Equal access to hospital care for children with learning disabilities and their families: a mixed-methods study

Kate Oulton,1* Jo Wray,1 Charlotte Kenten,1 Jessica Russell,1 Lucinda Carr,2 Angela Hassiotis,3 Carey Jewitt,4 Paula Kelly,1 Sam Kerry,1 Irene Tuffrey-Wijne,5 Mark Whiting6 and Faith Gibson1,7

1Centre for Outcomes and Experience Research in Children’s Health, Illness and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK
2Brain Directorate, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK
3Division of Psychiatry, University College London, London, UK
4UCL Knowledge Lab, UCL Institute of Education, University College London, London, UK
5Faculty of Health, Social Care and Education, Centre for Health and Social Care Research, Kingston University and St George’s, University of London, London, UK
6School of Health and Social Work, Centre for Research in Public Health and Community Care, University of Hertfordshire, Hatfield, UK
7School of Health Sciences, University of Surrey, Guildford, UK

*Corresponding author kate.oulton@gosh.nhs.uk

Declared competing interests of authors: Angela Hassiotis is a member of the National Institute for Health and Care Research (NIHR) Health Technology Assessment Commissioning committee (2018 to present). Kate Oulton is a seconded to the NIHR 70@70 Nurse Research Leader programme.

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

Published June 2022
DOI: 10.3310/NWKT5206
Plain English summary

Equal access to hospital care for children with learning disabilities
Health and Social Care Delivery Research 2022; Vol. 10: No. 13
DOI: 10.3310/NWKT5206

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

Background

There have been widespread concerns about differences in the quality of health care provided to adults with learning disability, and we do not know whether or not these differences also exist for children with learning disability. In addition, we lack an understanding of whether parents of children with learning disability and parents of children without learning disability have the same or different experiences of being in hospital with their child. The views and experiences of children with learning disability are almost non-existent in the literature.

Aims

We wanted to:

- identify the cross-organisational, organisational and individual factors in NHS hospitals that facilitate and prevent children with learning disability and their families receiving equal access to high-quality care and services
- develop guidance for NHS trusts.

Methods

The study had four phases and involved data collection in 24 hospitals in England in phase 1, including all 15 children’s hospitals, and seven of these hospitals in phases 2–4. In phase 1 we carried out interviews with 65 staff, and a staff survey was returned by 2261 hospital staff.

Phase 2 included interviews and photography with 63 children and their parents, alongside a parent hospital diary and a record of any safety concerns. We also interviewed 98 hospital staff and surveyed 429 community staff. During phase 3, a satisfaction survey was returned by 812 parents and 803 children. We analysed all data according to the method we used.

Findings

Staff are struggling to tailor care to the individual needs of children. This most greatly affects those with the greatest need for individualisation, namely children with learning disability. Well-meaning staff are being let down by an inadequate system and the negative attitudes and views of the minority, which can have a lasting impact on families.

Implications for practice

We have developed a model for practice and guidelines for staff about what factors to consider when making reasonable adjustments for children with learning disability.
Health and Social Care Delivery Research

ISSN 2755-0060 (Print)
ISSN 2755-0079 (Online)

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

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

This journal was previously published as Health Services and Delivery Research (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at 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

Criteria for inclusion in the Health and Social Care Delivery Research journal

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

HSDR programme

The HSDR 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 HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm

This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 14/21/45. The contractual start date was in December 2015. The final report began editorial review in September 2019 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 HSDR 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 and Care 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, the HSDR 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, the HSDR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2022. This work was produced by Oulton 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 and Care Research, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

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