

Disability and Rehabilitation Research Coalition

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Comprehensive Recommendations for Improving the Lives of Individuals with Disabilities by Enhancing the Federal Commitment to Disability and Rehabilitation Research

COMPREHENSIVE RECOMMENDATIONS SUBMITTED TO CONGRESS

**ON BEHALF OF THE FOLLOWING MEMBERS OF THE
DISABILITY AND REHABILITATION RESEARCH COALITION (“DRRC”):**

**American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association of Spinal Cord Injury Psychologists and Social Workers
American Congress of Rehabilitation Medicine
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Therapeutic Recreation Association
Amputee Coalition of America
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Brain Injury Association of America
Christopher and Dana Reeve Foundation
National Association for the Advancement of Orthotics and Prosthetics
National Association of Rehabilitation Research Training Centers
National Association of State Head Injury Administrators
National Council on Independent Living
National Spinal Cord Injury Association
United Spinal Association**

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INTRODUCTION

Individuals with disabilities and their families and representatives are demanding change—change that recognizes that disability, like race and gender, is a natural part of the human experience and change that is designed to maximize the achievement of the goals of federal disability policy articulated in the Americans with Disabilities Act, i.e., equality of opportunity, full participation, independent living and economic self-sufficiency. Disability and rehabilitation research plays a critical role in enabling and empowering individuals with disabilities to live the American dream, consistent with the precept and goals of federal disability policy.

The Disability and Rehabilitation Research Coalition (DRRC) is pleased to provide this policy analysis to Congress regarding how well the existing federal research programs are responding to the changing needs and expectations of individuals with disabilities. Based on this analysis, we suggest specific ways to enhance future disability and rehabilitation research efforts. The recommendations included in our analysis provide a roadmap for improving the employment, independent living, and health and function of individuals with disabilities by developing and implementing a comprehensive research agenda focused on disability and the rehabilitation of individuals with disabilities.

The DRRC is a coalition of national non-profit organizations committed to improving the science of rehabilitation and disability. The DRRC seeks to maximize the return on the federal investment in such research with the goal of improving the ability of Americans with disabilities to live and function as independently as possible. The Coalition plays a leadership role in increasing and leveraging federal resources devoted to disability and rehabilitation research.

Set out below is a summary of our major recommendations followed by a more detailed review of the findings and conclusions on which these recommendations are based. It should be noted that our analysis is based in large part on reports on disability prepared by the Institute of Medicine (IOM), reports by federal agencies, reports by prominent researchers in the field of disability and rehabilitation research, and input from individual members of the DRRC. The IOM reports on disability include: *Disability in America: Toward a National Agenda for Prevention* (1991 IOM Report); *Enabling America: Assessing the Role of Rehabilitation Science and Engineering* (1997 IOM Report); and *The Future of Disability in America* (2007 IOM Report).

SUMMARY OF MAJOR FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

The federal government has a central role to play in developing and implementing a comprehensive research agenda focused on disability and the rehabilitation of individuals with disabilities. The DRRC makes the following recommendations for enhancing future disability and rehabilitation research:

- Increase federal funding significantly in various agencies performing rehabilitation and disability research.
- Elevate the status of the National Center for Medical Rehabilitation Research (NCMRR) within the National Institutes of Health.

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- Clarify the National Institute for Disability and Rehabilitation Research's (NIDRR's) role to include health and function research as integrally related to employment and community participation research; alternatively, consider moving the health and function responsibilities to another agency.
- Create an Office of Disability and Health in the Centers for Disease Control and Prevention (CDC).
- Examine the role of the research programs within the Department of Veterans Affairs and the Department of Defense (VA/DoD) and enhance the interaction between these programs and civilian disability and rehabilitation research capacity.
- Expand and improve the authority of Interagency Committee on Disability Research (ICDR) to coordinate disability and rehabilitation research among the federal agencies.
- Develop a comprehensive government-wide strategic plan for disability and rehabilitation research.
- Develop government-wide methods for identifying disability and rehabilitation research as well as subtopics (e.g., studies of body structure/functional deficits, activities, participation, capacity building activities, treatment and service effectiveness research) so that the magnitude and trends in disability and rehabilitation research across various agencies can be tracked.
- Develop guiding principles for conducting disability and rehabilitation research.
- Support a research agenda-setting summit bringing together policymakers, representatives from federal agencies, non-governmental funders of rehabilitation research, and organizations representing researchers, providers, and individuals with disabilities.
- Expand support for efficacy studies documenting the benefit (including cost-benefit) of rehabilitation services, supports, treatments, and devices, including support for large scale randomized clinical trials (where appropriate).
- Support efforts to enhance knowledge translation so that research is more efficiently translated to practice in the rehabilitation and disability fields.

