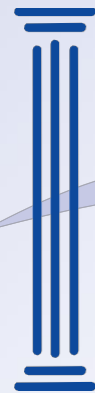


Creating a Sustainable Interagency Coordination Network on Disability Research

Report of the Expert Panel



Interagency
Committee on
Disability
Research
lcdr.ed.gov

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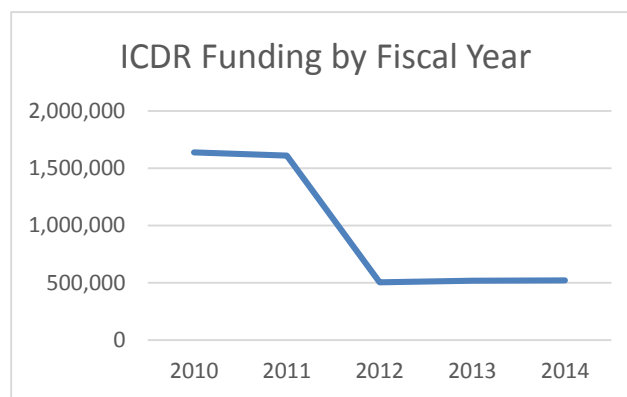
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Executive Summary

The mission of the Interagency Committee on Disability Research (ICDR) is to promote interagency coordination related to disability research. In carrying out its duties, the ICDR promotes activities to improve effectiveness of disability programs through better coordination and alignment of priorities and strategies. The ICDR identifies ways to optimize interagency efforts to achieve better results for individuals with disabilities through a coordinated, strategic Federal program of disability research. For the purpose of this report, collaboration is defined as any joint activity that is intended to produce more public value than could be produced when the agencies act alone.¹ Coordination is defined as two agencies working together but not dependent on each other for the project's success.²

Throughout its history, the ICDR has hosted topic-specific interagency meetings and state of the science (SOS) conferences. More recently, the ICDR hosted partnership opportunity meetings to examine the disability and rehabilitation research landscape. During the 2013 and 2014 fiscal years, the ICDR focused on increasing Federal agency awareness about disability and rehabilitation research and related activities across the Federal government. The partnership meetings highlighted the needs of Federal agencies for improved interagency communication, particularly the need for the ICDR to facilitate the development of partnerships and new connections across the disability and rehabilitation research community. Agencies indicated that improved interagency communication and access to centralized information about agencies' research agendas and activities would be beneficial to everyone involved.



The investment in the ICDR has been reduced in recent years from \$1.6 million to \$500,000. A desire to strategically invest these Federal research resources and the importance of interagency coordination were the impetus for the ICDR to proactively address the needs of the Federal disability and rehabilitation research community and its stakeholders. In December 2013, the ICDR organized an *ad hoc* expert panel to examine interagency coordination and collaboration efforts related to disability

¹ GAO. (2012). *Managing for results: Key considerations for implementing interagency collaborative mechanisms* (GAO-12-1022). Washington DC.

² National Research Council. (2011). *Assessment of impediments to interagency collaboration on space and earth science missions*. Washington, DC: The National Academies Press.

research and explore approaches to better achieve interagency coordination and collaboration. The panel also examined the organizational culture of coordination and collaboration; determined implications for better coordination and alignment of priorities and strategies; and outlined approaches to increase interagency partnerships to ensure a coordinated, strategic Federal program of disability research.

Consistent with the ICDR mandate to secure stakeholder input, the expert panel shared their experiences and expertise regarding specific steps to create and sustain interagency coordination and collaboration. Prior to convening the expert panel, the ICDR conducted a literature review to examine best practices for interagency collaboration and coordination. The review identified several approaches to collaboration and coordination and examples of collaboration and coordination methods that interagency committees currently use to guide their work. (See the [Appendix](#) for the literature review).

The ICDR was interested in determining how to apply identified best practices to its unique legislative mandate and subject matter. The panel activities were designed to inform future directions and enhance ICDR efforts to increase the effectiveness of Federal interagency cooperation and collaboration in disability research and related activities. Specifically, the panel of experts was asked to:

- Review scholarly knowledge regarding various types of interagency collaboration and identify best practices for engaging stakeholders to achieve ICDR goals.
- Identify promising roles and strategies to maximize ICDR capacity to foster Federal interagency collaboration in disability research and promote information sharing.
- Outline steps toward creating a sustainable interagency coordination and collaboration network that supports partnerships in disability and rehabilitation research.

The panel reviewed background materials, listened to expert presentations, and engaged in a facilitated dialogue during two in-person meetings (December 3, 2013 and January 31, 2014). The panel contributed to, reviewed, and provided input into draft versions of the present report during facilitated virtual meetings (March 7, 2014 and May 6, 2014). Panelists who volunteered, made suggestions and edits to the final report between June and July, 2014.

Findings and Recommendations

Over the course of the four meetings, the panel discussed the framework for the report and the successes and barriers to success, as well as strategic opportunities to improve the ICDR's mission of interagency collaboration and agenda-setting on disability research. Panel discussions covered a wide range of topics which resulted in specific recommendations that could help to further expand the ICDR agenda to address government-wide concerns related to disability and rehabilitation. In its discussions, the panel focused on actionable approaches designed to effectively achieve the ICDR goals. The Expert Panel discussed and identified recommendations intended to further promote the committee's capacity to fulfill its duties, as described in authorizing legislation. The Expert Panel recommendations are aligned with the ICDR's strategic goals and are summarized below. They are discussed in further detail in the section on [Panel Discussions](#) beginning on page 15 of this report.

Goal 1: Identify research gaps and improve information sharing among ICDR Federal partners to encourage coordination and collaboration on disability and rehabilitation research across the Federal government.

Recommendations

1.1. Identify research gaps. Conduct a scan of what research is currently being conducted. The ICDR committees may hold the key to maintaining a narrative with one voice and thus leveraging agency expertise.

1.2. Develop an inventory of Federal research priorities. Identify disability related research, by agency. Use this information to frame knowledge gaps in order to consider new priorities.

1.3. Establish a national clearinghouse. Consider a national clearinghouse for program managers to report standardized information about the projects they are funding so other program managers can easily see what is being funded.

1.4. Identify opportunities in communications and collaborations. Consider how the ICDR fits with existing efforts and what special characteristics ICDR brings.

Goal 2: Facilitate and increase opportunities for joint disability and rehabilitation research among Federal departments and agencies.

Recommendations

2.1. Public/Private Advisory Committee. Appoint a public/private advisory committee involving people with disabilities, disability advocates, a multi-disciplinary cadre of researchers whose expertise spans disability topics, and researchers from traditionally underrepresented populations. Stakeholder input from external researchers, representatives from the disability community and other priority communities can advise the ICDR on research or questions considered to be priorities for action.

2.2. Summer Training Institute. Encourage interdisciplinary research capacity by inviting trainees from different fields (e.g., social work, medicine, psychology, and rehabilitation counseling) who will perform or lead future collaborative disability research.

2.3. Encourage researchers with disabilities and from traditionally underrepresented racial and ethnic populations. Convene a group focused on increasing the supply of researchers with disabilities and researchers from traditionally underrepresented racial and ethnic populations, including people with disabilities.

Goal 3: Foster innovation to create shared solutions.

Recommendations

3.1. Focus on tackling one “wicked” problem at a time. Design a project carefully supported through a collaborative implementation process; devote sufficient resources into the process; invite people from agencies who strategically need to be involved; and create visibility at many levels including the White House.

3.2. Map the existing disability research networks. Identify influential enterprise leaders and build upon networks by creating and sustaining micro communities of people interested in a particular topic.

3.3. Consider more open source net-centric ways to convey information about the ICDR and the Federal disability research enterprise. Shed the bureaucratic instinct that the only way to convey information is in an annual report.

Goal 4: Encourage investment in government-wide coordination and collaboration on disability and rehabilitation research.

Recommendations

4.1 Host an ICDR summit. Bring together Federal agency representatives to develop a comprehensive, government-wide strategic plan for disability, independent living, and rehabilitation research.

4.2. Encourage agencies to contribute funds to support infrastructure and initiatives of ICDR as well as specific research initiatives. The ICDR needs to make a compelling case for the value of research collaboration on maximizing research funding through coordinated research agendas.

4.3. Articulate incentives for agency participation. Provide specifics about a particular issue, the community of practice effort, the exchange of information, and specify how that information might have an impact on particular agencies.

4.4. Link disability research to broader public health efforts. Identify prevention and intervention opportunities that improve health and potentially reduce expenditures for the general population by articulating the relationship of such efforts with disability populations at the national, state, and local levels.

About the ICDR

Overview

Authorized by the 1973 Rehabilitation Act, as amended, the Interagency Committee on Disability Research (ICDR) was established to promote a cohesive, strategic Federal program of disability research. The ICDR strives to enhance coordination of Federal disability and rehabilitation research activities through four strategic goals:

Goal 1: Identify research gaps and improve information sharing among ICDR Federal partners to encourage coordination and collaboration on disability and rehabilitation research across the Federal government.

Goal 2: Facilitate and increase opportunities for joint disability and rehabilitation research among Federal departments and agencies.

Goal 3: Foster innovation to create shared solutions.

Goal 4: Encourage investment in government-wide coordination and collaboration on disability and rehabilitation research.

To support these goals, ICDR activities include the following:

- semi-annual meetings of the Executive Committee (EC) and quarterly meetings of standing committees;
- state of the science events and meetings inviting the input of subject matter experts, individuals with disabilities and their representatives, and other stakeholders;
- development and execution of strategic plans to forward the disability research agenda and address strategic priorities and research gaps; and
- Web technologies to promote information sharing and interagency coordination and collaboration.

The ICDR currently faces challenges related to interagency cooperation and collaboration:

- The ICDR has a broad mandate with a complex mix of research topics within its purview.
- The ICDR does not fund research and has no authority to mandate agencies to adopt joint funding strategies such as MOUs or IAAs.
- By statute, only 12 agencies are mandated to participate in the ICDR. For a few of these agencies, disability and rehabilitation are not currently a major focus of their work. Other agencies that may be important and that focus on disability and rehabilitation are not required to participate.
- The ICDR has very limited resources to support its operation. There is no line item budget for the ICDR; thus, the designated chair agency, NIDRR, has discretion with respect to the amount of financial support it decides to contribute from its budget.

