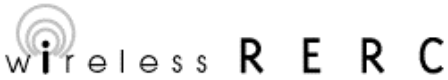

Working Paper #12-2009:

Research Brief: Analysis of Responses to the ICDR's 2009 Call for Recommendations on Emerging Disability Research Topics: The Central Role of Collaboration in Advancing a New Policy Agenda

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Introduction

Public policy, in general, and specifically, the development of public agency agendas and activities are most effectively crafted by including the participation of a wide range of stakeholders (Ward, Baker & Moon, 2009). This participatory approach is particularly valuable when dealing with issues related to vulnerable populations such as people with disabilities. Development and articulation of comprehensive, relevant, effective, and sustainable federal disability and rehabilitation research agendas, buttressed by appropriate policies and funding opportunities, need to be informed by input from people with disabilities, family members, and service providers. 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. Subsequently, participants were invited to review all comments submitted and vote on their top 10 concerns in each topic area during a specified one-week period. Overall, the initiative garnered a large number of thoughtful recommendations from the public on the six topics: 1) coordination and collaboration among federal agencies (158 responses); 2) health information technology and/or electronic health records (84 responses); 3) health disparities (133 responses); 4) health promotion in the workplace (58 responses); 5) employment and health (112 responses); and 6) other critical research issues (303 responses). 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

The results are far-reaching in their scope, reflecting a diversity of responses and areas of interest. In the service of focusing the discussion on key policymaking and funding concerns, this report centers on the specific topic area that received the greatest single number of responses: coordination and collaboration among federal agencies. Collaboration is a pivotal issue in the development of federal disability and rehabilitation research. Researchers, policymakers, and other key stakeholders have typically organized their analyses on groupings around functional impairments (i.e. sensory, mobility, cognitive) or disability categories (i.e. psychiatric, intellectual, physical), which have yielded user type-specific information, but failed to advance disability research as a whole, especially in cross-cutting issues of technology access, employment, learning, workplace environments, and social inclusion (Baker & Moon, 2008; Bricout, 2006). Collaboration across disability silos, and iteratively from the broad issues back to specific populations, on usability concerns is critical. Collaboration between federally funded researchers, service providers, and consumers creates a foundation for grounded local knowledge (Kruse et al., 2004), the basis for participatory research (Washington, 2004), and for navigating the 'polycentric' federal system to obtain resources for practitioners (Imperial, 2005). Similarly, cross-disciplinary research collaboration, particularly in the context of integrated (interdisciplinary) perspectives, is best suited to the complex, multidimensional problems of access, usability, environmental adaptation, and participation facing individuals with a disability and the communities in which they live (Melia, Pledger & Wilson, 2003; Pennington, 2008; Rentsch et al., 2001). A brief overview of the other topics will be provided, perhaps for further elaboration in succeeding reports.

Methods

A grounded theory methodology was chosen as the most appropriate research approach. This approach emphasizes emergent understanding from evidence (e.g. comments filed in response to the ICDR solicitation) rather than testable theory (O'Connor, Netting & Thomas, 2008). The grounded theory approach can point to knowledge building through deep understanding and meaning without recourse to generalizable theories (O'Connor et al., 2008). In addition, relationships and phenomena revealed through a grounded theory approach arise from the analysis of raw data, rather than phenomena observed directly (Bhal & Leekha, 2008). Given the importance of the recommendations for shaping policy and funding directions, researchers prioritized the emergent patterns in the data (evidence) over the initial topics (categories) in conceptualizing the results.

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 (White & Marsh, 2006). 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' (Elo & Kyngas, 2007). The phenomenon under study is presumed to be context-bound or embedded (White & Marsh, 2006). The recommendations made by members of the public to the ICDR's website reflected both the context in which the recommendations were made (online, to a federal entity) and the bounded experiences of the recommenders. Unfortunately, background data on the recommenders (respondents) were not collected, so the latter context is unknown, which places a limitation on the analysis to be discussed later. Nonetheless, the overarching issues under consideration made it possible to introduce some 'sensitizing concepts' without knowing anything in particular about the respondents. Sensitizing concepts refer here to those broad concepts for coding data relevant to the domains of the research recommendations. Examples included 'policy barriers and opportunities,' 'stakeholders and populations,' 'agency,' and 'electronic records.'

