

**DEPARTMENT OF EDUCATION****National Institute on Disability and Rehabilitation Research**

**AGENCY:** Department of Education.

**ACTION:** Notice of proposed priorities for fiscal years 1997–1998 for research and demonstration projects, rehabilitation research and training centers, and a knowledge dissemination and utilization project.

**SUMMARY:** The Secretary proposes priorities for the Research and Demonstration Project (R&D) Program, the Rehabilitation Research and Training Center (RRTC) Program, and the Knowledge Dissemination and Utilization (D&U) Program under the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years 1997–1998. The Secretary takes this action to focus research attention on areas of national need to improve rehabilitation services and outcomes for individuals with disabilities, and to assist in the solutions to problems encountered by individuals with disabilities in their daily activities.

**DATES:** Comments must be received on or before April 3, 1997.

**ADDRESSES:** All comments concerning these proposed priorities should be addressed to David Esquith, U.S. Department of Education, 600 Independence Avenue, S.W., Switzer Building, Room 3424, Washington, D.C. 20202–2601. Internet: NPP—ADA@ed.gov

**FOR FURTHER INFORMATION CONTACT:** David Esquith. Telephone: (202) 205–8801. Individuals who use a telecommunications device for the deaf (TDD) may call the TDD number at (202) 205–8133. Internet: David—Esquith@ed.gov

**SUPPLEMENTARY INFORMATION:** This notice contains proposed priorities to establish R&D projects for model systems for burn injury and traumatic brain injury, RRTCs for research related to aging with a spinal cord injury and severe problem behaviors, and a D&U project to improve the utilization of existing and emerging rehabilitation technology in the State vocational rehabilitation program.

These proposed priorities support the National Education Goal that calls for all Americans to possess the knowledge and skills necessary to compete in a global economy and exercise the rights and responsibilities of citizenship.

The Secretary will announce the final funding priorities in a notice in the Federal Register. The final priorities

will be determined by responses to this notice, available funds, and other considerations of the Department. Funding of particular projects depends on the final priorities, the availability of funds, and the quality of the applications received. The publication of these proposed priorities does not preclude the Secretary from proposing additional priorities, nor does it limit the Secretary to funding only these priorities, subject to meeting applicable rulemaking requirements.

Note: This notice of proposed priorities does *not* solicit applications. A notice inviting applications under these competitions will be published in the Federal Register concurrent with or following publication of the notice of the final priorities.

**Research and Demonstration Projects**

Authority for the R&D program of NIDRR is contained in section 204(a) of the Rehabilitation Act of 1973, as amended (29 U.S.C. 760–762). Under this program the Secretary makes awards to public agencies and private agencies and organizations, including institutions of higher education, Indian tribes, and tribal organizations. This program is designed to assist in the development of solutions to the problems encountered by individuals with disabilities in their daily activities, especially problems related to employment (see 34 CFR 351.1). Under the regulations for this program (see 34 CFR 351.32), the Secretary may establish research priorities by reserving funds to support the research activities listed in 34 CFR 351.10.

**Priorities**

Under 34 CFR 75.105(c)(3), the Secretary proposes to give an absolute preference to applications that meet one of the following priorities. The Secretary proposes to fund under this program only applications that meet one of these absolute priorities:

***Proposed Priority 1: Burn Injury Rehabilitation Model System*****Background**

Each year more than 2.0 million persons (about one percent of the population of the United States) receive a burn injury. Of these, 6,500 to 12,000 do not survive; 500,000 require medical care and result in temporary disability with respect to home, school, or work activities; and 70,000 to 100,000 are severe enough to be admitted to a hospital (Rice, D.P. and MacKenzie, E.J., "Cost of Injury in the United States: A Report to Congress," Atlanta, GA: Centers for Disease Control, 1989).