ICDR Executive Committee

The ICDR is comprised of such members as the President may designate, including the following (or their designees):

- Director of the National Institute on Disability and Rehabilitation Research, Chair
- Commissioner of the Rehabilitation Services Administration
- Assistant Secretary for the Office of Special Education and Rehabilitative Services
- Secretary of Education
- Secretary of Veterans Affairs
- Director of the National Institutes of Health
- Director of the National Institute of Mental Health
- Administrator of the National Aeronautics and Space Administration
- Secretary of Transportation
- Assistant Secretary of Indian Affairs
- Director of the Indian Health Service
- Director of the National Science Foundation

Individuals representing these agencies provide leadership and oversight for the Committee. Through standing committee activities, the statutory members secure the input of other Federal departments, offices, and agencies. The Executive Committee also includes ICDR standing committee co-chairs and other designated representatives. In carrying out its duties, the Executive Committee:

- sets the ICDR agenda;
- works to promote interagency coordination, collaboration, and communication;
- provides guidance to the ICDR standing committees;
- reviews and approves standing committee plans;
- develops the ICDR strategic plan; and
- hosts meetings to advance the agenda of Federal departments, offices, and partner agencies.

Federal Partners

Federal and non-Federal partners contribute to the deliberations, events, and products of the ICDR. Some Federal partners play key leadership roles on the ICDR by serving as co-chairs for standing committees, co-funding activities, and providing resources to support achievement of ICDR goals. The following, while not an exhaustive list, identifies some of the other Federal partners who have contributed:

- U.S. AbilityOne Commission
- Access Board
- Administration on Children and Families (ACF)

- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- Agency for Toxic Substances and Disease Registry (ATSDR)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Department of Defense (DoD)
- Department of Education, Office of Special Education Programs
- Department of Health and Human Services (HHS)
- Department of Homeland Security (DHS)
- Department of Justice (DOJ)
- Department of Labor (DOL)
- Department of State
- Department of Veterans Affairs, Rehabilitation Research and Development Service
- Eunice Kennedy Shriver National Institute on Child Health and Human Development
- Federal Communications Commission (FCC)
- Federal Emergency Management Agency (FEMA)
- Food and Drug Administration (FDA)
- Health Resources Services Administration (HRSA)
- National Center for Health Statistics (NCHS)
- National Center for Medical Rehabilitation Research (NCMRR)
- National Council on Disability (NCD)
- National Eye Institute (NEI)
- National Institute on Aging (NIA)
- National Institute of Child Health and Human Development (NICHD)
- National Institute on Minority Health and Health Disparities (NIMHD)
- National Institute of Standards and Technology (NIST)
- National Institute of Neurological Disorders and Stroke (NINDS)
- President’s Committee for People with Intellectual Disabilities
- Social Security Administration (SSA)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

ICDR Standing Committees

Five standing committees organize and implement the primary activities of the ICDR. Co-chairs lead each committee:

Interagency Committee on Assistive Technology (ICAT). The ICAT identifies, assesses, and seeks to coordinate all Federal programs and activities regarding the range of Federal AT research, as well as research that incorporates the principles of universal design.

Interagency Committee on Disability Statistics (ICDS). The ICDS provides a forum for statisticians, economists, and other individuals interested in disability statistics, terminology and definition concerns, and data collection.

Interagency Committee on Employment (ICE). The ICE provides a mechanism and forum for information sharing and dissemination between Federal agencies to facilitate and promote a cohesive, strategic Federal program of employment research that can help to further opportunities and economic security for people with disabilities, identify research gaps and synergies, and alleviate unnecessary duplication of research efforts.

Interagency Committee on Health and Health Disparities (ICHHD). The ICHHD is charged to coordinate programs, projects, activities, and plans for such with respect to the conduct of health and health disparities research and the needs of individuals with disabilities.

Interagency Committee on Medical Rehabilitation (ICMR). The ICMR defines medical rehabilitation research as “the field of study that encompasses basic and applied aspects of the health sciences, social sciences and engineering related to restoring and/or maintaining a person’s health and functional capacity and improving that person’s interactions with the surrounding environments.”

Committees prioritize their activities through a strategic planning process. Key activities and responsibilities are to:

- secure public input and stakeholder involvement in ICDR deliberations;
- promote interagency coordination and collaboration;
- identify and address interagency coordination concerns through collaborative efforts;
- identify research gaps and synergies, and promote the elimination of unnecessary duplication of research effort;
- initiate and support activities involving interagency coordination and collaboration;
- contribute to the ICDR Annual Report to the President and Congress, and accomplishments report;
- monitor progress toward achievement of goals and outcomes; and
- compile and report information to inform the ICDR agenda and related activities.

Highlights of ICDR Interagency Collaboration

The multiagency composition of the ICDR is essential to achieving its mission of promoting coordination across Federal departments, offices, and agencies. The ICDR gathers and reviews Federal and public stakeholder input to inform disability and rehabilitation research and related activities and disseminates information regarding the state of the science related to disability and rehabilitation research. The ICDR provides a forum to discuss research, emerging trends, and research gaps in disability and rehabilitation research, and inform the disability and rehabilitation research agendas of multiple Federal agencies and entities. Contributors to this effort include those agencies designated by the President to participate, as identified in the ICDR authority, (i.e., statutory members), and non-statutory Federal stakeholders. Non-Federal stakeholders play a key role with the ICDR and provide input via a variety of mechanisms such as webinars and meetings. Interagency discussions hosted by ICDR often lead to opportunities for collaboration and coordination, and development of interagency agreements.

With a network of ICDR participants from over 45 Federal entities, examples of requests for input in FY 2013 included:

- Department of Health and Human Services (HHS) Health Disparities and Disability Strategic Plan
- HHS Office of Minority Health input on the National Alzheimer’s Task Force on Specific Populations National Plan
- Review and prioritization of Social Security Administration (SSA) Disability Research Consortium research funding topics
- Input related to how Federal agencies are using the International Classification of Functioning Disability and Health (ICF) (SSA request)
- Participation in the Department of Defense (DoD) Clinical & Rehabilitative Medicine Research Program (CRM RP) research prioritization process

The following examples of multi-year collaboration efforts in which the ICDR committees participate and contribute are described below:

- The American Community Survey Six-Question Set (ACS-6) for Disability Measures
- International Classification of Functioning Disability and Health (ICF)
- Health and Health Disparities Research
- Assistive Technology and Technology Policy and Research
- Accessible Transportation Technologies Research Initiative (ATTRI)

The American Community Survey Six-Question Set (ACS-6) for Disability Measures

The American Community Survey (ACS) is an annual survey to collect demographic, social, economic, and housing information at the community level. Since an initial pilot in 2006, U.S. Census Bureau

(Census) has included a six question set (ACS-6) in the ACS in order to collect a core measure of disability that includes vision, hearing, ambulatory, cognitive, and self-care functioning.

Since 1982, the ICDR Interagency Committee on Disability Statistics (ICDS) has played an active and ongoing role in bringing together the Federal, research, and advocacy communities to identify gaps and collaboration on disability research and initiatives related to statistics and data collection. A recurring discussion among demographers and researchers had been an inability to compare information among various data sets because the way disability was defined or counted varied from survey to survey. In 2002, the ICDS documented the legislative mandates and programmatic uses of disability demographics to establish and prioritize recommendations for what should be measured.

After the passage of the Americans with Disabilities Act (ADA) in 1990, the Census Bureau became interested in having a standard set of questions to measure disability and consulted with the ICDS on their initial efforts. This initiative, headed by Census and the Office of Management and Budget (OMB), involved an interagency workgroup with invited ICDS members. After seeking input from ICDS member agencies, the workgroup made recommendations to the full ACS oversight committee regarding how the ACS could provide the best data available for specific legislative purposes.

Census began using the six questions in the ACS household survey in 2008. Since then, the ACS-6 has become a de facto measure of disability used in other Federal survey initiatives. Today, the ACS-6 question set is used in a number of Federal surveys and provides a regular stream of disability data used to make decisions at the local, state, and Federal levels. The Bureau of Labor Statistics has been asking the same six questions since 2006; the same questions are included in the Survey of Income and Program Participation (SIPP), the ACS, and the Current Population Survey for Employment (CPS). In 2011, HHS also adopted the six-question set for data collection efforts related to the Affordable Care Act (ACA) and their health disparities initiatives.

ICDS has continued to review demographic data from the ACS-6 and related surveys. Researchers use the ACS-6 data in combination with other surveys and data sets to understand emergency room utilization, income insecurity, and access to health care among people with disabilities. In 2013, the ICDS began working with a steering committee composed of representatives from the National Center for Health Statistics (NCHS) at the Centers for Disease Control (CDC), Department of Labor (DOL), National Institute on Disability and Rehabilitation Research (NIDRR), Census, HHS, and academia to develop a training to help ACS-6 users understand the question set, including what it measures and how it can be used. More information about the ACS-6 is available online at Census.gov.

International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) was endorsed by the United States and other members of the 54th World Health Assembly of the World Health Organization (WHO) in May 2001 to provide a new international standard language and framework for the description of health and health-related conditions. While the International Classification of Diseases (ICD) provides a diagnosis of diseases, disorders, and other health conditions, the ICF defines components of health and well-being in domains from the perspective of the body, the individual, and society. The classification is organized around

- body functions and structures;
- activities and participation;
- environmental factors; and

- personal factors.

According to WHO, disability is a universal human experience.

ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. (World Health Organization, 2002, p. 3).

During the development of the ICF, staff from the WHO briefed ICDR members regularly on significant issues, and the ICDS served as a conduit for new developments, comments, and questions. Once the ICF was adopted, the ICDR facilitated information sharing about how the ICF was being used throughout the government and hosted forums for discussions among Federal entities. In 2003, the ICDR hosted a forum to discuss future research endeavors and how the ICF might be used more effectively as a classification system and in disability research. By 2013, the work continued and expanded to the point that SSA asked for ICDR input into its proposed use of ICF to make disability determinations. The [WHO website](#) provides more information about the ICF.

Health and Health Disparities

The *Minority Health and Health Disparities Research and Education Act of 2000* (Public Law 106-525) defines health disparity populations as populations experiencing a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival in a population as compared to the health status of the general population. Many Federal agencies are required to identify health disparities for specific populations. In 2005, upon review of Healthy People 2010 (HHS, 2000) the ICDR determined that disability issues surrounding health disparities were not clearly understood or adequately addressed across Federal research agendas. Seeing the need for inclusion of disability issues in research on health disparities, the ICDR began discussing the need to consider disability in the health disparities agenda. In 2006, the ICDR and several member agencies participated in a Federal Collaboration on Health Disparities Research (FCHDR) Workgroup meeting, co-sponsored by CDC and the Office of Minority Health/Office of Public Health and Science. In 2007, the ICDR arranged a joint meeting with CDC and the Office of Minority Health/Office of Public Health and Science (HHS) to discuss future directions and how the ICDR could take an active leadership role in assuring the consideration of disability in health disparities research initiatives within HHS and across other Federal agencies.