Because of the sheer size of the data set, containing 847 raw recommendations, qualitative software was 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 (White & Marsh, 2006). 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 (Richards, 1999; Sorenson, 2008). 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

As noted previously, collaboration and coordination was the largest single topic in the raw data (N=158) and remained so in the final data reduction (N=174). Using 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. There is a great deal of debate and a paradigmatic divide between post-positivist and heuristic approaches to grounded theory and, similarly, over qualitative versus quantitative approaches (c.f. O'Connor et al., 2008; White & Marsh, 2006). 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. Content analysis revealed that collaboration was validated far more frequently than coordination as the focus of recommendations, receiving far more coding references (see Appendix, Figure 1). This is an important finding in its own right, noting that collaboration entails a network and orchestrated interactions among the actors, for both sharing knowledge and developing what Pennington (2008) has termed a 'knowledge ecology.' Coordination is a far more modest enterprise, as it does not entail the exchanges of information emphasized in the aggregated collaboration and coordination references (see Appendix, Figure 2). Some illustrative recommendations for collaboration for knowledge building across disciplines and sectors include:

> "More research is needed in collaboration with employers to test and implement best practices."
> "Advance research on effectiveness of adult basic skills (ABE) instruction in collaboration with universities and vocational rehabilitation agencies."
> "Conduct research on Best Practices in promoting interagency collaboration regarding vocational services that include work readiness/job training for the severely mentally ill."
> "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."

Similarly, recommendations were made for better communication and the exchange of resources across agency or organizational lines.

> "…further resource development and expansion needs to be taking place to provide support and assistance to families and individuals dealing with the challenges of autism. Perhaps there could be (more) collaboration or combining of efforts being made by (fractioned) groups such as CARD and others."
> "I believe there needs to be more collaboration and communication regarding the transition of the disabled high school students with agencies that provide adult services."
> "I am interested in collaboration among agencies that serve individuals with disabilities regarding employment and business schools to promote self-employment and entrepreneurship for those with disabilities."

Impediments to collaboration and the negative consequences of a lack of collaboration were also noted.

> "There is a strong lack of collaboration between substance abuse and mental health agencies that reaches the street level."

> "I want to see more reaching out to innovative thinkers and people who - perhaps as a

> community organizer - have gone around and cut through the stifling bureaucracy which always stops this type of collaboration."
>
> "Research should focus on breaking down barriers to collaboration, such as eligibility criteria, etc."

Coordination was perceived as a strategy to achieve a goal, whereas collaboration was framed as a goal, or perhaps a 'meta-goal' or value, supportive of transformational change rather than services or care.

> "Coordinated transportation would require stakeholders such as service provider for people with disabilities and seniors to share a common goal."
>
> "The concept of Universal Design can be an excellent interagency collaboration to work towards. Universal Design for housing, education, employment, communication, etc. is necessary for the full inclusion of all persons with disabilities. Healthcare for these children is disjointed and lacks a coordination of care."

Perhaps because of the central purpose ascribed to collaborations, the issues around collaboration resist thematic interpretations; rather, collaboration appears to have been an issue of concern across many unconnected domains: mental health and substance abuse, employment facilitation, interdisciplinary research, transitioning youth, sensory impairments, inclusion, and so on (see Appendix, Figure 3). The implication seems to be that enhanced collaboration is indicated across domains. Interestingly, inter- and intra-governmental relations appear to raise issues of collaboration, more so between federal entities than between federal and state agencies, but non-disability specific agencies (non-profit and for-profit) and interdisciplinary research are also strongly validated as raising collaboration issues (see Appendix, Figure 4). The conceptual model of collaboration that emerges from the data is consistent with views on collaboration in the research literature. Collaboration is contextualized in terms of organizations or other entities banding together to realize a shared purpose (Imperial, 2006), working relationships that are viewed as serving all participants' best interests (Washington, 2004), a mechanism for promoting collective learning (Kudaravalli & Faraj, 2008), and for creating both the environment and the dynamics for innovation (Pennington, 2008). It is also clear from the respondents that collaborations aimed at advancing research knowledge, policy, and practice in the domains of disability and rehabilitation, like other domains, also requires reducing cost, attitudinal, informational, network, and knowledge transfer barriers (Hansen, 2008). These considerations will be developed further in the discussion section.