In 1994, NIDRR provided funding to establish Burn Injury Rehabilitation Model Systems of Care. These R&D projects focused primarily on developing and demonstrating a comprehensive, multidisciplinary model system of rehabilitative services for individuals with severe burns, and evaluating the efficacy of that system through the collection and analysis of uniform data on system benefits, costs, and outcomes. NIDRR's multi-center model systems program is designed to study the course of recovery and outcomes following the delivery of a coordinated system of care including emergency care, acute care management, comprehensive in-patient rehabilitation, and long-term interdisciplinary follow-up services.

Burn rehabilitation requires interventions as soon as possible after admission to hospitals and has treatment implications for several years following hospital discharge. Burn trauma often causes injuries and impairments in addition to the burn, and many individuals with burn injuries have secondary complications related to the burn condition. These may include open wounds, contractures, neuropathies, cosmetic abnormalities, deconditioning, bony deformities, hypersensitivity to heat and cold, amputation, psychosocial distress, chronic pain, and scarring. The complicated nature of burn injuries, the difficulty of treatment, and the risk of infection with possible loss of function requires interventions quickly and frequently to attempt to maintain a functional lifestyle and return to living independently. Minimization of physical deterioration and prevention of further impairment and functional limitation is critical and research is needed to find the appropriate procedures for clinical applications. Research is needed to develop and refine methods to determine the effectiveness of interventions to prevent, manage, and reduce medical complications that contribute to short- and long-term disability in burn patients.

Improved measures are needed of an individual's functional ability as a result of burn rehabilitation interventions. Functional assessment brings objectivity to rehabilitation by establishing appropriate, uniform descriptors of rehabilitation care and changes in individual capacity to perform activities of daily living or other measurable elements of an individual's major life activities (Granger, C. and Brownschidle, C., "Outcome Measurement in Medical Rehabilitation," *International Journal of*

*Technology Assessment in Health Care*, 11:2, 1995). Increasingly, health and rehabilitation services require effectiveness and impact measures to evaluate their services as a part of procedures for cost-reimbursement and billing for services. With greater emphasis on individual choice in services delivery, consumers and advocates are likewise advocates for functional assessment measures as encoders of service effectiveness. Few existing functional assessment measures, however, address the specialized and complex combination of psychosocial and medical challenges encountered by an individual who has experienced severe burn injury (Rucker, K., et al., "Analysis of Functional Assessment Instruments for Disability Rehabilitation Programs," SSA Contract No. 600-95-2194, Virginia Commonwealth University, 1996).

Burn injuries can produce emotional problems, such as post-traumatic stress disorders, anxiety, and depression. These problems may result from a variety of causes (e.g., reaction to cosmetic alterations, changes in functional abilities, changes in work status, restrictions on recreational activities) (Cromes, G.F. and Helm, P.A., "Burn Injuries," in *Medical Aspects of Disability*, pgs. 92-104, 1993). The aesthetic disability of disfigurement is frequently more severe than the physical disability and may result in profound social consequences for those afflicted (Hurren, J.S., "Rehabilitation of the Burned Patient: James Laing Memorial Essay for 1993," *Burns*, Vol. 21, No. 2, 1995). The more severe the burn, the greater the likelihood of long-term psychosocial adjustment issues related to both physical and psychosocial problems, that affect quality of life. Although psychosocial adjustment is a critical factor in the long-term recovery of burn injury patients, there continues to be limited emphasis on research in the area of psychosocial rehabilitation and its relationship to quality of life. Family and friends play an important role and provide major support in the psychological recovery of burn patients. Research in this area needs to address the role of the family and personal advocacy systems in providing support during the burn injury rehabilitation process.

Difficulty with long-term follow-up of all patients after hospital discharge has always been a problem, but it is even more difficult when the individual lives far from the specialized rehabilitation unit. Problems are also encountered with those individuals living in rural areas, where access to burn injury

rehabilitation, including mental health services, may be quite limited due to lack of proximity to specialized practitioners, limited access to technological advances, and hospital closures.

Return-to-work and educational pursuits are important measures of rehabilitation success. Work is an important source of satisfaction, self-respect, and dignity, as well as an arena for socialization for individuals who have experienced burn injury (Salisbury, R., "Burn Rehabilitation: Our Unanswered Challenge," 1992 Presidential Address to the American Burn Association, April, 1992). However, the efficacy of vocational rehabilitation interventions for this population has not been documented adequately. The physical, psychosocial, and emotional factors that lead to successful employment have not been clearly identified. Research is needed to examine relationships between vocational interventions and supports, employment, functional capacity, and degree of burn injury, including secondary complications.

#### *Proposed Priority 1*

The Secretary proposes to establish Burn Injury Rehabilitation Model Systems R&D projects for the purpose of demonstrating a comprehensive, multidisciplinary model system of rehabilitative services for individuals with severe burns. An R&D project must:

- (1) Identify and evaluate techniques to prevent secondary complications;
- (2) develop and evaluate outreach programs to improve follow-up services for rural populations;
- (3) develop and evaluate measures of functional outcome for burn rehabilitation; and
- (4) identify and evaluate interventions, including vocational rehabilitation interventions, to improve psychosocial adjustment, quality of life, community integration, and employment-related outcomes.

In carrying out these purposes, the R&D project must:

- Participate in clinical and systems analysis studies of the burn injury rehabilitation model system by collecting and contributing data on patient characteristics, diagnoses, causes of injury, interventions, outcomes, and costs to a uniform, standardized national data base as prescribed by the Secretary; and
- Consider collaborative projects with other model systems.

#### *Proposed Priority 2: Traumatic Brain Injury Model Systems*

##### Background

An estimated 1.9 million Americans experience traumatic brain injury (TBI) each year (Collins, J.F., "Types of Injuries by Selected Characteristics: US 1985-87," National Center for Health Statistics, *Vital Health Stat* 10 (175), 1990). Incidence is highest among youth and younger adults. Young males have the highest incidence rates of any group ("Disability Statistics Abstract," No. 14, Disability Statistics Rehabilitation Research & Training Center, University of California, San Francisco, November, 1995). Each year approximately 70,000 to 90,000 TBI survivors enter a life of continuing, debilitating loss of function; an estimated 5,000 survivors experience seizure disorders; and 2,000 enter into a persistent vegetative state. The number of people surviving head injuries has increased significantly over the last 25 years as a result of faster and better emergency treatment, more rapid and safer transport to specialized treatment facilities, and advances in medical treatment (National Foundation for Brain Research, Washington, DC, 1994).

In 1987, NIDRR provided funding to establish TBI Model Systems of Care. These R&D projects focused primarily on developing and demonstrating a comprehensive, multidisciplinary model system of rehabilitative services for individuals with TBI, and evaluating the efficacy of that system through the collection and analysis of uniform data on system benefits, costs, and outcomes. NIDRR's multi-center model systems program is designed to study the course of recovery and outcomes following the delivery of a coordinated system of care including emergency care, acute neuro-trauma management, comprehensive in-patient rehabilitation, and long-term interdisciplinary follow-up services.

The TBI Model Systems serve a substantial number of patients, allowing the projects to conduct clinical research and program evaluation, which maximize the potential for project replication. In addition, the TBI Model Systems have the advantage of a complex data collection and retrieval program with the capability to analyze the different system components and provide information on project cost effectiveness and benefits. Information is collected throughout the rehabilitation process, permitting long-term follow-up on the course of injury, outcomes, and changes in employment status, community integration, substance abuse and family needs. The TBI Model Systems projects serve as

regional and national models for program development and as information centers for consumers, families, and professionals.

The TBI Model Systems National Database reports that the average length of stay in acute care has decreased approximately 50 percent, from 30 days in 1989 to 15 days in 1996; and the average length of stay in in-patient rehabilitation has decreased 38 percent, from 52 days in 1989 to 32 days in 1996. With the changing patterns of service delivery, there continues to be a need to establish and evaluate new rehabilitation interventions and strategies. Specialized measurement tools have been developed by the TBI Model Systems to assess progress and describe clinical and functional outcomes. Refinement of these measurement tools is necessary to demonstrate the effectiveness of rehabilitation interventions in in-patient and outpatient settings. After the individual is discharged from an in-patient setting, there is an ongoing need for outpatient and community reintegration services in order to continue therapeutic interventions and the educational and referral process. As the average length of stay in in-patient settings decreases, there is a greater need to evaluate outpatient and community reintegration programs.

Findings from a multi-center investigation of employment and community integration following TBI highlight the need for post-acute rehabilitation programs with particular emphasis on vocational rehabilitation (Sander, A., et al., *Journal of Head Trauma Rehabilitation*, Vol. 11, No. 5, pgs. 70–84, 1996). Kreutzer states that employment and productivity, relating to others in the community, and independently caring for oneself at home are important quality-of-life components ("TBI: Models and Systems of Care," Conference Syllabus, Medical College of Virginia, April, 1996). As functional recovery progresses during the first year or more after the injury, the focus of rehabilitation shifts from medical intervention and physical restoration to psychosocial and vocational adaptation. The ultimate goal of psychosocial and vocational rehabilitation is community reintegration and employment. It is important to emphasize that services aimed at community reintegration must consider not only attributes and limitations of the injured individuals, but also the social, educational, and vocational systems in which the individual will function. In addition, rates of competitive employment decrease substantially from pre-injury

levels. Head injury frequently results in unemployment, and there are significant relationships between risk factors (e.g., substance abuse) and this changed employment status. However, there is no reliable information regarding the magnitude of risk associated with different factors, or with different levels of these factors (Dikmen, S., et al., "Employment following Traumatic Head Injuries," *Archives of Neurology*, Vol. 51, February, 1994).

A major disability like TBI has a profoundly disorganizing impact on the lives of individuals with TBI and their families. Questions involving community, family, and vocational restoration, as well as generic concerns about future happiness and fulfillment, are common (Banja, J., & Johnston, M., "Ethical Perspectives and Social Policy," *Archives of Physical Medicine Rehabilitation*, Vol. 75, SC-19, December, 1994). Even individuals who have integrated well into society experience adverse psychosocial effects. Employment instability, isolation from friends, and increased need for support are a few of the problems encountered by individuals with TBI. Families often function as the primary support system for individuals with TBI after they are discharged. There is a clear need for research to develop family treatment strategies and explore their effect on outcomes for individuals with TBI.

The health care costs associated with TBI are staggering. The direct medical costs of TBI treatment have been estimated at more than \$4 billion annually (Max, W., et al., "Head Injuries: Costs and Consequences," *Journal of Head Trauma Rehabilitation*, Vol. 6, pgs. 76–91, 1991). In view of current scrutiny of all health care spending, which may result in pressures to constrict or deny rehabilitation care to individuals with traumatic brain injury, it is important to gather information on the efficacy and cost-effectiveness of various treatment interventions and service delivery models. Credible outcome monitoring systems are needed to establish guidelines by which fair compromises can be reached (Johnston, M. & Hall, K., "Outcomes Evaluation in TBI Rehabilitation, Part I: Overview and System Principles," *Archives of Physical Medicine and Rehabilitation*, Vol. 75, December, 1994). A greater emphasis on outcomes measurements and management will foster the gathering of information on efficacy and cost-effectiveness.

Violence-induced TBI is increasingly common, and has significant implications for rehabilitation and community reintegration. According to

the 1991 National Health Interview Survey data, violence was responsible for nine percent of all non-fatal TBIs. In addition, violence was a cause of injury in 30 percent of the 684 external injury cases in the TBI Model Systems database (a higher frequency due, in part, to the urban setting of one of the TBI Model Systems). The frequency of violence as a cause of TBI, in part, can be attributed to the fact that the individuals most likely to sustain TBI (i.e., males under age 18) are also those most likely to be involved in crimes and violence. The increase in violence as a cause of brain injury may have consequences with regard to rehabilitation costs, treatment interventions and long-term outcomes. For example, individuals with violence-related injuries show more difficulties with community integration skills one year following injury, which evidences itself in areas of social integration and productivity. Further research is needed to examine whether individuals who sustain a TBI as a result of violence require specialized rehabilitation interventions.

