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Review Article

A scoping review of end user involvement in disability research

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Abstract

Background: Involving clients and consumers of health care in research, policy and health service development has been widely advocated for across a number of different fields and disciplines. Despite some promising evidence, 'end users' have not been meaningfully involved in all stages of the research process in the area of disability research.

Objective: To conduct a scoping review on end user involvement in disability research, service and policy development.

Methods: Literature was searched using electronic databases, hand searching reference lists of papers and grey literature. Electronic databases searched included the Cochrane Database of Systematic Reviews, MEDLINE, EMBASE, CINAHL, PsycINFO and Google Scholar. The search was restricted to articles published in English between January 2000 and April 2013.

Results: Two clear themes emerged from a review of twenty-seven articles. Firstly, end users can benefit research as 'experts of experience' through their role as a co-researcher. Secondly, evidence suggests end users add value at different stages of the research process in this role. However, less is understood about end user involvement in the latter stages of the research process.

Conclusions: This review suggests that end users can meaningfully contribute to the quality of disability research. End users are likely to engage in research with differing perspectives, desires to be involved at distinct stages of the process, differing roles and different abilities to participate in the research. Academic rigor, however, must be maintained by the researcher.

Keywords: Disability; User involvement; Neurotrauma; End user

Involving clients and consumers of health care in research, health service development and policy has been widely recognized as effective in the literature across a variety of disciplines and fields. Most notable is the field of community-based participatory research (CBPR), which involves community members as equal partners working alongside expert researchers.[1] Participatory research has been reported to empower non-academic researchers and to build capacity within the research process that enables better research outcomes. Insider knowledge provided by clients and consumers, also known as 'end users,' can enrich research processes and outcomes to improve the relevance and applicability of the research.[2−4]

In the health care field, end user involvement has a history in client centered practice or client centered care.[5,6] Medicine,[7,8] nursing[9] and occupational therapy[10] have created models to undertake client centered practice, where the focus has been on a collaborative effort of care for the patient rather than the delivery of services.[5] The National Health Service (NHS) in the United Kingdom has successfully embedded end user involvement into their policy development and health care decision-making for over a decade; achieved by creating a patient-led health system through the Health and Social Care Act.[11] This development has been an important enabler for increasing end user involvement in research. NHS research and funding bids now require evidence of end user involvement,[12−14] with similar experiences in Europe; lay persons are involved on boards of health care organizations, groups have been set up for advocacy roles, and patients have formed partnerships with researchers thereby increasing their involvement in the research process.[15,16]

Despite promising evidence from other fields, end users have not been significantly involved in disability management and rehabilitation research historically. If they have been

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involved, this typically only occurs at the research priority setting stage and to a lesser extent, during the research design phase.[17–19] This has meant the data collection, analysis and translation of findings has been undertaken by the researcher, diminishing the contribution made by the end user.[20]

Little is understood about how the process of involvement might occur in order to ensure that it is authentic and beneficial to both the end users and researchers.[15] In recent years, a number of commentators have proposed that if end users of disability and rehabilitation related health services were more involved in research, this might well lead to improved knowledge translation; creating a comprehensive evidence base on which to make more informed decisions about improvements to health services and their delivery.[18,21–23]

The objective of this study was to conduct a scoping review of existing evidence about end user involvement in disability research. Scoping studies rapidly map, summarize and disseminate research findings in a particular area to inform future work.[24] These reviews differ from the traditional systematic reviews because they are dependent on the purpose of the review rather than an appraisal of the quality of studies; and may not extract the depth of information usually reported in systematic reviews because evidence is in its relative infancy.[24,25]

This review was conducted to improve discussion between members of a stakeholder advisory group about involvement of end users in the implementation a neurotrauma research strategy (NRS). The stakeholder group included policy makers, clinicians, and researchers. Group members wanted to better understand the evidence on end user involvement to start a conversation around meaningful ways to include end users in the NRS including the costs and benefits of this approach. For these reasons, a scoping study was deemed appropriate to inform the group about the status of evidence available.

Methods

This scoping review was conducted following the six stage framework developed by Arksey and O'Malley.[24]

Stage 1 and 2: identify research question and relevant studies

The identification of the research question and relevant studies was determined by a small expert group (EG) of researchers and policy makers which was formed to conduct the scoping review. The EG was coordinated by a research institute whose core business is in knowledge generation, brokerage and translation for policy makers and theirs clients in the areas of safety, compensation and recovery research. The EG comprised two researchers, two staff from the research institute, and a policy maker from the government department commissioning the research.

Given the small amount of literature available on end user involvement in the field of neurotrauma research, the EG decided to broaden the search to include disability research. This decision meant that the research question still had clarity to inform the search strategy while also providing a broader scope of inquiry to begin the scoping activity. The research question for this scoping study was: *How does end user involvement in disability research improve policy development and service delivery?*

Literature was searched in two categories: disability research and end user involvement. Keywords were combined with the Boolean operator 'AND' and search terms within each category were combined with 'OR'. Key words searched were:

Client-centered	Participatory research
Collaborative research	Neurotrauma
Disability	Spinal cord injury
Experiential knowledge	Traumatic brain injury
Knowledge translation	User involvement

Electronic databases searched were PubMed, CINAHL, PsychInfo, Cochrane Database of Systematic Reviews. Google Scholar was also searched for specific reports.

Stage 3: study selection

An inclusion/exclusion criteria was developed by the authors in consultation with members from the EG and applied post hoc to the initial search. Articles were included if they were published in the English language between the years January 2000 and April 2013 and involved the participation of patients, clients or consumers in disability research or policy development. Findings from systematic reviews were included alongside standalone review articles. Articles were excluded if they were not related to the disability setting and did not report on the process of end user involvement in the research, policy development or service delivery. Editorial articles were also excluded. Initial hits for this scoping review using academic databases were 3751. This was then reduced by a review of title and abstract and duplicates were removed. Google Scholar was also searched returning 100, 220 hits, however this was narrowed to key documents identified by the EG for inclusion.

Study selection was conducted by a primary reviewer and then confirmed by a secondary reviewer; applying the inclusion/exclusion criteria. The primary reviewer was a researcher with a background in public health research while the second reviewer has a background in public policy. Due to time restraints, a medical librarian was not included in the process.

Stages 4 and 5: charting, collating and summarizing the information

The characteristics of each article were recorded. Key information included author(s), year, study location, type