

**DEPARTMENT OF EDUCATION****National Institute on Disability and Rehabilitation Research—Disability and Rehabilitation Research Projects and Centers Program—Disability Rehabilitation Research Projects (DRRPs), Rehabilitation Research and Training Centers (RRTC), and Rehabilitation Engineering Research Centers (RERCs)**

**AGENCY:** Office of Special Education and Rehabilitative Services, Department of Education.

**ACTION:** Notice of proposed priorities for DRRPs, RRTCs, and RERCs.

**SUMMARY:** The Assistant Secretary for Special Education and Rehabilitative Services proposes certain funding priorities for the Disability and Rehabilitation Research Projects and Centers Program administered by the National Institute on Disability and Rehabilitation Research (NIDRR). Specifically, this notice proposes 10 priorities for DRRPs, 11 priorities for RRTCs, and 6 priorities for RERCs. The Assistant Secretary may use these priorities for competitions in fiscal year (FY) 2008 and later years. We take this action to focus research attention on areas of national need. We intend these priorities to improve rehabilitation services and outcomes for individuals with disabilities.

**DATES:** We must receive your comments on or before October 1, 2007.

**ADDRESSES:** Address all comments about these proposed priorities to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW., Room 6029, Potomac Center Plaza, Washington, DC 20204–2700. If you prefer to send your comments through the Internet, use the following address: [donna.nangle@ed.gov](mailto:donna.nangle@ed.gov).

You must include the term “Proposed Priorities for DRRPs, RRTCs, and RERCs” and the priority title in the subject line of your electronic message.

**FOR FURTHER INFORMATION CONTACT:** Donna Nangle. Telephone: (202) 245–7462.

If you use a telecommunications device for the deaf (TDD), you may call the Federal Relay Service (FRS) at 1–800–877–8339.

Individuals with disabilities may obtain this document in an alternative format (e.g., Braille, large print, audiotape, or computer diskette) on request to the contact person listed under **FOR FURTHER INFORMATION CONTACT**.

**SUPPLEMENTARY INFORMATION:** This notice of proposed priorities is in

concert with President George W. Bush’s New Freedom Initiative (NFI) and NIDRR’s Final Long-Range Plan for FY 2005–2009 (Plan). The NFI can be accessed on the Internet at the following site: <http://www.whitehouse.gov/infocus/newfreedom>.

The Plan, which was published in the **Federal Register** on February 15, 2006 (71 FR 8165), can be accessed on the Internet at the following site: <http://www.ed.gov/about/offices/list/osers/nidrr/policy.html>.

Through the implementation of the NFI and the Plan, NIDRR seeks to: (1) Improve the quality and utility of disability and rehabilitation research; (2) foster an exchange of expertise, information, and training to facilitate the advancement of knowledge and understanding of the unique needs of traditionally underserved populations; (3) determine best strategies and programs to improve rehabilitation outcomes for underserved populations; (4) identify research gaps; (5) identify mechanisms of integrating research and practice; and (6) disseminate findings.

One of the specific goals established in the Plan is for NIDRR to publish all of its proposed priorities, and following public comment, final priorities, annually, on a combined basis. Under this approach, NIDRR’s constituents can submit comments at one time rather than at different times throughout the year, and NIDRR can move toward a fixed schedule for competitions and more efficient grant-making operations. This notice proposes priorities that NIDRR intends to use for DRRP, RRTC, and RERC competitions in FY 2008 and possibly later years. However, nothing precludes NIDRR from publishing additional priorities, if needed. Furthermore, NIDRR is under no obligation to make an award for each of these priorities. The decision to make an award will be based on the quality of applications received and available funding.

NIDRR also intends to publish at least one additional separate notice of proposed priority for an additional DRRP that would focus on traditionally underserved populations, as required under section 21 of the Rehabilitation Act of 1973, as amended. Moreover, for FY 2008 competitions using priorities that already have been established and for which publication of a notice of proposed priority is unnecessary (e.g., competitions for Field-Initiated Projects, Advanced Rehabilitation Research Training Projects, Fellowships, and Small Business Innovation Research Projects), NIDRR has published or will publish notices inviting applications. More information on these other

projects and programs that NIDRR intends to fund in FY 2008 can be found on the Internet at the following site: <http://www.ed.gov/fund/grant/apply/nidrr/priority-matrix.html>.

**Invitation To Comment**

We invite you to submit comments regarding these proposed priorities. To ensure that your comments have maximum effect in developing the notice of final priorities, we urge you to identify clearly the specific proposed priority or topic that each comment addresses.

We invite you to assist us in complying with the specific requirements of Executive Order 12866 and its overall requirement of reducing regulatory burden that might result from these proposed priorities. Please let us know of any further opportunities we should take to reduce potential costs or increase potential benefits while preserving the effective and efficient administration of the program.

During and after the comment period, you may inspect all public comments about these proposed priorities in room 6030, 550 12th Street, SW., Potomac Center Plaza, Washington, DC, between the hours of 8:30 a.m. and 4 p.m., Eastern time, Monday through Friday of each week except Federal holidays.

**Assistance to Individuals With Disabilities in Reviewing the Rulemaking Record**

On request, we will supply an appropriate aid, such as a reader or print magnifier, to an individual with a disability who needs assistance to review the comments or other documents in the public rulemaking record for these proposed priorities. If you want to schedule an appointment for this type of aid, please contact the person listed under **FOR FURTHER INFORMATION CONTACT**.

We will announce the final priorities in one or more notices in the **Federal Register**. We will determine the final priorities after considering responses to this notice and other information available to the Department. This notice does not preclude us from proposing or using additional priorities, subject to meeting applicable rulemaking requirements.

**Note:** This notice does *not* solicit applications. In any year in which we choose to use these proposed priorities, we invite applications through a notice in the **Federal Register**. When inviting applications we designate the priorities as absolute, competitive preference, or invitational.

The effect of each type of priority follows:

**Absolute priority:** Under an absolute priority, we consider only applications that meet the priority (34 CFR 75.105(c)(3)).

**Competitive preference priority:** Under a competitive preference priority, we give competitive preference to an application by either (1) Awarding additional points, depending on how well or the extent to which the application meets the competitive preference priority (34 CFR 75.105(c)(2)(i)); or (2) selecting an application that meets the competitive preference priority over an application of comparable merit that does not meet the priority (34 CFR 75.105(c)(2)(ii)).

**Invitational priority:** Under an invitational priority, we are particularly interested in applications that meet the invitational priority. However, we do not give an application that meets the invitational priority a competitive or absolute preference over other applications (34 CFR 75.105(c)(1)).

#### Priorities

In this notice, we are proposing 10 priorities for DRRPs, 11 priorities for RRTCs, and 6 priorities for RERCs.

For DRRPs, the proposed priorities are:

- Priority 1—Health Care Coordination for Individuals with Physical Disabilities.
- Priority 2—Assistive Technology (AT) Reuse.
- Priority 3—Health and Health Care Disparities Among Individuals with Disabilities.
- Priority 4—Traumatic Brain Injury Model Systems (TBIMS) Centers Collaborative Research Projects.
- Priority 5—Classification and Measurement of Medical Rehabilitation Interventions.
- Priority 6—Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders.
- Priority 7—Center on Knowledge Translation for Assistive Technology Transfer.
- Priority 8—Asset Accumulation and Economic Self-Sufficiency for Individuals with Disabilities.
- Priority 9—Technology Transfer in Resource-Limited Environments.
- Priority 10—Research and Knowledge Translation Center for Individuals with Disabilities and Their Families.

For RRTCs, the proposed priorities are:

- Priority 11—General Rehabilitation Research and Training Center (RRTC) Requirements.
- Priority 12—Enhancing the Health and Wellness of Individuals with Neuromuscular Diseases.

- Priority 13—Enhancing the Health and Wellness of Persons with Arthritis.
- Priority 14—Stroke Rehabilitation.
- Priority 15—Personal Assistance Services (PAS) in the 21st Century.
- Priority 16—Participation and Community Living for Individuals with Psychiatric Disabilities.
- Priority 17—Multiple Sclerosis: Interventions to Maximize Health, Well-Being, and Participation.
- Priority 18—Aging with Physical Disability: Reducing Secondary Conditions and Enhancing Health and Participation.
- Priority 19—Disability Statistics and Demographics.
- Priority 20—Health and Function Across the Lifespan of Individuals with Intellectual and Developmental Disabilities.
- Priority 21—Participation and Community Living for Individuals with Intellectual and Developmental Disabilities.

For RERCs, the proposed priorities are:

- Priority 22—RERC for Hearing Enhancement.
- Priority 23—RERC for Accessible Public Transportation.
- Priority 24—RERC for Prosthetics and Orthotics.
- Priority 25—RERC for Communication Enhancement.
- Priority 26—RERC for Universal Interface and Information Technology Access.
- Priority 27—RERC for Wheeled Mobility.

#### Disability and Rehabilitation Research Projects (DRRP) Program

The purpose of the DRRP program is to plan and conduct research, demonstration projects, training, and related activities to develop methods, procedures, and rehabilitation technologies that maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities, especially individuals with the most severe disabilities, and to improve the effectiveness of services authorized under the Rehabilitation Act of 1973, as amended. DRRPs carry out one or more of the following types of activities, as specified and defined in 34 CFR 350.13 through 350.19: research, development, demonstration, training, dissemination, utilization, and technical assistance.

An applicant for assistance under this program must demonstrate in its application how it will address, in whole or in part, the needs of individuals with disabilities from

minority backgrounds (34 CFR 350.40(a)). The approaches an applicant may take to meet this requirement are found in 34 CFR 350.40(b). In addition, NIDRR intends to require all DRRP applicants to meet the requirements of the *General Disability and Rehabilitation Research Projects (DRRP) Requirements* priority that it published in a notice of final priorities in the **Federal Register** on April 28, 2006 (71 FR 25472).

Additional information on the DRRP program can be found at: <http://www.ed.gov/rschstat/research/pubs/res-program.html#DRRP>.

#### Proposed Priorities

##### *Priority 1—Health Care Coordination for Individuals With Physical Disabilities*

##### Background

Individuals with disabilities use a disproportional share of health care services in the United States (DeJong *et al.*, 2002). The Centers for Medicare and Medicaid Services (CMS) programs recognize this trend and try to control its economic consequences by enrolling individuals with disabilities in managed care programs in increasing numbers (Palsbo & Mastal, 2006). A small but growing number of Medicaid managed care plans are designed specifically for individuals with disabilities. These plans feature intensive care coordination services that integrate the complex health and long-term care needs of individuals with disabilities (Palsbo & Mastal, 2006; Master, 2003).

Pursuant to the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, CMS also contracts with a growing number of Medicare health plans to provide health care coordination and services for Medicare beneficiaries who have severe or disabling chronic conditions (Peters, 2005).

Health care coordination is an increasingly important component of high-quality health care for individuals with disabilities (Cheng *et al.*, 2004; Lawthers *et al.*, 2003; Kroll, 2003). On average, individuals with disabilities have more complex and multi-faceted health care needs than individuals without disabilities. For example, individuals with disabilities often require the involvement of multiple medical and ancillary providers, including long-term care providers (DeJong *et al.*, 2002). Individuals with disabilities also often find it difficult to navigate the complex, fragmented health and long-term care service systems that are critical to maintaining their health, functional abilities, and independence in the community. Recognizing the

importance of integration and coordination of health and long-term care services, NIDRR states that “individuals with disabilities should have access to an integrated continuum of health care services, including primary care and health maintenance services, specialty care, medical rehabilitation, long-term care, and health promotion programs” (NIDRR Long-Range Plan, 2005–2009). Toward this goal, NIDRR seeks to sponsor rigorous research to assess the outcomes associated with managed health care coordination programs for individuals with disabilities.

A number of small pilot studies suggest an association between enrollment in managed health care coordination programs for individuals with disabilities and positive outcomes such as increased satisfaction with health care services, greater access to a wide variety of health and long-term care services, and decreased utilization of costly emergency and hospital-based services (Surpin, 2007; Palsbo, Mastal, & O'Donnell, 2006; Master, 2003). More systematic, peer-reviewed research is required to determine the extent to which these health care coordination programs for individuals with disabilities relate to improvements in both the health and health care experiences of their clients and to cost savings for public financing mechanisms.

#### References

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- Lawthers, A., Pransky, G., Peterson, L., & Himmelstein, J. (2003). Rethinking Quality in the Context of Persons With Disability. *International Journal for Quality in Health Care*, 15(4): 279–281.
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- National Institute on Disability and Rehabilitation Research. Notice of Final Long Range Plan for Fiscal Years 2005–2009. Pages: 8166–8200. <http://www.ed.gov/about/offices/list/osers/nidrr/policy.html>.
- Palsbo, S., & Mastal, M. (2006). Disability Care Coordination Care Organizations: The Experience of Medicaid Managed Care Programs for People With Disabilities. Center for Health Care Strategies. Resource Paper. [http://www.chcs.org/usr\\_doc/DCCOs.pdf](http://www.chcs.org/usr_doc/DCCOs.pdf).
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- Surpin, R. (2007). Independence Care System: A Disability Care Coordination Organization in New York City. *Journal of Ambulatory Care Management*, 30(1): 52–63.
- Proposed Priority**
- The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability Rehabilitation Research Project (DRRP) on Health Care Coordination for Individuals with Disabilities. The purpose of this priority is to conduct research on the outcomes of Medicare or Medicaid managed health care coordination programs for individuals with disabilities. Under this priority, the DRRP must be designed to contribute to the following outcomes:
- (a) New knowledge about the extent to which enrollment in health care coordination programs enhances access to health care for individuals with disabilities. The DRRP must contribute to this outcome by conducting research on, and evaluating, one or more existing Medicaid- or Medicare-funded health care coordination programs for individuals with disabilities.
- (b) New knowledge about the health outcomes associated with participation in health care coordination programs for individuals with disabilities. The DRRP must contribute to this outcome by conducting research on, and evaluating, one or more existing Medicaid- or Medicare-funded health care coordination programs for individuals with disabilities.
- (c) New knowledge about potential Medicaid or Medicare cost savings that are associated with health care coordination efforts for individuals with disabilities. The DRRP must contribute to this outcome by conducting research on, and evaluating, one or more existing Medicaid- or Medicare-funded health care coordination programs for individuals with disabilities.
- In addition, the DRRP must work with the NIDRR Project Officer to coordinate its research efforts with the Centers for Medicare and Medicaid Services—Office of Research, Development, and Information.

