

# Implications for public health research of models and theories of disability: a scoping study and evidence synthesis

Maria Berghs,<sup>1</sup> Karl Atkin,<sup>1\*</sup> Hilary Graham,<sup>1</sup>  
Chris Hatton<sup>2</sup> and Carol Thomas<sup>2</sup>

<sup>1</sup>Department of Health Sciences, University of York, York, UK

<sup>2</sup>Faculty of Health and Medicine, Furness College, Lancaster University,  
Lancaster, UK

\*Corresponding author

**Declared competing interests of authors:** Karl Atkin is a member of the National Institute for Health Research Public Health Research Funding Board. Chris Hatton's salary is part-funded by Public Health England through his role as a codirector of their Learning Disabilities Public Health Observatory.

Published July 2016

DOI: 10.3310/phr04080

## Scientific summary

### Implications for public health research of models and theories of disability

Public Health Research 2016; Vol. 4: No. 8

DOI: 10.3310/phr04080

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

# Scientific summary

## Background

Nearly 10 million people in England experience significant difficulty with day-to-day activities linked to disability. Many of these people are living with other chronic conditions. Experiences of disability are also strongly age related. Moreover, the impact of impairments has a marked social gradient. People with disabilities are disproportionately disadvantaged with regard to the social factors that contribute to health inequalities, such as educational and employment opportunities, poverty and poor housing, and inequitable access to services. These environmental disadvantages are, in turn, disabling and create barriers to social inclusion.

Public health interventions that are effective in the general population are often assumed to apply to people with impairments. However, the evidence for this is limited. Our current evidence base, therefore, might not adequately capture the experiences of disability, with public health research having little to say on appropriate study designs and measures of how to actively engage disabled people. In addition, public health research does not demonstrate much of an understanding of the different consequences of having lifelong, acquired or fluctuating conditions, or of how social disadvantage, gender, ethnicity, sexual orientation and life-course mediate everyday experiences, including experiences of health. However, the potential impact of public health interventions on a particularly disadvantaged population is considerable, hence the need for more inclusive and better informed research. We have some important platforms on which to build, which offer alternative ways of defining and engaging with disability.

## Method and design

Our two-stage project scopes models and theories of disability, and, by assessing whether or not, and how, existing intervention studies incorporate more inclusive approaches consistent with these models, draws out implications for improving study designs and evidence-based practice.

First, we undertook a scoping review and synthesis of research critiquing models and theories of disability. This review summarised the range of models and theories (medical, human rights, social and critical), their place within disability studies and social movements of disabled people and their potential contribution to public health theory, research and policy. We then connected these disability models to public health paradigms to provide a conceptual framework and initial checklist or decision aid with which to explore critically the inclusivity of intervention studies in public health. This decision aid was iteratively developed as the research progressed.

Second, to test the applicability of our decision aid, we undertook a review of 60 purposively selected public health interventions from The Cochrane (International) Library of intervention reviews. A total of 30 reviews included more generic interventions, which had potential relevance to adults and children with disabilities. Our analysis enabled us to gain insights into the capacity of mainstream research to capture the experiences of disability. A total of 30 of the reviews identified people with disabilities as a key target group. This enabled us to identify the conceptual, methodological and practical potential of more inclusive designs. Supplementary insights were gained by sampling reviews identified in databases held by the Campbell Collaboration and the Joanna Briggs Institute. Our findings were refined in consultation with politically and socially active disabled people and public health professionals.

Our synthesis offers a critical commentary on the models and theories of disability underpinning the intervention and research; the terminology and categorisation of disability used or, if there is no discussion of this, a consideration of the potential relevance of the intervention to the experiences of disabled people; whether or not a life-course perspective is evident; methods of participant and public involvement; and (inclusive) study designs and outcomes.

## Findings

The review indicated that disability mainstreaming was not a part of generic evaluations and that many of the specific evaluations focusing on disability were not disability-sensitive. It identified a range of ethical and empirical gaps within the evaluation of interventions, including what appeared to be an absence, or inappropriate use, of outcome measures; the needless exclusion of disabled people; and difficulties in offering a meaningful analysis of disabling experiences. A particular disconnect occurred between theories of disability and the evaluation of public health interventions.

Our proposed human rights and ethical decision aid [Inclusion, Dignity, Equality, Accessibility and Intersectionality (IDEAS)] offers a critical framework by which to evaluate public health research. It can also function as a capacity-building tool, illustrating how different models of disability could positively inform the development and evaluation of public health interventions. Furthermore, our decision aid could help connect evidence-based practice to the diverse needs of those with disabilities, while also being ethically sensitive to broader concerns about social disadvantage, accessibility and inclusion. In doing so, it could connect the need for methodologically robust research with more inclusive and ethical social practices.

## Conclusion

The findings of this report illustrate a need for more guidance on how to integrate a disability-inclusive approach into durable evaluations of public health interventions. On the deliberation panels, socially and politically active disabled people, as well as professionals, agreed that having a disability-sensitive paradigm within which research could be designed and implemented represented a positive step forward. Our conclusions suggest that current evaluation designs, however, do not link to current disability and public health perspectives or develop outcome measures that evaluate how people could live well or flourish with disability. Our project illustrated how models and theories of disability remained untapped resources for establishing a more sensitive reinvention of public health research practices.

Our report gives a specific example of how disability equity could be achieved using a human rights paradigm. Human rights approaches, which can connect more critical models of disability to the ecological models evident in public health paradigms, offer a potential framework with which commissioners and researchers can assess the consequences of choices and decision-making when attempting to develop more inclusive and empirically robust public health research.



# Public Health Research

ISSN 2050-4381 (Print)

ISSN 2050-439X (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: [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)

The full PHR archive is freely available to view online at [www.journalslibrary.nihr.ac.uk/phr](http://www.journalslibrary.nihr.ac.uk/phr). 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 *Public Health Research* journal

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

Reviews in *Public Health Research* are termed 'systematic' when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

## PHR programme

The Public Health Research (PHR) programme, part of the National Institute for Health Research (NIHR), evaluates public health interventions, providing new knowledge on the benefits, costs, acceptability and wider impacts of non-NHS interventions intended to improve the health of the public and reduce inequalities in health. The scope of the programme is multi-disciplinary and broad, covering a range of interventions that improve public health. The Public Health Research programme also complements the NIHR Health Technology Assessment programme which has a growing portfolio evaluating NHS public health interventions.

For more information about the PHR programme please visit the website: <http://www.nets.nihr.ac.uk/programmes/phr>

## This report

The research reported in this issue of the journal was funded by the PHR programme as project number 12/182/14. The contractual start date was in May 2014. The final report began editorial review in November 2015 and was accepted for publication in March 2016. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PHR 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 PHR 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 PHR programme or the Department of Health.

**© Queen's Printer and Controller of HMSO 2016. This work was produced by Berghs *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](http://www.journalslibrary.nihr.ac.uk)), produced by Prepress Projects Ltd, Perth, Scotland ([www.prepress-projects.co.uk](http://www.prepress-projects.co.uk)).

## **Public Health Research Editor-in-Chief**

**Professor Martin White** Director of Research and Programme Leader, UKCRC Centre for Diet and Activity Research (CEDAR), MRC Epidemiology Unit, Institute of Metabolic Science, School of Clinical Medicine, University of Cambridge; Visiting Professor, Newcastle University; and Director, NIHR Public Health Research Programme

## **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 Elaine McColl** Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, 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 and Development Group, University of Winchester, UK

**Professor John Norrie** Health Services Research Unit, University of Aberdeen, 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](http://www.journalslibrary.nihr.ac.uk/about/editors)

**Editorial contact:** [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)