Researching outcomes from forensic services for people with intellectual or developmental disabilities: a systematic review, evidence synthesis and expert and patient/carer consultation

Catrin Morrissey,¹,²* Nicole Geach,¹ Regi Alexander,³ Verity Chester,³ John Devapriam,⁴ Conor Duggan,⁵ Peter E Langdon,⁶,⁷ Bill Lindsay,⁸,⁹ Jane McCarthy¹⁰ and Dawn-Marie Walker¹¹

¹Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham, Nottingham, UK
²Community Forensic Service, Lincolnshire Partnership NHS Foundation Trust, Lincoln, UK
³St John's House, Partnerships in Care, Diss, UK
⁴Community Learning Disability Service, Leicester Partnership NHS Trust, Leicester, UK
⁵Partnerships in Care, Nottingham, UK
⁶Tizard Centre, University of Kent, Canterbury, UK
⁷Hertfordshire Partnership University NHS Foundation Trust, Norfolk, UK
⁸Danshell Ltd, London, UK
⁹University of the West of Scotland, Paisley, UK
¹⁰John Howard Centre, East London NHS Foundation Trust, London, UK
¹¹Faculty of Health Sciences, University of Southampton, Southampton, UK

*Corresponding author

Declared competing interests of authors: none

Published January 2017
DOI: 10.3310/hsdr05030

Scientific summary

Forensic services for people with disabilities
Health Services and Delivery Research 2017; Vol. 5: No. 3
DOI: 10.3310/hsdr05030

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

Background

A small proportion of people with intellectual and other types of developmental disabilities (IDD) can present with behaviour that contravenes the law, or that is otherwise high risk, and cannot be safely managed in the community. These individuals typically present with a high degree of clinical complexity and may be detained for treatment in a secure hospital under the Mental Health Act 1983 (amended 2007) (Great Britain. Mental Health Act. London: The Stationery Office; 2007). Although it is a health service sector with high levels of expenditure, with the NHS currently funding around 1800 secure beds, there is limited empirical information on patient outcomes from such forensic mental health services for people with IDD. In order for a future substantive longitudinal outcomes study to be informed and feasible, more needs to be understood about the outcome domains that are of importance and how they should be measured. A preliminary series of studies was therefore undertaken.

Objectives

- To synthesise evidence on the outcome domains that have been investigated in existing research from forensic services for people with IDD, in the broad domains of service effectiveness, patient safety and patient experience.
- To identify the views of patients in forensic IDD services and their carers on the outcome domains of most importance and relevance to them.
- To gain consensus on expert views on the outcome domains of most importance for use in future evaluation of forensic IDD services, based on the domains identified from the existing research and patient/carers views.
- To identify a framework of outcome domains (and potential associated measures and indicators) based on the research evidence and on the views of patients, carers and clinicians.
- To synthesise the information gathered in order to inform the design of a future longitudinal research project in the sector.

Methods

Three linked studies were conducted:

- Stage 1: a systematic review of the literature pertaining to a range of forensic services for people with IDD, focusing specifically on the outcomes that have been researched. Searches of the following databases were conducted on 1 July 2015: MEDLINE, PsycINFO, EMBASE, Allied and Complementary Medicine, Health Management Information Consortium, the British Nursing Index and the Cumulative Index to Nursing and Allied Health Literature from inception to May 2015. Similar outcome domains and measures were clustered together in a qualitative synthesis.
- Stage 2: a series of consultation discussion groups with patients and carers.
- Stage 3: a modified online Delphi expert consensus process conducted over two rounds using the items generated at stages 1 and 2.

Results

At stage 1, 60 studies that researched outcome domains in forensic IDD services (which included secure hospital-based and community-based services) were identified from the literature. This resulted in the construction of an initial framework of 31 outcome domains, under three superordinate domains.
The consultation with 15 patients and six carers at stage 2 added a number of domains to this framework, which particularly related to carer experience.

The Delphi process at stage 3 had 15 respondents at both round 1 and round 2; these were primarily clinicians in forensic IDD services. This process highlighted support for the validity of the framework and identified several key domains of most importance to clinicians. This survey also identified the outcome measures or indicators preferred by clinicians and those that are utilised currently in services. Both this survey and the systematic review identified a paucity of appropriate measures in some key domains, particularly in relation to treatment progress.

**Conclusions**

Together, these three linked studies resulted in the consolidation of a framework of key outcome domains and subdomains. It also led to a long list of provisional associated measures and indicators for these domains. With further development, this could eventually be utilised both by services and commissioners and in any subsequent empirical longitudinal study of forensic IDD services.

**Implications for research**

The policy context in IDD at the present time is of importance when future research is concerned. The Transforming Care programme and related developments, including a national service model associated with reduction in IDD hospital bed numbers, require that secure hospitals treating people with IDD produce accurate and relevant outcome data, both during treatment and following discharge. This project has reviewed previous research on outcomes and clarified what a future outcome data set should look like. An outline research design is proposed.

**Study registration**

This study is registered as PROSPERO CRD42015016941.

**Funding**

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.
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 or programmes which preceded 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 Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr

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 13/114/37. The contractual start date was in May 2015. The final report began editorial review in March 2016 and was accepted for publication in June 2016. 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. 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.

© Queen’s Printer and Controller of HMSO 2017. This work was produced by Morrissey et al. under the terms of a commissioning contract issued by the Secretary of State for Health. 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).
Health Services and Delivery Research Editor-in-Chief

Professor Jo Rycroft-Malone  Professor of Health Services and Implementation Research, Bangor University, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley  Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

NIHR Journals Library Editors

Professor Ken Stein  Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May  Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key  Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck  Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke  Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Senior Scientific Advisor, Wessex Institute, UK

Ms Tara Lamont  Scientific Advisor, NETSCC, UK

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

Professor Geoffrey Meads  Professor of Health Sciences Research, Health and Wellbeing Research Group, University of Winchester, UK

Professor John Norrie  Chair in Medical Statistics, University of Edinburgh, UK

Professor John Powell  Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), 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 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 Jim Thornton  Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

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

Please visit the website for a list of members of the NIHR Journals Library Board: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk