

## EPICC-ID

# Evaluation of Parent Intervention for Challenging Behaviour in Children with Intellectual Disabilities (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.

This year has been an unusual one and we had to make a lot of changes to the study to keep ourselves and all the families involved safe. This has included completing all study assessments over the phone and changing the therapy to be delivered online instead of face-to-face. This move has not been without its challenges but we feel we have made the best of the situation and are still able to offer most of the study to families.

We hope you are all keeping safe during these uncertain times and look forward to a more positive year ahead.

### Current study numbers

We are delighted to announce that the study has reached its recruitment target of 258 participants. We were given a 10 month study extension and received an additional extension because of COVID-19. This has all paid off and we are finally closing recruitment this month.

So far 196 participants have completed the 4-month followup assessment and 150 have already had their final twelve month followup! There have been 24 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.



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**Here is a picture of some members of the team and parent advisors on a Zoom study call**

## A huge thank you

We would like to say a huge thank you to everyone who has given their time to take part in the study so far and to all the professionals who have helped us to reach as many families as possible. We still have a way to go before the study is finished in March 2022 but we really appreciate all your support!



## 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.



## Christmas/Holiday wishes



*We would like to wish all of the participants, families, carers, clinical study officers, 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!*

## New staff

### Helen Spencer

Helen is working as a Research Assistant for EPICC-ID at the North East site. She is employed by the NHS and is also studying part-time for her PhD in Psychology at Newcastle University. Helen likes to watch Netflix in her spare time (The Staircase is her favourite), and read books on criminology (especially books by Prof. David Wilson!). Helen would love to visit Dubai in the future, once her PhD is finished.



## Tamara Ondruskova

Tamara has joined the EPICC-ID team in London. She has recently graduated from UCL studying Clinical Mental Health Sciences and Psychology. Her main interests are child development, autism and challenging behaviours. Originally from Slovakia, she moved to London in 2016. She loves to play the piano and get out to nature with her camera to capture the surrounding beauty.



**contact** *For families  
with disabled children*

## A few words from our colleague Una from the charity Contact

Hello I'm Una from Contact. Contact is the charity helping the EPICC\_ID study with parent involvement. I wanted to tell you about a couple of things we have been doing to support families this year.

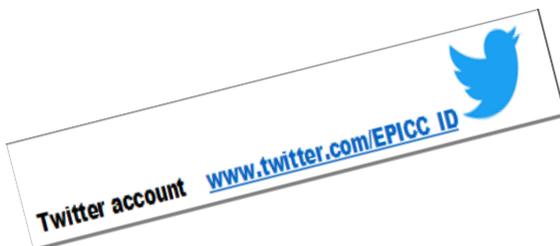
At the start of the pandemic, the length and emotional intensity of calls to Contact's free helpline **0808 808 3555** from parent carers increased. So we needed to find a way to offer parents more time for in-depth emotional support, and thankfully we were able to launch **our Listening Ear service**.

[Parents can book](#) a one to one telephone appointment with a Family Support Adviser. Each appointment is for one hour, and it's followed up with the information and advice discussed by email.

**So far, over 200 families have benefited from the service, parents like Jasmeet, who said:**  
*"I now feel much better and more positive about the future. If I need help and support, I know where I can turn. I am the only carer of four people, but now I feel like there is somebody to take care of me too."*

Find out more about how Contact helps families here: [Help for families | Contact](#)

We also know that Christmas can be tough so some families so all our products sold on [our Fledglings shop](#) are designed for children with additional needs, plus any profits go back into supporting other families through Contact's services. Our Christmas shop is open and full of great ideas including [sensory stocking fillers](#) , [Christmas gift ideas](#) and [gifts for under £25](#).



### Website

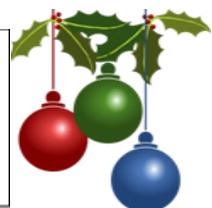
<https://www.ucl.ac.uk/psychiatry/research/epidemiology-and-applied-clinical-research-depa/projects/challenging-behaviour-early-intervention>



### Contact Details

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## 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

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## Study Collaborators



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If you have any suggestions regarding future newsletters please email Rachel on [r.royston@ucl.ac.uk](mailto:r.royston@ucl.ac.uk)