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

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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.

Published October 2020
DOI: 10.3310/hsdr08380
Plain English summary

The G-PATH mixed-methods study
Health Services and Delivery Research 2020; Vol. 8: No. 38
DOI: 10.3310/hsdr08380

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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)

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

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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.

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