Interagency Committee on Disability Research: History and Significance

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INTRODUCTION

The Interagency Committee on Disability Research (ICDR) mission is to promote coordination and collaboration among federal departments and agencies conducting disability, independent living (IL), and rehabilitation research programs, including programs related to assistive technology (AT) research and research that incorporates the principles of universal design (UD). This expansive mission includes research related to physical and mental function, rehabilitative services, technology, and social and community integration for all types of disabilities and chronic conditions over the lifespan.

The ICDR is housed in the Administration for Community Living in the U.S. Department of Health and Human Services (HHS). It is composed of 17 statutory member agencies and other participating agencies that represent the scope of the ICDR mission. The Director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) serves as the chair, by designation of the Secretary of HHS.

For 40 years, the ICDR has coordinated the federal disability research effort, evolving to address emerging needs, respond to government mandates, and advance the science. Through changes over time, it has remained committed to collaboration with key stakeholders — individuals with disabilities and their advocates, service providers, policymakers, and other researchers — contributing to continued growth in the field and incremental improvements in the quality of life for people with disabilities in the United States.

THE IMPORTANCE OF THE ICDR ROLE

The disability community represents a large part of American society. Per the American Community Survey (ACS), in 2018 there were over 40.5 million individuals with disabilities, or 12.6% of the population (Lauer, 2020). The Centers for Disease Control and Prevention [Disability and Health Data System](#) reported that in 2017, 26.4% of adults had some type of disability and that rates of disability are higher among subgroups of people including adults over 65, civilian veterans, and Native Americans. The number and breadth of people experiencing some disability, along with their families, caregivers, and neighbors who are affected, illustrates the magnitude of this issue in society. The Institute of Medicine

(IOM) put it simply: "disability affects today or will affect tomorrow the lives of most Americans" (IOM, 2007, p. 1).

Even as civil rights have been gained, most notably through the Americans with Disabilities Act (ADA) of 1990 and its reauthorizations, people with disabilities continue to experience economic and health care disparities. More adults with disabilities live in poverty than those without disabilities — 26% vs. 11% (Lauer, 2020). Full-time workers with disabilities make less than full-time workers without disabilities. People with disabilities are also more likely to have other health conditions such as obesity, heart disease, and diabetes, and yet they experience more barriers to health care (Centers for Disease Control and Prevention, 2020). These data indicate that significant needs exist.

Numerous federal programs — both services and research — exist to support people with disabilities and address important needs. However, the programs in both spheres are widely dispersed across the government, which can create silos of operation. The U.S. Government Accountability Office identified 20 federal agencies and almost 200 federal programs serving individuals with disabilities whose missions and funding streams were often different and could conflict (U.S. Government Accountability Office, 2005). In 2007, the IOM identified 26 different agencies that sponsor disability-related research. The patchwork nature of the federal landscape remains a challenge today.

While the federal government spends billions annually in monetary support to beneficiaries with disabilities through the Social Security Disability Insurance and Medicare programs alone, disability research funding is low. Research supported by the federal government helps to identify, understand, and address many of the problems experienced by citizens with disabilities and their families through innovation and change. The research budget for disability and rehabilitation is difficult to determine because the activity is so widely dispersed. The IOM reported the 2006 budget for the three primary disability research agencies as approximately $230 million. Since that time funding for all research and development has remained relatively flat (Hourihan & Parkes, 2019). That is, federal disability research continues to operate on a very limited budget.

Within this context of limited budgets, diffuse programs, and a broad scope for research, the ICDR coordination role is critical. The ICDR can be viewed as the starting point for research coordination. It is somewhat unique in bringing together a broad

swath of key stakeholders — individuals with disabilities, advocates, service providers, business and industry, policymakers, and researchers with diverse expertise. It represents the broadest view of disability research. The information sharing and networking among members fosters cross-fertilization of many different ideas. The prioritizing of research reduces gaps and promotes joint activities among agencies. This coordination enables each agency and the entire research program to efficiently accomplish more to advance knowledge, improve programs, and inform policy.

HISTORY AND EVOLUTION OF THE ICDR

Federal funding for disability and rehabilitation research began in the late 1930s and 1940s at the U.S. Department of Veterans Affairs (VA) and Rehabilitation Services Administration predecessors. The Vocational Rehabilitation Act Amendments of 1954 greatly expanded funding for research and demonstration grants and for training of rehabilitation professionals (Leclair, 1979). The first Spinal Cord Injury Model System Centers, Research and Training Centers, and Rehabilitation Engineering Centers were funded in the 1960s and 1970s. These centers covered a range of medical, vocational, and societal issues (Muzzio, 2010; Verville, 2011).

General Historical Trends

The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (PL 95-602), which amended the Rehabilitation Act of 1973, formally established the National Institute on Handicapped Research (NIHR), now NIDILRR, and its Interagency Committee on Handicapped Research (ICHR), the precursor to today's ICDR. Four subsequent laws have governed the ICDR:

- The Rehabilitation Act Amendments of 1986 (PL 99-506)
- The Workforce Investment Act of 1998 (PL 105-220)
- The Assistive Technology Act of 1998 (PL 105–394)
- The Workforce Innovation and Opportunity Act (WIOA) of 2014 (PL 113-128)

The evolution of ICDR operations was largely driven by the requirements in these laws and other federal initiatives. The changes in ICDR mission and duties, organizational structure, and budget are summarized.

