Collaboration and Its Centrality to Disability Policy: An Analysis of the ICDR's 2009 Call for Recommendations on Disability Research Topics

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ABSTRACT

This paper presents the initial findings of a qualitative content analysis of the federal Interagency Committee on Disability Research's 2009 Call for Recommendations on Disability Research Topics. Of the 847 recommendations received, 158 of the comments focused on the theme of collaboration and coordination, which was the single largest topic. This paper also provides examples of the types of collaboration and coordination that participating stakeholders believed most relevant. It also discusses the implications and complications of improving future collaborative activity.

KEYWORDS:

Interagency Committee on Disability Research (ICDR), collaboration, public policy, disability policy

BACKGROUND

Participation of the widest range of stakeholders is crucial to the crafting of effective public policy, especially the agendas and activities pursued by those federal agencies that serve the public at large. Such participation is even more vital when policy deals with constituencies who may be the most vulnerable communities in society, such as people with disabilities (1). Disability stakeholders, including individuals with disabilities and service providers, have many insights to offer whenever federal authorities routinely reassess their disability and rehabilitation research agendas.

In March 2009, the Interagency Committee on Disability Research (ICDR) launched a three-week Web-based initiative and 'call for comments' to help inform the development of federal disability and rehabilitation research agendas in 2010. Registered participants were invited to make comments on six key themes related to the research agenda. Participants were then invited to review all comments submitted and vote on their top 10 concerns in each topic area during a specified one-week period. The ICDR's initiative resulted in an unprecedented response from the public on the six topics: 1) coordination and collaboration among federal agencies, 2) health

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information technology and/or electronic health records, 3) health disparities, 4) health promotion in the workplace, 5) employment and health, and 6) other critical research issues.

OBJECTIVE

A rigorous qualitative analysis of the responses was conducted to advance the ICDR's stated goal of identifying the top ten public concerns in each of the topic areas.

METHODOLOGY

Data analysis was conducted using the constant comparison method of content analysis, in which emergent categories are iteratively refined and emergent relationships are tested through a comparison of new and prior data (2). All data are systematically compared to all other data in the constant comparison method. The purpose of content analysis is to derive concepts or categories that describe a conceptual system or provide a conceptual 'map' (3). The phenomenon under study is presumed to be context-bound or embedded (2). The recommendations made by members of the public to the ICDR Website reflected both the context in which the recommendations were made, online to a federal entity, and the bounded experiences of the recommenders.

The extremely large data set, containing 847 raw recommendations, demanded that qualitative software be employed to conduct the content analysis. The use of computer software permits both manipulation and extraction of data through several iterations of data reduction, facilitating global editing and coding while the researchers focus on emergent meaning (2). NVivo 8.0 software was used specifically for this task because of several NVivo features, including 'rich data' (i.e., rich narrative) coding, extensive coding, data management, interpretation and analysis capacity, and the way in which it facilitates re-weaving data through multiple levels of coding in an inductive analysis process (4)(5). Autocoding was used to perform text searches at the heading (topic) level, resulting in nodes or categories and coding trees, hierarchical structures for displaying codes into subcategories without necessitating a re-coding of the entire database. At the final state of data reduction the recommendation 'units' had expanded from 847 to 2063, arrayed in seven categories, the original six topics plus an aggregated category that regrouped the first five categories by population and organization.

RESULTS

Collaboration and coordination was the largest single topic in the raw data (N=158) and remained so in the final data reduction (N=174). NVivo frequency tables were generated to provide visual and quantitative metrics for comparing the number of times a given theme or topic was validated by respondents. For this study, the frequencies are interpreted as indicative of the relative strength of validation for a theme or topic, rather than representing an absolute number amenable to mathematical operations or strict quantification. Collaboration and coordination were grouped under a single topic in the call for comments and in the raw data. However, when the two topics were differentiated, our analysis revealed that collaboration was validated far more frequently than coordination as the focus of recommendations. This is an

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important finding, suggesting the salience of collaboration as key to federal agencies' disability research agenda. At the same time, however, collaboration is a somewhat complex undertaking in that it entails a network and orchestrated interactions among the actors, for both sharing knowledge and developing what Pennington has termed a 'knowledge ecology' (6). Coordination is a far more modest enterprise, and it does not entail the exchanges of information emphasized in the aggregated collaboration and coordination references.