In FY 2007, the ICDR surveyed health disparities research projects active in FY 2006 to identify federally funded health disparities projects, and to determine whether these projects specifically focused on individuals with disabilities or included individuals with disabilities in the target population. The committee identified 119 individual research projects or research programs focused on health disparities across HHS, Department of Veterans Affairs (VA), Department of Education (ED), and National Science Foundation (NSF). The studies focused on individuals grouped by age, gender, ethnicity, socio-economic status, nationality of birth, geographic location, homeless status, and income. Only one study specifically explored disabilities compared to the general population, examining disparities in oral health between children with special health care needs and other children (Interagency Committee on Disability Research, 2007).

Over the years, the ICDR has continued to work to ensure that disability is considered a part of the health disparities agenda, under the leadership of the Executive Director. In FY 2013, the ICDR was

active on the Federal Interagency Health Equity Team (FIHET), Patient Centered Care Collaboration to Improve Minority Health (PCCC), and the HHS Health Disparities and Disability Strategic Plan. The ICDR provided further input to the HHS Health Disparities agenda by reviewing and commenting on the HHS Report *Assuring Health Equity for Minority Persons with Disabilities*. This long-term investment in partnership has resulted in disability being considered a part of the health disparities agenda, particularly in the current HHS strategic plan, Healthy People 2020.

In FY 2013, the Interagency Committee on Health and Health Disparities (ICHHD) ensured that five disability-focused research presentations were part of the *2012 Summit on the Science of Eliminating Health Disparities: Building a Healthier Society* organized by HHS. The inclusion of disability issues into this major scientific event was a critical step toward increasing awareness about health disparities and disability. Presentations were diverse, reflecting the breadth of health disparity issues in the disability community. Speakers presented findings from research focused on a number of particular contexts and populations.

Assistive Technology

The Rehabilitation Act of 1973, as amended, requires the ICDR to focus on assistive technology research and research that incorporates the principles of universal design. Since 1996, the ICDR has convened the Interagency Committee on Assistive Technology (ICAT) as a vehicle for connecting researchers, Federal representatives, and non-Federal stakeholders and identifying areas of focus to inform the Federal research agenda and related activities. The ICAT brings together scientists, advocates, and individuals interested in the potential of assistive technologies and other technology to improve the lives of people with disabilities.

In 2010, the ICAT hosted a state of the science (SOS) meeting to contemplate a roadmap for establishing a coordinated research agenda and interagency research activities related to cloud computing and assistive technology for people with disabilities. This meeting brought together Federal agency representatives, experts, and stakeholders to consider the state of the science, promote strategies for collaborative development of evidence-based policy and practices, and recommend approaches that could help the ICDR inform strategic plans and activities across the Federal government (Interagency Committee on Disability Research, 2012). This effort identified research and knowledge gaps, proposed recommendations to address this emerging field, and described opportunities to enhance access for people with disabilities.

During a 2011 meeting, the ICAT engaged in a discussion about new research methods that could better inform decision making, and further ensure the methods used are more appropriate for people with disabilities who have difficulties selecting which assistive technology might work the best for them. New methods stem from patient-centered outcomes research and comparative effectiveness research.

From 2012 through 2013, the ICAT engaged Section 508 coordinators in a dialog to consider the role of research in promoting Section 508 compliance. Their efforts resulted in an SOS meeting on Research Perspectives on Supporting Section 508 Compliance that showcased current developments and identified knowledge gaps in developing and testing accessible technology (Interagency Committee on Disability Research, 2013).

Active participants on the ICAT collaborate on many other Federal initiatives including:

- The Joint Federal Assistive Technology Forum

- The M-Enabling Summit (mobile enabling)
- National Institute of Standards and Technology (NIST) Cloud Computing Blue Button Program
- NIDRR Cloud Computing Initiative
- Global Public Inclusive Infrastructure (GPII) Initiative
- [Health 2.0 Developer Challenge to develop an Electronic Health Records Accessibility Module](#)

Accessible Transportation Technologies Research Initiative (ATTRI)

In partnership with the ICDR, the Department of Transportation (DOT) is conducting interagency activities to consider accessible transportation concerns and emerging opportunities and launched its Accessible Transportation Technologies Research Initiative (ATTRI) in 2014. ATTRI is an intermodal, interdisciplinary, and interagency endeavor focused on improving accessibility and mobility of travelers with special needs using Intelligent Transportation Systems (ITS) and emerging technologies. It aims to maximize benefits from coordinated Federal research in collaboration with other Federal agencies within and outside of the Department of Transportation (DOT), recent technology innovations, and traveler-focused solutions to deliver quality door-to-door accessible transportation services for persons with disabilities, including the aging population.

Initial ATTRI research will focus on leveraging recent innovations in information management and mobile devices including vehicle- and infrastructure-based technologies and wireless capabilities to support accessible transportation. Building upon these emerging technologies, the DOT will develop and test innovative solutions specifically for people with disabilities to effectively plan and securely schedule tailored travel itineraries, as well as enhance the capability of these travelers to execute their travel plans reliably, safely, and independently.

The ICDR Executive Director coordinated meetings on behalf of the DOT to promote the ATTRI and assist to identify potential partners. Subsequently, the DOT met with several ICDR member agencies to explore options for collaboration.

Panel Discussion and Recommendations

Over the course of the four meetings, the panel discussed the framework for the report and the current status of the ICDR. As described above in the section [Highlights of ICDR Interagency Collaboration](#), there have been several ICDR successes, but the focus moving forward should be on the opportunities for improvement. Panel discussions covered a wide range of topics which resulted in specific recommendations which will help further expand the ICDR agenda and successes.

The starting point was the ICDR authorization, in which Congress created the ICDR to promote a cohesive, strategic Federal program of disability and rehabilitation research. In its deliberations, the panel considered the primary purpose of the ICDR, its successes and challenges, and best practices in interagency coordination. In its discussions, the panel focused on actionable approaches designed to effectively achieve the intention of the authorizing legislation and the ICDR goals. This section presents the views of the panel organized under the four ICDR goals.

Goal 1: Identify research gaps and improve information sharing among ICDR Federal partners to encourage coordination and collaboration on disability and rehabilitation research across the Federal government.

Coordination requires a solid foundation, or starting point, from which to build the collaborative network of Federal agencies. The authorizing statute provides the direction: “After receiving input from targeted individuals, the Committee shall identify, assess, and seek to coordinate all Federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities.”³

One of the key issues that the panel addressed was the overall purpose and function of ICDR. Within its broad mandate, what is the most effective means of coordinating disability research? Is it policy guidance with respect to disability and rehabilitation? Or should the ICDR limit its scope to address a few very specific projects that are feasible and that involve multiple agencies in achieving an outcome? Is it 100 percent specific strategic opportunities in terms of assistive technology? What's the right niche? The panel agreed that any strategies to maximize collaboration and coordination developed by the panel will depend on articulating the purpose of ICDR.

The panel considered four primary purposes: (1) setting the disability, rehabilitation, and independent living research policy platform; (2) identifying specific research opportunities; (3) setting research policy and the specific research opportunities as secondary; and (4) identifying specific opportunities, with disability and rehabilitation research policy as secondary, where policy would be informed by findings from the execution of strategic opportunities.

One viewpoint was concerned about placing too much emphasis on strategic opportunities and not enough focus on the broad disability and independent living research agenda. Such a broad research agenda could serve as an umbrella connecting different agencies. Sustaining a collaborative network

³ 29 USC §763(b)(1)

would have more impact if there were an interagency policy agenda that the research is supporting. If there is no policy, it is difficult to put together the research agenda. A question was raised about whether setting a research agenda would be of practical value. This perspective maintained that an incremental approach would best serve the ICDR goal of identifying research gaps and improving information sharing. This approach would have the ICDR identify shared interests and shared themes which are narrow and actionable and use specific strategies to reach policy. Such “early wins” have been shown to build momentum and establish working relationships among interagency participants.⁴

The ICDR has been doing some of that with its standing committees, and further identification of topics that may be of interest to some of the agencies that the ICDR seeks to engage would further the goal of identifying research gaps. However, the panel emphasized that this narrow pragmatic approach does not rule out the broad approach to research agenda-setting and in fact both approaches are needed, with the targeted topic identification ultimately leading to broader policy agenda-setting.

Although information sharing has been and will continue to be an important part of ICDR activity, it must be conducted toward some purpose. Sustaining a collaborative network of disability researchers requires agencies to communicate among themselves about their intentions to fund research (sometimes on similar topics) and to share research results from their grantees to better inform subsequent agency decision making. ICDR could play an important role as a clearinghouse for information on disability research opportunities and findings.

Another perspective viewed the ICDR as the broad policy arm which is the place to do strategic planning, conduct research summits, reach consensus, and develop a plan that includes concrete steps to maximize the likelihood that the strategies and priorities will be achieved and people are held accountable for outcomes and results. Involvement of higher tiered participants, policy makers, and decision-making leadership is critical.

The panel agreed to a dual approach that focused on (1) cross-agency strategic planning to set research policy and (2) topics that have constituency and are responsive to research opportunities.

Recommendations for Goal 1

1.1. Identify research gaps. Conducting a scan of current disability research. Instead of taking on the universe of disability issues, identify agencies with overlapping interests, identify the research pieces needed, describe how they interact, and work on the issues where there is overlap. The ICDR needs to recognize opportunities across agencies and develop a comprehensive narrative about disability and technology, disability and health disparities, and disability and employment. The ICDR committees may hold the key to maintaining a narrative with one voice and thus leveraging agency expertise.

1.2. Develop an inventory of Federal research priorities. Identify disability related research by agency. Use this information to frame knowledge gaps in order to consider new priorities.

1.3. National Clearinghouse. Consider a national clearinghouse for program managers to report standardized information about funded projects, so that other program managers can see what is being funded. This is not a one-time inventory, but rather a management system that could inform the front end of the process. This clearinghouse could also be used to map current

⁴ U.S. Government Accountability Office. (2014). *Managing for results: Implementation approaches used to enhance collaboration in interagency groups*. GAO-14-220. Washington, DC: Author.

research priorities and determine which agencies are addressing which topics and where research priority gaps exist.

1.4. Identify opportunities in communications and collaborations. There are other interagency groups, for example, the Interagency Autism Coordinating Committee and the Federal Partners in Transition Workgroup. Consider how the ICDR fits with existing efforts and what special characteristics ICDR brings.

Goal 2: Facilitate and increase opportunities for joint disability and rehabilitation research among Federal departments and agencies.

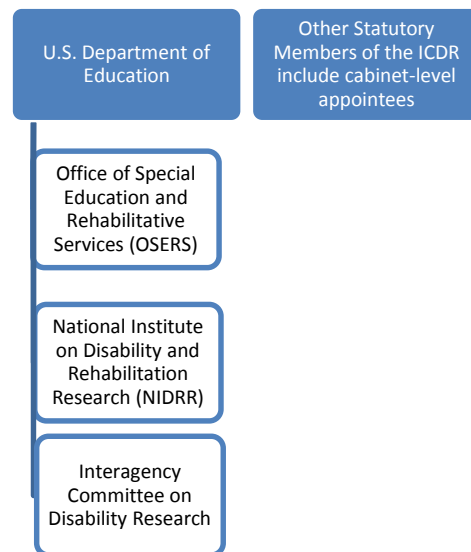
Sustaining the ICDR as a facilitator of increased opportunities for joint disability and rehabilitation research will require a comprehensive system of input from interested parties. Panel members focused on three themes in achieving Goal 2: (a) elevating the visibility of the ICDR within the Federal government, (b) engaging stakeholders, and (c) building research capacity.