#### Proposed Priority 2

The Secretary proposes to establish Model Systems TBI R&D projects for the purpose of demonstrating a comprehensive, multidisciplinary model system of care for individuals with TBI. An R&D project must:

- (1) Investigate efficacy of alternative methods of service delivery interventions after in-patient rehabilitation discharge;
- (2) Identify and evaluate interventions that can improve vocational outcomes and community integration;
- (3) Develop key predictors of rehabilitation outcome at hospital discharge and at long-term follow-up;
- (4) Determine relationships between cost of care and functional outcomes; and
- (5) Examine the implications of violence as a cause of TBI on treatment interventions, rehabilitation costs, and long-term outcomes.

In carrying out these purposes, the R&D Systems project must:

- Participate in clinical and systems analysis studies of the traumatic brain injury model system by collecting and contributing data on patient characteristics, diagnoses, causes of injury, interventions, outcomes, and costs to a uniform, standardized national data base as prescribed by the Secretary;
- Consider collaborative projects with other model systems; and

- Coordinate research efforts with other NIDRR grantees that address TBI-related issues.

#### Rehabilitation Research and Training Centers (RRTCs)

Authority for the RRTC program of NIDRR is contained in section 204(b)(2) of the Rehabilitation Act of 1973, as amended (29 U.S.C. 760-762). Under this program the Secretary makes awards to public and private organizations, including institutions of higher education and Indian tribes or tribal organizations for coordinated research and training activities. These entities must be of sufficient size, scope, and quality to effectively carry out the activities of the Center in an efficient manner consistent with appropriate State and Federal laws. They must demonstrate the ability to carry out the training activities either directly or through another entity that can provide such training.

The Secretary may make awards for up to 60 months through grants or cooperative agreements. The purpose of the awards is for planning and conducting research, training, demonstrations, and related activities leading to the development of methods, procedures, and devices that will benefit individuals with disabilities, especially those with the most severe disabilities.

Under the regulations for this program (see 34 CFR 352.32) the Secretary may establish research priorities by reserving funds to support particular research activities.

#### Description of the Rehabilitation Research and Training Center Program

RRTCs are operated in collaboration with institutions of higher education or providers of rehabilitation services or other appropriate services. RRTCs serve as centers of national excellence and national or regional resources for providers and individuals with disabilities and the parents, family members, guardians, advocates or authorized representatives of the individuals.

RRTCs conduct coordinated and advanced programs of research in rehabilitation targeted toward the production of new knowledge to improve rehabilitation methodology and service delivery systems, to alleviate or stabilize disabling conditions, and to promote maximum social and economic independence of individuals with disabilities.

RRTCs provide training, including graduate, pre-service, and in-service training, to assist individuals to more effectively provide rehabilitation

services. They also provide training including graduate, pre-service, and in-service training, for rehabilitation research personnel and other rehabilitation personnel.

RRTCs serve as informational and technical assistance resources to providers, individuals with disabilities, and the parents, family members, guardians, advocates, or authorized representatives of these individuals through conferences, workshops, public education programs, in-service training programs and similar activities.

NIDRR encourages all Centers to involve individuals with disabilities and minorities as recipients in research training, as well as clinical training.

Applicants have considerable latitude in proposing the specific research and related projects they will undertake to achieve the designated outcomes; however, the regulatory selection criteria for the program (34 CFR 352.31) state that the Secretary reviews the extent to which applicants justify their choice of research projects in terms of the relevance to the priority and to the needs of individuals with disabilities. The Secretary also reviews the extent to which applicants present a scientific methodology that includes reasonable hypotheses, methods of data collection and analysis, and a means to evaluate the extent to which project objectives have been achieved.

The Department is particularly interested in ensuring that the expenditure of public funds is justified by the execution of intended activities and the advancement of knowledge and, thus, has built this accountability into the selection criteria. Not later than three years after the establishment of any RRTC, NIDRR will conduct one or more reviews of the activities and achievements of the Center. In accordance with the provisions of 34 CFR 75.253(a), continued funding depends at all times on satisfactory performance and accomplishment.