SCOPE AND MAGNITUDE OF DISABILITY-RELATED ISSUES FACING THE NATION

Demographic shifts over the next two decades indicate a substantial increase in the number of people experiencing physical or mental impairments and the proportion of the population at risk of developing a physical or mental impairment that affects their ability to function. According to the 2007 IOM Report on disability:

“The future of disability in America is not a minority issue. If one considers people who now have disabilities, people who are likely to develop disabilities in the future, and people who are or who will be affected by the disabilities of individuals close to them, then disability affects today or will affect tomorrow the lives of most Americans.”

As a nation, we must recognize the documented trends relating to the aging of the population and the projections for the rates of disability among those aged 65 and over, the millions of younger people who live with disabilities, and the prevalence of chronic health problems and disabilities

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for adults who are now in early and midlife. For example, the percentage of the population aged 65 and over will increase from approximately 12 percent in 2000 to almost 20 percent in 2030 (i.e., from almost 35 million people to more than 71 million) with significant prevalence of disability amongst this population. In 2004, more than 4 million of all children and young people between the ages of 5 and 20 years (6.5 percent) had disabilities. In the same year, some 20 million people aged 21 to 64 years, or approximately 12.1 percent of the total population in that age group, reported disabilities. [2007 IOM Report on disability]

In addition, estimates indicate that 320,000 of those in the military returning from Iraq and Afghanistan have sustained a TBI and another 300,000 are returning with PTSD. (Tanielian T, Jaycox LH (eds.) *Invisible Wounds of War: Psychological and Cognitive Injuries, Their Consequences, and Services to Assist Recovery*. Santa Monica, CA: RAND Corporation, MG-720-CCF, 2008.) However, these numbers are likely to be underestimates as post-deployment screening has yet to be fully implemented, and many soldiers do not acknowledge their mental health challenges. Furthermore, statistics on other conflict-related injuries that result in disabling conditions—such as amputations and poly-trauma—are not available. These numbers will add to the individuals who will need the results of research to help regain their lives.

VALUE OF DISABILITY AND REHABILITATION RESEARCH IN IMPROVING THE LIVES OF INDIVIDUALS WITH DISABILITIES

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) conceptualizes a number of facets of disability. Abnormalities of body structure and function, caused by disease or injury, increase the risk of disability, but it is limitations in activity (e.g., inability to walk or communicate), and limitations in societal participation (e.g., inability to work, or parent) that are the primary focus of disability and rehabilitation research. Importantly, the ultimate level of disability a person experiences is a product of their own bodily impairments *in interaction with* the physical and social environment (e.g., the disability of a person with mobility impairment can be reduced *both* by strengthening their muscles *and* by reducing environmental barriers such as stairs and hostile social attitudes).

Because of the intermingling of biological and social factors in creating disablement, a disability and rehabilitation research agenda must be far broader than traditional biomedical research which focuses primarily on disease and abnormalities of body structure and function. Indeed, the recent Institute of Medicine's 2007 report, "The Future of Disability in America", stressed the current and projected growth of disability in America, the promise of research in blunting its impact on society, and, in particular, the need to increase the amount of research attention focused on activity and participation, and on treatments and services that can enhance them.

In sum, with the demographic shifts over the next two decades there will come a sharp increase in the need for quality rehabilitation and disability-related services. Significant disability and rehabilitation research, including translational research, is necessary to develop new and more effective approaches and to test and evaluate the costs and benefits of current services and use these findings to effect programs that maximize benefits to costs.