Elevate the Visibility of the ICDR Within the Federal Government

The panel determined that visibility is an important factor in facilitating and increasing opportunities for collaboration. The panel discussed how to elevate the visibility of the ICDR, and therefore the status and stature of disability research, within the Federal government and the disability research community.

The ICDR is chaired by NIDRR and located within the Department of Education. As a result, the ICDR is not highly visible, but is mandated to coordinate with larger departments and agencies. The panel agreed that more visibility for the NIDRR director, who is also the ICDR chair and indicated that increasing the ICDR's visibility would elevate disability research to the point where people wanted to collaborate. The panel noted that the 2007 Institute of Medicine report⁵ had recommended strengthening the ICDR's ability to coordinate Federal disability research by increasing funding and the 1997 report⁶ recommended raising the visibility of disability research by relocating NIDRR to the Department of Health and Human Services.

Currently the ICDR has three types of member participation: statutory members, active participants, and non-participants. There is some overlap, as not all statutory members are active participants, while not all active participants are statutory members. The Panel discussed one approach that could be used to address this issue: instead of trying to attract non-participating statutory members, recognize the agency personnel who are actively participating and give them leadership roles, such as a steering committee. This approach might have the effect of lessening the perception that ICDR belongs to NIDRR and further encourage engagement of potential participants.



⁵ Institute of Medicine. (2007). *The future of disability in America*. Washington DC: The National Academies Press.

⁶ Institute of Medicine. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering*. Washington, DC: The National Academy Press.

A bottom-up approach may be useful for increasing visibility. Following the bottom-up approach, the ICDR may benefit by implementing small steps of making a group grow and become more interesting and action-oriented so that potential leaders and collaborators would find it attractive to join. That is how networks grow and attract people. Once a professional network becomes thriving and visible, people are more likely to join.

Bringing together people who are doing highly visible research and who have an interest in developing solutions across different areas can also create future visibility. It needs to be something so interesting that not participating makes someone an outsider.

A fundamental question discussed by the panel was the merits of spurring collaboration from the top-down or bottom-up. Ultimately, the conditions seem to determine the right strategy to use. An example from the assistive technology group illustrates the bottom-up approach. The group thought about how to attract greater participation and decided to choose topics like the future of Section 508 of the Rehabilitation Act which requires Federal agencies to ensure that they take into account the needs of all end users when developing, procuring, maintaining, or using electronic and information technology. This topic affects all agencies, and as a result, many agencies participated, including some who would not have participated if the topic had been more strategic or controversial.

While visibility is desirable, it is not always productive to elevate to the point where only cabinet secretaries are talking to each other. The subcommittee on employment of youth with disabilities of the Presidential Task Force on Employment of Adults with Disabilities was considered an effective subcommittee because it was not chaired by a cabinet secretary or agency head. Free from the constraints of clearance requirements, the subcommittee was able to engage in making real change happen.

One of the challenges with sustaining visibility is change with every new administration. This change sometimes results in dramatic shifts and one of the ways to make this interagency effort sustainable is to have an external entity that will not change every four or eight years. That entity would include representation from private sector stakeholders to lend stability no matter who the president is.

The panel discussed the importance of timing when considering when best to convene a collaborative group with the potential to raise awareness and visibility of the ICDR. A logical time for agenda-setting to garner the attention of higher level decision makers may be at the beginning of an administration. Another catalyst may be reauthorization or anniversary of a law. The 25th anniversary of the Americans with Disabilities Act (ADA) will be observed in 2015, and it has been 40 years since the Rehabilitation Act was enacted. These landmark dates may be an opportunity to start an agenda that furthers the objectives of these Acts.

Engage Stakeholders

The ICDR authorizing legislation requires the committee to seek stakeholder input. In response, through the years the ICDR has solicited involvement from Federal disability researchers, policymakers, people with disabilities and their families, caregivers, and service providers. The panel stated that one of the weaknesses over the years has been a lack of involvement by people from outside the Federal government as a driving force for the ICDR. The panel believes that such involvement is necessary to the success of the ICDR. If the ICDR is concerned about coordination of research and the identification of priorities, then external input is critical. The external stakeholders are closer to the problems than the Federal project managers or leadership of these agencies. Identifying the problems that are worthy of

scientific investigation and the questions that need to be addressed can be informed by including the external stakeholders.

The panel also explored the idea of a community based participatory approach as an appropriate model for ICDR stakeholder participation. This approach recognizes the value of equally involving all partners with their unique perspectives in the research development, implementation, and dissemination processes.⁷ Meaningful research requires that stakeholders be involved at the very beginning when a research topic is conceptualized and that the research leads to changing the lives of the people who can benefit from that research. For example, HIV research has generated myriad interventions that are not always used by practitioners in order to help service consumers. This has resulted in a huge research to practice gap. Emphasizing the involvement of the people who can benefit from the research and the service providers who can implement research results will make it more likely that providers will adopt evidence-based services.

Knowledge translation (KT) is the process of creating and moving research findings to real-world applications in a variety of practice settings and circumstances.⁸ The Canadian Institutes of Health Research (CIHR) defines KT as a “dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge . . . This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user.”⁹ The ICDR authority provides the basis for the committee to play an important role in compiling and disseminating research results across projects funded by multiple agencies to help facilitate coordinated evidence-based decision making and policy making. This KT-oriented process may serve to inform future priorities and limit overlap. This effort would also address the problem of research diffusion that has been so poor that many service providers are not aware of research evidence that would allow them to provide better services. With limited awareness of research results, service providers become disengaged from research efforts.

The panel discussed participation issues and questioned whether the ICDR might benefit by expanding its stakeholder base to demonstrate more diversity through efforts to secure a multi-disciplinary cross-section of individuals in the disability community and related fields. Advocates, policymakers, researchers, research institutions, and service providers could advise the ICDR on issues and developing priorities that address the needs of both people with disabilities and service providers. Following a presentation to the panel about the role of underserved populations in the disability and rehabilitation research, the panel discussed the potential value of expanding the ICDR to represent groups that might not otherwise have an input such as historically black colleges and universities (HBCUs), other minority-serving institutions, advocacy groups, and researchers with disabilities. Increased opportunities for input would provide a perspective that could enhance or inform the development of research opportunities. Disability constituents and advocates might reach out to the Federal agencies that are not actively participating in ICDR and exert pressure to have them at the table in the future.

⁷ Minkler, M., & Wallerstein, N. (Eds.). (2008). *Community-based participatory research for health: From process to outcomes* (2nd ed.). San Francisco: Jossey-Bass. Pinto, R. M., Spector, S., Rahman, R., & Gastolomendo, J. D. (2013). Research advisory board members' contributions and expectations in the USA. *Health Promotion International*. doi: 10.1093/heapro/dat042.

*Pinto, R. M, Wall, M., & Spector, A. Y. (2014). Modeling the structure of partnership between researchers and front-line service providers: Strengthening collaborative public health research. *Journal of Mixed Methods Research*, 8, 83-106.

⁸ Sudsawad, P. (2007). *Knowledge translation: Introduction to models, strategies, and measures*. Austin, TX: Southwest Educational Development Laboratory, National Center for the Dissemination of Disability Research.

⁹ Canadian Institutes of Health Research. (2012). *Guide to knowledge translation planning at CIHR: Integrated and end-of-grant approaches*. Ottawa: Author.

Some entities that are funded by NIDRR are also funded by other government agencies. It might be possible to engage those entities as stakeholders who have the potential to articulate possible common agendas among the funding agencies because they are already coordinating within their own entities. For example, many of the University Centers of Excellence in Disability who receive core financial support from the Administration on Intellectual and Developmental Disabilities at the Department of Health and Human Services, also receive funding from multiple Federal agencies including NIDRR, the Office of Disability Employment Policy at the Department of Labor, the National Institutes of Health, the Centers for Disease Control and Prevention, Social Security Administration, and the Maternal and Child Health Bureau, among others. University Centers of Excellence and other Federally-funded research entities could be a source of ideas about how coordination could have an impact on research agenda-setting activities of mutual importance to multiple agencies that lead to increased interagency collaboration.

Build Research Capacity

Facilitating and increasing opportunities for joint research requires a capacity for carrying out federally funded priorities. Currently, the Federal disability research enterprise lacks the critical mass of researchers with disabilities and researchers from traditionally underrepresented populations needed to lead research and development projects aimed at answering the large questions that people with disabilities, policymakers, Federal disability researchers, rehabilitation service providers, and advocates need answered. Considering strategies to reach out to entities that have sometimes been overlooked and underserved such as historically black colleges and universities (HBCUs) and minority organizations may increase opportunities to contribute to capacity building efforts. The panel considered the potential impact an ICDR forum could have on capacity building; particularly one focused on increasing the supply of disability researchers from traditionally underrepresented populations. Such an ICDR-lead forum could expand diversity and welcome researchers from traditionally underserved populations. ICDR could appoint an external public/private advisory body to ensure that researchers from traditionally underrepresented populations are included in decision-making.

Recommendations for Goal 2

2.1. Public/Private Advisory Committee. Appoint a public/private advisory committee involving people with disabilities, disability advocates, a multi-disciplinary cadre of researchers whose expertise spans disability topics, and researchers from traditionally underrepresented populations. In this capacity the researcher would provide the ICDR with critical input from an external researcher perspective; and representatives from the disability community and other priority communities can advise the ICDR on research or questions they consider to be priorities for action.

2.2. Summer Training Institute. Encourage interdisciplinary research capacity by inviting trainees from different fields (e.g., social work, medicine, psychology, and rehabilitation counseling) who will perform or lead future collaborative disability research.

2.3. Encourage researchers with disabilities and from traditionally underrepresented racial and ethnic populations. Convene a group focused on increasing the supply of researchers with disabilities and researchers from traditionally underrepresented racial and ethnic populations including people with disabilities. NIDRR, NIH, and other Federal agencies have fellowships and other vehicles for increasing the diversity of disability and rehabilitation researchers. In addition, the agencies should consider increasing funding for researchers who are underrepresented in disability research.

Goal 3: Foster innovation to create shared solutions.

With limited visibility within the Federal disability research arena, and lacking the authority to fund research projects, the ICDR must look to innovative approaches to meet its mandate. As described in the section [About the ICDR](#), the standing committees have been involved in various information gathering and sharing activities. But sustaining such activities as new areas of research emerge and administrations change will require innovative approaches.