Mission and Duties

The ICDR's core mission to promote coordination and cooperation among federal departments and agencies conducting disability-related research has remained the same since its establishment. The consistency of its mission has helped anchor the ICDR in the face of other organizational changes. For example, new laws added specific areas of focus to the ICDR mission. The Assistive Technology Act added AT research and research that incorporates the principles of UD in 1998, while WIOA added disability and IL research in 2014.

In addition to authorizing legislation, other disability-related laws have affected the ICDR focus. The Technology-Related Assistance Act of 1988 stimulated AT and accessibility work. The passage of the ADA in 1990 brought attention to the need for policy-relevant data to advance full participation, IL, and economic self-sufficiency. The Supreme Court Olmstead decision in 1999 found that unjustified segregation is a form of discrimination under the ADA. With this finding, research related to community living was buoyed. The ICDR has remained current over the years by incorporating social and policy advancements into its research discussions.

Legislation also added specific duties over the years. The original duties were to identify, assess, and seek to coordinate federal research. In 1998, the requirement to receive input from individuals with disabilities and their representatives/targeted individuals was formally added through the Workforce Investment Act. The ICDR had already been soliciting input from the disability community, so this change codified existing practice. Later that same year, the Assistive Technology Act mandated the ICDR to share information, identify and address research gaps, identify and establish research priorities, promote interagency collaboration and reduce unnecessary duplication, and optimize productivity through resource sharing in the AT and UD topic areas. In 2014, WIOA added the IL topic to existing duties and required a formal strategic plan with specific components. While earlier ICDR strategic planning efforts had occurred, this directive prompted a comprehensive effort leading to a published plan covering 2018–2021 that is now driving ICDR activities.

Organizational Structure

The leadership of the ICDR has been consistent over the years. Between 1978 and 2014, NIDILRR was the formal chair. In 1980, NIHR and the Rehabilitation Services Administration were

transferred to the newly formed U.S. Department of Education (ED) from the Department of Health, Education and Welfare along with the ICHR. The first ICHR meeting was held after the transfer (Ackerman, 2002). The Rehabilitation Act Amendments of 1986 changed the name of the NIHR to the National Institute on Disability and Rehabilitation Research (NIDRR) and the name of ICHR to ICDR via technical amendment. WIOA brought significant changes for the ICDR in 2014. It relocated NIDRR to the Administration for Community Living in HHS and changed the agency name to NIDILRR. The ICDR chair was changed from NIDRR to the Secretary of HHS. However, once NIDRR was officially moved to HHS, the new chair elected to designate NIDILRR to remain as chair in its new home. Early on, NIDILRR established the Executive Secretary position, filled by a senior staff person, to oversee ICDR operations. The level of effort of this person varied over the years.

ICDR statutory membership expanded over the decades with various reauthorizations. The ICDR began with eight statutory members, which grew to 12 in 1986, and then to 17 in 2014. Founding statutory members were NIHR, the Rehabilitation Services Administration, ED, VA, the National Aeronautics and Space Administration, the National Science Foundation (NSF), the U.S. Department of Transportation (DOT), and the National Institutes of Health (NIH). In 1990, the National Center for Medical Rehabilitation Research (NCMRR) was created within the National Institute of Child Health and Human Development at NIH; NCMRR subsequently became the designated representative to the ICDR for NIH. The Office on Disability Employment Policy (ODEP) was created in 2001 at the U.S. Department of Labor. This new agency became an ICDR participant immediately and was named a statutory member in 2014. Importantly, from the very beginning, agencies that were not identified in the statutes but had an interest in disability programs, policy, or research were invited to participate. Non-government personnel were also invited to participate, ensuring representation of a wide range of perspectives.

To manage the range of issues under its purview, the ICDR employs subcommittees and working groups in various forms. Some working groups are short-term, responding to a specific issue, while others are ongoing. For example, the Interagency Subcommittee on Disability Statistics (ISDS) was continuously active from about 1981 to 2015. Typically, ongoing working groups reflect the ICDR mission and plans. Non-statutory

members are active in these groups. This structure has provided both consistency and agility in ICDR operations.

Budget

The ICDR is constrained by its limited budget. It is essentially a volunteer activity for everyone involved. As chair, NIDILRR provides professional staff time for leadership and management. Member agencies donate their representatives' time. In the mid-1990s, NIDILRR contracted for logistics support for ICDR meetings out of its own budget to help reenergize the ICDR. For a few years in the early 2000s, the ICDR received approximately $3 million annually as part of President Bush's 2001 New Freedom Initiative (NFI), designed to increase access and integration for the disability community. The NFI specifically charged the ICDR to improve coordination of the federal AT and development research program and provided funds to support the execution of that charge. That was the only time the ICDR experienced a large influx of funds. Otherwise, NIDILRR finances logistics and management support and other agencies donate their staff time and funds for specific activities on a case-by-case basis.

