

Interagency Committee on Disability Research (ICDR)

Executive Committee Meeting

Thursday June 4, 2015
9:00 a.m. - 12:00 p.m.

Leadership:

- John Tschida, ICDR Chair, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS)
- Kristi Wilson Hill, PhD, Interim Executive Director, ICDR and Deputy Director, NIDILRR, ACL, HHS

Welcome and Introductions

John Tschida, ICDR Chair, thanked attendees for joining the meeting and invited all to introduce themselves. He provided an update on the NIDILRR transition from the Department of Education to HHS.

Tschida reviewed the meeting agenda and meeting purpose to focus on continuing the strategic planning process for the ICDR.

ICDR Strategic Plan Update

John Tschida, ICDR Chair

The integration of NIDILRR into the ACL provides the opportunity for new partnerships. WIOA gives NIDILRR and the ICDR the responsibility of independent living. Though the core mission of the ICDR will not change, leadership will need to accommodate the interests of the rehabilitation, aging and independent living communities as well as services and research perspectives. Kathy Greenlee, Administrator of ACL, is working to gain support for the ICDR from the Secretary of HHS.

Key points from the discussion on merging services and research interests included:

- The National Institutes of Health (NIH) is recognizing that certain biomedical studies are best conducted in community settings, especially for longitudinal work. This may be an opportunity for the ICDR.
- The National Science Foundation (NSF) supports studies that incorporate networking with organizations that provide services as well as research networks.
- The Agency for Healthcare Research and Quality (AHRQ) is encouraging research that can occur in many settings and between settings. Topics of aging with a disability and aging into a disability are also of interest. This is an opportunity for partnerships.

Tschida noted that the ICDR will report on the status of the strategic planning process to Congress by the end of the calendar year, but the plan itself does not have to be completed by then. As a start, ICDR leadership is currently drafting letters to the following new statutory member organizations:

- Assistant Secretary of Labor, Disability Employment Policy
- Secretary of Defense
- Administrator, Administration for Community Living
- Administrator, Small Business Administration

Leadership is also considering resource documents to prepare a strategic planning framework. The ICDR Executive Committee will meet again around August or September to review a draft template or guide for the process.

Co-Chair Meeting Follow-Up

The ICDR Co-Chairs and Facilitators met in May to review and discuss standing committee roles and the ICDR's mission and operations moving forward. Tschida and ICDR Interim Executive Director, Kristi Wilson Hill, facilitated a frank and open discussion. The major recommendations for the ICDR leadership included:

1. Increasing transparency in ICDR processes, resources, and deliverables.
2. Improving the website as a tool to facilitate communication and recruit new members. The URL of the ICDR Collaborative Workspace (<https://icdrteam.ed.gov>) will change to <https://icdrteam.acl.gov>, to accommodate NIDILRR's move to ACL. ICDR leadership and New Editions Consulting, Inc. are also working to determine ways in which the Collaborative Workspace could be used and configured more effectively.

Rehabilitation and Independent Living: Exploring Models for Building Successful Collaboration and Outcomes

Glen W. White, PhD, Professor, Applied Behavioral Science, Director, Research and Training Center on Independent Living, University of Kansas

Dr. White shared a presentation on four research models that may support effective collaboration between rehabilitation and independent living. He co-developed the presentation with three of his colleagues: Kelly Buckland, Kurt Johnson, and Tom Seekins. The presentation draws from various disciplines and models to open up a broader discussion of ways to better understand the environment and its affect on people with disabilities who wish to live more independently in the community.

- Independent Living: From Social Movement to Analytic Paradigm (Glenn W. White, PhD)
 - DeJong's Paradigm Comparison parallels traditional and modern views of disability. The traditional model defines disability as a problem within an individual, requiring professional intervention. The independent living model states that disability arises from an inaccessible environment, and offers solutions such as barrier removal, advocacy, self-help, and consumer control.

