

Clinical and cost-effectiveness of an adapted intervention for preschoolers with moderate to severe intellectual disabilities displaying behaviours that challenge: the EPICC-ID RCT

Tamara Ondruskova,¹ Rachel Royston,¹
Michael Absoud,² Gareth Ambler,³ Chen Qu,³
Jacqueline Barnes,⁴ Rachael Hunter,⁵ Monica Panca,⁵
Marinos Kyriakopoulos,^{6,7,8} Kate Oulton,⁹
Eleni Paliokosta,¹⁰ Aditya Narain Sharma,¹¹ Vicky Slonims,²
Una Summerson,¹² Alastair Sutcliffe,¹³
Megan Thomas,¹⁴ Brindha Dhandapani,¹⁵
Helen Leonard¹⁶ and Angela Hassiotis^{1*}

¹Division of Psychiatry, University College London, London, UK

²Evelina Hospital, Guys and St Thomas's NHS Foundation Trust, London, UK

³Department of Statistical Science, University College London, London, UK

⁴Department of Psychological Sciences, Birkbeck University, University of London, London, UK

⁵Research Department of Primary Care and Population Health, University College London, Royal Free Medical School, London, UK

⁶South London and Maudsley NHS Foundation Trust, Michael Rutter Centre, Maudsley Hospital, London, UK

⁷National and Kapodistrian University of Athens, Vyronas-Kessariani Community Mental Health Centre, Athens, Greece

⁸Department of Child and Adolescent Psychiatry, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

⁹Great Ormond Street Hospital, London, UK

¹⁰The Tavistock and Portman NHS Foundation Trust, Kentish Town Health Centre, London, UK

¹¹Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust and Newcastle University, Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry, Newcastle upon Tyne, UK

¹²Contact, London, UK

¹³Institute of Child Health, University College London, London, UK

¹⁴Blackpool Teaching Hospitals NHS Foundation Trust, Blackpool, UK

¹⁵Lewisham and Greenwich NHS Trust, Queen Elizabeth Hospital, London, UK

¹⁶Great North Children's Hospital, Victoria Wing, Royal Victoria Infirmary, Newcastle upon Tyne, UK

*Corresponding author a.hassiotis@ucl.ac.uk

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Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/JKTY6144>.

Primary conflicts of interest: Professor Angela Hassiotis receives an annual honorarium from NADD for the editorship of the Journal of Mental Health Research in Intellectual Disabilities (since 2016). Her institution received £100 for her contributions to the British Association of Community Child Health. She is a DMEC member on the STRATA trial and has a non-fiduciary role on the HTA commissioning committee (2018–24). Dr Megan Thomas holds a grant with the Department of Paediatrics Development Fund of \$9500 for Sleep for Health in Hospital, Halifax (Shhh) exploring the sleep experiences of children and their coresident parent on the Paediatric Medical Unit at the IWK. She was also Chair of the Trial Steering Committee for the HTA-funded PREDNOS 2 trial (2013–20) and is an advisory board member for Martin House Children’s Hospice Research Centre, York. Dr Marinos Kyriakopoulos receives support for attending meetings and/or travel as part of an NHS study leave budget for Continuous Professional Development. Dr Michael Absoud charges consulting fees with NIHR, Guy’s and St Thomas’ charity and the King’s Health Partners. Ms Una Summerson holds grants with NIHR, Autistica and the GSTT charity. She is also a Trustee for Action for Stammering Children Charity. The remaining authors have no interests to declare.

Note: This trial is also known as EPICC-ID (Clinical and cost-effectiveness of a parent-mediated intervention to reduce challenging behaviour in preschoolers with moderate to severe intellectual disability) <https://www.ucl.ac.uk/psychiatry/research/epidemiology-and-applied-clinical-research-depa/projects/challenging-behaviour-early-intervention>.

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Plain language summary

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Plain language summary

Research shows that in children without learning disabilities, parenting groups which support parents to develop skills to manage behaviours that challenge in their child can be helpful. The National Institute of Health and Care Excellence recommended that more research was needed to strengthen the evidence for such interventions for children with moderate to severe learning disability who are more likely to display behaviours that challenge in England. In this study, we tested in real-world conditions a programme called level 4 Stepping Stones Triple P, which has shown positive results in trials outside of the United Kingdom. Trained therapists delivered six groups and three individual sessions over 9 weeks to parents of children aged 30–59 months with moderate to severe learning disabilities. Two hundred and sixty-one parents were allocated to one of two arms by chance (randomisation): one received Stepping Stones Triple P and treatment as usual and the other treatment as usual only. Treatment as usual included support and advice by general practitioners or community child development teams. Our primary outcome was parent-reported child behaviour at 12 months after randomisation. We also collected data on other outcomes and carried out interviews with parents, service managers and therapists to find out their views about Stepping Stones Triple P. We did not find that Stepping Stones Triple P reduces behaviours that challenge in the child more than treatment as usual at 12 months. However, when we looked at people who received more than half of the sessions, there was a larger reduction in behaviours which suggests that Stepping Stones Triple P works for families if they attend the full programme. Stepping Stones Triple P seems to be good value for money, as we found that at 12 months (covering 10 months of costs), the Stepping Stones Triple P cost £1058 less than treatment as usual from a health and social care perspective. As such, Stepping Stones Triple P is fairly cheap to deliver and a suitable early intervention for behaviours that challenge especially because of positive feedback from parents. Throughout the trial, we included a Parent Advisory Group that oversaw study materials, interview topic guides and promotion of the study.

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This report

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