#### Priority 2—Assistive Technology (AT) Reuse

##### Background

Reuse programs are emerging as one potential solution to providing more assistive technology (AT) to individuals with disabilities at lower costs (Pass It On Center). For example, the Rehabilitation Services Administration (RSA) of the U.S. Department of Education has funded model demonstration projects to establish or expand statewide AT device reutilization programs. Device reuse programs, such as exchange programs and reassignment programs, facilitate the transfer of previously-used AT from one consumer to another. Each of these programs has distinct features and benefits. An exchange program assists in connecting users to transfer AT directly among themselves. Reassignment programs, on the other hand, accept used AT, sanitize it, identify appropriate users, and redistribute the AT following sanitization and matching.

One advantage of reuse programs, in general, is that they provide consumers with access to AT devices at reasonably lower costs. AT equipment provided through these programs also leads to an increased capacity for community living and participation by individuals with disabilities. AT reuse programs meet varied needs and circumstances surrounding consumer access to AT, such as access on a temporary basis, or access for trial purposes to assess the benefit and effectiveness of a device for a consumer's use.

A number of barriers and obstacles limit the utility of AT reuse programs. A recent study found that individuals with disabilities or other family members, not third parties, most frequently pay for commonly used AT devices, special adaptations, and environmental accommodations (Carlson & Ehrlich, 2006). Consumer access to AT and compensation for AT is often limited by conflicting eligibility requirements of current policies regulating the provision of AT. In addition, third-party payment restrictions frequently minimize the extent to which Medicare, Medicaid, private insurance, and vocational rehabilitation can assist with AT costs. Increased awareness of the potential costs and benefits associated with AT reuse programs can positively impact their use, and in addition, has implications for third-party payment coverage for reused AT. Furthermore,

AT reuse programs do not have the benefit of a national coordinated system to assist in sustaining or expanding programs. Nor do AT reuse programs have the benefit of research that has identified methods, models, and measures for enhancing program effectiveness and improving consumer outcomes.

At the present time, there is little data available to guide the management, enhancement, or expansion of these programs. Few research studies have been conducted to inform the AT reuse field of validated methods, models, and measures that lead to improved program and consumer outcomes. This field needs new knowledge regarding factors that influence success of AT reutilization programs, *e.g.*, program design, staffing, training, funding sources, and use of collaborative partnerships in operating AT reuse programs. Specifically, more research is needed to examine how these and other factors affect program outcomes and to identify the most effective measures available to assess program quality as well as the costs and benefits of the program. Numerous reuse programs in the United States could benefit from research in this area.

#### References

Carlson, D. & Ehrlich, N. (2006). Sources of payment for assistive technology: Findings from a national survey of persons with disabilities. *Assistive Technology*, 18(1), 77–86.

Pass It On Center. [Http://www.passitoncenter.org](http://www.passitoncenter.org).

#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability Rehabilitation Research Project (DRRP) on Assistive Technology (AT) Reuse for individuals with disabilities. The purpose of this priority is to support research that will identify methods, systems, policies, and collaborative strategies to improve reutilization and recycling of AT. Under this priority, the DRRP must be designed to contribute to the following outcomes:

(a) Enhanced understanding of how third-party payments for purchases of AT affect AT reuse programs. The DRRP must contribute to this outcome by conducting an analysis of current policy and consumer eligibility requirements and by generating relevant recommendations related to AT reuse.

(b) New knowledge that positively affects the establishment, expansion, and maintenance of AT reuse programs. The DRRP must contribute to this outcome by conducting research studies

validating effective methods and models for conducting AT reutilization activities (*e.g.*, program design; alternative recycling methods; partnerships; program marketing strategies; and recruitment, retention, and training of AT reuse staff).

(c) Improved methods and strategies for assessing the costs and benefits, including cost-savings, of AT reuse programs. The DRRP must contribute to this outcome by identifying, developing, and testing appropriate models to be used at the program level that can help inform third-party payers of the costs and benefits associated with AT reuse programs.

(d) Improved understanding of AT reuse outcomes for individuals with disabilities. The DRRP must contribute to this outcome by conducting studies that assess and inform the AT field about the impact of acquiring AT through reuse programs.

(e) Improved collaboration and use of research findings through effective coordination within the network of relevant NIDRR RRTCs, Rehabilitation Engineering Research Centers, DRRPs, and federally funded programs, such as the Rehabilitation Services Administration (RSA) AT State grants, the National AT Device Reutilization Coordination and Technical Assistance Center, and grantees under RSA's Model Demonstrations for AT Device Reutilization program.

#### Priority 3—Health and Health Care Disparities Among Individuals With Disabilities

##### Background

In 2005, the U.S. Surgeon General released a "Call to Action to Improve the Health and Wellness of Persons With Disabilities" that delineated a series of strategies to optimize the health and wellness of individuals with disabilities, (U.S. Department of Health and Human Services (HHS), 2005). The Surgeon General proposed these strategies in light of the growing body of research literature indicating that individuals with disabilities are, on average, less likely than those without disabilities to report positive health (Krahn, Hammond, & Turner, 2006; Hough, 1999) and less likely to receive recommended health care services (Kroll *et al.*, 2006; McCarthy *et al.*, 2006; Jones & Beatty, 2003).

While the body of research that examines health disparities between individuals with and without disabilities is expanding, few studies have examined the health and health care disparities within the diverse population of individuals with

disabilities in the United States. Health disparities recently have been defined as "observed clinically and statistically significant differences in health outcomes or health care use between socially distinct vulnerable and less vulnerable populations" (Kilbourne *et al.*, 2006). The broad population of 52 million individuals with disabilities (HHS, 2005) is heterogeneous in terms of a number of factors that may be related to increased vulnerability for poor health care access and poor health. These factors include, but are not limited to, disabling condition category (*i.e.*, mental illness, sensory, physical, cognitive, or combinations thereof), disability severity, age, gender, race, ethnicity, socioeconomic status, education level, urban/rural status, health insurance payer type (Medicare, Medicaid, private insurance), provider type, and other social, personal, and environmental characteristics.

NIDRR recognizes that "while health services researchers are increasingly attuned to racial and ethnic disparities in health care, less attention and fewer resources are devoted to disability-related disparities and the innovations in policy and practice that might reduce them" (NIDRR Long Range Plan, 2005). The Health and Function chapter of the NIDRR Long Range Plan promotes research on the health and health care experiences of the wide diversity of individuals with disabilities (NIDRR Long Range Plan, 2005).

Given the wide diversity of individuals with disabilities and the limited information available about existing health care access and outcome disparities that exist within this population, research is needed to improve our understanding about the factors that contribute to health disparities. New knowledge about these factors can be used to create targeted policies, programs, and interventions that promote health and wellness among the individuals with disabilities who are most vulnerable and most likely to demonstrate health outcomes traditionally attributed to disparate treatment or health care access difficulties.

#### References

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#### *Proposed Priority*

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability Rehabilitation Research Project (DRRP) on Health and Health Care Disparities Among Individuals With Disabilities. The purpose of this priority is to build a knowledge base about health care access and health outcomes among the diverse population of individuals with disabilities. Under this priority, the DRRP must be designed to contribute to the following outcomes:

(a) A foundation of available knowledge about health disparities among subpopulations of individuals with disabilities. The DRRP must contribute to this outcome by conducting a review and synthesis of existing research on health and health care access among individuals with disabilities or subgroups of individuals with disabilities. The DRRP must then use this review and synthesis to inform the subsequent research and evaluation efforts of the DRRP.

(b) New knowledge about system-level factors that are associated with the health and health care access of individuals with disabilities. The DRRP must contribute to this outcome by conducting research on the extent to which the health and health care access of individuals with disabilities are related to system-level factors that include, but are not limited to, rural or urban status, as well as characteristics of their health care insurance or health care providers.

(c) New knowledge about the individual-level characteristics of individuals with disabilities that are associated with their health and access to health care. The DRRP must contribute to this outcome by conducting research on the extent to which the health and health care access of individuals with disabilities are related to their disabling condition categories (mental illness, sensory, physical, cognitive, or combinations thereof), disability severity, age, gender, race, ethnicity, socioeconomic status, education level, or other individual-level characteristics.

(d) Improved policies, programs, or interventions that promote the health and health care access of the subpopulations of individuals with disabilities who are least likely to receive recommended health care services. The DRRP must contribute to this outcome by applying knowledge derived from research conducted under paragraphs (a), (b), and (c) of this priority.

In addition, the DRRP must collaborate with the Rehabilitation Research and Training Center on Health and Wellness, and other projects as identified through consultation with the NIDRR project officer.

#### **Priority 4—Traumatic Brain Injury Model Systems (TBIMS) Centers Collaborative Research Projects**

##### *Background*

The Centers for Disease Control and Prevention (CDC) report that at least 1.4 million individuals sustain a traumatic brain injury (TBI) in the United States each year (Langlois, Rutland-Brown, & Thomas, 2004). Of these, approximately 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from emergency departments. These estimates do not include those individuals who sustained a TBI and did not seek medical care, or who were seen only in private doctors' offices. The three leading causes of TBI are motor vehicle/traffic collisions, falls, and assaults.

CDC reports that each year an estimated 80,000 to 90,000 Americans sustain TBI resulting in permanent disability. At least 5.3 million Americans have a long-term or lifelong need for help to perform activities of daily living as a result of TBI (Thurman *et al.*, 1999). The nature and extent of disability resulting from TBI depend on several factors, such as the severity and location of the injury, the length of impaired consciousness, the age and general health of the patient, and the intensity of rehabilitation services (Cifu *et al.*, 2003; Dikmen *et al.*, 2003; Sarajuuri *et al.*, 2005). Common clinical sequelae of TBI include problems with cognition, sensory processing, communication, and behavioral or mental health. Some TBI survivors also can develop long-term medical complications, such as Parkinson's disease and other motor problems, Alzheimer's disease, and post-traumatic dementia (National Institute of Neurological Disorders and Stroke, 2002).

NIDRR created the TBI Model Systems (TBIMS) program in 1987 to demonstrate the benefits of a coordinated system of neurotrauma and rehabilitation care and to conduct innovative research on all aspects of care for those who sustain TBI. The mission of the TBIMS program is to improve the lives of persons who experience TBI and their families by creating and disseminating new knowledge about the natural course of TBI and rehabilitation treatment and outcomes for individuals who sustain TBI. NIDRR currently funds 14 TBIMS centers throughout the United States. (Additional information on the TBIMS centers can be found at <http://www.naric.com>). These centers provide comprehensive systems of brain injury care to individuals who sustain TBI. They also conduct TBI research, including clinical research and the analyses of standardized data in collaboration with other related projects. The research activities of the TBIMS centers include participation in joint research module projects, which range from pilot research to more extensive studies. TBIMS centers also are required to contribute information on common data elements to a centralized TBIMS database. (Additional information on the TBIMS database can be found at <http://www.tbimsc.org>.) To date, TBIMS centers have contributed 6157 cases to the TBIMS database, with followup data extending to 15 years post injury.

In 2003 NIDRR leveraged the capacity of the TBIMS program by funding large-scale collaborative research projects.

These collaborative projects included a randomized controlled trial of the effectiveness of amantadine hydrochloride in promoting recovery of functioning following TBI, and a study of the effect of scheduled telephone intervention on outcomes after TBI. Through the funding of this priority, the TBIMS program will continue to serve as a platform for multi-site research that contributes to evidence-based rehabilitation interventions and improves the lives of individuals with TBI.

#### References

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- To be eligible under this priority, an applicant must be currently funded under NIDRR's TBIMS program.
- Under this priority, each DRRP must be designed to contribute to the following outcomes:
- (a) Increased utilization of the TBIMS capacity. The DRRP must contribute to this outcome by collaborating with three or more of the NIDRR-funded TBIMS centers (for a minimum of four TBIMS sites).
- Note:** Applicants under this priority may propose to include other TBI research sites that are not participating in a NIDRR-funded TBIMS program in their collaborative research projects.
- (b) Improved long-term outcomes of individuals with TBI. The DRRP must contribute to this outcome by using clearly identified research designs to conduct collaborative research on questions of significance to TBI rehabilitation. The DRRP's research must focus on one or more specific domains identified in NIDRR's Final Long-Range Plan for FY 2005–2009, including health and function, participation and community living, technology, and employment, and must be designed to ensure that the research study has appropriate research hypotheses and methods to generate reliable and valid findings.
- In addition, the DRRP must address the following requirements:
- Demonstrate the capacity to carry out collaborative, multi-site research projects, including the ability to coordinate research among centers; maintain data quality; and adhere to research protocols, confidentiality requirements, and data safety requirements.
  - Coordinate with the NIDRR-funded Model Systems Knowledge Translation Center to provide scientific results and information for dissemination to clinical and consumer audiences. (Additional information on this center can be found at <http://uwctds.washington.edu/projects/msketc.asp>).

#### Priority 5—Classification and Measurement of Medical Rehabilitation Interventions

##### Background

One of the central objectives of NIDRR-funded medical rehabilitation research is to “increase the number of interventions demonstrated to be efficacious in improving health and function outcomes in targeted disability populations” (NIDRR Long Range Plan, 2005–2009). To demonstrate that a treatment is efficacious, both the intervention and the intended outcome

must be operationally defined and measured in a rigorous way.