The repeated theme of increased collaboration in the ICDR's call for recommendations may be understood in a manner of ways. First, there is the concept of collaboration to enhance knowledge building across disciplines. For example, recommendations called for research in collaboration with employers to test and implement best practices in the accommodation of workers with disabilities, or they called for research into the effectiveness of adult basic skills instruction in collaboration with universities or vocational rehabilitation agencies in order to understand the best practices of educating adults with disabilities. A more specific example included a respondent who noted, "Working in collaboration with corporate partners, a federally sponsored research and development project should be focused on the introduction of new technologies and products that would allow seniors to continue to live in their own homes and community."

A second theme was collaboration for the sake of better communication and exchange of resources across agency or organizational lines. Pertinent examples included the need for communication between those institutions that oversee the education of high school students with disabilities and those agencies responsible for providing adult services, in order to facilitate the transition of these individuals. Another commenter related the need for "collaboration among agencies that serve individuals with disabilities regarding employment and business schools to promote self-employment and entrepreneurship for those with disabilities." At the same time, impediments to collaboration and the negative consequences of a lack of collaboration were also noted. For example, lack of collaboration between substance abuse and mental health agencies was mentioned by one respondent as an ongoing problem.

Coordination was perceived as a strategy to achieve a goal, whereas collaboration was framed as a goal, or perhaps a 'meta-goal,' or even a value, supportive of transformational change rather than services or care. The concept of universal design in the areas of housing, education, employment, communication, and the resulting coordination was touted by one respondent as essential to ensuring the full inclusion of citizens with disabilities. Likewise, a commenter observed that coordination within transportation would require stakeholders such as service providers for people with disabilities and seniors to share a common goal, thus enhancing synergy on this issue.

DISCUSSION

Content analysis revealed substantial gaps in research-related collaborations, with particular emphasis on interagency collaboration gaps, in the government or public sector, and also the provider systems. To a lesser degree, cross-sector collaborations were also implicated, with gaps identified in public-private relationships and provider-community networks. A decentralized approach to capitalizing on missed collaboration 'opportunities' seems sensible given that there is no single nexus for stimulating knowledge generating and disseminating collaborations. Moreover, collaborations, which are built on trust, shared purpose and common interests cannot be mandated (7). One approach of demonstrated effectiveness in building community, and more particularly knowledge-generating collaborations in a geographically dispersed and decentralized network is found in online communities of practice (8). Online communities of practice (CoP) for research collaboration building across systems and sectors could be actively promoted using policy tools. It is important to bear in mind the limiting factor that CoP are generally organized around identifiable communities which could be a constraint in cross-sector or cross-system collaborations.

Although there is no single nexus for building collaborations, the federal government was clearly identified by respondents as significantly impacting collaborations that foster knowledge for action, including evidence-based practices and interventions. Another model for leveraging federal research and research-related policy initiatives lies in Web-based, electronic or E-government and more broadly e-governance. E-governance uses Information and Communication Technologies (ICT) to promote the distribution of public policy decision making authority and power among a broad array of institutional actors: government, civil society, the private sector and other non-government entities (7)(9)(10). E-governance extends the frontier of citizen deliberation and participation to policy formulation and even to the redesign of public services, advancing democratization (11). The democratization aspect of governance means that public (i.e., community) inputs have the power to transform the decision making environment, which online CoP do not, thus enabling the development of an evolving common purpose (7).

Without a common purpose collaboration is not possible, so the capacity to evolve the decision making process with evolving purpose is critical. In this regard at least, e-governance may be preferable for building collaborations, especially across diverse, dynamic and changing 'publics' as compared to online CoP. Although information exchange and dissemination is not at the cutting edge of this democratization movement in e-governance, collaboration and information sharing across public, civil society and private sectors boundaries using e-governance is an emerging phenomenon (9). E-governance networks appear to be well suited for the kinds of collaboration entailed in developing disability and rehabilitation research. Thus, e-governance could provide a robust mechanism for federal agency efforts at engaging disability and rehabilitation stakeholders in reciprocal exchanges and collaborative efforts leading to more innovative and effective research agendas.

Historically, input to the policymaking process, especially related to disability issues was frequently the domain of a set of specialized actors: advocates, public sector officials, researchers, rehabilitation practitioners, and various other industry and special industry groups. Only occasionally did it include people with disability due to the complicated and somewhat non-transparent nature of the policymaking process. The development of Web 2.0 and other information and communication technology (ICT) based platforms offers the opportunity to open new dimensions of public participation and enhanced transparency in government functions (12)(13)(14).

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