U.S. DEPARTMENT OF EDUCATION

THE INTERAGENCY COMMITTEE ON DISABILITY RESEARCH

2004–06 REPORT TO THE PRESIDENT AND CONGRESS

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Prepared for: U.S. Department of Education
Office of Special Education and Rehabilitative Services
National Institute on Disability and Rehabilitation Research (NIDRR)

On behalf of: Interagency Committee on Disability Research (ICDR)
Chaired by: Tracy R. Justesen, Acting Director of NIDRR

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This report was produced by Cherry Engineering Support Services, Inc. (CESSI) under U.S. Department of Education Contract No. ED04CO0032 on behalf of the Interagency Committee on Disability Research (ICDR). Maggie Hatton served as the Contracting Officer's Representative. The views expressed herein do not necessarily represent the positions or policies of the U.S. Department of Education or member agencies of the ICDR. No official endorsement by the U.S. Department of Education, or any ICDR member agency, of any product, commodity, service, or enterprise mentioned in this publication is intended or should be inferred.

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December 2007

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This report is available on the Department of Education's Web site at http://www.ed.gov/rschstat/research/pubs/index.html.

It is also available on the ICDR's Web site at http://www.icdr.us.

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All hyperlinks and URLs were accessed on September 19, 2007.

December 2007

The Honorable George W. Bush
President of the United States
The White House
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500

Dear Mr. President:

As acting chair of the Interagency Committee on Disability Research (ICDR), I am pleased to submit the enclosed *2004–06 Report to the President and Congress*. The report details noteworthy activities in the reporting period, including ICDR scientific meetings and highlights of projects that support your New Freedom Initiative (NFI). As is the tradition of the ICDR, we also sought the input of individuals with disabilities and other stakeholders, with the goal of ensuring the relevance of our activities to their needs.

Of particular importance during this reporting period, the ICDR maintained interagency participation by 12 agencies statutorily mandated and five additional agencies, as well as adding three new agencies during the reporting period. Additionally, information dissemination; studies of emerging issues and topics in disability and rehabilitation; surveys of program, funding, and research activities; and assessment of gaps in research planning and coordination helped to increase the capacity of the ICDR and participating agencies to partner, enhance collaboration, and address potential duplication of effort.

On behalf of the members of the ICDR, I appreciate your continued support and interest in the ICDR's work. We will continue to work toward the success of the NFI by increasing access to assistive technologies, expanding educational opportunities, promoting integration of individuals with disabilities into the workforce and participation in community life, and contributing to efforts to improve the health and function of persons with disabilities.

Respectfully yours,

Tracy R. Justesen
Acting Chair, Interagency Committee on Disability Research
Acting Director, National Institute on Disability and Rehabilitation Research

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ABBREVIATIONS

ADA	Americans with Disabilities Act
CDC	Centers for Disease Control and Prevention
DoD	Department of Defense
FCHDR	Federal Collaboration on Health Disparities Research
GAO	Government Accountability Office
HD	Health Disparities
HHS	Department of Health and Human Services
ICDR	Interagency Committee on Disability Research
ISE	Interagency Subcommittee on Employment
IT	Information Technology
NFI	New Freedom Initiative
NIDRR	National Institute on Disability and Rehabilitation Research
NIH	National Institutes of Health
PTSD	Post-Traumatic Stress Disorder
RRTC	Research and Training Center on Workplace Supports and Job Retention
TBI	Traumatic Brain Injury
VA	Department of Veterans Affairs
VBA	Veterans Benefits Administration

EXECUTIVE SUMMARY

This report addresses the mission of the Interagency Committee on Disability Research (ICDR), as established in legislation. During the reporting period the ICDR continued to work to further interagency committee participation through expansion of its operational structure to include subcommittees on disability statistics, medical rehabilitation, technology, employment, and the New Freedom Initiative. Of particular note for this report is the Subcommittee on Employment established in 2004. While 12 agencies and offices are mandated by statute to participate in the ICDR, both representatives from those 12 agencies and representatives from an additional eight interested agencies participate in the committee. Of the eight additional agencies, three were new, having joined ICDR during the reporting period. From the beginning, ICDR has worked to broaden the range of participating federal agencies beyond those statutorily mandated, engaging them in deliberations that support the mission to coordinate disability research and foster collaboration and cooperation.