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 (Stivers, 2009). 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 (Hall & Graham, 2004). 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 (Dawes, 2008; Marche & McNiven, 2003; Stivers, 2009). E-governance extends the frontier of citizen deliberation and participation to policy formulation and even to the redesign of public services, advancing democratization (Chadwick, 2003). 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 (Stivers, 2009).

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 sector boundaries using e-governance is an emerging phenomenon (Dawes, 2008). 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.

Conclusion/Next Steps

Our study focused on an analysis of the responses submitted to the ICDR's Web-based platform set up to collect online comments on a proposed disability research agenda. The comments on six issue themes, was designed to assist in developing a coordinated federal disability and rehabilitation 2010 research agenda. The key finding, which we wish to highlight, is one that has several dimensions. It is a relatively straightforward one, in terms of identification, that is, a focus on collaboration and coordination in terms of research agenda. In terms of operationalization, or in policy terms, implementation, this is a much more interesting problem in that it embeds both an objective/outcome and a process, or approach.

To elaborate, while a wide array of topics and issues can be teased out of the data, we believe the more interesting results focus on the process aspects rather than on the specifics of the comments. This is for two reasons: first we were somewhat constrained due to the limitations of the data available, as well as in the time and resources available to complete the study. Secondly, given the increasing importance placed on stakeholder participation, a priori and iteratively, in the importance placed by the respondents on the role of collaboration and

coordination, we believe that teasing out the utility of Web based collaborative (and participatory) approaches both demonstrates the power of the tools and serves to address the issues raised by the respondents.

As we previously noted in the discussion section, collaboration and coordination are complex processes that operate within a larger aggregate context. So while it is necessary to recognize the need to undertake research in the areas, it is not sufficient to expect optimal results without exploring the larger context, that is, the community and networks of knowledge flow that enable advances to be made. These collaborative activities are both horizontal, that is, across and between stakeholder groups (both inside and outside of the public sector), as well as vertical, between organizational levels.

One approach to addressing the aspect of collaboration and coordination, in the broadest sense, deals with improved adoption and deployment of Web 2.0 technologies. First, as a matter of policy, if a key objective is to increase and enhance participation, then the deployment of tools that make it easier to participate in the agenda setting process should be a tactical priority. We propose a conceptual model for understanding the deployment of Web 2.0/ICT participatory technology composed of a three-pronged strategy: 1) platform (technology), 2) participants (stakeholders), and 3) process (the practices and process that allow the activity to be initiated as well as sustained). A full discussion of the model is beyond the scope of this research brief, but we will touch upon the components as part of our conclusions.

The *platform* component is, in reality, the most straightforward aspect of the model. There are a number of software applications that can provide, with minor tweaks, a majority of the utility needed to support collaborative processes, including adaptation of off-the-shelf solutions such as Google Groups, Facebook, LinkedIn, Microsoft VINE, Ning, etc. Again, an in-depth analysis of the specific is beyond the scope of this brief and is mentioned for illustrative purposes. The fact that the government has already adopted exploratory uses of these platforms (case in point: the ICDR effort on one end, and the FCC's recent use of social media to solicit wider stakeholder participation), suggests this is recognized. The complexities lie in 1) process, 2) practice, and 3) sustainability.

Involvement of *participants* is also relatively straightforward, in online contexts, as long as consideration is given to the somewhat intransigent issue of the digital divide in all its dimensions. Again, this problem is not one of complexity, but of continued, sustained effort to expand access to ICTs, which is evident in the recent federal broadband initiatives. The results of previous studies (i.e., Baker & Moon, 2008) suggest that the issues of outreach and awareness are an ongoing and critical necessity. Again, issues of recruitment and dissemination are beyond the scope of the brief.