Historical Overview by Decade

In its first decade, the ICDR was establishing itself. It had four different chairs during that time and meetings were irregular. The Executive Secretary position was created and 8–10 subcommittees were formed. All federal agencies with any disability-related responsibilities and interested non-government organizations were invited to participate. For example, in 1984, 32 federal agencies and 16 non-government organizations were active. The main threads of work during this decade were to consolidate information about federal rehabilitation research projects, analyze available survey data, and develop accessibility guidelines. The ICDR facilitated interagency agreements between NIHR and the VA as well as the National Institute of Mental Health (Ackerman, 2002).

In its second decade, the ICDR gathered strength in alignment with the success of the ADA and the increased attention to disability issues in the federal government. Members cooperated with National Council on Disability research and policy efforts and sponsored two comprehensive IOM assessments that established a shared conceptual framework for disability research programs. The ICDR advocated for new ways to measure disability in context, integration of disability issues into the mainstream of U.S. science and technology policy and research, and inclusion of

people with disabilities in the research process itself (i.e., participatory action research models). The ICDR contributed to accessibility guidelines, organized interdisciplinary conferences on emerging technologies, and advanced national health data collection efforts.

In its third decade, the ICDR was asked to do more. The White House and Congress requested several analyses, and President Bush's NFI directed the ICDR to improve coordination of the federal AT research and development. The ICDR formed working groups to meet these new requirements. The main emphases were technology development and transfer, emergency preparedness, employment, and traumatic brain injury (TBI) and mental health among veterans. Important interagency conferences and stakeholder focus groups were held to identify emerging research needs. With the availability of additional funds, the ICDR implemented management improvements such as strategic plans, search tools, and a website.

In the most recent decade, the ICDR continued work in national disability statistics and IL themes such as community living and accessible transportation. It brought heightened attention to employment research gaps and health disparities issues to help advance research in these areas. With the significant administrative changes in WIOA, the ICDR focused on executing the required move to the Administration for Community Living. Extensive work on the strategic plan was completed, including stakeholder input, expert panel recommendations, and working group deliberations. The mandated government-wide inventory was well underway. All current working groups were implementing the steps of the 2018–2021 strategic plan.

The ICDR has served well as a coordination hub for disability and rehabilitation research in the federal government. It has adapted and evolved with scientific advances, social and political change, and administrative priorities to move the research forward and sustain progress toward the empowerment and integration of people with disabilities.

ICDR ACHIEVEMENTS AND BENEFITS

A broad mission scope, low budget, and complex policy environment have challenged the ICDR for the past 40 years. The ICDR has focused on important topics such as statistics, technology, medical rehabilitation, employment, health care services, IL, and the research enterprise itself. It is difficult to trace

the impact of ICDR efforts that spark change. The tangible outcomes typically develop years later through the direct work of member agencies. Nonetheless, with the dedication and contributions of many ICDR leaders and members, the ICDR coordination activities have helped create new knowledge, enhance the federal scientific endeavor, improve disability programs and services, and inform policy to improve the quality of life for citizens with disabilities. Select achievements are described below.

Improving National Data Collection

Since its inception, the ISDS worked tirelessly to improve the quality and availability of data about people with disabilities. By the mid-1990s, the ISDS was an important forum for federal agencies and outside researchers to share information and technical assistance on a range of topics. It instituted worldwide Envision conferencing technology with six sites (one in Geneva, Switzerland, for the World Health Organization) for its meetings and boasted over 150 members and a 600-person mailing list at its height. High-quality data and statistics are needed to improve policies and programs and generate new research ideas. The ISDS focus evolved as the field progressed.

Expanded Available Data

The need for national-level data collection about people with disabilities was a major concern of the ISDS over many years. Such data is critical to understanding the status, progress, and current needs in the disability community. In the 1980s, ISDS advised HHS and the Census Bureau on the need for and strategies to collect data. The ISDS employed Dr. Inez Storck to compile statistics requested by federal agencies in 1989, which led to a 1991 commercial publication, *Disability in the United States: A Portrait from National Data*, edited by Dr. Storck and Susan Thompson-Hoffman (Ackerman, 2002).

In the early 1990s, the ISDS supported the development of the 1994–1995 National Health Interview Survey on Disability. This survey was the first comprehensive survey to collect national population-based data on children with disabilities and people with developmental disabilities. More than 15 different agencies participated in creating the survey, all needing data they did not have. The ISDS provided an active forum for sharing information and technical advice to develop the survey. This survey became a vital source of data to study disability, impairment, and health in the U.S. for 20 years and was used in 212 published papers over

20 years. It was unique in that it contained a variety of measures, covered an array of topics, and could be generalized to subpopulations (Ward et al., 2015).

Also in the 1990s, the ISDS participated in the formal interagency effort to update the 2000 Census. Two disability questions were added to the Census 2000 survey, a significant advancement toward more widely accepted measures (Adler, 1999). The ISDS then provided extensive consultation on the long form of the Decennial Census, which became the ACS. It reviewed the measure of disability, documented potential uses of the data, assessed the reliability of measures, and tested new questions. Ultimately, six disability questions were accepted into the ACS in 2005. Today the ACS offers a unique combination of data that can be analyzed at the national, state, and local levels and can be used to estimate trends over time. These data help target services, administer public and private disability programs, and evaluate new programs. (Weathers, 2005). In 2010, HHS established data collection standards for disability, designating the ACS disability questions as the minimum requirement for surveys. These questions are included in 17 different federal surveys today related to health, education, economics, housing, and crime victimization. Some of the major surveys are the Behavioral Risk Factor Surveillance System, Medical Expenditure Panel Survey, National Health Interview Survey, Survey of Income and Program Participation, Current Population Survey, and American Housing Survey.

