

# Psychosocial support for families of children with neurodisability who have or are considering a gastrostomy: the G-PATH mixed-methods study

Gillian M Craig,<sup>1,2\*</sup> Eva Brown Hajdukova,<sup>1</sup>  
Celia Harding,<sup>2</sup> Chris Flood,<sup>2</sup> Christine McCourt,<sup>2</sup>  
Diane Sellers,<sup>3</sup> Joy Townsend,<sup>4</sup> Dawn Moss,<sup>5</sup>  
Catherine Tuffrey,<sup>6</sup> Bryony Donaldson,<sup>7</sup>  
Maxime Cole<sup>8</sup> and Anna Gill<sup>9</sup>

<sup>1</sup>Centre for Research in Public Health and Community Care, University of Hertfordshire, Hatfield, UK

<sup>2</sup>School of Health Sciences, City, University of London, London, UK

<sup>3</sup>Brighton and Sussex University Hospitals NHS Trust, Brighton, UK

<sup>4</sup>Department of Social and Environmental Health Research, London School of Hygiene & Tropical Medicine, London, UK

<sup>5</sup>Borders General Hospital, Melrose, UK

<sup>6</sup>Solent NHS Trust, Southampton, UK

<sup>7</sup>Kent Community Health Foundation NHS Trust, Maidstone, UK

<sup>8</sup>Triangle, Brighton, UK

<sup>9</sup>Lay chairperson, Norfolk, UK

\*Corresponding author [drgillcraig@gmail.com](mailto:drgillcraig@gmail.com)

**Declared competing interests of authors:** Diane Sellers reports grants and personal fees from Nutricia Advanced Medical Nutrition (Trowbridge, UK) and personal fees from Nutricia Global (Danone, Hoofddorp, the Netherlands) outside the submitted work.

**Disclaimer:** This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

## Plain English summary

### The G-PATH mixed-methods study

Health Services and Delivery Research 2020; Vol. 8: No. 38

DOI: [10.3310/hsdr08380](https://doi.org/10.3310/hsdr08380)

NIHR Journals Library [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

## Plain English summary

Children with neurodisability, for example those with cerebral palsy, can experience difficulties eating and drinking. Professionals may recommend a surgical feeding tube because they are concerned about a child's growth or ability to swallow safely. Parents can find the decision to approve a feeding tube for their child difficult because they want to feed their child by mouth and maintain family routines. Evidence reviews recommend structured support to ensure informed decision-making.

We conducted a survey to identify types of psychosocial support for parents and their children and chose four services for in-depth study. We conducted interviews and focus groups with parents and professionals, observed clinics and reviewed service documents. We estimated the cost of providing psychosocial support through questionnaires, although our estimates were based on a small number of parents who responded.

Parents expressed differences in the amount and type of support they wanted. Some were more concerned about support for technical aspects of care whereas others wanted more emotional support. Psychosocial support was provided by members of a multidisciplinary team in clinical appointments, which sometimes made it difficult for parents to raise concerns. Psychologists were not usually part of the team and parents were rarely offered the chance to speak to one. In interviews, different views were expressed about the value of peer-to-peer parent support, which was not consistently offered, in part owing to concerns about confidentiality. When asked to state a preference, both parents and professionals preferred enhanced support involving peers and an appointment with a psychologist over usual care.

The study suggests that psychosocial support is personalised to the needs of families and should be assessed in appointments at which it is the main focus. Services should record the provision of psychosocial support so that the costs and benefits can be estimated. We make suggestions for staff training and discuss limitations of the study, including barriers to participation in the research.



# Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) ([www.publicationethics.org/](http://www.publicationethics.org/)).

Editorial contact: [journals.library@nihr.ac.uk](mailto:journals.library@nihr.ac.uk)

The full HS&DR archive is freely available to view online at [www.journalslibrary.nihr.ac.uk/hsdr](http://www.journalslibrary.nihr.ac.uk/hsdr). Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

## Criteria for inclusion in the *Health Services and Delivery Research* journal

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

## HS&DR programme

The HS&DR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HS&DR programme please visit the website at <https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-services-and-delivery-research.htm>

## This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 14/04/40. The contractual start date was in January 2016. The final report began editorial review in August 2019 and was accepted for publication in March 2020. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR 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 HS&DR 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 HS&DR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2020. This work was produced by Craig *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library ([www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)), produced by Prepress Projects Ltd, Perth, Scotland ([www.prepress-projects.co.uk](http://www.prepress-projects.co.uk)).

## Editor-in-Chief of *Health Services and Delivery Research* and NIHR Journals Library

---

**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 Senior Clinical Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

**Professor Andrée Le May** Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals) and Editor-in-Chief of HS&DR, 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** Senior Scientific Advisor, Wessex Institute, UK

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

**Ms Tara Lamont** Senior Scientific Adviser (Evidence Use), Wessex Institute, University of Southampton, UK

**Dr Catriona McDaid** Senior Research Fellow, York Trials Unit, 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** Professor of Wellbeing Research, University of Winchester, UK

**Professor John Norrie** Chair in Medical Statistics, University of Edinburgh, 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, UCL Great Ormond Street Institute of Child Health, 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

**Professor Martin Underwood** Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: [www.journalslibrary.nihr.ac.uk/about/editors](http://www.journalslibrary.nihr.ac.uk/about/editors)

**Editorial contact:** [journals.library@nihr.ac.uk](mailto:journals.library@nihr.ac.uk)