NIDRR-sponsored researchers have been leaders in the development of widely used outcomes measures that are employed to help determine the impact of medical rehabilitation on the health and function of individuals with disabilities, as well as the impact of medical rehabilitation on the participation of these individuals in society. While the ability to measure outcomes of medical rehabilitation continues to mature through recent and ongoing NIDRR-sponsored research, the ability to classify, measure, and replicate specific interventions within the complex medical rehabilitation process is still in its infancy. A recent analysis of published research on medical rehabilitation interventions indicates that nearly two-thirds of articles fail to describe adequately the rehabilitative treatment being evaluated (Dijkers *et al.*, 2002).

Medical rehabilitation has been referred to as a “black box” because the wide-range of interventions that take place within rehabilitation settings have not been classified or measured in a systematic way (DeJong *et al.*, 2004). Determining the components of the medical rehabilitation process that positively impact outcome (i.e., the “active ingredients”) is challenging. This is due to the simultaneous delivery of inter-related treatments by a variety of allied health professionals to individuals with unique needs. Development of a treatment taxonomy (i.e., a systematic method for classifying and measuring rehabilitation interventions) will promote the quality and rigor of rehabilitation research and will foster the transfer of evidence-based treatments into clinical practice (Whyte, 2003).

In the past, NIDRR has sponsored rehabilitation outcomes research that can serve as a basis for future efforts to develop a taxonomy of medical rehabilitation interventions. For instance, a recent NIDRR-funded stroke outcomes research project involved the creation of point-of-contact forms for recording the delivery of rehabilitation interventions provided by physical therapists (Latham *et al.*, 2005), occupational therapists (Richards *et al.*, 2005), speech-language pathologists (Hatfield *et al.*, 2005), and other allied health professionals. A major strength of this project was that it relied upon the rich experiences and expertise of front-line rehabilitation clinicians to create detailed forms for collecting data about specific interventions. A limitation of this bottom-up, inductive approach to classifying and measuring rehabilitation

#### Proposed Priority

The Assistant Secretary proposes a priority for Disability and Rehabilitation Research Projects (DRRPs) on Traumatic Brain Injury Model Systems (TBIMS) Collaborative Projects. Each DRRP under this priority must conduct research that contributes to evidence-based rehabilitation interventions, including, but not limited to, medical, psychological, vocational, and social interventions for the purpose of improving the lives of individuals with traumatic brain injury (TBI).

interventions is its general lack of a theoretical foundation. A theoretical foundation would have the benefit of guiding the collection and analysis of treatment and outcomes data, and increase the field's ability to see how seemingly disparate treatments fit together into a coherent framework for rehabilitation practice and functional recovery (DeJong *et al.*, 2004). Efforts to develop rehabilitation intervention taxonomies must be guided by treatment theories in order to increase the likelihood that "active ingredients" of rehabilitative care can be isolated and replicated (Whyte, 2006).

Other clinical fields, such as nursing (Dochterman & Bulechek, 2004), have been actively developing intervention taxonomies to guide clinical service delivery, rigorous clinical documentation, and effectiveness research in a wide range of nursing sub-fields. Literature describing intervention taxonomies and their development in other fields are likely to be instructive to those engaged in the development of a medical rehabilitation treatment classification system.

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability Rehabilitation Research Project (DRRP) on Classification and Measurement of Medical Rehabilitation Interventions. This DRRP must conduct research and development toward the creation of a taxonomy of medical rehabilitation interventions. Under this priority, the DRRP must be designed to contribute to the following outcomes:

(a) Enhanced research capacity and improved clinical practice in the field of medical rehabilitation. The DRRP must contribute to this outcome by conducting research to develop validated methods for the systematic classification of the broad range of medical rehabilitation interventions delivered by rehabilitation physicians, physical therapists, occupational therapists, speech language pathologists, rehabilitation nurses, rehabilitation psychologists, and other allied health professionals.

(b) Enhanced research capacity and improved clinical practice in the field of medical rehabilitation through the application of one or more treatment theories to guide the development of a rehabilitation treatment taxonomy.

(c) Collaboration with relevant NIDRR-sponsored projects, such as the Rehabilitation Research Training Center on Measuring Rehabilitation Outcomes, and other projects as identified through consultation with the NIDRR project officer.

#### Priority 6—Vocational Rehabilitation Service Models for Individuals With Autism Spectrum Disorders

##### Background

In recent years, policy makers, educators, and rehabilitation service providers have become increasingly aware of the critical shortage of services available to youth and young adults with Autism Spectrum Disorders (ASDs), including vocational rehabilitation services (Dew & Alan, 2007). ASDs are a group of lifelong developmental disabilities that include autistic disorder, pervasive developmental disorder-not otherwise

specified, and Asperger disorder. ASDs are characterized by impairments in social interactions and verbal and nonverbal communication, as well as the presence of repetitive or unusual behaviors and interests (Centers for Disease Control and Prevention (CDC), 2006a). The severity of impairments can range from mild to severe. Recent prevalence estimates vary, indicating that ASD occurs in 2 to 6 individuals per 1000 individuals, that is, between 1 in 500 and 1 in 166 children have an ASD. ASDs are four times more likely to occur in boys than in girls. The CDC (2006b) reported that ASDs are more prevalent than certain other childhood disabilities, such as cerebral palsy (2.8 per 1000 children), hearing loss (1.1 per 1000 children), vision impairment (0.9 per 1000 children), and Downs syndrome (1.25 per 1000 children) (CDC, 2006b). ASDs usually are diagnosed before the age of three, and the effects are lifelong, although impairments may be attenuated with intervention.

Like other transition-age youth with disabilities, students diagnosed with ASD who have turned 22 or graduated from high school with a regular diploma generally no longer have a legal right to appropriate transition services, such as life skills training, transportation, vocational training, and individual and family counseling, under the Individuals with Disabilities Education Act (IDEA) (National Longitudinal Transition Study-2 (NLTS-2) 2005). Large proportions of youth with ASD rated low on self-care tasks, functional cognitive skills, social skills and communication when compared to the entire population of youth with disabilities served under IDEA (NLTS-2, 2005). Many families find that the services provided to individuals diagnosed with ASD are not tailored to the needs of the children and young adults in this population. Families also report that locating, accessing, and financing needed services for these young adults requires navigating complicated public and private medical, social, and vocational rehabilitation service systems (American Society of Autism, 2001).

In 2005, fewer than 2,000 individuals with ASDs received vocational rehabilitation services. Of these individuals, only 1,200 were successfully employed (Dew & Alan, 2007). Of the youth with ASDs who were out of school one year or more, only 1 in 5 reported receiving services from a vocational rehabilitation State agency. These youth with ASDs also were less likely to be employed than youth with other disabilities, and the



employed youth with ASDs worked fewer hours than employed youth with other disabilities (NLTS–2, 2005). Increased vocational and rehabilitation interventions are needed if these individuals are to experience vocational and economic success equal to the success of transition-age youth without ASD.

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability Rehabilitation Research Project (DRRP) on Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders (ASDs). This DRRP must conduct research on vocational rehabilitation (VR) service models for individuals with ASDs that contributes to evidence-based rehabilitation interventions to improve the lives of individuals with ASDs. Under this priority, the DRRP must be designed to contribute to one or both of the following outcomes:

- (a) Improved vocational and postsecondary education outcomes of individuals with ASDs. The DRRP must contribute to this outcome by developing or testing VR intervention strategies for individuals with ASDs, the measures needed to assess the effectiveness of VR intervention strategies for individuals with ASDs, or both.
- (b) Improved long-term vocational and postsecondary education services

for individuals with ASDs. The DRRP must contribute to this outcome by analyzing the factors affecting the organization and delivery of these services to individuals with ASDs and by recommending changes that could improve these service delivery mechanisms.

#### Priority 7—Center on Knowledge Translation for Assistive Technology Transfer

##### Background

While billions of dollars are expended on technology-related research and development efforts in the United States each year (Association of University Technology Managers, 2005), very little of this funding is applied toward development of technology to improve the lives of individuals with disabilities (National Council on Disability, 2000). NIDRR addresses this critical niche with two grant programs that are dedicated to the application of technology and the development of products and devices that are intended to improve the lives of individuals with disabilities: The Rehabilitation Engineering Research Centers (RERC) and Small Business Innovation Research (SBIR) programs.

For 30 years, the RERC program and its predecessor, the Rehabilitation Engineering Centers program, have been a major force in the development of technology to enhance independent function and societal participation for individuals with disabilities. For over a decade, NIDRR's SBIR program has encouraged small businesses to explore their technological potential by supporting proof of concept investigations of prototype devices intended to benefit individuals with disabilities.

In addition to supporting the research and development of products and devices that are designed to improve the lives of individuals with disabilities through its RERC and SBIR programs, NIDRR is also expected, under section 200(3)(D) of the Rehabilitation Act of 1973, as amended, to promote the transfer of rehabilitation technology to individuals with disabilities through research and demonstration projects.

The term "technology transfer" has been defined as the process by which university-developed technologies are commercialized (Powers, 2004) and, more specifically, as the "transmittal of developed ideas, products, and techniques from a research environment to one of practical application by consumers" (National Council on Disability, 2000). The processes involved in technology transfer are understood to be an important

component of knowledge translation (KT), which refers to the steps between the generation of knowledge and its application to produce beneficial outcomes for society (Canadian Institutes for Health Research, 2005).

Technology transfer for individuals with disabilities is a specific subset of the current technology transfer effort. Technology transfer for products intended for use by individuals with disabilities is often difficult because of the small markets served by any one particular assistive technology product or device. While several government and private agencies are working to promote technology transfer for larger and more lucrative markets, very few Federal efforts focus on the transfer of technology for use by individuals with disabilities (National Council on Disability, 2000). Not only is NIDRR mandated to fill this gap, but it is well positioned to do so, given the research and development work supported and the scientist-market networks established through its RERC and SBIR programs.

Research from the broader technology transfer field provides limited guidance on how to improve technology transfer for individuals with disabilities. Although some researchers have examined the processes involved in technology transfer as well as methods for evaluating transfer efforts such as best practice analyses (e.g., Erich & Gutterman, 2003; Leahy, 2003; Tornatzky, 2001), research in this area is still limited. For example, best practices analyses have generally involved qualitative case descriptions rather than systematic tests of the models, methods, and measures used for successful technology transfer. A strong need remains for the systematic review of existing models, methods, and measures as well as for the identification of best practices in technology transfer. Once identified, best practices for technology transfer must be adopted by key stakeholders. Training and technical assistance have been named as important methods for promoting the adoption of best practices and, thus, for facilitating the success of the commercialization process (Canadian Institutes of Health Research, 2005).

Current Federal investments are attempting to meet the need for technology transfer research generally, but little research has been devoted to examining the potential relevance, applicability, or usability of general technology transfer research within the specific subfield of assistive technology for individuals with disabilities (National Council on Disability, 2000).



The need for further technology transfer research is especially acute among those who are developing and attempting to make technologies, products, and devices for individuals with disabilities.

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability and Rehabilitation Research Project to serve as the Center on Knowledge Translation for Assistive Technology Transfer (Center). The Center must conduct rigorous research, development, technical assistance, dissemination, and utilization activities to increase successful knowledge translation (KT) for technology transfer of products developed by NIDRR-funded technology grantees.

The Center must partner with key stakeholders such as trade and professional associations, and relevant industry representatives, and focus on no more than three of the following technology areas, which are referenced in the NIDRR Long-Range Plan, 2005–2009: Sensory, Communication, Informational Technology and Telecommunications, and Environmental Access.

Under this priority, the Center must be designed to contribute to the following outcomes:

(a) Improved understanding of barriers to and facilitators of successful KT for technology transfer in different

industries related to NIDRR's technology portfolio. The Center must contribute to this outcome by—

(1) Identifying and compiling existing research-based knowledge about barriers to and facilitators of successful KT for technology transfer; and

(2) Conducting research on barriers to and facilitators of successful KT for technology transfer related to the technology areas on which the Center focuses.

(b) Advanced knowledge of best practices in KT for technology transfer. The Center must contribute to this outcome by—

(1) Identifying existing models, methods, or measures of KT for technology transfer in different industries related to NIDRR's technology portfolio;

(2) Further developing and testing models, methods, or measures in the technology areas on which the Center focuses; and

(3) Establishing best technology transfer practices that can be used to effectively implement and evaluate the success of technology transfer activities in the technology areas on which the Center focuses.

(c) Increased utilization of the validated best practices for KT for technology transfer. The Center must contribute to this outcome by providing training and technical assistance to NIDRR-funded technology grantees to implement and evaluate the success of such practices.

#### Priority 8—Asset Accumulation and Economic Self-Sufficiency for Individuals With Disabilities

##### Background

The availability of savings and assets are important to all individuals because they promote and allow investment in long-term goals such as education and home ownership. Savings and assets are also associated with increased household stability, community involvement, political participation, and self-sufficiency in the general population (Abt Associates, 2000).

For individuals with disabilities, the availability of financial savings and assets facilitates progress toward a wide range of community participation goals. Financial savings and assets can facilitate this progress in numerous ways, such as making it possible to purchase needed assistive technology (AT), make down payments on a home, modify one's home for greater accessibility, start a business, or pay for college (Putnam *et al.*, 2005). Little is known about asset accumulation patterns among individuals with

disabilities. One of the few relevant studies comparing individuals with and without disabilities indicates that individuals with musculoskeletal conditions and related health difficulties have fewer assets than those without musculoskeletal conditions (Yelin, 1997). Because working-age adults with disabilities are more likely than their non-disabled counterparts to live in poverty (Weathers, 2005) and are less likely to be employed (U.S. Census Bureau, 2002), they have less opportunity to accumulate savings and other assets. However, being low-income does not preclude savings and asset accumulation (Beverly, 1997).

Research is required to generate new knowledge about both the barriers to, and facilitators of, savings and asset accumulation for individuals with disabilities. These barriers and facilitators are likely to exist at both the individual and system levels. At the individual level, the following factors have been shown to be associated with asset levels in the general population: income level, education level, employment status, marital status, motivation to save, racial and ethnic status, age, financial literacy, and maintenance of a bank account, among others (Putnam *et al.*, 2005; Beverly, 1997). In addition, factors associated with asset accumulation that are specific to individuals with disabilities may include type of disabling condition, disability severity, and age-of-onset.

In addition to the individual-level factors described in the previous paragraph, there are also a number of barriers to, and facilitators of, asset accumulation at the system level. For example, individuals with disabilities who participate in Federal income support programs are placed under strict asset limits that preclude substantial accumulation of savings (Stapleton *et al.*, 2006). Low employment rates among individuals with disabilities are associated with reduced access to institutionalized saving mechanisms such as pensions or payroll deductions for retirement savings accounts (Beverly, 1997). Sub-optimal access to bank buildings and general financial services for individuals with disabilities may also reduce asset accumulation opportunities (Putnam *et al.*, 2005).

New knowledge about both the barriers to, and facilitators of, asset accumulation must be applied to the development of targeted interventions or to tailoring currently existing asset accumulation interventions to the specific needs and circumstances of individuals with disabilities. Financial literacy education, for example, could

be tailored to address the needs and circumstances of individuals with specific disabling conditions (Cook, 2007). Individual Development Accounts (*i.e.*, special bank accounts that help individuals save money for a specific purpose such as their education or the purchase of a first home) could be established for savings goals that are particularly relevant to individuals with disabilities, such as offsetting out-of-pocket expenses for health care or personal assistance services, or purchasing AT or home modifications.

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- on Asset Accumulation and Economic Self-Sufficiency for Individuals with Disabilities. This DRRP must create new research-based knowledge to promote asset accumulation among individuals with disabilities. Under this priority, the DRRP must be designed to contribute to the following outcomes:
- (a) New knowledge of both the barriers to, and facilitators of, asset accumulation and economic self-sufficiency for low- to moderate-income individuals with disabilities and their families. This DRRP must contribute to this outcome by focusing on the individual-level characteristics that may affect savings and asset accumulation, as well as system-level factors that include policies or programs designed to create system-level incentives or disincentives to the accumulation of assets.
  - (b) Improved asset accumulation outcomes and economic self-sufficiency among individuals with disabilities. The DRRP must contribute to this outcome by developing and testing no more than two interventions that capitalize on the facilitators and address the barriers to asset accumulation described in paragraph (a) of this priority. These interventions may include the tailoring of existing asset accumulation interventions to the specific needs and circumstances of individuals with disabilities.

#### Priority 9—Technology Transfer in Resource-Limited Environments

##### Background

Growth in the number of older people in the populations of the United States, Europe, Asia, and elsewhere suggest that there will be a steady increase in demand over the next several decades for a broad spectrum of assistive technology (AT) devices from hearing aids and canes to advanced wheelchairs, specially equipped automobiles, and personal communication devices. However, despite an increasing demand for AT, many individuals with disabilities still cannot access the AT devices they need (Bureau of Industry and Security, 2003).

Moreover, in developing countries, environmental constraints often affect the usability of many AT products. For example, products that are developed to enhance mobility may be affected by the lack of paved roads. Lack of maintenance and repair facilities also may affect distribution to, and usability of, technology by individuals with disabilities in many parts of the world. Distance and limited distribution networks tend to inhibit access to AT equipment and services. These

constraints are particularly significant in rural areas, where farm accidents account for many disabilities, and in countries where landmine injuries affect individuals whose primary occupation is farming (Swanson, 2007).

In the United States, the U.S. Department of Agriculture has recognized the needs of farmers and ranchers with disabilities by funding the AgriAbility project, which provides training, technical assistance, and information about technology and other services through agricultural extension services. NIDRR has also funded research projects to examine service delivery needs for farmers with disabilities. While NIDRR and other Federal agencies have funded successful projects in this area, and although these projects have resulted in the development of low-tech products for use by individuals with disabilities in the United States and in international settings, there is still a persistent need to develop methods of moving new technologies into practice in settings where resources may be scarce.

Many barriers to implementing knowledge translation (KT) strategies for technology development also exist. The three major barriers to the acquisition of technology products in developing countries, and certain parts of the United States, are: lack of awareness of their existence or how to acquire them, lack of necessary materials to produce them, and lack of expertise needed to produce them locally (Jeserich, 2003a; Jeserich, 2003b; Ripat & Booth, 2005; Robitaille, 2003).

Several models exist to guide the development, manufacture, and distribution of low-cost, high-quality products in developing countries or economically disadvantaged areas within the United States. Each of these models highlights different aspects of product development, manufacturing or distribution processes. For example, in the charitable model, it is common to use regional distribution points to make products available to those who need them. Likewise, the workshop model focuses on training individuals to construct products that are needed by individuals in their community by using locally available resources, and the manufacturing model requires teaching individuals to construct products by setting up local factories and distributing the products regionally or nationally. The globalization model requires that an established company expand into a region either by establishing a factory or importing products there (Pearlman *et al.*, 2006).

None of these models, however, offers a universal solution to the challenge of

#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability and Rehabilitation Research Project (DRRP)

designing, developing, manufacturing, and distributing low-cost, high-quality products to individuals in developing countries or in economically disadvantaged regions of the United States. Different aspects of these models work well under different environmental conditions. Research is needed to expand our understanding of how best to foster the transfer of technology in these settings.

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability Rehabilitation Research Project (DRRP) on Technology Transfer in Resource-Limited Environments. Under this priority, the DRRP must be designed to contribute to the following outcomes:

(a) Increased access to, and acquisition of, high-quality, low-cost technology products by individuals with disabilities who need them. The DRRP must contribute to this outcome by conducting research to evaluate the application of various models of transferring technology products to individuals with disabilities in resource-limited environments, either in the United States or abroad. The DRRP's research must examine the relationship of factors such as type of technology, delivery system options, socio-economic conditions, and disability type, on successful transfer of needed technologies to individuals with disabilities. NIDRR is particularly concerned about providing technology to support individuals engaged in agricultural occupations due to a significant need for AT by this population.

(b) Increased awareness by individuals with disabilities of high-quality, low-cost technology products, already developed or in development, for use in resource-limited environments. The DRRP must contribute to this outcome by conducting research on methods of providing information on available products to individuals with disabilities and their caregivers in resource-limited environments in the United States, developing countries, or both. The DRRP's research must examine the relationship of factors, such as literacy rates and the availability of print, Internet, or other communication resources, as well as socioeconomic factors and disability type on effective strategies to increase awareness among individuals with disabilities in these areas.

#### Priority 10—Research and Knowledge Translation Center for Individuals With Disabilities and Their Families

##### Background

In the United States, there are approximately 20.3 million households in which at least one individual has a disability. This includes households in which at least one child under the age of 18 has a disability and those in which at least one adult has a disability. NIDRR has funded research on children with disabilities and their families (e.g., the Rehabilitation Research and Training Center on Policies Affecting Families of Children With Disabilities), as well as on adults with disabilities who are parents of children under the age of 18 (e.g., the National Resource Center for Parents with Disabilities). The family is a critical unit of analysis

in both of these important research areas.

It is necessary to understand the experiences of individuals with disabilities and their families as they attempt to navigate programs and service delivery systems that are critical to their participation in society. The needs and experiences of individuals with disabilities and their families differ based on the underlying condition and age of the individual, as well as key sociodemographic characteristics and structure of the individual's family. High-quality, in-depth research on these heterogeneous needs and experiences must serve as an empirical basis for the ongoing development, delivery, and evaluation of targeted information resources for families that include an individual with a disability, whether that individual is a child or the parent of a child.

Individuals with disabilities and their families could benefit from research-based training and technical assistance resources that are designed to help them navigate relevant programs and service delivery systems more effectively (Mitchell & Sloper, 2002). These programs and service delivery systems include, but are not limited to, childcare, family law, long-term care, and health care programs and services. Accordingly, NIDRR seeks to fund a center that will translate existing research-based knowledge about these complex programs and service delivery systems to ensure that such resources are available to individuals with disabilities and their families. Additional work in this area will help promote the achievement of one of NIDRR's primary goals, the successful dissemination of research-based knowledge and products for use by intended target audiences, including individuals with disabilities and their families and caregivers (NIDRR Long Range Plan, 2005–2009).

Research has been conducted on the many programs and service delivery systems that individuals with disabilities and their families must navigate. There is a need for translation of this research into materials that can be used by individuals with disabilities and their families as they make critical decisions and choices about the services that are available to them. For example, the families of children with disabilities could benefit from translation and widespread dissemination of peer-reviewed research on child care services (Devore & Bowers, 2006), respite and related support services (McGill, Papachristoforou, & Cooper, 2006), and effectively meeting the complex health care needs of children with disabilities

in the community (American Academy of Pediatrics, 2005).

In addition, adults with disabilities who are parents may come into contact with components of the complex family law system that often assume that disability precludes effective parenting (Kirshbaum & Olkin, 2002). These components of the family law system include statutes and case law related to custody, adoption, and divorce. Translation of legal research on parenting with a disability (Odegard, 1993) may be useful to parents with disabilities and their families. Parents with physical disabilities also would benefit from translation of research on baby care adaptations (Tuleja & DeMoss, 1999), as well as research on the more general experiences of parents with disabilities (Wade, Milton, & Matthews, 2007; Conley-Jung & Olkin, 2001).

Families that include one or more individuals with disabilities must often make decisions about an array of options for providing and financing the long-term services and supports that are necessary to help the family member live and participate in the community. Research on the effectiveness of various service delivery models (Hagglund, Clark, Farmer, & Sherman, 2004; Benjamin, Matthias, & Franke, 2000) could be translated into information that helps individuals with disabilities and their families make critical long-term care decisions.

Regardless of the age of the family member with a disability, working within the health care system to receive needed services is important to maintaining health, function, and high levels of participation in the community. The translation of peer-reviewed research on health promotion programs (Raveslout, Seekins, Cahill, Lindgren, & Nary, 2006), health care coordination programs (Palsbo, Mastal, & O'Donnell, 2006), and preventive care (Smeltzer, 2006) are likely to be useful to individuals and their families as they make decisions about their health and well being.

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## Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Disability and Rehabilitation Research Project (DRRP) to serve as the Research and Knowledge Translation Center for Individuals with

Disabilities and Their Families (Center). The Center must conduct research on the experiences and knowledge needs of individuals with disabilities and their families, and translate these findings into training, technical assistance, and informational resources.

The Center must focus on the knowledge needs of families that include a child with a disability, an adult with a disability who is a parent of at least one child under the age of eighteen, or both.

Under this priority, the Center must be designed to contribute to the following outcomes:

(a) Increased knowledge about the experiences and information needs of individuals with disabilities and their families, and how those experiences and needs differ by variables such as condition type, severity, and age, as well as key characteristics of other family members and the overall structure of the family. The Center must contribute to this outcome by synthesizing existing research and advancing the knowledge base through the collection and analysis of data about the experiences and knowledge needs of families that include one or more individuals with a disability. Through this research and analysis, the Center must examine the extent to which the needs of individuals with disabilities and their families are being met by the programs and service systems that are critical to their community integration and participation (e.g., statutes and case law related to custody, adoption, and divorce; health care; long-term care; assistive technology provision programs; child care; transportation; and a wide variety of related social support services).

(b) Improved participation and community integration of individuals with disabilities. The Center must contribute to this outcome by developing, implementing, and evaluating research-based training, technical assistance, and informational resources that are targeted to the specific knowledge needs of individuals with disabilities and their families, as those needs are identified through the research activities described in paragraph (a) of this priority, or other research-based knowledge.

In addition, the Center must coordinate with relevant NIDRR Knowledge Translation grantees to develop and implement a method for identifying high-quality, research-based information for dissemination to individuals with disabilities and their families.

## Rehabilitation Research and Training Centers (RRTCs)

RRTCs conduct coordinated and integrated advanced programs of research targeted toward the production of new knowledge to improve rehabilitation methodology and service delivery systems, alleviate or stabilize disability conditions, or promote maximum social and economic independence for individuals with disabilities. Additional information on the RRTC program can be found at: <http://www.ed.gov/rschstat/research/pubs/res-program.html#RRTC>.

### Statutory and Regulatory Requirements of RRTCs

RRTCs must—

- Carry out coordinated advanced programs of rehabilitation research;
- Provide training, including graduate, pre-service, and in-service training, to help rehabilitation personnel more effectively provide rehabilitation services to individuals with disabilities;
- Provide technical assistance to individuals with disabilities, their representatives, providers, and other interested parties;
- Demonstrate in their applications how they will address, in whole or in part, the needs of individuals with disabilities from minority backgrounds;
- Disseminate informational materials to individuals with disabilities, their representatives, providers, and other interested parties; and
- Serve as centers of national excellence in rehabilitation research for individuals with disabilities, their representatives, providers, and other interested parties.

### Priority 11—General Rehabilitation Research and Training Center (RRTC) Requirements

#### Background

NIDRR proposes the following *General RRTC Requirements* priority because it believes that the effectiveness of any RRTC depends on, among other things, how well the RRTC coordinates its research efforts with the research of other NIDRR-funded projects, involves individuals with disabilities in its activities, and identifies specific anticipated outcomes that are linked to its objectives in applying for RRTC funding. Accordingly, NIDRR intends to use proposed *Priority 11—General RRTC Requirements* in conjunction with each of the other RRTC priorities proposed in this notice (i.e., priorities 12 through 21).

#### Proposed Priority

To meet this priority, the Rehabilitation Research and Training Center (RRTC) must—

- (a) Conduct a state-of-the-science conference on its respective area of research by the fourth year of the grant cycle and publish a comprehensive report on the final outcomes of the conference by the end of the fourth year of the grant cycle. This conference must include materials from the experts internal and external to the RRTC;
- (b) Coordinate on research projects of mutual interest with relevant NIDRR-funded projects as identified through consultation with the NIDRR project officer;
- (c) Involve individuals with disabilities in planning and implementing its research, training, and dissemination activities, and in evaluating the RRTC; and
- (d) Coordinate with the appropriate NIDRR-funded Knowledge Translation Centers and professional and consumer organizations, to provide scientific results and information for dissemination to policymakers, service providers, researchers, and others.