One such innovative approach considered by the panel was the enterprise structure¹⁰ which creates a culture of collaboration by building and leveraging social networks that cut across bureaucratic boundaries. Two conditions are necessary for successful enterprise networks. First, the organization must mean what it says. Unfortunately many performance plans and expectations are too aspirational and fail to hold people accountable for performance. Part of accountability is describing the observable behaviors needed to achieve a goal. Second, people need to be taught how to collaborate. Enterprise leaders with the skills to encourage and facilitate collaboration are needed to realize the potential of an enterprise structure. The panel explored the option to identify enterprise leaders from current ICDR participants and considered how this approach could help advance ICDR visibility and productivity. Accountability can be achieved by building it into performance appraisals. These appraisals would maintain the technical competencies, but also hold staff accountable for evidence of their collaboration abilities. Some agencies have incorporated interagency group activities into individual performance expectations.¹¹

NIDRR can and should promote research on interagency collaboration research as well as researcher-community-practitioner collaboration. This type of research, which is funded by other institutes, is fundamental in building knowledge not only about disability and rehabilitation but about the mechanisms of collaboration across different constituents.

One way of measuring success of ICDR collaboration is to map its networks. It would be a powerful way of determining whether, because of the ICDR, members are connected to more people and more investigators than they would be if they had not been connected to the ICDR.

The panel also considered how the ICDR could lead without formal authority in a highly bureaucratic environment. Leading without formal authority always takes time and involves trying to find the shared interests, and in the case of bureaucratic organizations, finding who has influence. In some cases, the person with influence may be the head of an organization, but sometimes it may be a change leader with informal influence whose advice and input is trusted and sought out and who is not always visible to organizational or industry leaders. These hidden influencers can be a source of best practices, new ideas, and collaborative solutions to organizational challenges.¹²

A strategy that the ICDR has not fully utilized is recognizing that policymakers could benefit if the disability research community would package research findings that help inform a legislative reauthorization that has impact on people with disabilities or bring evidence to bear when policymakers are thinking about an issue. Another policy opportunity is to monitor the important policy issues of the day. It could be in response to gun violence, it could be immigration, or whatever issues are in the news.

¹⁰ Partnership for Public Service; Booz Allen Hamilton. (2013). *Building the Enterprise: Nine Strategies for a More Integrated, Effective Government*.

¹¹ U.S. Government Accountability Office. (2014). *Managing for results: Implementation approaches used to enhance collaboration in interagency groups*. GAO-14-220. Washington, DC: Author.

¹² Duan, L., Sheeren, E., & Weiss, L.M. (2014, March). Tapping the power of hidden influencers. *McKinsey Quarterly*, 2014(1).

ICDR could present research in a way that helps people understand the disability component of the issue. Packaging the information requires distilling information, simplifying it without losing important facts, and presenting it in a way that a broad audience can understand the implications. In sum, paying attention to what is going on in the policy environment and having the capacity in real time to quickly bring research findings to the White House, Capitol Hill, and the media is an innovative way to bring shared solutions to policymakers.

Recommendations for Goal 3

3.1. Focus on tackling one “wicked” problem at a time. Wicked problems are those that require coordinating and collaborating across agencies with interrelated responsibilities but competing and unaligned interests.¹³ Design a project carefully supported through a collaborative implementation process; devote sufficient resources into the process; invite people from agencies who strategically need to be involved; create visibility at many levels including the White House; and be successful. This enterprise approach would create a dominant coalition of Federal people who work in the disability area who begin to value interagency collaboration.

3.2. Map the existing disability research networks. Identify influential enterprise leaders and build upon networks by creating and sustaining micro communities of people interested in a particular topic. This initiative could be further supported through an investment of funding in research in interagency collaboration and in social networking software to map research networks.

3.3. Consider more open source net-centric ways to convey information about the ICDR and the Federal disability research enterprise. Shed the bureaucratic instinct that the only way to convey information is in an annual report.

Goal 4: Encourage investment in government-wide coordination and collaboration on disability and rehabilitation research.

This goal is focused on encouraging agencies to invest time and staff resources in ICDR activities and to help agencies consider how disability research fits their missions. Toward this goal, the panel discussed how to incentivize agencies to devote staff participation time to the ICDR.

Recommendations related to Goal 2: *Facilitate and increase opportunities for joint disability and rehabilitation research among Federal departments and agencies* offer suggestions for addressing people and agencies that are unaware of the applicability of disability research to their agency agendas. This understanding by decision-makers is critical to agencies understanding the value of collaborating and increasing their investment in disability research.

Convening individuals from agencies who share an interest in a research issue to discuss problems and solutions is also important for collaboration. Generating greater participation from the different Federal agency leaders or their delegates requires incentivizing their participation by identifying issues that are pertinent to their specific agency rather than a broad disability or rehabilitation issue in which an agency may not see the value. ICDR should also bring together people and agencies who don't necessarily understand the value of disability research to their mission. For instance in work being conducted internationally, it would be interesting to know how we are reaching out to people with intellectual

¹³ Nickerson, J., & Sanders, R. (Eds.). (2013). *Tackling wicked government problems: A practical guide for developing enterprise leaders*. Washington, DC: Brookings Institution Press.

disabilities, sensory disabilities, and physical disabilities. Do people doing work in the area of HIV consider disability? Do health clinics have signing for people with deafness? Do transportation initiatives consider accessibility? The ICDR has an important role to play in bringing people together who haven't thought about it to understand that they need to consider disability in their portfolio, research agenda, and priorities. This goes to the broader policy agenda of ICDR intended by Congress.

Regarding cross-disability work, the policy goals in the Rehabilitation Act may be different than the policy goals in the authorizing statutes for other agencies. For example, people who work in the areas of diabetes and chronic conditions work to prevent disability, while disability researchers work to support people who have acquired or are born with disabilities. So in trying to be more inclusive, part of the problem is that there are people who need to be at the table, but who haven't yet recognized the applicability of disability research to their agency agendas. It may help to expand consideration to chronic conditions and prevention of secondary conditions.

One factor that presents the preeminent challenge in sustaining a collaborative network on disability research is the lack of a government-wide definition and domain of disability. Without a common standard definition of disability, Federal agencies have differing paradigms for defining disability and developing research priorities. One panel member noted that a common definition of disability might be impractical. The existing definitions of disability used in national surveys, such as the American Community Survey (ACS), may not be detailed enough to enable health programs to adequately serve people with disabilities. Even in the absence of a common definition, however, ICDR has an important role in clarifying that disability includes people who are born with disabilities, people who acquire a disability as a result of injury or accident, and people who develop a disability as a result of a chronic condition, disease, or aging. Making these distinctions clear to potential collaborators may serve as an effective strategy for bringing them to the ICDR table.

To get the attention of potential leaders and collaborators, it is necessary to speak their language and emphasize things that matter to them. Getting the right people to the table involves giving them a reason to participate. The panel discussed the idea that agency staff do not attend interagency meetings because they do not see the benefit to themselves or their agencies. For example, potential stakeholders such as the Defense Advanced Research Projects Agency (DARPA) may not be aware of the ICDR, but they certainly care about the practical results of what disability researchers do. If success is driving this research to some immediate practical effect for people with disabilities, there are ways to work across bureaucracies. One approach is to emphasize that collaboration will involve outcomes that benefit many other people besides those who are involved in the collaboration. Benefiting a third party adds an important level of incentive and is a linkage that makes a group more influential and would attract more Federal agencies to the table.

An invitation to a planning process needs to be powerful enough that it is considered an honor to be invited. An advocacy framework suggests giving a compelling reason to participate. Concepts of marketing, branding, mutual benefits and value base all ensure that agency leaders recognize the benefit of investing staff time into participation.

Researchers are more likely to sustain collaboration if they coalesce around common research interests. It doesn't take long for participants who share a particular research interest to realize that they can learn from each other very quickly and move forward, not just their projects, but also the body of knowledge. One effective technique is to create horizontal connectivity which makes officials co-responsible for integrated projects. The Homeless Veterans Initiative Team is a model of shared leadership between the Department of Housing and Urban Development (HUD) and the Department of Veterans Affairs (VA). This initiative combines HUD vouchers for veterans to rent privately-owned

housing, with VA case management services that include health care, mental health treatment, vocational assistance and job development. The team was credited with eliminating the “stovepipes” that had prevented full cooperation between the VA and HUD.¹⁴

The panel also stated that encouraging investment in government-wide disability and rehabilitation research requires a sustainable system that meets the diverse needs of everyone who uses it. It also requires a sustainable system that is flexible enough to respond to changes in the environment, in resources, and in processes. A sustainable system is responsive to feedback: the interagency coordination network will be sustainable to the extent that stakeholders know about the ICDR and give meaningful input and feedback to the work of the committee.

Recommendations for Goal 4

4.1 Host an ICDR summit. Bring together Federal agency representatives to develop a comprehensive, government-wide strategic plan for disability, independent living, and rehabilitation research. The plan should outline measurable goals, research priorities and recommendations; and require development of a searchable government-wide research inventory, a set of guiding principles and policies and procedures, and a summary of underemphasized and duplicative areas of research. Progress toward achievement of the strategic plan goals should be reported in the annual report to the President and Congress, and identify timetables, budgets, and the assignment of responsible individuals and agencies.

4.2. Encourage agencies to contribute funds to support infrastructure and initiatives of ICDR as well as specific research initiatives. Agencies could commit funds and have commitment to ICDR. Consistent with the discussion above, the ICDR needs to make a compelling case for the value of research collaboration on maximizing research funding through coordinated research agendas.

4.3. Articulate incentives for agency participation. Provide specifics about a particular issue, the community of practice effort, the exchange of information, and specify how that information might have an impact on particular agencies.

4.4. Link disability research to broader public health efforts. Identify prevention and intervention opportunities that improve health and potentially reduce expenditures for the general population by articulating the relationship of such efforts with disability populations at the national, state and local levels. A considerable financial investment at the Federal, state and local level goes to treating people with disabilities but little is known about their healthcare utilization, costs and needs. In addition, understanding the relationship between disability and other public health efforts could spur additional attention to research aimed at understanding and better targeting interventions relevant to people with disabilities.

¹⁴ Partnership for Public Service (2012). 2012 Citizen Services Medal Recipient. Retrieved from http://servicetoamericamedals.org/SAM/recipients/profiles/csm12_angell-johnston.shtml

Panel Member Biographical Information

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Charles E. Drum, MPA, JD, PhD, is the director of the Institute on Disability and Professor of Health Management and Policy at the University of New Hampshire. Drum's international and national work in disability and health focus on health disparities, health care access, and health promotion, community development, consumer empowerment, knowledge translation, accessibility, employment, maltreatment, and the Americans with Disabilities Act. He was founding director of the Center on Community Accessibility at Oregon Health & Science University. His numerous publications include journal articles, reports, book chapters, and training curricula. He was the lead editor of the first textbook on disability and public health. His honors and awards include the National Distinguished Disability Research Award.

Andrew Imparato, JD, is the Executive Director of Association of University Centers on Disabilities. Imparato served as Senior Counsel and Disability Policy Director for the U.S. Senate Committee on Health, Education, Labor, and Pensions, chaired by Senator Tom Harkin of Iowa. He is the former president and CEO of AAPD, General Counsel and Director of Policy for the National Council on Disability, an attorney advisor with the U.S. Equal Employment Opportunity Commission, counsel to the U.S. Senate Subcommittee on Disability Policy, and a staff attorney with the Disability Law Center in Boston.

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Rogério M. Pinto, PhD, Associate Professor of the Columbia University School of Social Work is an expert in interagency and transdisciplinary collaboration. He has been awarded several grants to study collaboration. His five-year (2012-17), \$3.3 million grant, Interagency Collaboration to Implement Evidence-Based Practices, from the National Institute of Mental Health, promotes evidence-based services through interagency collaboration. Pinto is an expert in Community Based Participatory Research, and he uses mixed method approaches and longitudinal designs to study factors that facilitate partnerships between researchers, practitioners and health service consumers. He has conducted research in the United States, Brazil, and Spain, studying the impact of interagency and transdisciplinary collaboration on the delivery of evidence-based services to vulnerable populations, particularly those

affected by HIV. He has more than 40 peer-reviewed publications and has given more than 60 scientific presentations around the world. Dr. Pinto is a scientific reviewer for the National Institutes of Health and Brazil's Ministry of Health and for seventeen scientific journals here and abroad.

Ronald Sanders, PhD, a Senior Executive Advisor and Fellow at Booz Allen Hamilton, supports Federal and other clients in the areas of human capital, learning, and organizational transformation. His career in Federal service spans 37 years, including 20 years were in senior executive positions. He played a key role in establishing the Office of the Director of National Intelligence (ODNI) as the first chief human capital officer and in restructuring the Internal Revenue Services (IRS) as chief human resources officer. Recognitions include the National Intelligence Distinguished Service Medal; three Presidential Rank Awards; two OPM Theodore Roosevelt Awards for Distinguished Public Service; and the American Society for Public Administration Award for Outstanding Career Service. Sanders taught and directed research centers at the George Washington University (GWU) and Syracuse University's Maxwell School of Citizenship and Public Affairs. He is an adjunct faculty member with the Brookings Institution Center for Public Policy Education, chairs its Executive Education Advisory Board, serves on the board of the American Society for Training and Development and is a Fellow of the National Academy of Public Administration.

Katherine D. Seelman, PhD, associate dean and professor of rehabilitation science and technology in the School of Health and Rehabilitation Sciences at the University of Pittsburgh, also holds secondary appointments in the School of Public Health and Institute for Bioethics and is co-scientific director of the National Science Foundation-supported Quality of Life Technology Engineering Research Center. She is a former Director of the National Institute on Disability and Rehabilitation Research (NIDRR). Her research interests include science and technology R&D that enhance independence for people with disabilities and older adults; end-user and stakeholder participation; Disability Studies; Science, Technology and Public Policy; and International Rehabilitation. Seelman served on the World Health Organization (WHO) 9-member international editorial committee guiding the first world report on disability. Her appointments include the AHIMA Foundation and the Disability Studies Quarterly boards, two disability State Advisory Committees, the Pennsylvania Senate Technology Healthcare Working Group, and the co-chair of the City of Pittsburgh/Allegheny County Task Force on Disability. She was named "A Person Who Made a Difference" in 2002 by the Pittsburgh Post-Gazette.

Robert "Bobby" Silverstein, JD, is an attorney with over 35 years of public policy and advocacy experience. For more than a decade, he served as staff director and chief counsel for the Senate Subcommittee on Disability Policy, chaired by Senator Tom Harkin, where he was a behind-the-scenes architect of more than 20 disability-related bills enacted into law including the landmark Americans with Disabilities Act, the Rehabilitation Act of 1973, as amended, and the Individuals with Disabilities Education Act, as amended. Currently, Silverstein is a principal in the law firm of Powers Pyles Sutter & Verville, PC. He has a Federal regulatory and legislative practice in the areas of disability and rehabilitation research, civil rights, health care, employment, education, and social security. Silverstein has a B.S. in Economics, *cum laude*, from the Wharton School, University of Pennsylvania and a J.D. from Georgetown University Law Center. Mr. Silverstein is the recipient of more than 15 national awards, including the Distinguished Services Award of the President of the United States. Bobby has been inducted into the Public Interest Hall of Fame.

Sue Swenson is the Deputy Assistant Secretary of OSERS (the Office of Special Education and Rehabilitative Services). She is the former Commissioner of the U.S. Administration on Developmental Disabilities and the past Executive Director the Joseph P. Kennedy, Jr. Foundation and The Arc of the United States. Ms. Swenson also ran her own company which specialized in management, payment technologies, and social entrepreneurship to support people with disabilities and their families.

Swenson's experience in disability related issues includes family support, inclusion, transition, and public policy.

ICDR Authorization

Rehabilitation Act of 1973

TITLE 29--LABOR

CHAPTER 16--VOCATIONAL REHABILITATION AND OTHER REHABILITATION SERVICES

SUBCHAPTER II--RESEARCH AND TRAINING

Sec. 763. Interagency Committee

(a) Establishment; membership; meetings

(1) In order to promote coordination and cooperation among Federal departments and agencies conducting rehabilitation research programs, including programs relating to assistive technology research and research that incorporates the principles of universal design, there is established within the Federal Government an Interagency Committee on Disability Research (hereinafter in this section referred to as the "Committee"), chaired by the Director and comprised of such members as he President may designate, including the following (or their designees): the Director, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services, the Secretary of Education, the Secretary of Veterans Affairs, the Director of the National Institutes of Health, the Director of the National Institute of Mental Health, the Administrator of the National Aeronautics and Space Administration, the Secretary of Transportation, the Assistant Secretary of the Interior for Indian Affairs, the Director of the Indian Health Service, and the Director of the National Science Foundation.

(2) The Committee shall meet not less than four times each year.

(b) Duties

- (1) After receiving input from targeted individuals, the Committee shall identify, assess, and seek to coordinate all Federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities.
- (2) In carrying out its duties with respect to the conduct of Federal research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities, the Committee shall—
 - (A) share information regarding the range of assistive technology research, and research that incorporates the principles of universal design, that is being carried out by members of the Committee and other Federal departments and organizations;
 - (B) identify, and make efforts to address, gaps in assistive technology research and research that incorporates the principles of universal design that are not being adequately addressed;
 - (C) identify, and establish, clear research priorities related to assistive technology research and research that incorporates the principles of universal design for the Federal Government;
 - (D) promote interagency collaboration and joint research activities relating to assistive technology research and research that incorporates the principles of universal design at the Federal level, and reduce unnecessary duplication of effort regarding these types of research within the Federal Government; and

(E) optimize the productivity of Committee members through resource sharing and other cost-saving activities, related to assistive technology research and research that incorporates the principles of universal design.

(c) Annual report

Not later than December 31 of each year, the Committee shall prepare and submit, to the President and to the Committee on Education and the Workforce of the House of Representatives and the Committee on Labor and Human Resources of the Senate, a report that—

- (1) describes the progress of the Committee in fulfilling the duties described in subsection (b) of this section;
- (2) makes such recommendations as the Committee determines to be appropriate with respect to coordination of policy and development of objectives and priorities for all Federal programs relating to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities; and
- (3) describes the activities that the Committee recommended to be funded through grants, contracts, cooperative agreements, and other mechanisms, for assistive technology research and development and research and development that incorporates the principles of universal design.

(d) Recommendations

- (1) In order to promote coordination and cooperation among Federal departments and agencies conducting assistive technology research programs, to reduce duplication of effort among the programs, and to increase the availability of assistive technology for individuals with disabilities, the Committee may recommend activities to be funded through grants, contracts or cooperative agreements, or other mechanisms—
 - (A) in joint research projects for assistive technology research and research that incorporates the principles of universal design; and
 - (B) in other programs designed to promote a cohesive, strategic Federal program of research described in subparagraph (A).
- (2) The projects and programs described in paragraph (1) shall be jointly administered by at least 2 agencies or departments with representatives on the Committee.
- (3) In recommending activities to be funded in the projects and programs, the Committee shall obtain input from targeted individuals, and other organizations and individuals the Committee determines to be appropriate, concerning the availability and potential of technology for individuals with disabilities.

(e) Definitions

In this section—

- (1) the terms “assistive technology” and “universal design” have the meanings given the terms in section 3002 of this title; and
- (2) the term “targeted individuals” has the meaning given the term “targeted individuals and entities” in section 3002 of this title.

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Appendix: Summary of Literature on Interagency Coordination

This literature review examined the literature related to best practices for interagency research coordination. The review focused on findings that are relevant to the mission and structure of the Interagency Committee on Disability Research (ICDR). This review presents examples of the various methods interagency committees use to guide their work.

The following method was used to identify literature on best practices in interagency coordination and collaboration:

- Identification of existing interagency committees to document the methods used to foster research collaboration and coordination. Each committee's published reports, history, mission, membership, scope of authority, strategic planning processes, operating format, stakeholder input procedures, and coordination accomplishments were examined. Interagency efforts concerned with service provision and committees whose function was purely advisory were excluded.
- Keyword search of academic literature and published reports to find articles that identified factors for successful interagency research coordination, provided information that is relevant and useful to the ICDR as it promotes research coordination and partnerships, and will assist ICDR members in planning and executing interagency research projects.

Concepts of Collaboration

Interagency work begins with defining the desired collaboration and ensuring that the necessary resources and organization are in place. In 2005, the U.S. Government Accountability Office (GAO) put forth eight practices that agencies could use to promote collaborative efforts. GAO defined collaboration as any joint activity that is intended to produce more public value than could be produced when the agencies act alone. The eight practices are:

1. define and articulate a common outcome;
2. establish mutually reinforcing or joint strategies;
3. identify and address needs by leveraging resources;
4. agree on roles and responsibilities;
5. establish compatible policies, procedures, and other means to operate across agency boundaries;
6. develop mechanisms to monitor, evaluate, and report on results;
7. reinforce agency accountability for collaborative efforts through agency plans and reports; and
8. reinforce individual accountability through performance management systems.

Since that 2005 report, interagency efforts have continued to recognize that no single Federal agency has all resources or expertise to answer complex research questions or to develop national policies.