ADEQUACY OF FUNDING FOR DISABILITY AND REHABILITATION RESEARCH

The IOM studies on disability acknowledge that disability and rehabilitation research programs have been chronically underfunded for many years, especially considering the magnitude of the need for rehabilitation and disability services. Funding for disability research is not in line with the current, and particularly, the future projected impact of disability on individuals, families, and American society. The 1997 IOM report on disability bluntly stated that the combined federal research effort was not adequate to address the needs of people with disabilities and that more funding would be required to expand research to meet these needs. According to the 2007 IOM report on disability, despite modest increases in funding, the situation essentially remains the same today.

We recommend that Congress increase funding in the various agencies performing disability and rehabilitation research. This increase should be significant—the kind of investment that will stimulate new interest and enthusiasm inside and outside the rehabilitation and disability research fields.

VISIBILITY AND RECOGNITION OF DISABILITY AND REHABILITATION RESEARCH WITHIN MAJOR FEDERAL AGENCIES

In General

The three major federal agencies that have disability and rehabilitation research as their primary missions include the Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR); the National Center for Medical Rehabilitation Research (NCMRR), which is housed in NIH's National Institute of Child Health and Human Development (NICHD); and the Rehabilitation Research and Development Service in the Department of Veterans Affairs.

Several other federal agencies include disability and rehabilitation research as a part of their broader research missions. These agencies include:

- The National Science Foundation;
- The Centers for Disease Control and Prevention;
- Other institutes and centers at NIH;
- Other components of the DHHS including the Agency for Healthcare Research and Quality, the Maternal and Child Health Bureau, the Substance Abuse and Mental Health Administration, and the Office of Disability, Aging, and Long-Term Care Policy;
- The Army Medical Research and Materiel Command, Department of Defense, which funds, among other things, the Telemedicine and Advanced Technology Research Center which manages several projects related to advanced prosthetics, orthotics, and rehabilitation through partnerships with federal agencies, academic institutions and commercial firms; and
- The Office of Disability Employment Policy in the Department of Labor.

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We agree with the assessment in the 2007 IOM Report on disability. Little has changed with respect to the 1997 report's critique that disability research has limited visibility within the respective parent agencies. In fact, for most federal agencies it is extremely challenging to even identify the level and extent of disability research being supported by each agency. Action must be taken to increase the visibility of federal rehabilitation and disability research within federal agencies.

NCMRR: NCMRR's mission is to support "the development of scientific knowledge needed to enhance the health, productivity, independence and quality of life of persons with disabilities" through research focused on the "functioning of people with disabilities in daily life." According to IOM, NCMRR recently defined the areas which it identified as having the greatest opportunities for research in the next 5 years, including translation research (from the laboratory bench to the "bedside"), basic research to advance rehabilitation, and plasticity and adaption of tissue in response to activities and the environment. Because NCMRR is not an independent center and does not have its own federal appropriation separate from its parent agency, the NICHD, the amount of funding that is devoted to rehabilitation research primarily depends on how rehabilitation research proposals are scored in relation to proposals on other topics of interest to NICHD and NIH generally.

The 1997 and 2007 IOM Reports on disability recommend that Congress elevate NCMRR's status to that of a full Institute or free standing center within NIH with its own budget. **We agree with this recommendation.** Doing so will create a much more visible entity within NIH that has disability and rehabilitation research as its primary mission and that appropriately occupies an organizational level that is comparable to that of other institutes. Disability is an issue that crosses all age, gender, racial, and geographic groups and all dimensions of public health, a reality that is confused by the current location of NCMRR within an institute focused on child health and human development. Legislation will be necessary because when Congress established NCMRR, it was placed by statute within NICHD. Further, the National Institutes of Health Reform Act of 2006 capped the number of freestanding NIH institutes and centers at 27 (the existing number) and, therefore, this cap would need to be addressed legislatively.

Elevating NCMRR to independent status would achieve the following objectives:

- Increase the responsiveness of research to the rehabilitation needs of people with physical and cognitive disabilities and the professionals who provide services to them;
- Enhance the stature, emphasis and leadership at NIH on cross-cutting, multidisciplinary disability and rehabilitation research across the lifespan, including translational research; and
- Increase the authority of the director of NCMRR to plan, prioritize, coordinate, and collaborate across institutes and centers, including with other agencies involved in disability and rehabilitation research.