Updated Measurement Model

The development of a clear and consistent conceptual model of disability across the government was another major concern of the ISDS. In 1995, the ICDR study on the statutory definitions of disability in 50 federal acts and programs found that many different definitions were in use. Most were designed to determine program eligibility or benefits, making interagency data comparisons difficult. This effort highlighted the definitional problems and was widely distributed and cited. The ISDS also advised the U.S. Social Security Administration (SSA) on definitional questions related to its disability determination process and the National Committee on Vital and Health Statistics on definitions of disability for data standards for Health Insurance Portability and Accountability Act implementation (ICDR, 2000).

The ISDS incorporated the concept of disability as an "enabling/disabling" continuum from health condition to disability

into large population-based surveys. ISDS members worked with the World Health Organization to understand its classification system — the International Classification of Impairment, Disability and Handicap — and to later advise on its revision. The new version, the International Classification of Functioning (ICF), released in 2001, synthesized the medical and social models of disability. The ISDS then encouraged use of the new schema in federal research. It held two state-of-the-art conferences on the application of the ICF in 2002–2003 and produced a catalog of studies using the ICF model in 2004. The major disability research funding agencies — NCMRR, NIDRR, and VA — support research applying the concepts from the ICF model, which illustrates how the model has become an integral part of the research portfolio.

Promoting Research on Emerging Technologies

Technology, AT, and UD have been key components of the ICDR agenda from its early days. Technology applications were expanding rapidly during this time and the AT field began to take shape. When the ICDR received funds through the NFI, a wide range of activities were completed. The ICDR completed literature reviews, solicited stakeholder input, and held agenda-setting conferences on specific AT topics such as mobility devices, prosthetics, hearing aids, brain-computer interfaces, and alerting devices. These meetings included multiple federal agencies, outside researchers, and stakeholders. They provided current data to help agencies plan their research agendas and identify opportunities for joint activities. The proceedings were widely distributed to the field. The ICDR has identified and promoted emerging technologies that could improve health, work, and IL outcomes for people with disabilities.

Identified Vision Technologies

In the 1980s, the ICDR facilitated interagency agreements between NIHR and VA that funded 16 technology development projects. The Kurzweil reader for people with blindness was one of the technology advancements supported by these projects (Ackerman, 2002). Ray Kurzweil developed the optical character recognition and text-to-speech technologies for the reader and is considered a pioneer in this field. These innovations have stimulated other improvements and applications for both the disability and mainstream communities. For example, optical character recognition led to new scanning technology, closed captioning, and voice activation. These applications are now commonly used with phones, computers, and virtual assistants.

Wayfinding was new technology recognized by the ICDR. In 1999, the technology working group completed a literature review and then held a conference on wayfinding for persons with visual disabilities. The conference included NIDRR, VA, Access Board, and NSF experts as well as consumer advisors. NIDILRR later funded a research and training center on the topic for many years. Products such as Talking Signs for indoor navigation and, later, an app for talking signs were developed. Work in this area now focuses on using Global Positioning System technology. NIDILRR, NSF, and the U.S. Department of Defense (DOD) continue to fund research and development of cutting-edge accessible wayfinding products that support community participation for individuals with visual impairments.

Accelerated Cognitive Technologies

In 2006, the ICDR addressed early cognitive technologies. The ICDR catalogued current federal research projects and completed a literature review on the topic. It then held a 2-day national forum for clinicians, researchers, consumers, providers, advocates, and industry to share information and innovative ideas about the state of the science in assistive and accessible technologies that support the needs of people with cognitive disabilities. Findings were published in two journals: *Disability and Rehabilitation* and *Disability and Rehabilitation: Assistive Technology*. Now, cognitive aids are more integrated into classrooms and workplaces. Memory and organization aids are in common use. NSF, NIH, NIDILRR, and VA continue to support advanced technology research and development projects that can benefit everyone.

Facilitated New Transportation Technologies

The ICDR facilitated new research on accessible transportation through interdisciplinary conferences and advising on standard development and UD. As part of a weeklong accessible transportation forum in 2003, the ICDR sponsored the *Wheeled Mobility and Accessible Transportation Summit*, which produced prioritized research needs for safe and accessible paratransit, intelligent transportation systems, and UD. The ICDR also coordinated with the DOT Federal Transit Administration and the National Council on Disability to identify strategies to enhance ridership on public transportation. Beginning in 2014, the ICDR collaborated with the DOT Accessible Transportation Technologies Research Initiative. The ICDR provided input into the planning and user profiles proposed by DOT, and in June 2015 cosponsored a

Roundtable on Accessible Transportation Technologies Research, which addressed the need for interagency collaboration to advance accessible transportation research. Representatives of 12 federal agencies identified promising technologies and generated ideas for future collaborations to create an inventory of related research, to pilot and demonstrate new accessible technologies, and to share data. Subsequently, DOT and NIDILRR co-sponsored a 2018 *Accessible Transportation Symposium* to discuss how autonomous solutions can transform accessible transportation, personal mobility, and independent travel. In addition, NIDILRR currently partners with the Accessible Transportation Technologies Research Initiative by funding a research center on applications in robotics and automation technology.