#### General

The Secretary proposes that the following requirements will apply to these RRTCs pursuant to the priorities unless noted otherwise:

Each RRTC must conduct an integrated program of research to develop solutions to problems confronted by individuals with disabilities.

Each RRTC must conduct a coordinated and advanced program of training in rehabilitation research, including training in research methodology and applied research experience, that will contribute to the

number of qualified researchers working in the area of rehabilitation research.

Each Center must disseminate and encourage the use of new rehabilitation knowledge. They must publish all materials for dissemination or training in alternate formats to make them accessible to individuals with a range of disabling conditions.

Each RRTC must involve individuals with disabilities and, if appropriate, their family members, as well as rehabilitation service providers, in planning and implementing the research and training programs, in interpreting and disseminating the research findings, and in evaluating the Center.

#### Priorities

Under 34 CFR 75.105(c)(3), the Secretary proposes to give an absolute preference to applications that meet one of the following priorities. The Secretary proposes to fund under these competitions only applications that meet one of these absolute priorities:

#### *Proposed Priority 3: Effective Interventions for Children and Youth With Disabilities Who Exhibit Severe Problem Behaviors*

#### Background

In recent years researchers have focused on the application of non-aversive approaches to reduce and eliminate severe problem behaviors (SPBs) exhibited by children and youth with disabilities. This has been the case because of ethical concerns about aversive interventions expressed by disability professionals, parents, and advocates, as well as research findings which indicate that aversive interventions are largely ineffective in eliminating or reducing SPBs over an extended period of time. Because of their disruptive nature, SPBs such as physical aggression, self-injury, violence, and property destruction are among the primary obstacles to full inclusion of children and youth with disabilities in age-appropriate community-based activities and regular education settings. School and community-based program personnel need effective methods to reduce and eliminate SPBs in order to provide these children and youth with disabilities with opportunities to learn, play, and work with their non-disabled peers.

Previous research in this area has improved our understanding of the early indicators of SPBs. For example, children with disabilities who display minor self-injurious behavior during the preschool years are strong candidates to exhibit more SPBs within two years (Hall, S., "Early Intervention of Self-

injurious Behavior in Young Children with Intellectual Disabilities: Naturalistic Observation," Presented at the Annual Meeting of the American Association of Mental Retardation, San Francisco, June, 1995). Further research is needed on how severe problem behavior patterns develop and whether early intervention efforts can reduce, and perhaps prevent, SPBs.

Preliminary research has also indicated that problem behaviors can be reduced by understanding the antecedents to and function of the behavior. Accordingly, children and youth with disabilities who exhibit SPBs may be able to learn to self-manage their problem behaviors.

While there are encouraging indications that non-aversive approaches can be effective in reducing and eliminating SPBs, there is a need to develop effective interventions that can be maintained over extended periods of time. Treatments of self-injurious behaviors are particularly problematic in regard to long-term effectiveness. Research has shown that children who exhibit self-injurious behaviors, even after intensive non-aversive treatment programs, may revert to self-injury at high rates within a few months of intervention (Durand, V.M., et al., "The Course of Self-injurious Behavior Among People with Autism," Paper presented at the Annual Meeting of the Berkshire Association for Behavior Analysis and Therapy, Amherst, MA, 1995).

Information from functional assessments can be used to develop educational plans and address inappropriate behavior. Functional assessment is the general label assigned to describe a set of processes (e.g., interviews, rating, rating scales, direct observations, and systematic experimental analyses of specific situations) for defining the events in an environment that reliably predict and maintain behaviors. More research needs to be done in order to expand the application of functional assessments with children and youth with disabilities who exhibit severe behavior problems.

Under normal circumstances, children and youth with disabilities who exhibit SPBs in school and the community are also exhibiting these behaviors at home. In order for non-aversive approaches to be implemented consistently across environments, parents and other caregivers must not only consent to the approach, but also be capable of implementing the approach effectively in the home environment. The non-aversive strategies that are developed must be

compatible with the home environment, and take into account providing parents and guardians with the skills they need to implement the program effectively.