The linchpin, metaphorically, is the aspect of *process,* Based on our analysis of the results and a review of the literature, our conclusions are that the key to effective implementation of Web 2.0 (or social media) are the *processes and practices* that allow group activity/participation to occur. Again, this is both subject and object, in that the study of the specific conditions, practices and techniques that can be used to facilitate, develop, and sustain group collaborative processes is critical to understanding how to deploy collaborative approaches to research. And, it is object in that we are also interested in studying how best to determine the optimal operations of these processes.

Finally, this focus on collaborative processes has import beyond a research agenda, and a research process. Indeed, Web 2.0 and online processes also offer the opportunity to enhance not just the research process, per se, but as noted above, to encourage the participation of citizens as

well as more traditional participants in the policymaking process. By better understanding how to collaborate in a virtual environment we also acquire understanding of how to make governmental processes more open and transparent, a key objective toward enhancing and encouraging the participation of people with disabilities in society.

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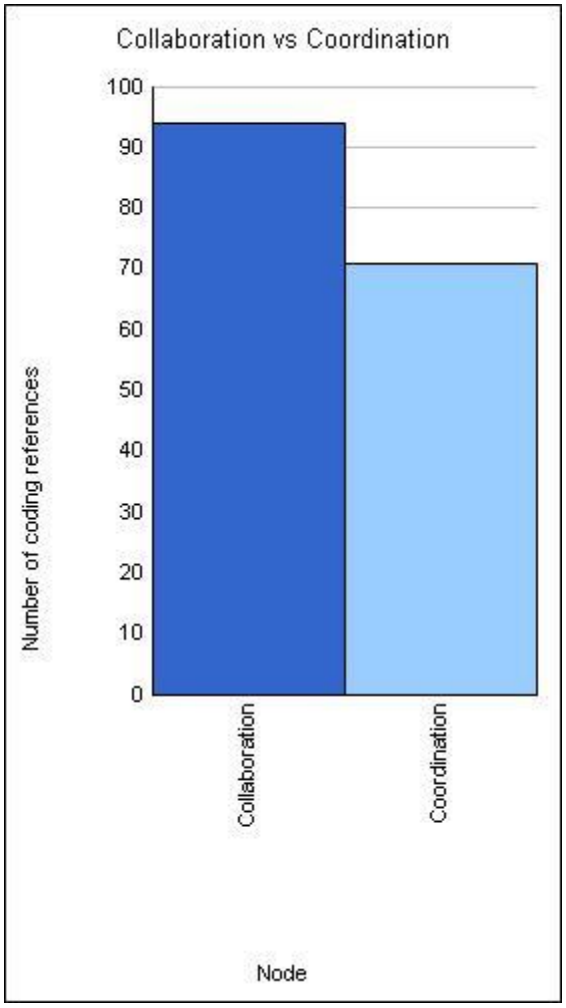
APPENDIX

Figure 1.