Although federal agencies are the primary membership of the ICDR, in accordance with legislative mandate the ICDR is also guided by stakeholder input. The involvement of stakeholders helps to ensure the relevance of the federal research agenda and provides new perspectives on the disability experience, sometimes suggesting the need for reassessment of the disability research portfolio. Notable during the reporting period was the input from a pair of focus groups held with U.S. military veterans and a 2006 public stakeholder meeting, both of which continue to inform the ICDR agenda on veterans' issues.

During this period, ICDR member agencies began to communicate with military agencies such as the office of the Deputy Assistant Secretary of the Navy and the U.S. Army Wounded Warrior Program in order to explore potential ways to coordinate research and collaborate to improve information sharing and outcomes. From such work, the ICDR has learned more about the need for a better-coordinated system to provide services to veterans returning with disabilities, especially veterans with brain injuries and post-traumatic stress disorder. This new knowledge has informed ICDR proposals for enhanced research on the VA hospital system capacity for provision of care and coordination across systems and other selected topics of concern related to veterans returning home with disabilities.

Similarly, the ICDR's employment agenda is based on an evolutionary process involving ongoing assessment of the state of the science and stakeholder needs. The ICDR's Interagency Subcommittee on Employment (ISE) was established in 2004 with the goal of assessing gaps and needs in disability employment research and knowledge. ISE's assessment of the state of the science in employment research led the subcommittee to conduct the 2006 employment summit involving public and private agencies. From this summit, the ICDR has learned that there is a dearth of research on the question of how corporate hiring and retention policies and practices affect employment of persons with disabilities. The summit provided the opportunity for greater understanding of employer needs and perspectives on disability employment. As a result of the summit, employers have asked the ICDR to establish a forum for ongoing dialogue and information-sharing partnerships.

While these two topics, veterans' issues and employment, present critical concerns, health disparities between persons with disabilities and persons without disabilities and within and across disability populations present an equally challenging concern. The ICDR placed the topic of health disparities on its agenda in 2005. Initially this topic received limited attention. However, two factors led to the realization that health disparity research merits increased attention. First, during the reporting period the ICDR reviewed *Healthy People 2010* (2nd edition, published in 2000 by HHS) and saw that disability issues surrounding health disparities were not well developed. Second, on May 24, 2006, CDC and the Office of Minority Health/Office of Public Health and Science (HHS) cosponsored the Federal Collaboration on Health Disparities Research (FCHDR) Workgroup meeting in Washington, D.C., focused on collaborative research efforts to eliminate health disparities. Seeing the need for inclusion of disability issues in research on health disparities, ICDR responded. Several ICDR member agencies participated in the workgroup, and one initiated discussions about the possibility of inviting representatives from the workgroup, other federal agencies, and experts from the private sector to meet with the ICDR to discuss the state of the science in health disparities research and disability issues. As a result of this discussion, the ICDR arranged a joint meeting with CDC and the Office of Minority Health/Office of Public Health and Science (HHS) scheduled for 2007 to determine future directions and the role of the ICDR, including the possibility that ICDR will co-lead health disparities research initiatives with the CDC and other federal agencies.

With regard to the ICDR mission, health disparities, and the other key topics mentioned in this section (i.e., veterans and disability employment), this report represents a compilation of highlights of the activities and accomplishments from 2004–06. Although the dynamic nature of ICDR interagency activities cannot be fully captured in this report, the narrative reflects the collaborative process and efforts to fulfill the unique mission of the ICDR. This report primarily features the ICDR's identification of issues in each of the three key topics; the committee's assessment of the program, funding, and research activities in each to determine gaps and duplication in research; and the committee's research recommendations intended to inform the federal disability research agenda.