- The Independence-Interdependence Model describes a continuum of independence and interdependence. At the interdependence end of the continuum, there is a greater emphasis on building social capital capacity among consumers so they can participate in their communities to the fullest extent.
- In the Consumer-Empowered Team approach, input from consumer-consultants, advocate leaders, and parents/liaisons drive the research questions, shape procedures, and develop methods in order to carry out more socially relevant studies.
- Independent Living Perspective (Kelly Buckland)
 - Disability is a social construct.
 - People with disabilities are the best experts on their own needs, and require opportunities to make decisions on their own lives.
 - Data from RSA-funded Centers for Independent Living indicate that outreach to Hispanics with disabilities, peer support, and skills training are three knowledge gaps in need of research.
- Health and Function Research Perspective Involving Independent Living (Kurt Johnson)
 - Following the Agricultural Extension Model, research for independent living should cycle from identifying problems/opportunities in the community; to developing solutions with researchers; to participative planning by the communities and supported implementation from the communities.
 - Evaluation is part of the program design. The researchers help the participants review and reflect on implementation to adapt the program and manage from the experience.
 - Clinical trials, research studies, and surveillance research should include opportunities for people with the disabilities to collaborate by defining research agendas; deploying and evaluating outcomes and products; refining and revisiting research questions; and incorporating ecological validity.
- Rehabilitation and Independent Living Research and Practices for an Era of Community Living (Tom Seekins)
 - Ecological models link to the International Classification of Functioning, Disability and Health (ICF). Environment influences disability.
 - An ecological model can lead to a better understanding of disability and participation. Two surveys that gauge this are:
 - The Survey of Participation and Receptivity in Communities (SPARC)
 - The Community Health Environment Checklist (CHEC)
 - Established ecosystem methods such as camera trap, remote sensing, and capture-recapture can be adapted to understand community dynamics and establish baselines; monitor community conditions and participation; and promote advocacy and community development.

Discussion/Q & A

- Health disparities research is supporting interdisciplinary and collaborative research through the team science model and considers environmental factors. A recent journal

- article made the case to include people with disabilities in the health disparities concept. There is a recognized need to move people out of silos in this field as well.
- NSF has used the extension model successfully for training activities in gender studies. It is a natural model for serving people with disabilities in rural areas.
 - AHRQ also encourages research that includes extension agents. They utilize large networks and personal connections with the community to promote participation in research.
 - The ICF plus other measures have potential applications for assessing outcomes in the community context model.
 - While independent living centers promote independence, people often remain dependent on the center. Teaching people with disabilities to advocate for themselves in the community is key to real independence and participation.

WIOA Requirement for a “Searchable Government-Wide Inventory” of Research

Daofen Chen, PhD, National Institute of Neurological Disorders and Stroke, National Institutes of Health

Wilson Hill expressed the need to determine how the ICDR will meet the WIOA mandate for a “searchable, government-wide inventory,” and asked Daofen Chen, Co-Chair of the Interagency Committee on Medical Rehabilitation (ICMR) to further discuss the Federal RePORTER; a government-wide research repository.

Chen noted that the ICDR currently lacks landscape knowledge of existing research projects. A database containing such information can minimize duplication and maximize research efforts and funding. The Federal RePORTER has a potential to become a powerful disability research search tool if multiple agencies were willing to contribute. Ideally, the repository would allow federal-wide identification of research trends, funding information, and researcher contacts. Initially developed as a tool to track the American Recovery and Reinvestment Act of 2009 (ARRA) spending, NIH and NSF lead the Federal RePORTER initiative. Other participating agencies include the VA, AHRQ, FDA, and CDC.

Wilson-Hill opened up the discussion to the Executive Committee. The following outlines the Committee’s initial thoughts on using the Federal RePORTER/a searchable repository:

- ICDR needs to outline requirements and a budget for the use and adoption of a repository.
- Since projects come and go, it may be useful to focus on programs that are more stable.
- An inventory of existing government search engines may be helpful.
- It is important to determine the end user of this repository. For instance, if the repository is open to the public, it may be different than one that is used internally in the federal government.
- The [Query, View and Report \(QVR\)](#) repository could be used as a model for what Federal RePORTER use should look like. However, the QVR holds certain information that cannot be released to the public.

- The ICDR would have to obtain backing from upper level decision makers to achieve widespread agency adoption of the Federal RePORTER.
- The [U.S. Government Accountability Office \(GAO\)](#) could be a strong supporter of the Federal RePORTER as they push for research uniformity.
- A unified code for disability recommended by agencies would increase the usefulness of the inventory.
- Results of searches on the Federal RePORTER could potentially be posted on the ICDR web site.

Following the discussion, the Executive Committee endorsed the ICMR plan to explore the option for the ICDR to use the Federal RePORTER.