### Priority 12—Enhancing the Health and Wellness of Persons With Neuromuscular Diseases

#### Background

The term “muscular dystrophy” is used to refer to the more than 40 neuromuscular diseases (NMDs). The Muscular Dystrophies are currently classified in nine types (Myotonic, Duchenne, Becker, Limb-Girdle, Facioscapulohumeral, Congenital, Oculopharyngeal, Distal and Emery-Dreifuss), and some of these are categorized into further subtypes. NMDs affect individuals of both sexes at every stage of life: infancy, adolescence, adulthood, and old age. Their effects range from gradual loss of mobility and independence to severe disability and death. The most common NMD is Duchenne/Becker Muscular Dystrophy (DBMD). DBMD affects approximately 1 out of every 3,500 to 5,000 boys (Single Gene Disorders and Disability, 2006).

Individuals with NMDs face health, psychosocial, and economic problems that negatively affect their overall health and well-being, as reported at the National Institutes of Health (NIH) “Burden of Muscle Disease Workshop,” hosted by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the NIH Office of Rare Diseases on January 26–27, 2005 (Burden of Muscle Disease Workshop, 2005). Neuromuscular diseases may contribute to significant health

problems because of muscle weakness, difficulty with exercise, fatigue, poor endurance, weight problems (e.g., obesity), pulmonary complications and associated sleep disorders. Research is needed to generate new knowledge about secondary conditions of NMD that are not as well understood—such as pain, reduced bone content, and metabolic complications.

Exercise and nutrition have been a focus of rehabilitation interventions because they are key factors in successful participation in health and wellness programs for individuals with NMDs (Kilmer, 2002). However, due to the loss of functional muscle tissue from NMDs, few studies have examined the response of individuals with NMDs to cardiopulmonary testing and aerobic exercise training (McDonald, 2005). In order to facilitate high-quality research in the areas of cardiopulmonary testing and aerobic exercise training, the capacity to measure physical, functional, and social participation outcomes must be enhanced (Muscular Dystrophy Coordinating Committee Report, 2005) through the development of new outcome measures, or validation of existing measures in populations of individuals with NMD.

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Enhancing the Health and Wellness of Persons with Neuromuscular Diseases (NMDs). This RRTC must conduct rigorous research, training, technical assistance, and dissemination activities to improve rehabilitation outcome measures and rehabilitation interventions that can be applied in clinical or community-based settings.

In doing so, the RRTC must focus on no more than two of the following dimensions: Prevention or reduction of secondary conditions (e.g., pain, fatigue, muscle weakness, associated sleep disorders, metabolic complications); improved mobility; emotional well-being; and access to community-based health promotion services and programs (e.g., fitness, recreation, and nutrition). Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Improved outcome measures for use with individuals with NMDs. The RRTC must contribute to this outcome by identifying or developing and testing methods and measures to assess health and rehabilitation outcomes, participation in community-based programs, or both.

(b) Improved medical rehabilitation or community-based rehabilitation interventions. The RRTC must contribute to this outcome by identifying or developing and testing new rehabilitation interventions, replicating promising practices or programs, or both.

### Priority 13—Enhancing the Health and Wellness of Individuals With Arthritis

#### Background

Approximately 60 million adults in United States will have arthritis by the year 2020. Currently, approximately 21 million individuals have osteoarthritis, and another 2.1 million have rheumatoid arthritis (National Arthritis Action Plan, 1999). Arthritis is the leading cause of disability in the United States for individuals 15 years of age and older, potentially limiting affected persons from walking a few blocks or climbing a flight of stairs (Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report, (2007)). Arthritis is also the second leading cause of work-related disability in the United States (Cakmak & Bolukbas, 2005).

Arthritis impacts an individual physically, emotionally, and socially and is characterized by several factors such as pain, inflammation, damage to joint tissue, decreased mobility, fatigue, stress, and depression. Developing interventions to alleviate arthritis pain and functional limitations that are associated with arthritis are particularly important. Exercise is an essential tool in managing arthritis pain and stiffness and in improving mobility. Muscle strength training is considered to be an important cornerstone of non-pharmacological treatment for individuals with arthritis (Hakkinen, 2004). However, the rates of

participation in regular exercise are lower among individuals with arthritis than those without arthritis (Barclay, 2006).

Arthritis also can lead to diminished enjoyment of, and participation in, daily activities and community-based programs (e.g., going to church and socializing), which in turn can contribute to feelings of isolation and depression. A depression management program consisting of coordination of medications and counseling can reduce both depression and arthritis pain and disability in older adults (Lin *et al.*, 2003).

Outcome measures are required to assess the effectiveness of specific interventions to reduce the physical, functional, emotional, and social sequelae of arthritis. While arthritis researchers have access to effective measures of disease status, physical and functional abilities, and quality of life, measures of social participation for this population are less well developed (Backman, 2006). Research is required to fill this gap in outcome measures through the development of arthritis-specific measures of participation, or the validation of existing measures of participation that have been developed for other subpopulations of individuals with disabilities (Whiteneck *et al.*, 1992).

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Enhancing the Health and Wellness of Individuals with Arthritis. This RRTC must conduct rigorous research, training, technical assistance, and dissemination activities to improve rehabilitation outcome measures and rehabilitation interventions that can be applied in clinical or community-based settings.

In doing so, the RRTC must focus on no more than two of the following dimensions: prevention or reduction of secondary conditions (e.g., pain, fatigue, depression); improved mobility; emotional well-being; and access to community-based health promotion services and programs (e.g., fitness, recreation, and nutrition). Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Improved outcome measures for use with persons with arthritis. The RRTC must contribute to this outcome by identifying or developing and testing methods and measures to assess health and rehabilitation outcomes, participation in community-based programs, or both.

(b) Improved medical rehabilitation or community-based rehabilitation interventions. The RRTC must contribute to this outcome by identifying or developing and testing new rehabilitation interventions, replicating promising practices or programs, or both.

### Priority 14—Stroke Rehabilitation

#### Background

Approximately 730,000 individuals experience strokes in the United States each year. Nearly five million individuals in the United States today have survived a stroke. Stroke patients continue to be the largest diagnostic group in medical rehabilitation, and stroke is often associated with high levels of disability (American Heart Association, 2006).

With the help of new technologies, significant progress has been made in the development of rehabilitation

interventions and in the assessment of outcomes for those who have experienced a stroke. Examples of recent advances in rehabilitation interventions and outcomes assessment include the Extremity Constraint-Induced Therapy Evaluation (EXCITE), a repetitive training of upper extremities on task-oriented activities that enhances functional abilities of stroke survivors 3 to 9 months after stroke (Wolf *et al.*, 2006; Messe & Cucchiara, 2006). A novel and promising technology, the BION, is an implantable neuromuscular stimulation device to treat complications of paralysis and disuse atrophy, including shoulder subluxation, hand contractures, drop foot, and osteoarthritis (Loeb *et al.*, 2006).

Given the large and growing incidence of stroke in the United States and the high levels of physical and cognitive disability often associated with stroke, there is a need for further research on promising new interventions, such as constraint-induced (CI) therapy, bodyweight-supported treadmill training (BWS-TT), electrical stimulation, and robotic technology (Bassett, 2006). In addition, research is needed to develop more sensitive measures of neuro-recovery and post-stroke secondary health conditions, as well as to develop interventions to prevent a variety of post-stroke secondary health conditions such as fatigue (Gladstone *et al.*, 2002; Roth, 2005).

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## Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Stroke Rehabilitation. This RRTC must conduct rigorous research, training, technical assistance, and dissemination activities to improve rehabilitation outcome measures and rehabilitation interventions that can be applied in clinical or community-based settings.

In doing so, the RRTC must focus on no more than two of the following dimensions: prevention or reduction of secondary conditions (e.g., pain, fatigue, depression); improved mobility; emotional well-being; and access to community-based health promotion services and programs (e.g., fitness, recreation, and nutrition). Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Improved outcome measures for use with persons with stroke. The RRTC must contribute to this outcome by identifying or developing and testing methods and measures to assess health and rehabilitation outcomes, participation in community-based programs, or both.

(b) Improved medical rehabilitation or community-based rehabilitation interventions. The RRTC must contribute to this outcome by identifying or developing and testing new rehabilitation interventions, replicating promising practices or programs, or both.

## Priority 15—Personal Assistance Services (PAS) in the 21st Century

### Background

In 2005, health-related problems resulted in about 3.8 million adults needing help from another person with personal care activities, and about 7.8 million adults requiring help from another person with daily activities, such as household chores or shopping. Among adults ages 75 and over, a rapidly growing population, about 10 percent required help with personal care and 19 percent required help with daily activities (Adams, Dey, & Vickerie, 2005; Population Projections Branch, 2004). Most personal assistance services (PAS) are provided by unpaid caregivers

such as family members or friends; in 2004, over 44 million adults provided help with care to an adult family member or friend (Naiditch & Wasan, 2006). However, paid personal and home care aides held only about 701,000 jobs in 2004 (Bureau of Labor Statistics (BLS), U.S. Department of Labor (DOL), 2006).

The demand for personal and home care aides is expected to increase greatly over the next 10 years because of the aging of the U.S. population (BLS, DOL, 2006). The expected increase in demand is especially troubling because a labor shortage crisis in the available pool of caregivers already exists. This labor shortage crisis has “potentially negative consequences for quality of care and quality of life” for individuals requiring personal and home care (Stone & Wiener, 2001). In addition, many unpaid caregivers themselves are aging and face their own “considerable personal toll—physically, mentally, emotionally, and financially, and in terms of retirement insecurity, lost jobs or other missed opportunities” (Miller & Mor, 2006). Finally, the need for an improved network of PAS providers extends beyond day-to-day activities; there is also an emerging need for PAS providers during emergencies and disaster situations (National Council on Disability, 2006).

The cost of PAS can be covered by a variety of sources, depending on a person’s income and the type of services provided. For example, individuals with disabilities who work and receive Supplemental Security Income (SSI) benefits may deduct PAS performed in an employment setting or in preparing for, or traveling to or from, the workplace as an Impairment-Related Work Expense. This deduction is used to calculate available income and ultimately the amount of a person’s SSI cash benefit (Social Security Administration, 2006). While the loss of such benefits has frequently been seen as a hindrance to securing or maintaining employment, there is little research on the economic impact of covering PAS costs for adults who are working and not eligible for public assistance. A study of elderly adults with disabilities also suggests that the use of assistive technology by an individual with disabilities reduces the number of PAS hours required for that individual (Hoenig, Taylor, & Sloan, 2003). However, there has been little research on the relationship between the use of AT by working-age adults with disabilities and the number of PAS hours required by those individuals.



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- RRTC must be designed to contribute to the following outcomes:
- (a) Improved access to PAS by individuals with disabilities. The RRTC must contribute to this outcome by: (1) Analyzing and describing trends and needs of the population of PAS consumers; (2) identifying gaps in programs and services; (3) developing effective evidence-based interventions to address unmet needs for PAS; and (4) proposing strategies to coordinate and secure PAS services during emergencies.
- (b) A larger and better prepared paid and unpaid PAS workforce. The RRTC must contribute to this outcome by: (1) Developing tools and supports for unpaid caregivers that reflect the changing needs of caregivers as they age; (2) developing strategies that lead to a PAS workforce that is geographically diverse and that maximizes workforce recruitment, retention, compensation and benefits, professional training, development, and networking; and (3) identifying and evaluating interventions and labor resources, such as job training services, that help to improve workforce capacity of PAS providers.
- (c) An understanding of the complexity of the economics of PAS. The RRTC must contribute to this outcome by: (1) Analyzing the interrelationship between the use of assistive technology, employment supports, and PAS; and (2) analyzing the role of tax laws that affect reimbursement for PAS.

### Priority 16—Participation and Community Living for Individuals With Psychiatric Disabilities

#### Background

Individuals with psychiatric disabilities have one of the lowest rates of employment of any disability group—only 1 in 3 individuals with psychiatric disabilities is employed (Kaye, 2002). They also comprise the largest diagnostic category of working-aged adults receiving Supplemental Security Income or Social Security Disability Insurance (McAlpine and Warner, 2001).

In addition, individuals with psychiatric disabilities constitute a large proportion of the homeless population. Of 2 million adults experiencing an episode of homelessness, for example, 46 percent have a psychiatric disability (Burt, 2001).

In April 2002, the President signed Executive Order 13263, establishing a New Freedom Commission on Mental Health, and charged the Commission with completing a comprehensive study of the mental health service delivery

system in the United States. The Commission's report, *Achieving the Promise: Transforming Mental Health Care in America*, set the course for public and private efforts across the country to improve the state of mental health care (New Freedom Commission on Mental Health, 2003). The Commission calls for a transformation of the mental health service delivery system, focusing on recovery and resilience for individuals with psychiatric disabilities. Recovery is, in part, "the process in which people are able to live, work, learn, and participate fully in their communities," while resilience indicates "the personal and community qualities that enable us to rebound from adversity, trauma, tragedy, threats, or other stresses—and to go on with life with a sense of mastery, competence, and hope" (New Freedom Commission on Mental Health, 2003).

Being part of a community means being included, involved, and valued; it means holding social roles that are meaningful. Inclusion requires full access to opportunities and support in areas such as employment, housing, education, health and mental health care, recreation, social relationships, and other public and private sector activities. Research, including NIDRR-funded research, has advanced the knowledge base in these and other areas through a focus on recovery-oriented services, peer supports, supported education, psychiatric rehabilitation, and the avoidance of stigma. This research has led to advances in theory development, measurement tools, treatment options, and a variety of community-based supports. However, further research is needed in these areas to maximize participation and community living outcomes.