While this report identifies ICDR activities that have potentially informed federal agency disability research activities, no attempt is made to demonstrate a direct relationship or cause-and-effect based on ICDR activities, as this is not the mission of the committee. However, informal feedback from the representatives of multiple agencies indicates that ICDR discussions and deliberations have influenced federal agency research agendas and activities.

INTRODUCTION

The Interagency Committee on Disability Research (ICDR), authorized by the *Rehabilitation Act of 1973* as amended[1], seeks to promote coordination, collaboration, and cooperation among federal departments and agencies conducting disability and rehabilitation research. It comprises 12 agencies mandated by statute and eight additional participating agencies. Of the eight additional agencies, three were new, having joined ICDR during the reporting period. The ICDR features interagency subcommittees on disability statistics, medical rehabilitation, technology, employment, and the New Freedom Initiative, but the Interagency Subcommittee on Employment (ISE) is the one of most concern to this report. The mandate of the ICDR specifies the following:

- Identify emerging issues and topic areas in disability and rehabilitation that would benefit from coordinated research planning, program development, and federal funding efforts;
- Assess gaps and duplication in existing research programs, activities, and plans across agencies; and
- Seek to coordinate existing or planned research, programs, activities, or projects among federal agencies.

Below are highlights of key activities and priority issues identified and addressed during the reporting period. Each of the following sections attempts to capture the state of the science in the associated priority area, followed by a summary of related committee activities for 2004–2006 and recommendations for future directions.

Highlights of Key Activities and Key Issues

Issue Identification: To identify relevant items for the federal disability research agenda, the ICDR full committee directs stakeholder input activities to hear from individuals identified in the ICDR authorizing statute as targeted individuals. Stakeholder input activities help the ICDR build a picture of current and projected disability research needs, as well as increase understanding of strengths, gaps, and opportunities for collaboration among existing or planned disability research efforts. Stakeholder input activities held during the reporting period include: three stakeholder meetings; an online consumer advocacy group review; collection of public comments regarding disability research needs via the ICDR public Web site; and 36 regional consumer focus groups. Reports from these efforts will be available following approval for public release at the ICDR public Web site at http://www.icdr.us.

Research Coordination: Research coordination activities build on stakeholder input activities. ICDR members select topics for an annual ICDR summit as well as state-of-the-science conferences sponsored by the ICDR subcommittees. Invitees for these meetings include ICDR members, other federal experts, and experts from universities, research institutes, and policy organizations. Meetings foster potential collaborations among researchers who meet during events, and proceedings are disseminated to the wider research

[1] *Rehabilitation Act of 1973, U.S. Code* 29 (2006), §763.

community. For example, ICDR sponsored the 2004 conference "Emergency Evacuation of People With Physical Disabilities from Buildings," and the proceedings document was shared widely[2]. In December 2005, based on the number of recorded downloads, this document was the third most popular link on the DisabilityInfo.gov Web site[3]. It is also one of the most frequently downloaded documents from the ICDR Web site (http://www.icdr.us)[4].

In 2006, the Interagency Subcommittee on Employment sponsored "Employer Perspectives on Workers with Disabilities: A National Summit to Develop a Research Agenda." This summit represented one of the few opportunities for researchers, business leaders, industry representatives, policymakers, and advocates to jointly discuss the research issues related to improving employment opportunities for people with disabilities.

Gap Assessment: In addition to identifying emerging issues and promoting research coordination, the ICDR takes steps to assess gaps and duplication in existing disability and rehabilitation research programs, activities, and plans across agencies. As mentioned above, one way such problems may be discovered is through discussion at conferences. Other efforts to achieve this goal include reviews of studies conducted by federal agencies to identify critical issues and research gaps. However, many studies do not give adequate attention to disability issues, as ICDR discovered in reviews of research related to veterans' issues, unemployment, and health disparities. This lack of attention to disability issues may result from agencies' lack of capacity and expertise to do so, as well as the fact that agency missions are not generally focused on disability. For example, the 2004 ICDR conference mentioned above highlighted the near absence of research into issues faced by persons with disabilities in situations requiring rapid evacuation from locations in which an emergency is occurring. From its 2006 annual summit, the ICDR learned that there is a dearth of research into how corporate hiring and retention policies and practices affect employment of persons with disabilities.

Healthy People 2010[5], while not explicitly identifying disability research gaps, does suggest a multitude of issues that can be extrapolated to reveal disability research gaps. After analysis of the content of *Healthy People 2010*[6], the ICDR established the goal of communicating with researchers who are pursuing topics identified in this document to promote research that sufficiently includes disability issues. More specifically, the committee maintains the issue of health disparities on its agenda and will do so through at least 2007. It also advocates for disability issues as a regular item on the agenda of the Federal Collaboration on Health Disparities Research (FCHDR) Workgroup.

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[2] U.S. Department of Education, Interagency Committee on Disability Research, *Emergency Evacuation of People With Physical Disabilities From Buildings: 2004 Conference Proceedings,* http://www.icdr.us/proceedings.html.

[3] Robert Jaeger, personal communication, January 2006.

[4] U.S. Department of Education, Interagency Committee on Disability Research, Monthly Web Usage reports for ICDR Public Site (ICDR internal document), January 2006–September 2006.

[5] U.S. Department of Health and Human Services, *Healthy People 2010*. 2nd ed. (Washington, D.C.: U.S. Government Printing Office, 2000), http://www.healthypeople.gov/Document/tableofcontents.htm#under.

[6] Ibid.

Through the key activities described above, ICDR has sought to coordinate federal disability research, assess gaps, and identify emerging issues. The remainder of this report presents highlights of activities and accomplishments from 2004–06 with regard to the three topics identified as priority issues for disability and rehabilitation research:

- Veterans;
- Disability employment; and
- Health disparities.

Please note that while the ICDR makes recommendations, it does not prescribe the federal research agenda and activities for agencies.

SECTION I—VETERANS

Notable during the reporting period was the input from a pair of focus groups held with U.S. military veterans. Input from the 2006 public stakeholder meeting, a review of rehabilitation research funding trends in the Department of Veterans Affairs, and two forums reported in 2004 also informed the ICDR agenda and research agendas of some member agencies.

Assessment of Gaps and Duplication

During the reporting period, ICDR research coordination activity in this topic area centered on information gathering. The ICDR conducted an extensive research review to identify contemporary work on veterans' issues. This review was conducted over a period of several weeks by ICDR contract staff who consulted defense-related Web sites, federal research repositories such as the *Computer Retrieval of Information on Scientific Projects (CRISP*) database and the *National Rehabilitation Information Center (NARIC)* database, and contemporary news sources. It is important to note that at present the vast majority of veterans' disability research is conducted by either the Department of Veterans Affairs (VA) or the Department of Defense (DoD) Health Program.

VA has responded to the Traumatic Brain Injury (TBI) issue by implementing policy guidance[7] for screening and clinical management of TBI, as well as by establishing four regional poly-trauma rehabilitation centers to provide poly-trauma beneficiaries necessary specialized intensive rehabilitation processes and coordination of care across the full continuum[8]. The U.S. Government Accountability Office (GAO) calls for DoD and VA to provide adequate staff resources and improve business processes, involving coordination of a single physical exam process and information sharing between both agencies[9].

Significant efforts launched by DoD and VA continue to be aimed at discerning the specific impact of post-traumatic stress disorder (PTSD) on service members and veterans, defining meaningful strategies to improve psycho-social outcomes, and developing policy guidance and concurrent programs which can enable the reintegration of service members and veterans suffering from PTSD[10]. These efforts encompass an overall goal of amplifying resources available for multidisciplinary programs and services in health care, compensation and benefits, housing, education and training, employment, and other community-based initiatives for short-term and long-term recovery and reintegration of service members. For example, the National Center for PTSD is heavily involved in efforts to facilitate both outreach and self-help strategies for military personnel desiring to overcome the circumstances of PTSD and potential barriers to treatment.

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[7] U.S. Department of Veterans Affairs, Veterans Health Administration, *Undersecretary for Health Information's Letter: Screening and Clinical Management of Traumatic Brain Injury, IL 10-2006-004* (Washington, D.C., January 25, 2006), http://www1.va.gov/environagents/docs/USHInfoLetterIL10-2006-004.pdf.

[8] U.S. Department of Veterans Affairs, James A. Haley Poly-trauma Rehabilitation Center Web site, http://www.polytrauma.va.gov/facilities/Tampa.asp.

[9] GAO, *06-225T, VA Disability Benefits: Improved Transparency Needed to Facilitate Oversight of VBAs Compensation and Pension Staffing Levels* (Washington, D.C., Nov. 7, 2005), http://www.gao.gov/new.items/d06225t.pdf.

[10] Charles W. Hoge, M.D., et al., "Combat Duty in Iraq and Afghanistan, Mental Health Problems, and Barriers to Care," *New England Journal of Medicine* 351(1):13–22. (July 1, 2004).

On a broader scale, there is increasing concern about casualty care for injured veterans and access to a comprehensive continuum of care and case management services. Concerns related to transition between various components of care and localities, the availability of interdisciplinary expertise, and whether there is a coordinated plan of care for injured soldiers and veterans are priority issues.

Ongoing Research Recommendations

Ongoing research is urgently needed in the areas of TBI, PTSD, and continuity of care; such research is being advocated by VA and DoD, among other federal agencies. For TBI patients, future research should focus on the rapid evaluation of patients with neurological injuries, so that more functional examination algorithms and diagnostics tools and devices may be designed for use in the combat environment. Research addressing the challenges of providing continuing medical care and vocational and emotional support is also needed, especially because the cognitive and psychological after-effects of TBI can predispose this significant population to falling through the cracks of the military and veterans' healthcare systems[11]. The ICDR is in agreement that these are important issues, and recommends that the issues be addressed collaboratively. Non-DoD agencies such as NIH and the Department of Transportation are already engaged in research pertinent to the concerns identified by DoD and VA. However, knowledge translation and information dissemination across systems is often limited.

For PTSD patients, research is needed to investigate possible stigmatization of, rates of usage of, and barriers to mental health services, to ensure that those who are most at risk receive the necessary services, interventions, and applicable reintegration modalities. The need may be most acute for service members on active duty in Iraq, who have indicated that rates of combat and frequency of contact with the enemy are much higher than combat and contact experiences for their counterparts in Afghanistan[12]. The ICDR recommends that the DoD and VA's National Center for PTSD should coordinate immediate evaluations of service members upon their return home, and simultaneously address the problem of stigma and other barriers to seeking mental health care through outreach, education, increasing the allocation of mental health services in primary care settings, and counseling through employee assistance programs. These goals will continue to form a part of the ICDR effort to disseminate knowledge of its recommendations to member and non-member agencies, and to encourage agencies to incorporate these goals into their funding decisions.

The ICDR recommends further research in the areas listed below as they relate to veterans returning with disabilities:

- Traumatic Brain Injury (TBI);
- Poly-trauma;
- Psychiatric disability, especially post-traumatic stress disorder (PTSD);

[11] U.S. Department of Education, Interagency Committee on Disability Research, *Physical Rehabilitation Funded Research Assessment* (ICDR internal document, not yet cleared for public release).

[12] Charles W. Hoge, M.D., et al., "Combat Duty in Iraq and Afghanistan, Mental Health Problems, and Barriers to Care," *New England Journal of Medicine* 351(1):13–22. (July 1, 2004).

- The need for prosthetics and orthotics resulting from trauma or poly-trauma;
- VA hospital system capacity for provision of care and coordination across systems;
- Need for job training and assistance in gaining employment;
- Need for better information on available benefits; and
- Need for computer access to reduce isolation and provide information.

Military entities such as the Department of the Navy and U.S. Army Wounded Warrior Program are now in closer communication with some ICDR member agencies to explore potential ways to coordinate research and collaborate to improve information sharing and outcomes. As a result, the ICDR is in a position to play a guiding role in disability and rehabilitation research coordination activities through facilitation of discussions between DoD and other federal entities.

SECTION II—EMPLOYMENT

Employment research can be characterized as either supply-side (worker-focused) or demand-side (employer-focused). The ICDR selected the topic of demand-side employment issues relevant to persons with disabilities based on public recommendations for disability research received via the ICDR's public Web site at http://www.icdr.us, as well as public comments received during a public stakeholder meeting in May 2006. Members of the ICDR's Subcommittee on Employment also contributed perspectives based on their professional experience in the field of disability employment.

In September 2006, the Interagency Subcommittee on Employment (ISE) sponsored "Employer Perspectives on Workers with Disabilities: A National Summit to Develop a Research Agenda." This summit represented the beginning of an ongoing partnership among researchers, business leaders, industry representatives, policymakers, and advocates to jointly discuss research and concerns about improving employment opportunities for people with disabilities.

Assessment of Gaps and Duplication

Prior to 2006, most research in the area of disability and employment focused on people with disabilities as the unit of analysis. Research examined such individual characteristics as age, gender, ethnicity, education, socio-economic status, social support, degree of disability, and past work history. Past research also looked at environmental factors that influence employment outcomes for people with disabilities. While some research was conducted on employer attitudes, this represented the only relevant demand-side research for the period we examined, though subsequent meta-analysis might reveal other information[13].

During a four-month period in 2005, ICDR contract staff conducted an extensive Internet database and Web site search to collect information on all federally funded disability employment research and programs that were currently ongoing or were about to be undertaken. This systematic Internet search began with acquiring information from the Web sites of any federal agency and the offices within each agency relevant to the topic "employment and individuals with disabilities." ICDR reviewers used the following search terms:

- employment and disabled/disabilities
- disabilities/disabled and jobs
- disabilities/disabled and careers
- ADA

After completing the data collection, the reviewers used qualitative-analysis software (NVivo) to sort the information into such categories as:

- Supply-side research initiatives

[13] U.S. Department of Education, Interagency Committee on Disability Research, *Demand-side Research on Employment for People with Disabilities: An Emerging Area of Inquiry* (ICDR internal document, not yet cleared for public release).

- Supply-side programs
- Demand-side research initiatives
- Demand-side programs
- Target populations

In reviewing these findings, ICDR noted a strengthening in focus on demand-side studies in terms of a trend away from a narrow focus on employer attitudes toward a broader focus on employers' needs, concerns, and actual day-to-day practices. The committee found a growing interest in exploring corporate culture and its impact on hiring and retention of people with disabilities. This trend and the state of the science in employment research informed development of the ICDR employment agenda and committee activities.

Through its review of disability employment research programs and studies, the ICDR identified the following five formative or ongoing demand-side initiatives in the federal disability research arena:

- The School of Management and Labor Relations at Rutgers University is conducting a study analyzing a large employee survey dataset from the National Bureau of Economic Research. It will compare the work experiences and attitudes of employees with and without disabilities in relation to a set of distinct organizational cultures[14].
- The National Institute of Mental Health has a project called "Research on Community Reintegration for People with Psychiatric Disabilities." This project includes the identification and testing of strategies to help employers accept, train, and support employees with mental illnesses who are working to reintegrate into the community. (http://grants1.nih.gov/grants/guide/pa-files/PA-03-144.html)
- The Brain Injury Research Center (a NIDRR-funded Rehabilitation Research and Training Center) administers a program which includes assessment of employers' attitudes toward persons with traumatic brain injury and a pilot educational intervention to reduce attitudinal barriers in the workplace. (http://www.tbicommunity.org/training/newsletter/Spring2004.pdf)
- The (NIDRR-funded) IT Works Project's goal is to identify barriers to and facilitators of the hiring, retention, accommodation, and advancement of persons with disabilities in the IT industry. (http://bbi.syr.edu; http://disability.law.uiowa.edu/lhpdc/research/index.html)
- The NIDRR-funded Research and Training Center on Workplace Supports and Job Retention (RRTC) funds two long-term research projects: (1) determining the efficacy of public/private partnerships, and (2) determining the efficacy of business mentoring and career-based interventions with college students with disabilities. (http://www.worksupport.com/research/index.cfm)

Viewed as a group, these initiatives begin to address all of the ICDR-identified recommended areas for specific focus in employment research.

[14] Lisa Schur and Douglas Kruse, "Corporate Culture and the Attitudes of People with Disabilities in Organizations," part of the symposium on "Potentially Negative Effects of Corporate Culture on People with Disabilities" sponsored by the Society for Industrial and Organizational Psychology, Inc., Division 14 of the American Psychological Association, 2006. (Contact APA for copy.)

Ongoing Research Recommendations

The above activities represent important first steps in developing a demand-side knowledge base that can be relied on by employers, service providers, persons with disabilities, policymakers, and researchers. The amount of attention and funding being given to demand-side research is, however, still not commensurate with its importance or with the stated goals of federal policy to increase employment and retention rates for people with disabilities. Through discussions in ISE meetings, especially the 2006 ICDR summit, and through research reviews, the ICDR has learned that there is a dearth of research into the ways in which corporate culture and corporate decision-making in terms of hiring and retention affect employment of persons with disabilities.

The ICDR identified a set of recommended areas for specific focus in employment research:

- The impact of employer organizational culture on disability employment;
- Employer needs and concerns regarding hiring and retention;
- Employer and co-worker perceptions and attitudes toward persons with disabilities;
- Research into devices and approaches that enable people with mental disabilities to participate in work;
- The potential positive effect of training and mentoring programs;
- Research into job structures and accommodations necessary to hire and retain people with disabilities in the IT job market;
- The role of government in promoting hiring of persons with disabilities; and
- Employment data and other national health surveys that provide data on the employment status of people with disabilities.

The ICDR is aware of the importance of improving communication and information sharing between public and private entities with an interest in disability employment topics, and will work to promote such information sharing. Improved communication between such entities will help form the basis for a better-informed federal research agenda in this area. ICDR-led activities will significantly contribute to this important dialogue and coordinated effort.

SECTION III—HEALTH DISPARITIES

The ICDR began to discuss the topic of health disparities in full committee and subcommittee meetings in 2005. Although attention to this issue was limited between 2005 and 2006, the ICDR has since determined that health disparities should receive additional attention through at least 2007. A number of factors, including ICDR's review of disparity-related material in *Healthy People 2010* and the recent establishment of the CDC-led Federal Collaboration on Health Disparities Research (FCHDR) Workgroup, influenced and supported the ICDR's decision to promote appropriate attention to health disparities issues for persons with disabilities within the overall ICDR agenda.

Assessment of Gaps and Duplication

The *Minority Health and Health Disparities Research and Education Act of 2000* (Public Law 106-525)[15] defines health disparity populations as those 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. In general, this is interpreted to mean significant inequalities or inequities in access to, utilization of, or quality of care, health status, or health outcome between the general population and subpopulations as defined by racial and ethnic minority status, residents of rural areas, women, children, the elderly, persons with disabilities, and other vulnerable populations. The CDC notes that many federal agencies are mandated by law to define health disparities for specific populations, or to use specific reference points for measuring disparity. The ICDR is in a unique position to promote integration of disability issues across the federal health disparities agenda.

Little is known about health disparities within and across disability conditions or between people with disabilities and those without, and support for further exploration is needed. Such was ICDR's determination based on the results of an ICDR survey of health disparities research projects active in fiscal year 2006. The goal of this review was to identify any 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 review will be available upon clearance for public release on the ICDR's Web site at http://www.icdr.us.

The committee identified 119 individual research projects or research programs on health disparities. Funded by agency:

- Department of Health and Human Services, 51 projects or programs;
- Department of Veterans Affairs, 31 projects or programs;
- Department of Education, 30 projects or programs; and
- National Science Foundation, 7 projects or programs.

[15] *Minority Health and Health Disparities Research and Education Act of 2000*, Pub. L. No. 106-525, http://www7.nationalacademies.org/ocga/laws/PL106_525.asp.

In nearly all of the 119 projects or programs, the concept of persons with disabilities as a group is absent or at least not stated. The studies focus on individuals grouped by age, gender, ethnicity, socio-economic status, nationality of birth, geographic location, homeless status, or income, but they almost uniformly neglect to look at persons with disabilities as a group. Only one study, sponsored by the National Institute of Dental and Craniofacial Research, specifically examined disparities in oral health between children with special health care needs and other children.

Ongoing Research Recommendations

As a strategy to promote research to eliminate such health disparities across racial, ethnic, and socioeconomic groups, in 2006 the Centers for Disease Control and Prevention (CDC) in collaboration with the Department of Health and Human Services Office of Minority Health convened a meeting to discuss exploratory recommendations from an earlier federal partners meeting. During its initial deliberations, the Federal Collaboration on Health Disparities Research (FCHDR) selected four initial focus areas—obesity, co-morbidity; mental health, and the built environment—as representing areas of opportunity for reducing health disparities among demographic groups[16].

The committee continues working with the FCHDR to:

- Increase understanding of the emphasis on health disparity-related activities, especially disparities between persons with disabilities and persons without disabilities and within and across disability populations, in the missions and priorities of other agencies involved in the federal research collaborative;
- Contribute to discussion about issues directly related to the four priority topic areas (i.e., disability concerns related to obesity, built environment, co-morbidity, and mental health);
- Identify and bring together subject matter experts and use their expertise to review recommendations and expand and refine those recommendations to create an interagency strategic plan for collaboration;
- Expand on the selected research priorities to include a focus on identification, translation, and dissemination of interventions that are effective in preventing, reducing, and eliminating health disparities for people with disabilities; and
- Consider potential opportunities and steps needed to create joint funding opportunity announcements and other strategies and mechanisms.

In 2006, ICDR members who were also members of the FCHDR approached the full ICDR committee to initiate discussion about ways in which the committee could help further the work of the CDC-led workgroup. One potential activity discussed was sponsorship of a conference that would include representatives from the workgroup, other federal agencies, and experts from the private sector. These individuals would meet, along with the ICDR members, to discuss the state of the science in health disparities research as it pertains to people with disabilities. As a result of these preliminary talks, the ICDR made plans to host, with CDC, a joint conference on

[16] Office of Behavioral and Social Sciences Research, National Institutes of Health, *Health Disparities PAR–R01: Behavioral and Social Science Research on Understanding and Reducing Health Disparities* (June 7, 2007), http://obssr.od.nih.gov/Content/Health_DisparitiesPAR_R01.htm.

health disparities and disability to take place sometime in fall 2007.[17] The committee is also in discussion with the FCHDR to co-lead other health disparities initiatives. The ICDR will continue to assist in furthering the goals of the FCHDR as they pertain to disability-related research issues, and contribute to outcomes by taking the lead in promoting dialogue among the various agencies involved.

[17] Please note: The two-day Health Disparities Summit was held on Sept. 18–19, 2007, in Alexandria, Va. The meeting summary will be posted on the ICDR Web site, http://www.icdr.us, following approval for release to the public by the Department of Education.

APPENDIX A: STATUTORY AUTHORITY FOR THE ICDR

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.

APPENDIX B: ICDR MEMBERS

Statutory members include:

- 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 the Interior for Indian Affairs
- Director of the Indian Health Service
- Director of the National Science Foundation

Other participating agencies include:

- Department of Agriculture
- Department of Commerce
- Department of Defense
- Department of Energy
- Department of Housing and Urban Development
- Department of Justice
- Department of Labor
- Social Security Administration

POINT OF CONTACT

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