Standing Committee Reports

Interagency Committee on Assistive Technology (ICAT)

- David Baquis, U.S. Access Board, will join Kathy McCoy as co-chair.
- *ICDR Roundtable on Accessible Transportation Technologies Research* will be held on June 26, 2015, 8:30am – 12:30pm. The Roundtable will involve sharing scholarly and experiential knowledge related to accessible technology and transportation to identify partnership opportunities that will spur innovation and increase transportation and mobility options for people with disabilities. Mohammed Yousuf (DOT) is chairing this Roundtable.
- *Accessible Health Information Technology (HIT) State of the Science Conference* is being planned for September 17-18, 2015. Margaret Campbell (NIDILRR) and Samantha Meklir (ONC) are co-chairing this conference. The SOS co-chairs are reworking the agenda to update the event's objectives and redesign the current panels. Two topics that are being considered on the conference agenda are using technology for self-managing health, and accessibility in Health IT.

Interagency Committee on Employment (ICE)

- The *Disability and Employment Symposium: Research Informing Practice and Policy* will be held on June 24, 2015, 8:45 am – 4:30 pm at the U.S. Department of Labor. The Symposium will examine the state of the science and interactions among employment, research, practice, and policy. Leslie Caplan (NIDILRR), Cassandra Shoffler (RSA) and Cherise Hunter (DOL) co-chair this conference.

Interagency Committee on Disability Statistics (ICDS)

- Co-chair John Hough was unable to attend, so he submitted a report that summarized the topics presented at recent ICDS quarterly meetings. He also requested guidance from the ICDR on what the committee's goals should be, and suggested the need for additional agency representatives from Census Bureau, Centers for Medicare and Medicaid Services (CMS), U.S. Department of Housing and Urban Development (HUD), Social Security Administration, and the U.S. Department of Transportation (DOT). A complete ICDS update can be found in [Appendix B](#).

Interagency Committee on Health and Health Disparities (ICHHD)

- ICHHD is hosting a series of webinars to promote awareness of current research related to the biological, sociocultural, environmental, and behavioral determinants of health disparities for people with disabilities. The next webinar, “Health Disparities: Race and Ethnicity” will be held on Tuesday, July 21, 2015 from 2:00 – 3:00 pm. The following two presentations will be given:
 - Persons with Disabilities and Participation in Clinical Trials – Raegan W. Durant, MD, MPH, University of Alabama at Birmingham
 - Multiethnic Caregiving for Disability Populations – Heather M. Young, PhD, RN, FAAN, University of California, Davis.

Interagency Committee on Medical Rehabilitation (ICMR)

- ICMR co-chairs Harvey Schwartz (AHRQ) and Daofen Chen (NINDS/NIH) stated that the ICMR is focusing on the potential relevance of the Federal RePORTER to meet ICDR needs for government-wide disability research portfolio.

Agency Announcements

- *2015 Agency for Healthcare and Research Quality Research Conference: Producing Evidence and Engaging Partners to Improve Health Care* will be held on October 4-6, 2015. AHRQ will hold the conference at the Crystal Gateway Marriott Hotel in Crystal City, Virginia. AHRQ is cohosting the event with Academy Health to bring authorities in health care research and policy together to participate in sessions focused on addressing today’s challenges in improving quality, safety, access, and value in health care.
- Kathy McCoy noted that few data sources utilizing questions regarding people with disabilities are currently available, and with increasing use of Information and Communication Technologies (ICT) and health data, this is a big issue.
- Regarding the reporting process, John Tschida explained the ICDR will update Congress on the status of the strategic plan in the annual report, but will not compress the strategic planning process into that timeframe. Structural frameworks and guidelines will be presented at the next Executive Committee meeting.
- The ICDR Collaborative Workspace site will also need to be updated. Several committee members expressed that it is unusable in its current state. ICDR leadership and contractor, New Editions Consulting, Inc., are working to remedy this issue.

Adjournment

Appendix A

Participants

Statutory Members and Co-chairs

- Eric Ansoorge, PhD, U.S. Army
- Dawn Beraud, PhD, Science Policy Analyst, National Institutes of Health
- Timothy Brindle, PhD, Scientific Program Manager, U.S. Department of Veterans Affairs
- Daofen Chen, PhD, Program Director, Extramural Research Program, National Institute of Neurological Disorders and Stroke
- Susan Daniels, PhD, Director, Office of Autism Research Coordination, NIMH
- Carl V. Hill, PhD, MPH, Director, Office of Special Populations, National Institute on Aging
- Cherise Hunter, PhD Social Science Research Analyst, DOL/ODEP
- Mark H. Leddy, PhD, Program Director, Division of Human Resource Development, Directorate for Education and Human Resources, National Science Foundation
- Kathy McCoy, PhD, NIDILRR, U.S. Department of Health and Human Services
- Harvey Schwartz, PhD, Senior Advisory, Priority Populations, Agency for Healthcare Research & Quality, U.S. Department of Health & Human Services
- Cassandra Shoffler, Management and Program Analyst, Rehabilitation Services Administration, U.S. Department of Education