In addition, there is a strong need for research on understudied aspects of participation and community living for individuals with psychiatric disabilities. Two examples among many are emergency preparedness and mental health disparities for traditionally underserved populations (e.g., individuals from diverse racial, ethnic, linguistic, and geographic backgrounds, and individuals with multiple disabilities) (National Council on Disability, 2006; New Freedom Commission on Mental Health, 2003; U.S. Public Health Service, Office of the Surgeon General, 2001).

Finally, there is extensive documentation about the need to accelerate the incorporation of research findings in mental health service delivery so that individual lives can change as a result of the research.

#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Personal Assistance Services (PAS) in the 21st Century. This RRTC must conduct rigorous research, develop interventions, and provide training that address future demands for PAS and caregiving. Under this priority, the

According to the Institute on Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, the time lag between the discovery of effective medical treatments and the incorporation into practice is 15 to 20 years. The President's New Freedom Commission on Mental Health has called for a reduction in this delay as part of an overall transformation of mental health care in America (Substance Abuse and Mental Health Services Administration, 2005; New Freedom Commission on Mental Health, 2003; Institute of Medicine, 2001).

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- Individuals with Psychiatric Disabilities. The RRTC must conduct rigorous research, training, technical assistance, and dissemination activities that contribute to improved participation and community living outcomes for individuals with psychiatric disabilities. Under this priority, the RRTC must be designed to contribute to the following outcomes:
- (a) Improved individual and system capacity to maximize the meaningful involvement of individuals with psychiatric disabilities in community life. The RRTC must contribute to this outcome by:
    - (1) Advancing the knowledge base and application of theories, measures, methods, interventions, or a combination of those activities that facilitate participation and community living. This must include a focus on at least three of the following areas: employment, housing, education, health and mental health care, recreation, social relationships, or other public and private sector activities related to community living.
    - (2) Reducing disparities in service delivery and program development by including a focus on one or more of the following understudied areas: (i) Emergency preparedness for individuals with psychiatric disabilities; (ii) individuals with psychiatric disabilities from diverse racial, ethnic, linguistic, and geographic backgrounds; or (iii) individuals with psychiatric disabilities who have co-occurring sensory or physical disabilities.
    - (b) Increased incorporation of mental health research findings into practice or policy. The RRTC must contribute to this outcome by coordinating with appropriate NIDRR-funded knowledge translation grantees to advance or add to their work in the following areas:
      - (1) Developing and implementing procedures to evaluate the readiness of mental health research findings for translation into practice.
      - (2) Collaborating with stakeholder groups to develop, evaluate, or implement strategies to increase utilization of mental health research findings.
      - (3) Conducting training, technical assistance, and dissemination activities to facilitate knowledge translation in the context of mental health research.
- Priority 17—Multiple Sclerosis: Interventions To Maximize Health, Well-Being, and Participation**

#### Background

Approximately 400,000 Americans have multiple sclerosis (MS), and, each week, about 200 more individuals in the

United States are diagnosed with MS (National Multiple Sclerosis Society, 2005). Individuals with MS may have symptoms such as fatigue, motor weakness, spasticity, poor balance, heat sensitivity, pain, cognitive impairment, and mood disorders (Wynn, 2006; Mikol, 2006). The impact of the variety of symptoms that an individual with MS may experience and the uncertain prognosis of a given course of MS can impair an individual's routine activities; vocational, social and interpersonal functioning; and quality of life (Kalb, 2004). Treatment of MS may include: medication, rehabilitation, integrative medicine, and other interventions (Yadav *et al.*, 2006). Surveys indicate that 50 to 75 percent of individuals with MS have tried dietary changes, nutritional or herbal supplements, mind-body therapies, and similar approaches to manage MS. Interestingly, patients seem unlikely to discuss these types of strategies with their neurologists (Yadav *et al.*, 2006).

While some research has been conducted regarding the functional outcomes of individuals with MS, there is a significant need for further research in the areas of outcomes measurement and rehabilitation interventions to maximize the health, well-being, and participation of individuals with MS. Providers of care who treat individuals with MS have cited their own need for clinical consultation and continuing medical education (CME) about treatment of MS-associated symptoms (Turner *et al.*, 2006). Fatigue, depression, cognitive impairment, and pain are among the most frequently cited areas for consult and CME (Mikol, 2006). Future research should address the frequent co-occurrence of these four symptoms as well as the impact of central-nervous-system-active medications used to treat them (Oken *et al.*, 2006). For individuals with MS, there is a "continued need for effective therapeutic approaches to symptom management" (Joy & Johnston, 2001).

Recent research underscores the need for a continued focus on the role of environmental and lifestyle factors affecting individuals with MS, and also on the impact co-existing chronic health conditions have on an aging population of individuals with MS (Marrie, 2006; Buchanan *et al.*, 2006; Snook *et al.*, 2006). For example, treatment disparities and variations in disease characteristics have been found when comparing individuals with MS from rural versus urban environments (Buchanan *et al.*, 2006). There is also a strong relationship between physical inactivity and risk for obesity among individuals with MS (Snook *et al.*,

#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Participation and Community Living for

2006). In addition, a variety of autoimmune diseases “are reported to occur more frequently than expected in patients with MS” (Marrie, 2006). These findings support the need for further research on outcomes measurement and promotion of health and participation for individuals with MS.

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#### Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Multiple Sclerosis: Interventions to Maximize Health, Well-Being, and Participation. This RRTC must conduct rigorous research, training, technical assistance, and dissemination activities to improve rehabilitation outcome measures and rehabilitation interventions that can be applied in clinical or community-based settings.

In doing so, the RRTC must focus on no more than two of the following dimensions: prevention or reduction of secondary conditions (e.g., pain, fatigue, depression); improved mobility; emotional well-being; and access to community-based health promotion services and programs (e.g., fitness, recreation, and nutrition). Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Improved outcome measures for use with persons with MS. The RRTC must contribute to this outcome by identifying or developing and testing methods and measures to assess health and rehabilitation outcomes, participation in community-based programs, or both.

(b) Improved medical rehabilitation or community-based rehabilitation interventions. The RRTC must contribute to this outcome by identifying or developing and testing new rehabilitation interventions for individuals with MS, replicating promising practices or programs for individuals with MS, or both.

#### Priority 18—Aging With Physical Disability: Reducing Secondary Conditions and Enhancing Health and Participation

##### Background

With medical and technological advancements, many individuals with early onset physical disabilities, acquired at birth, in childhood or young adulthood, are surviving long enough to experience the rewards and challenges of aging (Campbell, Sheets & Strong, 1999). Determining the size of this emerging segment of the disabled population has been difficult due to the lack of sufficient population data on age of onset and duration of disability (Kemp, 2005). The only national estimate available to date comes from a secondary analysis of the 1990 U.S. Census data, which suggests that there may be as many as 25,000,000 Americans who are aging with various long-term disabilities (McNeil, 1994).

As many researchers have documented, a primary challenge associated with increased longevity among this population is an increased risk of “secondary conditions.” The term secondary conditions, or secondary health conditions, is shorthand for the various types of medical and functional problems that individuals with long-term physical disabilities experience post-onset as they age (Kemp & Mosqueda, 2004). Although there is widespread agreement that secondary conditions can be debilitating, costly in terms of financial and social consequences, and potentially fatal in some circumstances, how to define secondary conditions remains an active debate within the disability community (Wilber *et al.*, 2002; Rimmer, 2005).

While a precise definition of secondary conditions is still evolving, the emerging consensus is that secondary conditions often increase the severity of an individual's disability (Brandt & Pope, 1997). As individuals with long-term physical disabilities age into middle and later adulthood, there is an enormous physical and psychological burden associated with having to manage various secondary health conditions, in addition to managing the chronic health effects related to the aging process generally (Rimmer, 2005). There is, however, widespread agreement that certain secondary conditions are preventable, and that learning how to prevent the onset or reduce the severity and impact of these new or increased impairments, functional limitations, and age-related health problems is vital to enhancing the health and participation of individuals aging with long-term disabilities (Simeonsson *et al.*, 1999; Lollar, 2002; Wilber *et al.*, 2002).

To date there are no national estimates of the number of individuals with long-term physical disabilities who are experiencing one or more types of secondary conditions. Most of what is known about the prevalence and consequences of secondary conditions for health and participation comes from clinical studies of patients, a handful of community-based studies and secondary analyses of population surveys, and the evolving theoretical understanding of the general aging process (Cristian, 2005; Kemp, 2005; Seekins *et al.*, 1994; Campbell, Sheets, & Strong, 1999; Wilber *et al.*, 2002; Verbrugge & Yang, 2002; Kinne *et al.*, 2004).

Results of these studies underscore the importance of improving treatment options to prevent or reduce the consequences of secondary conditions. Exercise, lifestyle and behavioral

changes, and psychosocial and environmental factors are acknowledged as mediators, or potential mediators, for the development of secondary health conditions (Seekins *et al.*, 1994; Wilber *et al.*, 2002; Kemp, 2005; Rimmer, 2005). However, research on these factors has been limited by the lack of measurement tools to characterize the types and severity of secondary conditions experienced by individuals aging with disabilities, and the lack of experimental and quasi-experimental studies to test the effectiveness of various intervention strategies (Wilber *et al.*; Rimmer, 2005).

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## Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Aging with Physical Disability: Reducing Secondary Conditions and Enhancing Health and Participation. This RRTC must conduct rigorous research, training, technical assistance, and dissemination activities to improve rehabilitation outcome measures and rehabilitation interventions that can be applied in clinical or community-based settings and used by other researchers. The intended outcome of the RRTC is to enhance the health and participation of individuals aging with long-term physical disabilities in work and the community by advancing knowledge about the identification, assessment, treatment and improved management of the secondary conditions likely experienced by this target population.

In addressing this priority, the RRTC must propose no more than four synergistic, cross-disability research projects to address the secondary conditions that are most relevant to the health, employment, or community participation of individuals with disabilities. To ensure the feasibility of the RRTC's proposed activities and increase the likelihood of achieving planned outcomes, the RRTC must focus on no more than three discrete impairment groups, and must limit interventions strategies to no more than two of the following modalities: exercise, health promotion, psychological adaptation, life planning or self-management skills, and environmental or technological supports. Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Enhanced understanding of the natural course of aging with physical disability. The RRTC must contribute to this outcome by documenting the life trajectories and average age of onset of the major types of secondary conditions

experienced by individuals living with long-term physical disabilities, and examining the interrelationships among different types of secondary conditions and the consequences of variations in timing of onset for health and participation.

(b) Improved tools and measures for use with individuals aging with long-term physical disabilities. The RRTC must contribute to this outcome by identifying, developing or modifying, and testing new measurement tools that improve the identification and assessment of the major types of secondary conditions discussed in the literature, as well as the outcomes of interventions designed to prevent or reduce these conditions.

(c) Improved rehabilitation or community-based interventions that enhance the health and participation in work and the community of individuals aging with physical disabilities. The RRTC must contribute to this outcome by identifying, developing, or modifying, and testing new interventions that are effective in preventing the onset or improving the management and reducing the impact of secondary conditions, and replicating promising practices or programs that are effective in preventing the onset or improving the management and reducing the impact of secondary conditions, or both.

## Priority 19—Disability Statistics and Demographics

### Background

A 2003 report from the Interagency Committee on Disability Research (ICDR) identified 67 Federal statutory definitions of the term "disability." These definitions directly influence the collection of national, State, administrative, and other data about individuals with disabilities (Cherry Engineering Support Services (CSSI), Inc., 2003). "Because surveys produce different types of information on disability, they can provide additional perspectives on the sources and effects of disabilities, but they can also cause confusion because of the differences in the way disability is being measured" (Government Accountability Office, 2006). As a result of such confusion, policymakers, service providers, individuals with disabilities, and others may not be able to identify the best available statistics to inform their efforts to enhance the well-being and participation of individuals with disabilities.

An ongoing need exists to bridge the gap between producers and users of disability statistics, particularly as the

population ages and injuries caused by such factors as war and environmental changes lead to growing numbers of individuals with disabilities (National Council on Disability (NCD), 2006). Policymakers cite the need for information about the indirect and direct costs of disability, unmet needs for services or technologies that facilitate environmental access and enhance participation, and individuals with disabilities living in institutional settings (Healthy People 2010, 2000; NCD, 2006).

Though there are a number of useful sources of disability data, "controversy has been generated by variations in disability statistics achieved by different researchers, using varied data collection instruments, differing data sources and different data mining techniques" (NCD, 2006). Methodological research will improve the quality and consistency of data and increase confidence in the research findings (Stern, 2004; McMenamin, Miller, & Polivka, 2006). Improved questionnaire design and innovative data collection strategies can facilitate availability of valid and reliable data (NCD, 2006; Kroll *et al.*, in press). Research to evaluate best practices for conducting surveys of and about individuals with disabilities will improve our understanding of the needs of the population. Development of methodologies to improve collections or analyses of data about populations with low-incidence disabilities, or small demographic subgroups of individuals with disabilities, would advance knowledge about the population. A recent review indicates that "there is a solid base of theory on which to base research among low-incidence populations" but notes the lack of "a large body of work in which this theory has been applied to populations with disabilities" (CESSI, 2005). For these reasons, NIDRR seeks to fund an RRTC that improves the quality of disability statistics.

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## Proposed Priority

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Disability Statistics and Demographics. This RRTC must conduct rigorous research, knowledge translation, training, dissemination, and technical assistance that advance the use of rigorous disability statistics and demographics to inform disability policy and service provision. Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Rigorous and timely demographic research to inform the development of disability policy and programs. The RRTC must contribute to this outcome by: (1) Producing meta-analyses of national, State, and administrative data that address critical program and service needs; and (2) providing statistical consultation, including specialized analyses, to facilitate the use of survey and administrative data by policymakers and others.

(b) Improved disability data and statistics. The RRTC must conduct research about methodologies that advance the practice for (1) Conducting surveys of individuals with disabilities, including individuals with low-prevalence disabilities; (2) analyzing data about low-incidence populations of individuals with disabilities; and (3) other issues related to survey or administrative data.

(c) Effective use of disability statistics and demographic information. The

RRTC must contribute to this outcome by: (1) Serving as a resource on disability statistics and demographics for Federal and other government agencies, policymakers, consumers, advocates, researchers, and others; and (2) transferring research findings to enhance planning, policymaking, program administration, and delivery of services to individuals with disabilities.

## Priorities 20 and 21—Health and Function Across the Lifespan of Individuals With Intellectual and Developmental Disabilities (Priority 20) and Participation and Community Living for Individuals With Intellectual and Developmental Disabilities (Priority 21)

### Background

For purposes of priorities 20 and 21, individuals with intellectual, developmental, mental, and cognitive disabilities, including individuals with cerebral palsy, Downs syndrome, autism, and related conditions, will be referred to as persons with intellectual disabilities or developmental disabilities (ID/DD). Individuals are considered to have an intellectual disability (ID) when their intellectual functioning level (IQ) is below 70–75; they have significant limitations in conceptual, social, and practical adaptive skills such as communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics (reading, writing, basic math), and work; and the disability originated before the age of 18. Developmental disabilities (DD) are defined as severe, chronic disabilities that first appear before age 22, are likely to continue indefinitely, and cause substantial limitations in three or more of the following areas: Self-care, language, learning, mobility, self-direction, and capacity for independent living. These definitions of ID and DD, however, may have limitations when applied in research or in the administration of public assistance programs because of diagnostic ambiguities, implementation and measurement problems, or the temporary nature of certain context-specific disabilities (Larson *et al.*, 2001).

Individuals with ID/DD constitute a diverse group of underserved, underemployed or unemployed, and marginalized individuals. While estimates about the size and composition of this population in the United States range from 1.6 percent to nearly 3 percent of the population (between 4.5 million and 8 million), depending on the source of data and the types of diagnoses used, clear patterns

of disadvantage are apparent in this population (Lakin & Turnbull, 2005; National Institute of Child Health and Human Development, 2002; U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2006).

According to a 2004 report issued by the President's Committee for People with Intellectual Disabilities (2004), around 90 percent of adults with ID/DD were not employed. Among those individuals with ID/DD who were employed, over 365,000 attended sheltered workshops or were in day programs or prevocational services. Levels of educational attainment are quite low for individuals with ID/DD. According to the 2004 report, 26 percent of youth with ID/DD dropped out of school, and fewer than 15 percent participated in postsecondary education. Levels of income and wealth are also low among individuals with ID/DD. Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) were a major source of income for individuals with ID/DD (in December 2001, there were almost 1.1 million adults and children receiving SSI payments based on ID/DD; there were almost 600,000 receiving SSDI benefits). Over 700,000 individuals with ID/DD lived with parents aged 60 or older. Less than one percent of individuals with ID/DD owned their own home (President's Committee for People with Intellectual Disabilities, 2004).

These statistics provide a small glimpse into the everyday life experiences of individuals with ID/DD and their families and caregivers. Depending on the severity of their disability, individuals with ID/DD need assistance in most, if not all, activities of daily living (e.g., walking, dressing, bathing) and instrumental activities of daily living (e.g., shopping or managing money). Such assistance is time consuming and costly, particularly if skilled personal assistance services and professional rehabilitation services are needed.

Besides needing significant amounts of care, many individuals with ID/DD are at an increased risk of being isolated from the community, particularly if they have been placed under institutional supervision or care. Limited educational attainment and job skills are key barriers to inclusion in communal activities. As a result, many individuals with ID/DD have difficulties developing independent living and social skills. They remain dependent on family, friends, and personal caregivers. Where

such supports are not available, they must resort to institutional care.

Individuals with ID/DD have been found to suffer from a wide range of illnesses and impairments (National Institute of Child Health and Human Development, 2002). The onset of many conditions is at birth or in infancy (for example, cerebral palsy). Moreover, many other conditions, such as obesity, diabetes, or Alzheimer's disease occur earlier in adulthood for individuals with ID/DD than most individuals in the general population. As a result, individuals with ID/DD have greater needs for health care services than members of the general population. To obtain the full benefits of these services, the individuals must have access to skilled staff at service facilities who are informed about, and equipped to respond to, the special needs of individuals with ID/DD. If skilled staff are not available, consumers and providers may consider the help of intermediaries, direct support providers, or other social service providers specializing in the care of individuals with ID/DD.

For these reasons, NIDRR seeks to fund two RRTCs designed to increase the levels of health, function, and community living/participation of individuals with ID/DD by developing and applying scientifically validated procedures, treatments, and interventions. The goal of these procedures, treatments, and interventions is to create measurable benefits or outcomes for individuals with ID/DD and their families and caregivers.

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#### Proposed Priority 20—Health and Function Across the Lifespan of Individuals With Intellectual and Developmental Disabilities

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) on Health and Function Across the Lifespan of Individuals with Intellectual and Developmental Disabilities (ID/DD). This RRTC must focus on rigorous research, training, technical assistance, and dissemination of strategies and interventions that improve the health and function of individuals with ID/DD, and access to community-based health and social services by individuals with ID/DD. The research conducted by this RRTC also must focus on improving the health and function of individuals with ID/DD and on promoting family and caregiver supports that enable persons with ID/DD to receive long-term care.

When applying for a grant under this priority, an applicant must identify, in its application, the subjects of interest from the diverse population of individuals with ID/DD to be served by the proposed research and describe how the proposed research will benefit this group.

Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Conceptually sound theories and methodologies for research on community-based rehabilitation and health and social service provision, including research on long-term care or care provided by family members to individuals with ID/DD. The RRTC must contribute to this outcome by investigating existing theories that may help organize or frame research on ID/DD, including theories from fields such as long-term care, or frameworks related to delivery of rehabilitation or health services in the community.

(b) Improved instruments and measures that help to evaluate the suitability and quality of personal assistance services, and the effectiveness and efficiency of community-based health and social services for individuals with ID/DD. The RRTC must contribute to this outcome by assessing current measures and instruments, reporting on their validity



and reliability, and then developing and testing improved measures as needed.

(c) Improved rehabilitation or community-based interventions that demonstrate measurable reductions in barriers to access and utilization of community-based services or community-based interventions that otherwise contribute to improved health and function of individuals with ID/DD. The RRTC must contribute to this outcome by identifying and testing potential interventions and providing a thorough assessment of the basis on which these interventions were selected, including any preliminary evidence of their usefulness and relevance to individuals with ID/DD and their families.

#### **Proposed Priority 21—Participation and Community Living for Individuals With Intellectual and Developmental Disabilities**

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for a Rehabilitation Research and Training Center (RRTC) for Participation and Community Living for Individuals with Intellectual and Developmental Disabilities (ID/DD). The RRTC must focus on rigorous research, training, technical assistance, and dissemination to enhance inclusion and self-determination of individuals with ID/DD. This RRTC also must focus on developing interventions that support self-determination, informed choice, consumer control, family involvement, and participation and community living of individuals with ID/DD.

When applying for a grant under this priority, an applicant must identify, in its application, the subjects of interest from the diverse population of individuals with ID/DD to be served by the proposed research and describe how the proposed research will benefit this group.

Under this priority, the RRTC must be designed to contribute to the following outcomes:

(a) Improved concepts and theories of societal participation and community living, and self-determination to guide the study of needs and abilities of individuals with ID/DD. The RRTC must contribute to this outcome by investigating existing theories of societal participation, community living, and self-determination to frame research on these topics for individuals with ID/DD.

(b) Improved instruments and measures of participation and community living to assess the type, frequency, and quality of activities that individuals with ID/DD wish to engage in, or are able to engage in outside the home or residential facility. The RRTC

must contribute to this outcome by assessing current measures and instruments used to determine outcomes in the areas of access to community facilities, social participation, self advocacy, employment choice, and housing selection by individuals with ID/DD, reporting on the validity and reliability of these measures, and then developing and testing improved measures as needed.

(c) Improved rehabilitation or community-based interventions that demonstrate a measurable impact in areas such as access to communal facilities and events, social participation and interaction with members of the community, self-advocacy, employment opportunities, and housing choices. The RRTC must contribute to this outcome by identifying and testing potential interventions for individuals with ID/DD, providing a thorough assessment of the basis on which these interventions were selected, including any preliminary evidence of their usefulness and relevance to individuals with ID/DD and their families.

#### **Rehabilitation Engineering Research Centers Program General Requirements of Rehabilitation Engineering Research Centers (RERCs)**

RERCs carry out research or demonstration activities in support of the Rehabilitation Act of 1973, as amended, by—

- Developing and disseminating innovative methods of applying advanced technology, scientific achievement, and psychological and social knowledge to: (a) Solve rehabilitation problems and remove environmental barriers; and (b) study and evaluate new or emerging technologies, products, or environments and their effectiveness and benefits; or
- Demonstrating and disseminating: (a) Innovative models for the delivery of cost-effective rehabilitation technology services to rural and urban areas; and (b) other scientific research to assist in meeting the employment and independent living needs of individuals with severe disabilities; and
- Facilitating service delivery systems change through: (a) The development, evaluation, and dissemination of consumer-responsive and individual and family-centered innovative models for the delivery to both rural and urban areas of innovative cost-effective rehabilitation technology services; and (b) other scientific research to assist in meeting the employment and independence needs of individuals with severe disabilities.

Each RERC must be operated by or in collaboration with one or more institutions of higher education or one or more nonprofit organizations.

Each RERC must provide training opportunities, in conjunction with institutions of higher education and nonprofit organizations, to assist individuals, including individuals with disabilities, to become rehabilitation technology researchers and practitioners.

Additional information on the RERC program can be found at: <http://www.ed.gov/rschstat/research/pubs/index.html>.

#### **Priorities 22, 23, 24, 25, 26, and 27—Rehabilitation Engineering Research Centers (RERCs) for Hearing Enhancement (Priority 22), Accessible Public Transportation (Priority 23), Prosthetics and Orthotics (Priority 24), Communication Enhancement (Priority 25), Universal Interface and Information Technology Access (Priority 26), and Wheeled Mobility (Priority 27)**

##### *Background*

Individuals with disabilities regularly use products that have been developed as the result of rehabilitation and biomedical research in order to achieve and maintain maximum physical function, live independently, study and learn, and attain gainful employment. Rehabilitation engineering research encompasses research on assistive technology, technology at the systems level (e.g., the built environment, transportation), and technology that allows individuals to interface with technology at the systems or environmental levels.

Advancements in basic biomedical science and technology have resulted in new opportunities to enhance further the lives of individuals with disabilities. Specifically, recent advances in biomaterials research, composite technologies, information and telecommunication technologies, nanotechnologies, micro electro mechanical systems (MEMS), sensor technologies, and the neurosciences provide a wealth of opportunities for individuals with disabilities and could be incorporated into research focused on disability and rehabilitation.

Through the following proposed priorities, NIDRR intends to fund RERCs that advance rehabilitation engineering research in the following priority research areas: Hearing Enhancement, Accessible Public Transportation, Prosthetics and Orthotics, Communication Enhancement, Universal Interface and Information



Technology Access, and Wheeled Mobility.

### Priority 22—Hearing Enhancement

Approximately 28.6 million Americans have an auditory disorder. In the United States, an estimated 1 to 6 in 1,000 newborns are born profoundly deaf, and another 2 to 3 out of 1,000 babies are born with partial hearing loss, making hearing loss the number one birth defect in America (Kochkin, 2001; Kemper & Downs, 2000; Cunningham & Cox, 2003).

Despite advances in hearing assistive technologies such as digital hearing aids, cochlear implants, induction loop (IL), frequency modulation (FM) and infrared (IR) assistive listening systems, and video relay, many challenges and opportunities for future research and development exist (Stika, Ross, & Cuevas, 2002; Schow *et al.*, 1993). For example, there is a need for new fitting methods for hearing aids and cochlear implants that adaptively adjust signal processing parameters such as compression threshold, compression ratio, gain, and frequency to maximize performance goals for an individual, both in the clinic and in the field (Stika, Ross & Cuevas, 2002; Schow, Balsara, Smedley & Whitcomb, 1993). In addition, there is a need to explore how rehabilitation or training can be provided so that individual users of hearing enhancement technologies can readily adopt new technologies and adapt to the new stimulation and information being received (Schow *et al.*, 1993).

Accordingly, NIDRR seeks to fund an RERC that researches and develops innovative models of aural rehabilitation tools, services, and training, in order to improve assessment and fitting of hearing enhancement technologies and to increase the availability, knowledge, and use of hearing enhancement devices and services.

#### References

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Stika, C.J., Ross, M., & Cuevas, C. (2002). Hearing Aid Services and Satisfaction: The Consumer Viewpoint, *Hearing Loss: the Journal of Self Help for Hard of Hearing People*, 23(3): 25–31.

### Priority 23—Accessible Public Transportation

Inaccessible transportation is a major barrier to independent living and limits the ability of individuals with disabilities to participate fully in their communities. One-third of individuals with disabilities report that inadequate transportation is a significant problem, and they are twice as likely to have inadequate transportation than individuals without disabilities (N.O.D./Harris Survey, 2004). Addressing the problems of accessibility of public transportation may help to provide the same degree of convenience, connection, and safety the general public enjoys when traveling via plane, train, or bus.

Points of entry and exit, public rights-of-way, communications, and bus and rail stations and stops are just a few of the areas posing transportation accessibility problems for individuals with disabilities. The physical dimensions and space limitations of the transport vehicle may prohibit easy entry, transfer to vehicle seats, or use of the services and facilities available on a plane, train, or bus. In addition, costs, physical ability, and perceptions of safety are all considered barriers to public transportation (Peck & Hess, 2006).

Accordingly, NIDRR seeks to fund an RERC on Accessible Public Transportation to address the need for improvements in the accessibility of public transportation, provide safe and dignified travel for individuals with disabilities, and increase community participation by individuals with disabilities. The focus of this RERC is on travel via air, rail, and bus.

#### References

- N.O.D./Harris Survey of Americans with Disabilities (2004). Harris Interactive, 111 Fifth Avenue, New York, NY 10003.
- Peck, M. & Hess D. (2006). Barriers to Using Public Transit among Diverse Older Adults: Implications for Social Work. <http://sswr.confex.com/sswr/2007/techprogram/P7047.HTM>

### Priority 24—Prosthetics and Orthotics

In the United States, it is estimated that there are 1.2 to 1.9 million individuals living with limb loss (Adams, Hendershot, & Marano, 1999). In addition, it is estimated that 75 percent of individuals with limb loss use a prosthetic device (Nielsen, 2002). The majority of amputations are

generally the result of peripheral vascular disease. Cancer, congenital limb loss, and trauma are the other major causes of amputation. It is difficult to accurately estimate orthotic use in the United States, because orthotics are used by many different pathology populations (stroke, spinal cord injury, cerebral palsy, orthopedic impairment) and orthoses are not often used on a permanent basis.

Increased knowledge and understanding about prosthetics and orthotics, and a greater emphasis on objective measures, such as performance, efficacy, and energy expenditures, that inform clinical practice should lead to the development of new concepts and devices to improve the quality, cost-effectiveness, and delivery of prosthetic and orthotic fittings.

Accordingly, NIDRR seeks to fund an RERC that researches and develops innovative prosthetic and orthotic technologies and designs to enhance the ability of individuals with limb loss and impaired limb function to perform activities of daily living, to have expanded employment options, to participate in sports and leisure activities, and to improve their health and participation outcomes.

#### References

- Adams, P.F., Hendershot, G.E., & Marano, M.A. (1999). Current estimates from the National Health Interview Survey, 1996. *National Center for Health Statistics. Vital Health Stat* 10(200).
- Nielsen, C. (2002). Issues Affecting The Future Demand for Orthotists and Prosthetists: Update 2002. A study updated for the National Commission on Orthotic and Prosthetic Education, May 2002.

### Priority 25—Communication Enhancement

“Approximately 1.3 percent of all individuals [in the United States] (*i.e.*, more than 3.5 million Americans) have such significant communication disabilities that they cannot rely on their natural speech to meet their daily communication needs.” (Beukelman, 2005). For these individuals, augmentative and alternative communication (AAC) strategies would facilitate participation and independence.

The number of individuals who may benefit from AAC will continue to grow as the American population ages and the associated prevalence of acquired communication disorders increases. Also, improvements in medical practices and technologies have resulted in increased survival rates among at risk infants and children, which, in turn, has

led to an increase in the number of individuals with moderate to severe disabilities (Hack *et al.*, 2005). In addition, the prevalence of autism spectrum disorders (ASD) has increased and more individuals with ASD and their caregivers are actively seeking, and expecting to find, intervention services that include AAC (Blackstone, 2005).

Accordingly, NIDRR seeks to fund an RERC that enhances communication for individuals with communication disabilities, promotes greater participation of individuals with communication disabilities in employment and education, increases independence for these individuals, and researches and develops innovative technologies and techniques to improve the state of the science and usability of AAC technology.

#### References

- Beukelman, D.R. & Mirenda, P. (2005). *Augmentative and Alternative Communication: Supporting children and adults with complex communication needs*. (3rd edition). Baltimore: Paul H. Brookes Publishing, p.3.
- Blackstone, S.W. (2003). Overview and Update. *Augmentative Communication News*. 15:4, 2–3.
- Hack, M., Taylor, H., Drotar, D., Schluchter, M., Cartar, L., Andreias, L., Wilson-Costello, D., & Klein, N. (2005). Chronic Conditions, Functional Limitations, and Special Health Care Needs of School-Aged Children Born with Extra Low Birth Weight in the 1990's. *Journal of the American Medical Association (JAMA)*, 294(3), 318–325.

#### Priority 26—Universal Interface and Information Technology Access

Information technologies have the potential to provide or increase access to professional, educational, social, and economic resources among individuals with disabilities (Gorski & Clark, 2002). Unfortunately, large discrepancies in the rates of use of information technologies exist between individuals with and without disabilities. According to data collected by the Bureau of Labor Statistics and the U.S. Census, 57.6 percent and 54.4 percent of individuals without disabilities use a computer at home and access the Internet at home, respectively. These same data suggest that only 30.2 percent and 26.4 percent of individuals with disabilities use a computer at home and access the Internet at home, respectively. In addition, while 63.6 percent of individuals without disabilities access the Internet at some location, only 30.8 percent of individuals with disabilities do so (Dobrinsky & Hargittai, 2006).

Information technology access development efforts are utilizing V2 Information Technology Access

Interface standards to build and test new universally designed interfaces that accommodate individuals with and without disabilities (International Committee for Information Technology Standards, 2006). These “smart devices” would automatically offer the user the appropriate interface and adapt to the way in which the user interacts with it (Horn & West, 2005).

Despite the promise of a universally designed information technology (IT) interface or device, most currently existing IT devices still need to be retrofitted with customized input and output interfaces so individuals with disabilities can use them. Further research on the effectiveness of existing alternative input and output interfaces and the design specifications necessary to construct universally designed IT interfaces and devices of the future is needed.

Accordingly, NIDRR seeks to fund an RERC that enhances the effectiveness of currently available input and output IT interfaces and devices used by individuals with varying disabilities to facilitate community participation and independent living.

#### References

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- Gorski, P. & Clark, C. (2002). Multicultural Education and the Digital Divide: Focus on Disability. *Multicultural Perspectives*. 4(4), 28–36.
- Horn, P. & West, F. (2005). Introduction. *IBM systems Journal*. 44(3), 1–2.
- International Committee for Information Technology Standards (2006). V2—Information Technology Access Interfaces. Gaithersburg, MD: National Institute of Standards and Technology. See: <http://v2.incits.org/>.

#### Priority 27—Wheeled Mobility

Among the United States population of individuals aged 15 years and older, 2.7 million individuals use a wheelchair or similar device (2002 SIPP data cited in Steinmetz, 2006). As more individuals with disabilities advance in age and as more aging individuals acquire disabilities, the number of wheeled-mobility device users will increase (White House Conference on Aging, 2005). Addressing the needs of this diverse population requires engineering and related fields to develop new solutions to existing problems and provide innovation and advancement in wheeled mobility.

Despite advances in knowledge in wheelchair propulsion technique, secondary injury prevention, wheelchair-user interface, and wheelchair skills training, many

challenges and opportunities for future research and development exist. For example, over-use injuries resulting from long-term wheelchair use are still a major problem (Arthanat & Strobel, 2006; Van der Woude, de Groot, & Janssen, 2006; Van der Woude, Janssen, & Vegger, 2005). In addition, there is a need for more information on the ergonomics of wheelchair and scooter design and use within and across different environments (e.g., work, home, school, and outdoors) (Arthanat & Strobel, 2006; Van der Woude, de Groot, & Janssen, 2006).

Advances in wheelchair technology may provide users with greater functional potential, including increases in participation and activity, and decreases in secondary injuries, such as pressure sores and repetitive strain injuries. Accordingly, NIDRR seeks to fund an RERC that improves understanding of the ergonomics, design, development, testing, and use of wheelchairs and scooters within and across different environments.

#### References

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- Van der Woude, L.H., de Groot, S., & Janssen, T.W.J. (2006). Manual wheelchairs: Research and innovation in rehabilitation, sports, daily life and health. *Medical Engineering & Physics*, 28(9), 905–915.
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- White House Conference on Aging (2005). Final Report to the President and Congress: The Booming Dynamics of Aging: From awareness to action. See: <http://www.whcoa.gov/about/about.asp#report>.

#### Proposed Priorities

The Assistant Secretary for Special Education and Rehabilitative Services proposes the following six priorities for the establishment of (a) An RERC for Hearing Enhancement (priority 22); (b) an RERC for Accessible Public Transportation (priority 23); (c) an RERC for Prosthetics and Orthotics (priority 24); (d) an RERC for Communication Enhancement (priority 25); (e) an RERC for Universal Interface and Information Technology Access (priority 26); and (f)

an RERC for Wheeled Mobility (priority 27). Within its designated priority research area, each RERC will focus on innovative technological solutions, new knowledge, and concepts that will improve the lives of individuals with disabilities.

(a) *RERC for Hearing Enhancement (Priority 22)*. Under this priority, the RERC must research and develop methods, systems, and technologies that will assist hearing professionals with the process of matching hearing enhancement assistive technologies to individuals with hearing loss and associated conditions such as tinnitus. This includes improving the compatibility of hearing enhancement technologies with various environments such as school, work, recreation, and social settings.

(b) *RERC for Accessible Public Transportation (Priority 23)*. Under this priority, the RERC must research and develop methods, systems, and devices that will promote and enhance the ability of individuals with disabilities to safely, comfortably, and efficiently identify destination information, board and disembark, and use services and facilities on various types of public transportation systems such as buses, passenger trains, and airplanes. This RERC must emphasize the principles of universal design in its product research and development.

(c) *RERC for Prosthetics and Orthotics (Priority 24)*. Under this priority, the RERC must increase the understanding of the scientific and engineering principles pertaining to human locomotion, reaching, grasping, and manipulation, and incorporate those principles into the design and fitting of prosthetic and orthotic devices.

(d) *RERC for Communication Enhancement (Priority 25)*. Under this priority, the RERC must research and develop augmentative and alternative communication technologies and strategies that will enhance the communicative capacity of individuals of all ages with significant communication disorders across environments (i.e., education, employment, recreation, social).

(e) *RERC for Universal Interface and Information Technology Access (Priority 26)*. Under this priority, the RERC must research and develop innovative technological solutions for, and promote universal access to, current and emerging information technologies and technology interfaces that promote a seamless integration of the multiple technologies used by individuals with disabilities in the home, the community, and the workplace. This RERC must work collaboratively with the RERC on

Telecommunication Access, the RERC on Mobile Wireless Technologies, and the NIDRR-funded Information Technology Technical Assistance and Training Center.

(f) *RERC for Wheeled Mobility (Priority 27)*. Under this priority, the RERC must research and develop innovative technologies and strategies that will improve the current state of the science, design standards, and usability of wheeled mobility devices and wheelchair seating systems.

Under each priority, the RERC must be designed to contribute to the following outcomes:

(1) Increased technical and scientific knowledge base relevant to its designated priority research area. The RERC must contribute to this outcome by conducting high-quality, rigorous research and development projects.

(2) Innovative technologies, products, environments, performance guidelines, and monitoring and assessment tools as applicable to its designated priority research area. The RERC must contribute to this outcome through the development and testing of these innovations.

(3) Improved research capacity in its designated priority research area. The RERC must contribute to this outcome by collaborating with the relevant industry, professional associations, and institutions of higher education.

(4) Improved focus on cutting edge developments in technologies within its designated priority research area. The RERC must contribute to this outcome by identifying and communicating with NIDRR and the field regarding trends and evolving product concepts related to its designated priority research area.

(5) Increased impact of research in the designated priority research area. The RERC must contribute to this outcome by providing technical assistance to public and private organizations, individuals with disabilities, and employers on policies, guidelines, and standards related to its designated priority research area.

(6) Increased transfer of RERC-developed technologies to the marketplace. The RERC must contribute to this outcome by developing and implementing a plan for ensuring that all technologies developed by the RERC are made available to the public. The technology transfer plan must be developed in the first year of the project period in consultation with the NIDRR-funded Disability Rehabilitation Research Project, Center on Knowledge Translation for Technology Transfer.

In addition, under each priority, the RERC must—

- Have the capability to design, build, and test prototype devices and assist in the transfer of successful solutions to relevant production and service delivery settings;

- Evaluate the efficacy and safety of its new products, instrumentation, or assistive devices;

- Provide as part of its proposal, and then implement, a plan that describes how it will include, as appropriate, individuals with disabilities or their representatives in all phases of its activities, including research, development, training, dissemination, and evaluation;

- Provide as part of its proposal, and then implement, in consultation with the NIDRR-funded National Center for the Dissemination of Disability Research (NCDDR), a plan to disseminate its research results to individuals with disabilities, their representatives, disability organizations, service providers, professional journals, manufacturers, and other interested parties;

- Conduct a state-of-the-science conference on its designated priority research area in the fourth year of the project period, and publish a comprehensive report on the final outcomes of the conference in the fifth year of the project period; and

- Coordinate research projects of mutual interest with relevant NIDRR-funded projects, as identified through consultation with the NIDRR project officer.

#### *Executive Order 12866*

This notice of proposed priorities has been reviewed in accordance with Executive Order 12866. Under the terms of the order, we have assessed the potential costs and benefits of this regulatory action.

The potential costs associated with this notice of proposed priorities are those resulting from statutory requirements and those we have determined as necessary for administering this program effectively and efficiently.

In assessing the potential costs and benefits—both quantitative and qualitative—of this notice of proposed priorities, we have determined that the benefits of the proposed priorities justify the costs.

#### *Summary of Potential Costs and Benefits*

The benefits of the Disability and Rehabilitation Research Projects and Centers Programs have been well established over the years in that similar projects have been completed successfully. These proposed priorities

will generate new knowledge and technologies through research, development, dissemination, utilization, and technical assistance projects.

Another benefit of these proposed priorities is that the establishment of new DRRPs, new RRTC's, and new RERCs will support the President's NFI and will improve the lives of individuals with disabilities. The new DRRPs, RRTC's, and RERCs will generate, disseminate, and promote the use of new information that will improve the options for individuals with disabilities to perform regular activities in the community.

#### *Intergovernmental Review*

This program is not subject to Executive Order 12372 and the regulations in 34 part 79.

*Applicable Program Regulations:* 34 CFR part 350.

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(Catalog of Federal Domestic Assistance Numbers 84.133A Disability Rehabilitation Research Projects, 84.133B Rehabilitation Research and Training Centers and 84.133E Rehabilitation Engineering Research Centers Program)

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Dated: August 27, 2007.

**William W. Knudsen,**

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