Interagency collaboration also takes on greater importance with the Government Performance and Results Act (GPRA) Modernization Act of 2010, which requires the Office of Management and Budget (OMB) to set cross-agency priority (CAP) goals for cross-cutting policy and government-wide management areas at least every four years starting with the 2015 budget, and set interim CAP goals with the 2013 Budget. OMB also designated relevant agencies and programs that will be responsible for each interim goal. OMB is relying on a range of collaborative mechanisms to address these goals.

In its examination of impediments to interagency collaboration, the National Research Council (2011) distinguished among collaboration (a general term that denotes more than one agency working together), coordination (two agencies work together but are not dependent on each other for the project's success), and cooperation (each agency is dependent on the other for the project's success). As collaborative arrangements proceed from coordination to cooperation, the level of complexity and risk increases. The authors further observed that "inefficiencies arise when collaborating agencies' goals, authorities, and responsibilities are not aligned. Thus, collaborations require higher levels of coordination, additional management layers, and greater attention to mechanisms for conflict resolution." (p. 4).

Kaiser (2011) identified six types of interagency arrangements:

1. **Collaboration**, which relies on voluntary or discretionary participation among the members, who are relatively equal or have parity in the activity.
2. **Coordination**, in which a lead agency or officer directs an operation, project, or program among one or more other agencies.
3. **Merger**, which transfers all or parts of different agencies or their authorities, jurisdictions, personnel, and resources on a permanent basis to another organization, either a new or existing department, agency, bureau, office, or other entity.
4. **Integration**, which brings together relevant parts of agencies on either a long-term or a temporary ad hoc basis, to carry out a particular operation, project, program, or policy; these endeavors, unlike mergers, involve nonpermanent transfers of personnel, resources, or authority among relevant agencies.
5. **Networks**, which involves the Federal Government and all or several other levels of government: Federal, state, local, tribal, or, in some cases, foreign countries.
6. **Partnerships**, which feature public-private partnerships, with the public sector entities extending from the Federal Government to state, local, or tribal governments, as well as, in some cases, foreign governments; and with the private sector involving different types of entities: non-governmental organizations (NGOs), not-for-profit organizations, for-profit companies and firms, government-sponsored enterprises, and government-chartered corporations.

For agencies that fund research, collaboration is used to answer research questions that are most effectively addressed through collaborative studies; to share responsibility, expertise or perspective; to pool financial and human resources; to increase efficiency and funding opportunities; or to gain greater credibility (Resnick, 2011).

Interagency collaboration can also be used for policy development, program implementation, oversight and monitoring, information sharing and communication, and building organizational capacity (GAO,

2012) and can serve to reduce potentially fragmented, overlapping, and duplicative efforts. GAO (2013) defined these terms as follows:

- Fragmentation refers to those circumstances in which more than one Federal agency (or more than one organization within an agency) is involved in the same broad area of national need and opportunities exist to improve service delivery.
- Overlap occurs when multiple agencies or programs have similar goals, engage in similar activities or strategies to achieve them, or target similar beneficiaries.
- Duplication occurs when two or more agencies or programs are engaged in the same activities or provide the same services to the same beneficiaries.

Federal interagency committees operate under a variety of authorities including legislative mandate, executive order, and voluntary memorandum of understanding. Congress has established most interagency committees and their duties, but there are examples of voluntarily formation. The Federal Healthy Homes Work Group adopted a formal interagency structure after agency staff had worked together informally and successfully on a program level (Brown, Ammon, & Grevatt, 2010). Along with working to implement Federal and community healthy homes policies and interventions, the group's strategic action plan also identified research needs (Federal Healthy Homes Work Group, 2013).

When committees begin to form research collaborations, the National Research Council (2011) found that "grassroots collaboration is preferred because it is based on technical necessity and a desire to work together . . . top-down collaboration will be burdened from the beginning with a lack of working-level buy-in. Teams that want to work together far outperform those that are forced together, and they also facilitate the application of the tools and techniques associated with good program and project management. Successful collaboration is more likely when each agency considers the partnership one of its highest priorities; such an understanding should be codified in signed agreements that also document the terms of the collaboration's management and operations (p. 38)."

Best Practices

The literature review identified the core activities for interagency committees: a state of the science research review, strategic planning with a process for linking research efforts to strategic plan goals, and disseminating research results. Depending on the depth and complexity of the subject matter, these elements varied in intensity, but all interagency committees reviewed engaged in some form of those activities. The remainder of this review will examine how various committees undertook these activities:

- **State of the science review.** Also called a research inventory or portfolio analysis, this review identifies all research currently conducted on a specific topic or field and is used to identify duplication, gaps, and opportunities for advancing knowledge. Some committees use expert panels to review the existing scientific literature and assess the effectiveness of interventions.
- **Strategic planning.** The strategic planning process involves articulating goals, objectives, timelines, and accountability for progress. It is usually based on the findings of the state of the science review, but sometimes a strategic plan is used to guide the research review. External review of strategic plans ranged from formal review by the National Academies to informal requests for comment from stakeholders.

- **Disseminate research results.** An often overlooked piece of interagency collaboration, disseminating the results of interagency planning and research to other Federal partners and to non-Federal stakeholders promotes further coordination and can be valuable input for future research plans.

State of the Science Review

Before beginning a research collaboration, committees identify related past or current research. Depending upon the committee, this process is referred to as a state of the science review, a research inventory, or a research portfolio review. This review is accomplished through a variety of means such as literature searches to find published studies, committee members contributing information on studies underway in their agencies, state of the science conferences, and expert panels. The resulting inventory provides a detailed analysis of duplication, overlap, and fragmentation, and is used to plan future research or to develop or update strategic plans.

The newly formed Committee on Science, Technology, Engineering, and Mathematics (STEM) Education (CoSTEM) used a portfolio review as a first step in developing its 5-year strategic plan (National Science and Technology Council, 2011; 2012). The America COMPETES Reauthorization Act of 2010 established the committee within the National Science and Technology Council to create a coordinated portfolio of STEM education and research investments across the Federal Government. Findings from the portfolio report are being used to develop a strategic plan with annual milestones, criteria for success, a process for creating the priority area roadmaps, and a tracking and accountability plan. The strategic plan will also identify which investment gaps the Federal agencies can fill and which agencies can collaborate to bring the resources and expertise to fill these gaps.

To be useful in planning collaborations, the inventory needs to be more than a listing of current or planned projects. In a report assessing the Interagency Coordinating Committee on Oil Pollution Research, GAO (2011), stated that a comprehensive inventory of member agency research projects is a necessary step to assessing past research. However, the inventory must assess whether the research addressed knowledge gaps identified in the strategic plan and whether the research was contributing to advancing the plan priorities. A report that provides only summaries of research projects is not sufficient to determine what new knowledge Federal research is contributing to the field or what new research is needed.

In 2012, the Interagency Autism Coordinating Committee (IACC) published a comprehensive analysis of the 2010 autism spectrum disorder research portfolio of major Federal agencies and private organizations (Office of Autism Research Coordination, 2012). This analysis informs the Committee and interested stakeholders about funding and current directions for autism research. Importantly, this analysis examined the extent to which current funding and research topics align with the strategic plan. The portfolio analysis is also used by Federal agencies and private research organizations to help guide future funding priorities by outlining research gaps and opportunities. The IACC portfolio is supplemented by the Autism Spectrum Disorder Research Portfolio Analysis Web Tool,¹⁵ a searchable database that contains each research project included in the portfolio analysis. Each of those projects is connected to a strategic plan objective.

Research inventories may also include an assessment of intervention effectiveness. A CDC panel reviewed housing interventions designed to reduce adverse health outcomes and categorized interventions as (1) with sufficient evidence for implementation; (2) needing more field evaluation; (3)

¹⁵ <https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects>

needing basic research and (4) with sufficient evidence demonstrating that they are ineffective or harmful (Jacobs et al., 2010). The panel's recommendations were incorporated into HUD and CDC healthy homes programs (Brown, Ammon, & Grevatt, 2010) and into the healthy homes strategic plan which forms the basis for identifying priority intervention research (Federal Healthy Homes Work Group, 2013).

Strategic Planning

The literature suggests that a strategic plan is a cornerstone mechanism of interagency collaboration. The purpose of the strategic plan is to build upon member agency ongoing research and identify emerging trends in a particular scientific field. The plan is organized by research objectives and specifies time frames for meeting those objectives.

The National Research Council undertook a review of the Federal strategy for nanotechnology-related environmental, health, and safety research and identified key elements of a research strategy: "an evaluation of the existing state of science, an overarching vision or statement of purpose, goals to ensure safe development of nanotechnologies, a road map for ensuring achievement of stated goals, evaluation for assessing progress in achieving the goals, a process of review to ensure the strategy remains responsive to the overarching vision and goals, identification of resources, mechanisms to achieve goals, and accountability (National Research Council, 2009, p. 40)." The National Nanotechnology Initiative has since revised its strategic plan (2011a) and also adopted a research strategy document that identifies opportunities for collaboration and cooperation (2011b).

Interagency groups approach strategic planning in similar ways. The Diabetes Mellitus Interagency Coordinating Committee (DMICC) illustrates the typical planning process (Diabetes Mellitus Interagency Coordinating Committee, 2011). One working group was convened for each of 10 scientific areas. An additional working group composed of representatives from each of the 10 groups addressed needed scientific expertise, tools, technologies, and shared resources. Each working group was chaired by and composed of external scientific experts, representatives of DMICC member agencies, and diabetes organizations. The working groups surveyed the state of the science and developed a summary of progress and needed research relevant to each goal. A public comment period allowed for stakeholder input. Each of the 10 chapters in the strategic plan includes an introduction, summaries of recent research advances, key research questions and goals, and a summary of how the research outlined in the chapter will improve the health of people with respect to diabetes.

Most interagency entities develop a five-year strategic plan, but the Interagency Autism Coordinating Committee (2012a) updates its plan annually by determining what they already know, and what else they need.

Strategic planning can also include a cross-agency plan. GAO (2010) reviewed human factors research coordination and found that the research portfolio contained only a listing and description of research and development projects and results, and lacked a cross-agency plan with role definitions, goals, and time frames. GAO concluded that a cross-agency plan could help the collaborating agencies better follow the key practices for enhancing and sustaining collaboration identified by GAO in its 2005 report.

Strategic planning must also solicit and incorporate input from non-Federal stakeholders (GAO, 2011), public comment on the draft plan is not sufficient (National Research Council, 2009). Involvement of external stakeholders lessens the tendency for Federal agencies to focus on research that can be done within existing capabilities and instead promotes agencies to focus on "What research should we be doing? (p. 8)."

Solid strategic planning upfront can contribute to an interagency collaboration that ensures that priority areas are identified, relevant research completed or underway that addressed those priorities is identified, and the research questions that should be addressed through future grants are specified.

Dissemination of Research Results and Coordination Success

Committees vary in how they disseminate the results of research that was the product of interagency coordination or collaboration. Dissemination has important uses beyond publicizing successes. Disseminating the results of completed Federal research to non-Federal audiences is needed to inform the plans of non-Federal research organizations (GAO, 2011).