Recommended Technology Transfer Improvements

Technology transfer, or getting new products to commercial market, is an important part of improving the availability of assistive devices. The technology working group addressed a wide range of commercialization impediments. In the 1990s, the working group coordinated with the Federal Laboratory Consortium to link university-based researchers with its regional laboratories. In the 2000s, it examined and made recommendations for improving public-private partnerships, intellectual property concerns and patents, and funding mechanisms such as the Small Business Innovation Research program. To better understand the industry perspective, the ICDR worked with the U.S. Department of Commerce to design a survey of the AT industry and conducted two focus groups in 2004 with AT industry representatives. The reports were shared with working group members. In addition, the ICDR examined consumer perspectives on barriers to acquiring AT through an extensive series of regional focus groups. ICDR work during this period contributed by describing the federal effort and gaps, identifying consumer wants and needs, and then bringing together researchers, manufacturers, end-users, and policymakers to prioritize a research agenda, facilitating a breadth of federal support for AT research, development, and transfer in a fast-moving field.

Developing Accessibility Guidelines

Improving accessibility of all kinds has been and continues to be a major theme for the ICDR. The form of accessibility-related activity changed over time as the policy and technology worlds evolved. The ICDR worked with many other agencies to bring

research-based evidence and UD principles to the development of standards and guidelines for the physical, electronic, and information environments. In the 1980s, one working group provided input to standards development for accessibility to the built environment as required by the Architectural Barriers Act of 1968. It published a primer, *Toward an Accessible Environment: Effective Research*, that informed the work of the now-named Access Board (Ackerman, 2002). After that early period, the ICDR largely focused on electronic and information technology access.

Advised on Electronic, Communication, and Information Technology Guidelines

As laws were passed promoting full access for people with disabilities, the ICDR offered technical expertise in developing standards, guidelines, and regulations to support implementation of these laws. Section 508 of the Rehabilitation Act requires federal agencies to make their electronic and information technology accessible to all. Section 508 first appeared in law in 1973. Early on, the ICDR produced a report that became a Federal Information Resources Management Regulation on Section 508 and a booklet entitled *Access to Information Technology by Users with Disabilities* (Ackerman, 2002).

A series of laws in the 1990s — the ADA, the Television Decoder Circuitry Act of 1990, and the Telecommunications Act of 1996 — acknowledged the accessibility rights of people with disabilities and amplified the federal government's role in addressing solutions through new technology, systems change, and UD. Section 508 was strengthened in 1998 by amendment to the Rehabilitation Act through the addition of compliance mechanisms. The ICDR participated on the Advisory Committee on the Section 508 Recommendations for Government Procurement to develop accessibility guidelines for electronic office equipment (ICDR, 2000).

Under the NFI directives in the early 2000s, the ICDR addressed a wide range of electronic and information technology accessibility topics. The ICDR held agenda-setting conferences and completed literature reviews on telecommunications, broadband access, cloud computing and the Global Public Inclusive Infrastructure, and Section 508 implementation. The ICDR worked with ED, Access Board, Federal Communications Commission, and DOD on these topics. For example, in 2003, the AT working group sponsored a conference on *Interference to Hearing Technologies by Digital Wireless Telephones* at Gallaudet University to address

the lack of usability of digital cellular phones by both hearing aid users and cochlear implant wearers. The hearing aid and telecommunications industries, consumer advocacy groups, health providers, academic research centers, and relevant federal agencies were all represented. This conference occurred 1 month after the Federal Communications Commission released its final *Report and Order* requiring U.S. telecommunications handset manufacturers to design hearing aid-compatible telephones, thus promoting a more effective industry response to the requirements, which led to better cell phone access for individuals with hearing limitations.

Fostered Accessibility of Health Information Technology Systems

More recently, the ICDR focused on the accessibility of health information technology (HIT). The ICDR began to monitor developments in 2005, reviewing federal activities to incorporate standard disability terminology into electronic health records. After the Health Information Technology for Economic and Clinical Health Act of 2009 was passed, the ICDR played a key role in bringing accessibility issues to the table during the implementation process. In collaboration with NIDILRR and Healthy People (HP) 2020 participants, the ICDR convened a working group that contributed to the development of accessibility standards for the new HIT system to ensure that people with disabilities would not be excluded. The group also identified research needs to promulgate accessibility, usability, and UD principles within the HIT community (ICDR, 2011). In 2015, the ICDR cosponsored a large conference on the topic, leading to collaboration with the Office of the National Coordinator at HHS, the lead agency for HIT. This ongoing relationship is critical to keep attention on the needs of the disability community. Each time technology advances or systems change, the accessibility concerns must be reevaluated.