NIDRR: In contrast to NCMRR's demonstrated focus on the pathophysiology of secondary conditions, NIDRR focuses on the larger context of disability, its measurement and the efficacy of treatment interventions. NIDRR is the primary base of federal support for research related to activity and participation by individuals with disabilities i.e., research focusing on the interaction

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of the person and the environment. Title II of the Rehabilitation Act directs NIDRR to administer research and related activities to “maximize the inclusion and social integration, employment, and independent living of individuals of all ages with disabilities.”

The 5-year long-range plan for fiscal years 2005-2009 identifies the major domains of NIDRR’s research program as employment, participation and community life, and health and function. In addition, NIDRR’s portfolio includes technology for access and function, and disability demographics. Health and function rehabilitation research can be seen as occupying a space between basic science (attempts to understand the physical and psychological impairments typical of specific diseases and conditions), and disability studies and other research that focuses on quality of life and the activity and participation domains that matter to individuals with disabilities.

Medical rehabilitation research resembles purely biomedical research in that it involves “treatments” for individuals with “conditions”. However, the principal goal of those treatments is to enhance various aspects of activity and participation. Many of those treatments do not “cure” the underlying condition, but nevertheless allow the individual with a condition greater participation. Such research requires interdisciplinary collaboration between researchers who understand the basic science aspects as well as those who are familiar with the real-world impact of disability in its social, political and economic settings.

The 2007 IOM report on disability reiterates the concern initially articulated in the 1997 IOM report on disability regarding the relatively weak position of NIDRR in the Department of Education. The 1997 IOM report on disability recommended that NIDRR be moved out of the Education Department into the Department of Health and Human Services as the Agency on Disability and Rehabilitation Research. The 2007 IOM Report does not include this recommendation because of administrative steps NIDRR has taken between 1997 and 2007 e.g., improvements in the peer review process.

Based on recent actions taken by NIDRR, including public statements and pronouncements in the *Federal Register*, there is significant concern by many organizations that NIDRR may be decreasing its historically strong commitment to health and function research (including medical rehabilitation research) as a result of shifting priorities in which research with an employment focus is being emphasized to the detriment of health and function research. Observing what some have referred to as a “sea change” at NIDRR, a number of organizations have raised the question whether it is time to reinforce the historical commitment to health and function research at NIDRR or, in the alternative, limit the focus of NIDRR to employment and community participation research in line with the mission of the Education Department and reestablish the health and function research portfolio in a different federal agency.

We agree with IOM’s concern regarding NIDRR’s relatively weak position in the Department of Education, particularly the position of research regarding health and function research. One need only review the Department of Education’s stated mission, goals and objectives to conclude that health and function research has limited standing within the Department. **We recommend** that Congress amend the Rehabilitation Act to explicitly recognize the health and function domain of disability and rehabilitation research (in addition to the domains of employment and community

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participation) to solidify what has been long-standing practice at NIDRR. We also recommend that the Education Department include specific goals and objectives related thereto in its strategic plan and accountability documents. In the alternative, Congress may want to consider moving the health and function responsibilities to another relevant agency where this portfolio of research can flourish.

CDC: With respect to the CDC, the 2007 IOM report reiterates the recommendation first made in the 1997 IOM report on disability to create an Office of Disability and Health (similar to the Office of Minority Health and the Office of Women’s Health) in the Director’s Office. We support this recommendation. The mission of the Office would be to promote integration of disability issues into all CDC programs. Disability is an issue that crosses all age, gender, racial, and geographic groups and all dimensions of public health, a reality that is confused by the current location of the Disability and Health Team within CDC’s National Center on Birth Defects and Developmental Disabilities.

Department of Veterans Affairs’ Rehabilitation Research and Development Service: The 2007 IOM report on disability noted a particular asset of the VA rehabilitation research program—its continued association with a nationwide integrated health care system with a strong patient and financial information system. The 1997 IOM report on disability noted that “no other health care system, public or private, has a similar unified research program with the breadth and depth” of the VA program. However, the IOM Committee also noted criticisms of the research environment at the VA, including excessive bureaucratic requirements, disincentives for outside researchers to collaborate with VA researchers, and workload concerns.

