Early positive approaches to support for families of young children with intellectual disability: the E-PAtS feasibility RCT

Elinor Coulman,1 Nick Gore,2 Gwenllian Moody,1 Melissa Wright,1 Jeremy Segrott,1 David Gillespie,1 Stavros Petrou,3 Fiona Lugg-Widger,1 Sungwook Kim,3 Jill Bradshaw,2 Rachel McNamara,1 Andrew Jahoda,4 Geoff Lindsay,5 Jacqui Shurlock,6 Vaso Totsika,7 Catherine Stanford,5 Samantha Flynn,5 Annabel Carter,2 Christian Barlow1 and Richard Hastings5*

1Centre for Trials Research, Cardiff University, Cardiff, UK
2Tizard Centre, University of Kent, Canterbury, UK
3Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK
4Institute of Health and Wellbeing, University of Glasgow, Glasgow, UK
5Centre for Educational Development Appraisal and Research, University of Warwick, Coventry, UK
6Challenging Behaviour Foundation, Chatham, UK
7Division of Psychiatry, Faculty of Brain Sciences, University College London, London, UK

*Corresponding author R.Hastings@warwick.ac.uk

Declared competing interests of authors: Nick Gore reports payment to train study site facilitators in the Early Positive Approaches to Support (E-PAtS) intervention from the Royal Mencap Society during the conduct of the study; and payments to the University of Kent (Canterbury, UK) for training facilitators in the delivery of the E-PAtS intervention at other sites not involved in this research from the Royal Mencap Society, Université du Québec à Montréal (Montreal, QC, Canada), Mencap Northern Ireland (Belfast, UK), Mencap Leeds (Leeds, UK), Mencap Wales (Aberaeron, UK), Child and Family Psychological Therapies Service (Newport, UK), Cerebra (Carmarthen, UK), Mencap Carlisle (Carlisle, UK) and the Norwegian Health Services (Stavanger, Norway) outside the submitted work. In addition, the intellectual property for the E-PAtS intervention is held by the University of Kent, deferred to Dr Nick Gore. The E-PAtS materials are copyrighted in this regard also. The E-PAtS intervention has been developed through leadership from Nick Gore. A non-commercial (free) licence to deliver E-PAtS is provided to organisations where facilitators have completed E-PAtS training licensed to University of Kent. Jill Bradshaw reports other from the Royal Mencap Society, during the conduct of the study; other from the Royal Mencap Society, Université du Québec à Montréal, Mencap Leeds, Mencap Wales and Cerebra, outside the submitted work; and personal fees from Child and Family Psychological Therapies Service, outside the submitted work. Jacqui Shurlock reports that the organisation in which she is employed, the Challenging Behaviour Foundation, was involved in the initial development of the E-PAtS intervention. Richard Hastings reports that he has collaborated with both Nick Gore (E-PAtS intervention developer) and the Challenging Behaviour Foundation (Chatham, UK; a charity that contributes to the development of E-PAtS) on other research.
Plain English summary

The E-PAtS feasibility RCT
Public Health Research 2022; Vol. 10: No. 2
DOI: 10.3310/HEYY3556

NIHR Journals Library www.journalslibrary.nihr.ac.uk
Plain English summary

We developed a parenting programme called Early Positive Approaches to Support (E-PAtS) for parents of young children (1.5–5 years of age) with an intellectual disability. The E-PAtS programme is co-delivered to a group of parents by a professional facilitator and a parent of a child with disabilities. Parents are given practical strategies over an 8-week period to help them to look after themselves and to support them with their child’s development.

We recruited 74 parent carers of young children with intellectual disabilities to take part. They were assigned, by chance, to attend an E-PAtS group or to receive their usual support only. All parents, whether or not they attended the E-PAtS group, were asked to complete some measures of things that might change during the E-PAtS programme. The most important measure was changes in parents’ psychological well-being. Other measures included parents’ mental health, positive perceptions, approaches to parenting, relationships with their child with intellectual disability, relationships with their partner (if they had one), the positive and problem behaviour of brothers or sisters, sibling relationships and how much the family accessed a variety of services (especially social care and health services).

This study was a feasibility study. We were checking whether or not the research worked well so that a much larger study could be planned in the future. Among other things, we found that parents were willing to take part in the research, attended most of the E-PAtS sessions and completed the research measures, and organisations that delivered parenting courses expressed an interest in taking part in a larger study.

We also interviewed parents, the facilitators (i.e. those delivering the E-PAtS programme) and people from the organisations that delivered E-PAtS. People enjoyed being part of E-PAtS groups and were positive about taking part in the study. We are now ready to go on to a larger study.
Criteria for inclusion in the Public Health Research journal

Reports are published in Public Health Research (PHR) if (1) they have resulted from work for the PHR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Reviews in Public Health Research are termed ‘systematic’ when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

PHR programme

The Public Health Research (PHR) programme, part of the National Institute for Health Research (NIHR), is the leading UK funder of public health research, evaluating public health interventions, providing new knowledge on the benefits, costs, acceptability and wider impacts of non-NHS interventions intended to improve the health of the public and reduce inequalities in health. The scope of the programme is multi-disciplinary and broad, covering a range of interventions that improve public health. For more information about the PHR programme please visit the website: https://www.nihr.ac.uk/explore-nihr/funding-programmes/public-health-research.htm

This report

The research reported in this issue of the journal was funded by the PHR programme as project number 15/126/11. The contractual start date was in January 2018. The final report began editorial review in June 2020 and was accepted for publication in December 2020. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PHR editors and production house have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the PHR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PHR programme or the Department of Health and Social Care.

Copyright © 2022 Coulman et al. This work was produced by Coulman et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaption in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
NIHR Journals Library Editor-in-Chief

Professor Ken Stein  Professor of Public Health, University of Exeter Medical School, UK

NIHR Journals Library Editors

Professor John Powell  Chair of HTA and EME Editorial Board and Editor-in-Chief of HTA and EME journals. Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Professor of Digital Health Care, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May  Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Professor Matthias Beck  Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Dr Peter Davidson  Consultant Advisor, Wessex Institute, University of Southampton, UK

Ms Tara Lamont  Senior Adviser, Wessex Institute, University of Southampton, UK

Dr Catriona McDaid  Reader in Trials, Department of Health Sciences, University of York, UK

Professor William McGuire  Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads  Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery  Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma  Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts  Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, UK

Professor Jonathan Ross  Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein  Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton  Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk