What is Stepping Stones Triple P?** Stepping Stones Triple P is a therapy for parents who have children with challenging behaviour. This therapy provides strategies to parents on how to manage challenging behaviour and also teaches family coping skills. * **How do you decide who gets Stepping Stones Triple P therapy?** The decision on whether you are offered the therapy or not is not based on any assessments and is decided by a computer so it is completely random. * **Does Stepping Stones Triple P work?** We are not sure if the therapy works and we are testing it to see if the therapy is helpful to families. When you take part in the study, there is a 60% chance that you will be offered the therapy sessions and 40% chance that you will not be offered the therapy sessions, but you will still be a part of the study * **How can I be still part of the study if I am just allocated normal care?** If you are recruited into the study we will ask you to complete 3 research assessments. Many families that are already part of the study have told us that they *enjoy meeting research assistants to talk about their child’s behaviour and to reflect on how they are feeling*. As a part of the assessments, research assistants use a play based assessment with your child. Many parents *enjoy seeing this assessment being carried out* as it can provide strategies and tips on how to best engage with their child and what sort of play exercises may stimulate learning and development that parents can try themselves. * **These assessments require a lot of our and our children’s time. How else can we benefit**? The assessments involve filling in some questionnaires about your child’s behaviour and taking part in a video assessment with your child. After each research assessment, you will receive a £15 shopping voucher as a thank you for your help and time * **Can we get travel expenses if we join the group**? If you need help with travel or child care we can discuss this with the individuals involved. * **Will this therapy be more widely available after the study**? Our study will provide important evidence and may highlight the need for more resources to be given to parents of young children with behaviours of concern. We need more evidence that the therapy works in England and whether it is value for money. We need your help with this. * **Should we tell the research assistants if we are in the treatment part of the study**? Please do not mention to the researchers when they visit you or on the telephone if you attend any groups or not | |
| **Website**  <https://www.ucl.ac.uk/psychiatry/research/epidemiology-and-applied-clinical-research-depa/projects/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 Rachel Royston [r.royston@ucl.ac.uk](mailto:r.royston@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 Gemma Brown [gemma.brown7@nhs.net](mailto:gemma.brown7@nhs.net)  Newcastle research assistant Abigail Coulson [Abigail.Coulson@ntw.nhs.uk](mailto:Abigail.Coulson@ntw.nhs.uk) | |

**Study Collaborators**



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If you have any suggestions regarding future newsletters please email Tommy on [t.coyle@ucl.ac.uk](mailto:t.coyle@ucl.ac.uk)