We recommend that the Interagency Committee on Disability Research (ICDR), which is described below, examine the role of the VA/DoD research programs and enhance the interaction between these programs and civilian disability and rehabilitation research capacity.

COORDINATION, COOPERATION, AND COLLABORATION

Coordination, cooperation, and collaboration regarding the design and implementation of disability and rehabilitation research are critical among and between federal agencies conducting research, agencies funding treatment and services, foundations and the private sector, and international organizations.

As described above, a significant number of federal agencies fund disability and rehabilitation research. With so many agencies sponsoring some aspects of disability and rehabilitation research, the lack of coordination in establishing and implementing priorities for the use of federal research resources is a continuing concern. Ultimately, this lack of coordination tends to reduce the payoff from the precious federal resources currently invested in this activity.

We recognize that efforts to develop and coordinate a coherent program of disability and rehabilitation research across federal agencies will encounter a number of barriers. First, each agency has to address the intra-agency burdens of dealing with the internal bureaucracy and its own priority setting, grant making, peer review, and budgeting, leaving little inclination to address multi-agency concerns.

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Second, the development and implementation of long-range strategic plans are, for the most part, conducted separately in agencies. In addition, research funding mechanisms, application deadlines, peer-review processes, and progress reporting and performance evaluation procedures differ across agencies. These differences complicate any attempt to achieve collaborative priority setting and to realize adequate and timely funding of collaborative research initiatives.

Third, differences in agency missions and organizational cultures can make communication, cooperation, and coordinated priority setting difficult. The 1997 IOM report on disability observed that NCMRR's medical orientation—a function of its organizational home in NIH—is perceived to be a strength by some but is perceived to be a potential weakness by those who contend that the medical model of disability may be inconsistent with the contemporary orientation which focuses on the interaction between the individual and the physical and social environment (or what is called the “social model” of disability).

Thus, many researchers involved in disability and rehabilitation research are concerned that NIH tends to equate scientific rigor with a range of research designs that are more easily applied to medical and impairment interventions than to psychosocial and participation research. After more than 15 years of NCMRR research, the track record is clear. Despite the comprehensive research plan established early in the agency's development, the majority of NCMRR-supported research has focused on the pathophysiology of disability, not the remainder of the disability continuum. The basic science of disability is clearly important, but the NIH has been slow to recognize the value of research proposals that seek to apply rehabilitation interventions to real people and assess their ability to improve human function. We believe that disability and rehabilitation research at NIH and across the federal agencies must recognize the full continuum of disability.

Given the complexity of the research questions introduced by this social model of disability, it is also important to recognize that more diverse research methods are needed. These include focus groups, key informant surveys, case studies and case series, large national surveys, clinical trials, and other methods that provide valid results, depending on the nature of the research. Clinical trials should be defined not just as randomized clinical trials, but all research designs that can be used to demonstrate causality with high levels of confidence. It is unlikely that any single method will provide the evidence needed to remove barriers to independent living facing individuals with disabilities.

Role and Authority of ICDR

When Congress established the Interagency Committee on Disability Research (ICDR), it had high expectations that it would promote meaningful coordination and cooperation among federal departments and agencies conducting rehabilitation research programs, including identification, assessment, and coordination of all federal programs, activities and projects. Congress directed the Committee to submit an annual report making recommendations with respect to coordination of policy and development of objectives and priorities for all federal programs relating to the conduct of research on disability and rehabilitation of individuals with disabilities. Thus, a primary mission of ICDR is to promote the coordination and cooperation among federal

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departments and agencies which are conducting rehabilitation research programs. ICDR is housed within the Department of Education and is chaired by the Director of NIDRR.

We believe that ICDR should play an active role in coordinating the research activities of the various federal agencies. ICDR should work cooperatively to leverage the federal investment in disability and rehabilitation research and break down the agency “silos” that prevent meaningful collaborative projects and initiatives. The 1997 IOM Report on disability noted “the ineffectiveness of ICDR as a federal coordinating body.” The 2007 IOM report concludes that it is dismaying that the ICDR remains a weak instrument for coordinating disability and rehabilitation research. We agree with this judgment.

We recognize that the ICDR does serve a function in creating a forum for communication for federal agencies as they set their respective agendas and implement their programs. We agree with IOM in its 2007 report on disability that communication is a worthy function but a weak coordination tool. We also agree with IOM in its 2007 report on disability that true cooperation is unlikely to occur absent meaningful financial incentives or expectations for agencies to cooperate if problems of duplication or insufficient attention to research areas are identified.

We recommend that the Rehabilitation Act be amended to give ICDR the tools and the financial resources that it needs (i.e., a line-item budget and authority to receive transfers of funds from other agencies) to compel or entice cooperation (financial incentives from powerful agencies such as NIH and the VA). The line-item budget should include financial incentives to support multi-agency projects that meet priorities developed by ICDR. **We also recommend that ICDR** work cooperatively to propose (internally through traditional administrative processes) cross-agency increases in funding for disability and rehabilitation research.

Further, **we recommend** that ICDR play a critical role in promoting the balanced approach to collecting evidence consistent with the social model of disability. ICDR is also in a strong position to facilitate an integrated approach to the dissemination and utilization of research.

Finally, if Congress were to decide to move the health and function responsibilities of NIDRR to another agency, **we recommend** that the Director of NIDRR no longer serve as the chair of the ICDR and the chair be reassigned to the head of another agency (to be determined).

Lack of Government-wide Databases.

According to IOM, no agency within the federal government maintains a government-wide database on federally supported or federally conducted disability and rehabilitation research i.e., research that has been completed, that is in process, or that is planned. IOM could not identify any government-wide definition or categorization of the domain of disability research and could not obtain consistent information about the definition of disability research that specific agencies use. This lack of any compendium of current and past research necessarily leads to duplication of efforts, lack of coordination, and failure to recognize gaps in addressing important disability-related issues.

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This problem may become less salient in the future. The National Institutes of Health Reform Act of 2006 requires the NIH director to report to the Congress every two years on the state of biomedical and behavioral research. Among other information, the report is to include a catalog of research activities as well as a summary of research in several key areas including life stages, human development, and rehabilitation. In addition, the legislation provides for the creation of a research project data system that uniformly codes research grants and activities at NIH and that is searchable by a variety of codes, such as the type of research grant, the research entity managing the grant, and the public health area of interest.

In order to be comprehensive in scope, this database needs to include rehabilitation and disability research that is funded by all federal agencies, not just NIH.

The 2007 IOM report on disability recommends that Congress should authorize and fund the ICDR to:

- Undertake an ongoing government-wide inventory of disability research activities using the International Classification of Functioning, Disability, and Health;
- Identify underemphasized or duplicative areas of research;
- Develop priorities for research that would benefit from multi-agency collaboration; and
- Appoint a public-private advisory committee that actively involves people with disabilities and other relevant stakeholders to provide advice on the above activities.

We support these recommendations. In addition, we recommend that ICDR:

- Develop a comprehensive government-wide strategic plan for disability and rehabilitation research.
- Develop government-wide methods for identifying disability and rehabilitation research as well as subtopics (e.g., studies of body structure/function deficits, activities, participation, capacity building activities, treatment and service effectiveness research) so that the magnitude and trends in disability and rehabilitation research across various agencies can be tracked.
- Develop a common set of guiding principles for conducting disability and rehabilitation research based on the social model of disability.
- Support a research agenda-setting summit, bringing together policymakers, representatives from federal agencies, non-governmental funders of rehabilitation research, and organizations representing researchers, providers, and individuals with disabilities. The agenda should include consideration of the recommendations by IOM in the 1991, 1997, and 2007 reports on disability and the recommendations of the Rehabilitation Medicine Summit: Building Research Capacity (April 2005), as well as a review of the progress the nation has made in implementing these recommendations.
- Establish a government-wide database on disability and rehabilitation research.

Coordination between Agencies that Fund Disability and Rehabilitation Research and Agencies that Fund Treatment and Support Services.