Enhancing Emergency Management Practices

After 9/11, it became glaringly apparent that the needs of people with disabilities in emergency situations had not been well considered. The newly formed NFI working group took on the challenge. In 2003, the group completed a review of research on evacuation technologies and UD applications. In 2004, President Bush issued Executive Order 13347 establishing the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC). The NFI working group served as the ICC

Research Subcommittee chair (DHS, 2005). In 2004, the ICDR compiled data on relevant federal research projects and reviewed the literature, revealing a paucity of empirical research and data. The ICDR sponsored a 2-day conference in October 2004 on *Emergency Evacuation of People with Physical Disabilities from Buildings* involving federal agencies, first responders, building safety experts, evacuation device manufacturers, people with disabilities, and mobility device and human factors researchers. An extensive set of recommendations highlighting the need for federal support for emergency evaluation guidelines, training, standards for evacuation devices, and egress modeling were offered. The proceedings document was widely distributed. In December 2005, it was the third most popular link on the DisabilityInfo.gov web site (ICDR, 2007).

The working group continued assessing the status of disability-related emergency management research in 2005–2006 by surveying federal agencies, compiling research recommendations, leading interagency discussions, and soliciting public input. The ICDR collected input from the public on this topic through its existing website, bringing it to the ICC deliberations. The ICDR also reviewed the accessibility and compatibility of existing emergency mass communications systems with AT such as TTY devices. As a member of the ICDR, the Access Board took a lead role in planning a 2-day conference entitled *State-of-the-Art Conference on Technologies and Strategies for Physical Transfers of Individuals with Motor Impairments*. In 2007, an online document, [Emergency Management Research and People with Disabilities: A Resource Guide](#), was published reflecting a joint effort by NIDILRR, ED, the ICC Research Subcommittee, and the ICDR NFI working group. In addition, NIDILRR began funding research on emergency management topics. Ultimately, the Federal Emergency Management Agency hired its first disability coordinator in 2007 and established a new [Office of Disability Integration and Coordination](#) in 2010 to lead the federal effort. The ICDR responded to an important national concern and led the research component of a comprehensive federal effort to improve the safety and well-being of people with disabilities in an emergency. New research was supported and a new federal program was created to ensure ongoing attention to the issue.

Advancing Traumatic Brain Injury Knowledge
In the early 2000s, the medical rehabilitation working group focused on TBI when it became priority concern due to the

increase in combat injuries and sports concussions. Significant discussions were held around surveillance and data needs, robotic assistive device support for rehabilitation, and treatment guidelines for pediatric TBI. A task group with seven different agencies was formed to explore the feasibility of a common minimum data set for TBI interventions, and the National Institute of Neurological Disorders and Stroke took the lead on this issue. In 2012, the Federal Interagency Traumatic Brain Injury Research Informatics System was established to develop a biomedical informatics system and data repository for TBI research using common data elements. This "big data" system holds promise for accelerating TBI research (Thompson, 2015). Numerous agencies are collaborators, including ICDR member agencies.

In 2006, the ICDR held two focus groups with U.S. military veterans and a public stakeholder meeting that informed the ICDR agenda on veterans' issues, including TBI and PTSD. The ICDR coordinated with the office of the Deputy Assistant Secretary of the Navy and the U.S. Army Wounded Warrior Program and proposed strategies to enhance research on the VA hospital system capacity for care and other strategies to improve access to care for veterans with mental health disabilities (ICDR, 2007). The Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury was established in 2007 at the Defense Health Agency to promote comprehensive state-of-the-science care and reintegration services. These improved information-sharing activities led to broader participation by military research entities in the ICDR.

In 2012, President Obama issued an Executive Order directing DOD, VA, HHS, and ED to develop a National Research Action Plan on PTSD, other mental health conditions, and TBI to improve the coordination of agency research and improve prevention, diagnosis, and treatment. With this mandated interagency effort, the ICDR closed out its own work. The Action Plan was published in 2013. Among its many recommendations were the need for ongoing portfolio analyses, development of standard data elements that could be shared, and leveraging of other research initiatives such as DOD's Brain Research through Advancing Innovative Neurotechnologies Initiative. By bringing an awareness to important TBI concerns, the ICDR helped kindle the creation of specific, targeted interagency efforts to continue the work.

Informing the Employment Research Agenda

Vocational rehabilitation services and employment research have been a regular feature of ICDR pursuits for decades. The employment working group has examined issues such as supported employment, employment measurement, work disincentives, transition to work, access to postsecondary education, employment and mental health, and employment policy barriers and best practices. It has collaborated with the President's Task Force on Employment of Adults with Disabilities, the Bureau of Labor Statistics, SSA, ODEP, and others. ODEP became the co-chair of the employment working group upon its formation as a new agency. The working group organized large summits and focus groups and conducted literature reviews that informed the federal research agenda. Member agencies entered into joint activities. For example, SSA and NIDILRR agreed to promote return-to-work for beneficiaries, ODEP and the Office of Special Education and Rehabilitative Services collaborated to support information exchange and consensus-building activities on employment issues, and the National Institute of Child Health and Human Development and NIDILRR agreed to partner to address health and employment gaps relevant to the NFI (ICDR, 2003).

Highlighting the Employer Perspective Research Gap

Since 2005, the employment working group has focused extensively on employer perspectives in disability employment issues, an identified research gap. The working group organized a series of large, collaborative meetings to inform the federal research agenda.

