The decision-making process in recommending electronic communication aids for children and young people who are non-speaking: the I-ASC mixed-methods study

Janice Murray,^{1*} Yvonne Lynch,¹ Juliet Goldbart,¹ Liz Moulam,¹ Simon Judge,² Edward Webb,³ Mark Jayes,¹ Stuart Meredith,¹ Helen Whittle,¹ Nicola Randall,² David Meads³ and Stephane Hess⁴

Declared competing interests of authors: David Meads was previously a member of the National Institute for Health Research (NIHR) Health Technology Assessment programme Prioritisation Panel (2013–17) and is currently a member of the NIHR Programme Grants for Applied Research subpanel (2017–present).

Published November 2020 DOI: 10.3310/hsdr08450

Plain English summary

I-ASC – Identifying Appropriate Symbol Communication Health Services and Delivery Research 2020; Vol. 8: No. 45 DOI: 10.3310/hsdr08450

NIHR Journals Library www.journalslibrary.nihr.ac.uk

¹Department of Health Professions, Manchester Metropolitan University, Manchester, UK

²Barnsley Assistive Technology Service, Barnsley Hospital NHS Foundation Trust, Barnsley, UK

³Leeds Institute of Health Sciences and Choice Modelling Centre, University of Leeds, Leeds, UK

⁴Choice Modelling Centre and Institute of Transport Studies, University of Leeds, Leeds, UK

^{*}Corresponding author J.murray@mmu.ac.uk

Plain English summary

This research looked at how people choose communication aids and match them to children and young people who cannot speak. The results of the research were used to develop tools and resources. These resources will help professionals, families and young people to make communication aid decisions.

The Identifying Appropriate Symbol Communication (I-ASC) project had two researchers with personal experience of using communication aids. The project also evaluated the success of our public involvement approach.

We held discussion groups with professionals after an assessment appointment. We interviewed children, young people and adults who could tell us about their experiences of how they got their communication aid(s). We interviewed parents and the professionals who knew the communication aid users. We asked professionals to answer two surveys. A total of 354 people were involved in looking at communication aid decision-making and 22 people were involved in the evaluation of the public involvement activities.

The process of deciding what is the best communication aid is not straightforward. Decisions are affected by many things, for example professionals' experience, access to services or the service structure. These factors vary across the UK.

We found that during actual appointments everyone present focused on the child's physical access abilities and motivation to use a communication aid. By contrast, when professionals where asked to say what they would do in an imaginary situation (when presented with a description of a young person), they said that they would focus more on language, communication and learning abilities. In addition, things that professionals chose as important were not necessarily the important choices for family members, children and young people.

This research informed the development of guidance tools (URL: https://iasc.mmu.ac.uk/).

The public involvement evaluation suggests that inclusion across all aspects of a research project would benefit from additional resources, for example more staff time, some training and personal support (URL: https://iasc.mmu.ac.uk/publicinvolvement).

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/).

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

The full HS&DR 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 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 14/70/153. The contractual start date was in January 2016. The final report began editorial review in July 2019 and was accepted for publication in January 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 Murray 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), produced by Prepress Projects Ltd, Perth, Scotland (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 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 (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 Emeritus 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

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