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

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Scientific summary

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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.
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**This report**

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