- *Employer Perspectives on Workers with Disabilities: A National Summit to Develop a Research Agenda* was held in 2006. This was an early meeting bringing the business and research worlds together. Many of the recommendations focused on making better use of research and data through partnerships and knowledge translation as well as prioritizing employer-side research. Subsequently, both NIDILRR and ODEP began to fund research and demonstration projects in line with the recommendations.
- *The Research Roundtable* was held in 2007. This was a working meeting of federal agencies designed to shape a more specific agenda.

- *Strengthening the Intersection of Demand-Side and Supply-Side Disability Employment Research: Toward a Coordinated Federal Research Agenda* was a 3-day conference held in 2008. Participants identified nexus research activities to inform a 5-year disability employment research agenda, suggested ways to translate research into action, and discussed partnering opportunities.
- *Disability and Employment Symposium: Research Informing Practice and* Policy was held in 2015. Symposium participants included approximately 150 researchers, practitioners, policymakers, advocates, students, consultants, and others interested in disability and employment issues. Employer perspectives was a major theme discussed at the symposium. Recommendations centered on how to promote the use of research among employers and practitioners.

The foundational work of the ICDR — bringing together the many stakeholders in the disability employment system to promote collaboration — has contributed to advancements in the employment environment. Employer awareness was increased and useful policy incentives, supportive resources, and recognition programs exist to support businesses in hiring and retaining people with disabilities. There is also an array of research and demonstration programs and technical assistance resources offered by NIDILRR, ODEP, SSA, and the Employment Training Administration.

Integrating Disability into the Federal Health Disparities Agenda

The federal health disparities agenda, largely focused on racial and ethnic groups, gained prominence in the 2000s. The Centers for Disease Control and Prevention HP program, begun in the 1990s, identifies and measures a broad range of health improvement goals by decade. HP 2000 included a goal to reduce health disparities. In 2000, President Clinton signed the Minority Health and Health Disparities Research and Education Act (P.L. 106-525), which created the National Institute on Minority Health and Health Disparities at NIH to lead scientific research to improve minority health and eliminate health disparities. This law raised the visibility of the NIH minority health disparities agenda. In 2005, the ICDR determined that disability issues needed to be more fully integrated into these broader federal actions.

The ICDR began to participate in HP 2010 planning activities and the newly formed Federal Collaboration on Health Disparities Research working group managed by the National Institute on Minority Health and Health Disparities. In 2007, the ICDR conducted a survey of active health disparities research projects. It found 119 projects of which only one identified disability as a target group. In 2010, the ICDR hosted listening sessions and an expert panel on health disparities and disability. It also held health disparities discussions as part of its 2010 *Health, Disability and Technology State of the Science Conference*. In 2011, the ICDR established a formal working group on health and health disparities. The group participated in the Federal Interagency Health Equity Team and the Patient Centered Care Collaboration to Improve Minority Health and reviewed the Agency for Healthcare Research and Quality's National Healthcare Quality and Disparities Reports.

Through ICDR efforts, disability is being incorporated into the federal health disparities agenda. For example, the ICDR co-sponsored the HHS *2012 Summit on the Science of Eliminating Health Disparities* and secured five disability-related sessions on the agenda that were well attended. The HP 2010 included a separate chapter for disability for the first time, which has continued. Health disparities remains an important component of the ICDR strategic plan today.

Modeling Stakeholder Input

While in 1998 the ICDR was directed by law to gather input from individuals with disabilities and their representatives, in alignment with the disability rights movement the ICDR has included people with disabilities since its establishment. The ICDR has excelled at obtaining input from disability research stakeholders, including individuals with disabilities. Every year, thousands of people and organizations provide input through various mechanisms: working group membership; specific priority planning meetings and webinars; formal hearings and conferences; and focus groups, surveys, and written public comment. Some notable efforts over its history include:

- The highly visible *Public Forum on Disability Research* was held on June 7, 1995, in the Hearing Room of the Dirksen Senate Office Building in Washington, D.C., to collect consumer input on the research agenda. Senior government officials heard the testimony of disability

research stakeholders in the areas of technology, employment, IL, and data.

- For 6 months in 2003, the ICDR collected comments from the public on its website. There was wide promotion in the disability community about the new site and comment form. The ICDR collected comments from the public about technology, education, employment, community life, and health care. Seven hundred seventy-three individuals provided 1,872 comments. The analysis was shared with the ICDR membership.
- From 2003–2005, the ICDR conducted 36 focus groups across the country with people with disabilities on their AT needs. Approximately 300 consumers participated. The qualitative data were analyzed and findings presented to the ICDR to ensure consumer perspectives were considered in the setting of agency research priorities.
- More recently, for the preparation of the government-wide strategic plan, the ICDR used an inclusive process. All working groups included nonfederal stakeholders recruited through outreach to organizations related to disability, rehabilitation, and IL research and other relevant topics. The ICDR also held three stakeholder webinars, widely publicized in the disability community. In 2016, NIDILRR invited public comment on the ICDR draft plan through a formal *Federal Register* Notice. The ICDR formally addressed all feedback in the final strategic plan.