All interagency efforts are by definition multidisciplinary which requires reaching researchers and stakeholders in diverse disciplines. Techniques include websites, professional journals, presentations at scientific conferences, workshops, databases of ongoing and completed research projects, and virtual communities of practice. Dissemination to the public and interested non-Federal stakeholders is also relying increasingly on social media (Interagency Breast Cancer and Environmental Research Coordinating Committee, 2013).

Summarizing the scientific literature and making the summaries available to the stakeholder community informs policy decisions and helps researchers build on past efforts. Each year, the Interagency Autism Coordinating Committee (2012b) accomplishes this by publishing a list of scientific advances that represent significant progress in the field. The *Summary of Advances* provides short, plain language summaries of the top research breakthroughs selected from peer-reviewed articles nominated by the members. Articles are grouped according to the questions in the strategic plan.

Addressing Impediments to Interagency Collaboration

While interagency collaboration has its benefits, collaboration involves responsibilities and risks that need to be actively managed. Two studies have addressed its limitations and impediments.

The Committee on the Assessment of Impediments to Interagency Cooperation on Space and Earth Science Missions (National Research Council, 2011) found that a multiagency approach typically results in additional complexity and cost and that “advocates of collaboration have sometimes underestimated the difficulties and associated costs and risks of dividing responsibility and accountability between two or more partners; they also discount the possibility that collaboration will increase the risk in meeting performance objectives (p. 1).” The Committee further noted that while collaboration is sometimes used to share costs, “inefficiencies arise when collaborating agencies’ goals, authorities, and responsibilities are not aligned. Thus, collaborations require higher levels of coordination, additional management layers, and greater attention to mechanisms for conflict resolution (p. 4).”

Although the report addressed space science missions, its conclusions are worth considering for any interagency effort. The committee noted that impediments to interagency collaboration can result from both internal sources (e.g., differences in goals, ambitions, cultures, stakeholders, and agency-specific standards and processes) and external sources (e.g., different budget cycles, and changes in policy direction from the administration and Congress). The committee recommended that agencies conduct earth and space science projects independently unless:

- Cooperation will result in significant added scientific value to the project over what could be achieved by a single agency alone; or

- Unique capabilities reside within one agency that are necessary for the mission success of a project managed by another agency; or
- The project is intended to transfer from research to operations, necessitating a change in responsibility from one agency to another during the project; or
- There are other compelling reasons to pursue collaboration, e.g., a desire to build capacity at one of the cooperating agencies (p. 1).

The Committee on Science, Technology, Engineering, and Mathematics (STEM) Education (CoSTEM) (National Science and Technology Council, 2012) identified factors that limit the ability of agencies to achieve the collaborative goals and objectives regarding STEM education, but these factors also apply to any interagency effort.

- Agency budget fluctuations and changing views of an agency's role make long-term planning difficult.
- Limited funding to support coordination and collaboration across agencies leads to ad hoc coordination which makes coordination difficult to sustain.
- Challenges associated with collecting and sharing data can limit program evaluation strategies.
- Solicitation, review, and award processes for research grants are inconsistent.
- Creating joint solicitations, memoranda of understanding, and other agreements that support interagency coordination and resource-sharing can be time-consuming and costly.

Agencies can overcome these limitations by adapting CoSTEM approaches to their own interagency efforts. For each priority area, agencies can seek to align programmatic goals and objectives; create clear and connected mechanisms for aligning investment dollars; implement joint communication and outreach strategies; and identify investments that can be adjusted to focus on a priority area. CoSTEM also recommends developing a roadmap for addressing each of the priority areas. The roadmaps should identify specific actions needed to address the priority areas and describe how specific investments fit within the roadmap. The roadmaps should include implementation timelines with action items, milestones, and common metrics to track progress on outputs and outcomes.

Committee Operations

Once an interagency committee has been established, the collaboration needs to operate efficiently. The Federal Collaboration on Health Disparities Research, in which the ICDR is participating, identified several general guiding principles for successful collaboration (Rashid et al., 2009):

- **Respect agency missions.** Maintain equitable agency representation on interagency committees to ensure that agency missions and priorities are recognized.
- **Create common language.** Develop a common language for cross-agency initiatives to help partnerships operate effectively.
- **Build on existing groups.** Network with other groups that focus on similar issues to minimize duplication and promote efficiency.
- **Address support needs as they arise.** Co-lead agencies need to work together to provide logistical support to maintain momentum and productive networking.

- **Provide infrastructure for collaboration.** Maintain participant engagement and success by providing the technical support.
- **Establish an identity.** A unique identity will increase recognition and understanding of the collaboration and how it relates to the work of others.
- **Overcome barriers.** Proactive efforts are needed to address and resolve new issues as they arise.

The National Research Council (2011) identified several specific characteristics that facilitate successful interagency collaborations. Success is defined as achieving stated objectives and satisfying sponsor goals. Although designed for space science collaboration agreements, these elements are also applicable to any interagency effort and are worth quoting at length.

- **A small and achievable list of priorities.** Projects address a sharply focused set of priorities and have clear goals. Agreement is based on specific projects rather than general programs.
- **A clear process to make decisions and settle disputes.** Project decision making is driven by an intense focus on mission success. This is facilitated by formal agreement at the outset on explicitly defined agency roles and responsibilities and should involve agreed processes for making management decisions, single points of accountability (i.e., not committees), and defined escalation paths to resolve disputes. Long-term planning, including the identification of exit strategies, is undertaken at the outset of the project and includes consideration of events that might trigger a reduction-in-scope or cancellation review and associated fallback options if there are unexpected technical difficulties or large cost overruns that make the collaboration untenable.
- **Clear lines of authority and responsibility for the project.** Technical and organizational interfaces are simple and aligned with the roles, responsibilities, and relative priorities of each collaborating entity. Project roles and responsibilities are consistent with agency strengths and capabilities. Expert and stable project management has both the time and the resources available to manage the collaboration. Specific points of contact for each agency are identified. Agency and project leadership provides firm resistance to changes in scope. When possible, one of the collaborating agencies should be designated as the lead agency with ultimate responsibility and accountability for executing the mission within the agreed set of roles and responsibilities, command structure, and dispute resolution process defined in a Memorandum of Understanding (MOU). In some cases the lead agency might change as a function of time, as for missions in which the lead agency differs between the implementation and operations phases.
- **Well-understood participation incentives for each agency and its primary stakeholders.** All parties share a common commitment to mission success and are confident in and rely on the relevant capabilities of each collaborating agency. Each agency understands how it benefits from the cooperation and recognizes that collaborative agreements may need to be revisited at regular intervals in response to budgetary and political changes. There is buy-in from political leadership (e.g., senior administration, Congress, and agency-level administrators), which can help projects move past the inevitable rough spots. There is a general spirit of intellectual and technical commitment from the agency workforce and contractors to help projects mitigate the disruptive effects of technical and programmatic problems that are likely to occur. Early and frequent stakeholder involvement throughout the mission keeps all stakeholders informed, manages expectations, and provides appropriate external input.

- **Single acquisition, funding, cost control, and review processes.** There is a single agency with acquisition authority, and each participating entity accepts financial responsibility for its own contributions to joint projects. Reliance on multiple appropriation committees for funding is avoided or reduced to the greatest possible extent. Cost control is ideally the responsibility of a single stakeholder or institution, because without a single point of cost accountability, shared costs tend to grow until the project is in crisis. Single, independent technical and management reviews occur at major milestones, including independent cost reviews at several stages in the project life cycle.
- **Adequate funding and stakeholder support to complete the task.** Funding adequacy is based on technically credible cost estimates with explicitly stated confidence levels (pp. 36-37).

The committee also recommended that in addition to a Memorandum of Understanding, interagency collaborations also agree to an implementation plan that “establishes management authority, organizational responsibilities, integrated review plans, budgets, schedule, and priorities at the outset and explicitly spells out how conflicts over scarce resources are to be handled (p. 37).”

In addition to these formal agreements, committees must commit to “open, honest, effective, and complete communications” encompassing “all types of communication—written, oral, formal, and informal—from program and project plans, schedules, requirements, and contracts, to technical interchange meetings, interface control documents, MOUs, and configuration control boards, including telephone calls, e-mail, and on-site visits (p. 38).”

Implementing Interagency Collaborative Mechanisms

GAO (2012) identified issues to consider when implementing collaborative mechanisms by conducting a literature review on interagency collaborative mechanisms, interviewing 13 academic and practitioner experts in the field of collaboration, and reviewing the work of these experts. GAO also conducted a detailed analysis of 45 of its reports selected from more than 300 reports published between 2005 and 2012 that examined aspects of collaboration within the Federal Government. Based on this review, GAO identified key issues to consider for implementing interagency collaborative mechanisms. This template, described below, provides valuable guidance for any interagency undertaking.

Outcomes and accountability

- Have short-term and long-term outcomes been clearly defined?
- Is there a way to track and monitor progress toward the short-term and long-term outcomes?
- Do participating agencies have collaboration-related competencies or performance standards against which individual performance can be evaluated?
- Do participating agencies have the means to recognize and reward accomplishments related to collaboration?

Bridging organizational cultures

- What are the missions and organizational cultures of the participating agencies?
- What are the commonalities between the participating agencies’ missions and cultures and what are some potential challenges?

- Have participating agencies developed ways for operating across agency boundaries?
- Have participating agencies agreed on common terminology and definitions?

Leadership

- Has a lead agency or individual been identified?
- If leadership will be shared between one or more agencies, have roles and responsibilities been clearly identified and agreed upon?
- How will leadership be sustained over the long-term?

Clarity of roles and responsibilities

- Have participating agencies clarified the roles and responsibilities of the participants?
- Have participating agencies articulated and agreed to a process for making and enforcing decisions?

Participants

- Have all relevant participants been included?
- Do the participants have:
 - Full knowledge of the relevant resources in their agency?
 - The ability to commit these resources?
 - The ability to regularly attend activities of the collaborative mechanism?
 - The appropriate knowledge, skills, and abilities to contribute?

Resources

- How will the collaborative mechanism be funded? If interagency funding is needed, is it permitted?
- If interagency funding is needed and permitted, is there a means to track funds in a standardized manner?
- How will the collaborative mechanism be staffed?
- Are there incentives available to encourage staff or agencies to participate?
- If relevant, do agencies have compatible technological systems?
- Have participating agencies developed online tools or other resources that facilitate joint interactions?

Written guidance and agreements

- If appropriate, have the participating agencies documented their agreement regarding how they will be collaborating? A written document can incorporate agreements reached in any or all of the following areas: Leadership; Accountability; Roles and Responsibilities; and Resources.
- Have participating agencies developed ways to continually update or monitor written agreements?

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