Collaboration vs Coordination
100
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70
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50
40
30
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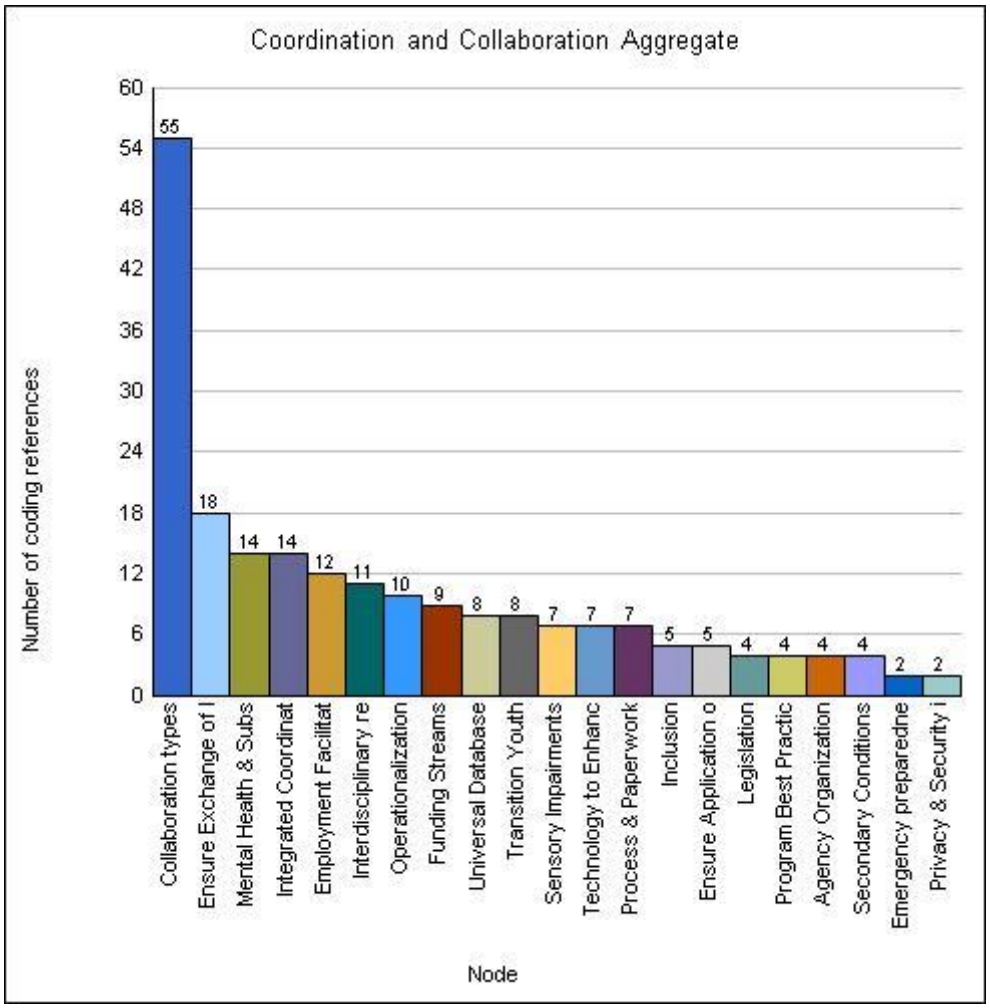
10
0
Number of coding references
Collaboration
Coordination
Node

Figure 2.


Coordination and Collaboration Aggregate
Number of coding references
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54
48
42
36
30
24
18
12
6
0
55
18
14
14
12
11
10
9
8
8
7
7
7
5
5
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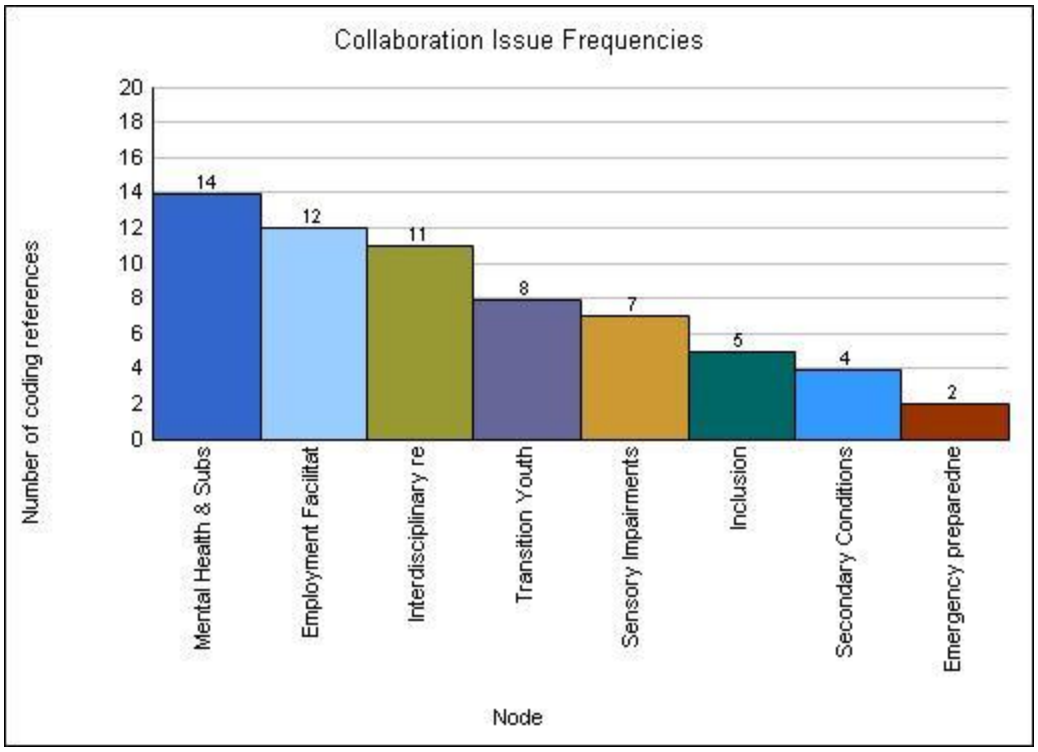
4
4
4
2
2
Collaboration types
Ensure Exchange of I
Mental Health & Subs
Integrated Coordinat
Employment Facilitat
Interdisciplinary re
Operationalization
Funding Streams
Universal Database
Transition Youth
Sensory Impairments
Technology to Enhanc
Process & Paperwork
Inclusion
Ensure Application o
Legislation
Program Best Practic
Agency Organization
Secondary Conditions
Emergency preparedne
Privacy & Security i
Node