Stakeholder input is vital information to identify and prioritize research needs. Most other agencies sponsoring disability and rehabilitation research and programs now include representatives of the disability community in their peer review operations, advisory boards, and other planning activities. Some agencies require grant applicants to show how consumers were part of the proposal and will be part of the program. Through its successful outreach and accessible event management, the ICDR has encouraged more inclusive research planning and evaluation approaches in the federal government.

Facilitating Information Sharing and Networking

The ICDR's primary mission is to promote coordination of the federal disability and rehabilitation research effort. Before coordination can begin, a common knowledge base and good working relationships are needed. Over the years, the ICDR has

advanced coordination through information sharing and networking activities that build connections among members.

The ICDR has conducted extensive information sharing with ICDR members as well as the general public. The Executive Committee and working groups hold regular meetings. Typically, these meetings included substantive presentations and discussion. Larger activities and conferences were organized as agreed upon by the ICDR membership. All of these forums consistently provided venues for information exchange. In addition, the ICDR prepared background research papers and technical reports as needed to both compile and analyze the status of federal research in various topical or administrative areas. These reports provided a consolidated view to help members more readily assess next steps.

To address the broader scope of disability research, the ICDR developed systems to collect and share cross-agency funding information. The systems changed with technology advancements. Each of these tools was designed to gather and combine funding information to help members identify gaps, duplications, and opportunities for joint projects. In the 1980s, the ICDR created the Interagency Rehabilitation Research Information System. It was a simple database of active federal research projects, compiled manually. In 2000, the ICDR developed a web gateway to consolidate access to existing agency sites. An effort to develop a more sophisticated tool, the Research Manager, began in 2002. The Research Manager was a 508 compliant "portal" that searched four agencies' (NIH, NSF, NIDRR, Agency for Healthcare Research and Quality) public project databases and combined the results in one set. Significant effort went into aligning search terms and their meanings across databases. Changes in the targeted agency databases and a loss of funding led to the discontinuation of the tool around 2007. Currently, the ICDR is developing the mandated government-wide inventory using NIH RePORTER as detailed in the strategic plan. In 2017, the National Institute of Neurological Disorders and Stroke, NCMRR, and NIDILRR contributed funds for the NIH Library to create disability portfolio analyses using the Federal RePORTER system to meet the ICDR inventory objective.

Participation in these information-sharing and other ICDR activities helps develop informal relationships among agency representatives. Good working relationships can foster collaboration. Members have invited each other to participate in

other interagency groups, offer expert advice, and serve as peer reviewers. Other collaborations to share data and align funding efforts have occurred. Examples of these outcomes are documented throughout the report. While formal collaborations are difficult to achieve, the short-term individual connections made through networking can provide a foundation for future interagency cooperation on a larger, more formal scale.

FUTURE OUTLOOK

Federal research and development has contributed to significant gains in quality of life for people with disabilities, their families, and caregivers. Still, many important needs remain for this diverse and growing population. The nature of disability and rehabilitation is cross-cutting and the scope of concerns is extensive. Issues related to health, technology, employment, and IL are often complex and intertwined. They can involve individual, community, and service system arenas. The federal effort continues to be widely dispersed and underfunded. This set of circumstances clearly points to the critical need for interagency coordination and collaboration to better address multifaceted issues.

More generally, the federal government focuses on the importance of coordination and collaboration. In the last decade, due to the increase in agency responsibilities, program complexity, and pressure to reduce expenditures, calls for better collaboration between federal agencies have increased (Kaiser, 2011). For example, the Government Performance and Results Act Modernization Act of 2010 requires agencies to set goals and measure performance, including the use of cross-organizational collaboration to achieve shared goals. A recent analysis on the future of government by the Partnership for Public Service and Ernst & Young, offered the following conclusion:

> *We learned that for the government of the future to flourish, agencies must develop more robust and broad-based connections—doing a better job of working with one another, collaborating internally, engaging the public and establishing ties with stakeholders from outside government.*

This analysis validates the effectiveness of the very types of activity the ICDR has engaged in for decades. It is clear there is broad federal support for the ICDR role.

The ICDR has served well in this coordination function over its history and will continue to do so. But it is by no means a simple task. By building on and expanding its inclusive approach, the ICDR can continue to make progress in this complex environment. To strengthen its approach, the ICDR will need to carefully prioritize its agenda. The ICDR can identify cross-cutting research topics that are important and that the science can address. The new strategic plan with goals, objectives, and strategies reflects a prioritization process. It is an effective way to systematically reduce research gaps, leverage coordination, and encourage collaboration with buy-in from member agencies. This coordination enables each agency to use available resources more efficiently in service of its own goals as well as the federal research enterprise as a whole. It will also enhance the documentation of collaborative activities and outcomes, building the case for future partnerships. At the same time, one of the ICDR's strengths has been its ability to respond to unexpected external events to advance disability research. It will be important to recognize and leverage such opportunities when they may arise.

The ICDR has contributed by analyzing and strengthening the federal research enterprise, advancing new research ideas and technologies, expanding disability data collection, promoting stakeholder inclusion, stimulating new programs, and encouraging research partnerships across myriad disability topics. With active participation by federal agencies, the ICDR can continue to coordinate the federal disability and rehabilitation research program to maximize its value and improve the quality of life for U.S. citizens with disabilities.

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