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In addition to coordination among research agencies that fund disability and rehabilitation research, coordination between agencies that fund disability and rehabilitation research and those that fund treatment and support services for individuals with disabilities is critical. This coordination will lead to research that informs disability and health care policy and addresses priorities identified in a service context. For instance, the Centers for Medicare and Medicaid Services (CMS) should be authorized and prepared to allow greater flexibility in its coverage and payment rules so that demonstration programs can be pursued by rehabilitation researchers.

EFFICACY RESEARCH

Throughout the disability and rehabilitation fields, efficacy research must be enhanced and made a priority. Insufficient research is having a deleterious impact on the provision of quality, technologically-advanced rehabilitation services, supports, treatments, and devices. As all payers look to research-based evidence to assess the efficacy and medical necessity of various healthcare interventions, it is critical that the field of rehabilitation, which has a paucity of research evidence, not get left behind. There is a need for more efficacy research to prevent the lack of sufficient evidence on effectiveness from being misread as evidence of lack of effectiveness.

There is also a need for increased support for development and testing of adequate instruments for measuring the effectiveness of specific medical rehabilitation interventions and their duration or setting. A major expansion of research is necessary to develop measurement approaches for disability that will assist in research regarding the outcomes of specific rehabilitation interventions and measuring the independence of the person with a disability in community living and the job environment.

We recommend that a substantial federal commitment be made to better support efficacy studies designed to document the input and output of rehabilitation interventions concerning particular rehabilitation services, supports, treatments, and technologies. For example, research needs to be funded (including large scale randomized clinical trials) to develop unambiguous functional and medical appropriateness standards that will make it possible for patients to be admitted to the proper rehabilitation care setting without the need for federal enforcement authorities to retroactively review and deny coverage and payment to providers of care.

BUILDING RESEARCH CAPACITY

On April 28 and 29, 2005, the Foundation for Physical Medicine and Rehabilitation, the American Academy of Physical Medicine and Rehabilitation, the American Congress of Rehabilitation Medicine, and the Association of Academic Physiatrists sponsored a “Rehabilitation Medicine Summit: Building Research Capacity.” A wide range of participants identified a number of problems relating to rehabilitation research capacity, including:

- Insufficient numbers of adequately prepared rehabilitation researchers;
- Minimal recognition of the value of scientific research by relevant professional and clinical organizations and academic rehabilitation institutions;

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- Inadequate funding to support superior rehabilitation research education programs and training opportunities;
- Limited models of interdisciplinary collaboration, which is important, given the diversity of people, interventions, and environments that are the subject of rehabilitation and disability research;
- Weak partnerships with different professional and academic groups and consumer groups; and
- Lack of an effective strategy of advocacy to build support for rehabilitation research from government agencies and academic institutions.
- Lack of models and venues for interdisciplinary and collaborative research;
- Lack of appropriate scientific training curriculum for the current needs and of training support given the extreme research manpower shortage in rehabilitation medicine;
- Lack of infrastructure particularly for the complex and demanding clinical research area; and
- Lack of effective models of clinical research short of clinical trials.

We recommend that specific strategies be adopted to address each of the problems identified by Summit participants.

KNOWLEDGE TRANSLATION—TRANSLATION OF RESEARCH INTO EDUCATION AND TRAINING (PRE-SERVICE AND IN-SERVICE) PROGRAMS

Enhancing outcomes for individuals with disabilities in employment, independent living and health and function requires adequate academic research capacity. Such capacity rapidly translates best practices and current scientific findings into programs that educate practitioners (including practicing clinicians) and facilitate evidence-based practice for the benefit of individuals with disabilities. Disability and rehabilitation researchers are already taking leadership roles in the field of translational research. What is needed now is additional focus and funding for these critical endeavors.

We recommend additional focus and funding to support knowledge translation of research, including centralized expertise to optimally move the most promising findings into widespread application.

CONCLUSION

Our policy analysis describes how well existing federal research programs are responding to the changing needs of individuals with disabilities and suggests ways to improve future disability and rehabilitation research. The recommendations included in our analysis provides a roadmap for how the federal government could play a more effective role in enhancing the employment, independent living, and health and function of individuals with disabilities by developing and implementing a comprehensive research agenda focused on disability and the rehabilitation of individuals with disabilities.