Figure 3.


Collaboration Issue Frequencies
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18
16
14
12
10
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6
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Mental Health & Subs
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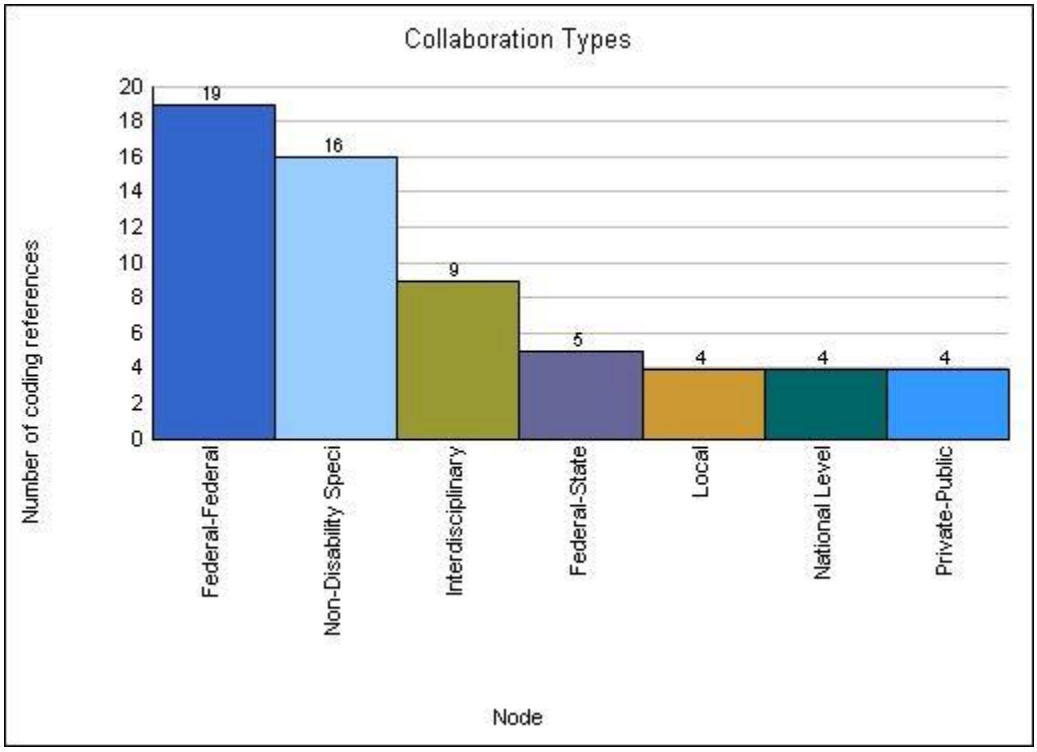
Inclusion
Secondary Conditions
Emergency preparedne
Node

Figure 4.


Collaboration Types
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4
4
Federal-Federal
Non-Disability Speci
Interdisciplinary
Federal-State
Local
National Level
Private-Public
Node