NIDILRR Staff

- John Tschida, Director, NIDILRR, U.S. Department of Health and Human Services
- Kristi Wilson Hill, PhD, Deputy Director, NIDILRR, U.S. Department of Health and Human Services

Speakers and Others

- Glen White, PhD, Professor, Applied Behavioral Science; Director, Research and Training Center on Independent Living, University of Kansas

New Edition's Consulting, Inc. Staff

- Betsy Tewey, Vice President
- Cherie Takemoto, MPA, Project Director
- Sadie Hagberg, Standing Committee Coordinator
- Rachel Saenz, Standing Committee Coordinator
- Robin L. Toliver, Conference Manager

Appendix B

INTERAGENCY COMMITTEE ON DISABILITY STATISTICS Calendar Year 2015 Activities and Report on “2015 Specific Goals”

The ICDS has conducted two meetings this year, featuring good presentations by talented investigators whose research had utilized a variety of federal data sets containing disability-related variables. We have to report limited progress, though, on achieving the Committee’s “2015 Specific Goals.”

The ICDS meeting on February 11th featured a timely presentation by Dr. Wan He from the Aging Studies Branch at the Bureau of the Census, on the report she co-authored entitled [Older Americans with a Disability: 2008-2012](#). This report utilized the “Six-Question Set” for determining disability status within the American Community Survey. One important finding had been the geographic distribution of older Americans who reported having a disability: not just in the well-known “Stroke Belt,” but in very large proportions within specific large counties in those states. This indicates a need for intervention programs at the level of the big-county health department, to engage in targeted health promotion toward prevention of secondary conditions.

The second presentation had been equally timely. Dr. Susan Havercamp and Haleigh Scott from the Nisonger Center on Developmental Disabilities at Ohio State University delivered a presentation entitled [“National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with No Disabilities.”](#) This CDC-funded research combined data from the Ohio Behavioral Risk Factor Surveillance System and the National Core Indicators Consumer Survey, to outline potential health disparities among Ohio adults with intellectual disabilities. Their study involved a unique combination of two surveys.

The Committee’s May 13th meeting featured Dr. Alisha Coleman-Jensen from the Economic Research Service within the Department of Agriculture. She summarized her seminal 2013 publication entitled [“Food Insecurity Among Households with Working-Age Adults with Disabilities.”](#) Then, Dr. Dianna Carroll, Senior Health Scientist from the CDC Disability and Health Branch, delivered an extensive presentation from a 2014 “Vital Signs” report published through the *Morbidity and Mortality Weekly Report*, entitled [“Vital Signs: Disability and Physical Activity – United States, 2009-2012.”](#) Dr. Carroll’s team utilized data from the National Health Interview Survey to prepare a nifty package of “Vital Signs” resources, including an infographic and tips for physicians. Dr. Carroll also provided a short report on her deployment to Sierra Leone as part of the agency’s response to the Ebola outbreak.

Our Committee can report only limited progress toward achieving the “Specific Goals” set forth in the ICDR’s FY15 Strategic Plan. For example, we were to begin working on a series of webinars, including ones entitled “Getting Started with Disability Statistics” and “How to Use the *Integrated Health Interview Series* to Assess Health Status among Americans with Disabilities.” And, although we made some progress with our colleagues in the Interagency Committee on Health and Health Disparities (ICHHD) toward preparing a webinar potentially entitled “How to Use the NCI Health Disparities Calculator to Assess Disability-Related Health Disparities,” such a product might no longer be in demand. To their credit, on April 7th our ICHHD colleagues produced an outstanding webinar featuring the authors of a recent article in the American Journal of Public Health entitled [“Persons with Disabilities as an Unrecognized Health Disparity Population.”](#) But ICDS needs more guidance from the ICDR leadership about whether the “Specific Goals” remain pertinent or within the scope of available resources. The depth of the Committee’s meetings would also benefit from having consistent “seat-at-the-table” representation from such Departments or agencies as Agriculture (as demonstrated by Dr. Coleman-Jensen’s report), the Census Bureau, CMS, HUD, SSA, and Transportation.