#### Proposed Priority 3

The Secretary proposes to establish an RRTC for the purpose of providing school and community-based program personnel with effective methods to reduce and eliminate SPBs in children and youth with disabilities. The RRTC shall:

(1) Develop and evaluate non-aversive interventions that reduce and eliminate severe behavior problems exhibited by children and youth with disabilities;

(2) Investigate the etiology of SPBs for the purpose of developing prevention and early intervention strategies;

(3) Investigate the durability and maintenance of effective non-aversive interventions;

(4) Investigate the effectiveness of self-management strategies;

(5) Develop and evaluate functional assessments to address SPBs in educational and community-based settings;

(6) Develop materials and provide training to educators, community-based program personnel, parents, and caregivers who address SPBs; and

(7) Develop and disseminate informational materials and provide technical assistance to local and State educational agencies to address SPBs.

In carrying out the purposes of the priority, the RRTC shall disseminate materials and coordinate training activities with related projects supported by the Office of Special Education Programs, including the Regional Resource Centers and Parent Information Centers.

#### Proposed Priority 4: Aging With Spinal Cord Injury

##### Background

Persons who experience a spinal cord injury (SCI) and related conditions are surviving in significant numbers to late middle age and beyond. Less than fifty years ago the average life expectancy for a spinal cord injured individual in the United States was approximately three years post-injury; today life expectancy approaches that of the general population (Enders, A., "Issues and Options in Technology for Disability and Aging," National Conference on Disability and Aging, Institute for Health and Aging, San Francisco, 1986). Estimates of spinal cord injury prevalence in America range from 180,000 to 250,000 with between 7,000 and 10,000 new spinal cord injuries each year (National Spinal Cord Injury

Statistical Center, The University of Alabama at Birmingham, 1995). One of four individuals who previously sustained a spinal cord injury is now at least 20 years post-onset. The average age of a SCI survivor is now about 48 years and about 20 percent of SCI survivors are over age 60.

Many SCI survivors develop new medical, functional, and psychological problems that threaten their independence. In addition, many experience job loss, barriers to accessing proper health maintenance and caregiver/personal assistance services, loss of financial assistance, and economic hardship. Persons aging with SCI are susceptible to multiple health maintenance problems including cardiovascular, urinary tract infections, pressure sores, hypertension, fractures, blood in the urine or bowel problems, diabetes, respiratory and neurological problems (Whiteneck, G. (Ed.), *Aging with a Spinal Cord Injury*, 1992). The leading medical cause of death and further disability that affects people with SCI is now premature cardiovascular disease of the atherosclerotic kind. Whiteneck, using data from England, found that cardiovascular disease is now tied with genito-urinary problems as the leading cause of death in people aging with SCI.

Individuals aging with a SCI also experience complications as a result of osteoporosis and lower extremity fractures (Garland, D.E., "Bone Mineral Density about the Knee in SCI Patients with Pathological Fractures," *Contemporary Orthopaedics*, 1992 and Garland, D.E., "Osteoporosis Following SCI," *Journal of Orthopaedic Research*, 1992). Garland discovered a high prevalence of carpal tunnel syndrome, which increased with the length of time after injury. In addition, Sie found an increased prevalence of general upper extremity pain and shoulder pain with time since injury in both paraplegic and tetraplegia individuals (Sie, I., "Upper Extremity Pain in the Post-Rehabilitation SCI Injured Patient," *Archives of Physical Medicine and Rehabilitation*, 1992). Shoulder pain occurs in about 50 percent of people with paraplegia secondary to prolonged wheelchair use. Pain, fatigue and weakness are also commonly reported but accommodations for them are poorly understood.

Further research is needed to determine the changes in functional ability to perform activities of daily living (ADL) and work. Research related to work performance and employment status indicates that ten years after the SCI, the employment rate peaks at about 40 percent for persons with paraplegia

and at 28 percent for persons with quadriplegia, and sharply declines about 18 years after the post-injury (SCI Model Systems Annual Report, 1992). Interventions are needed to maintain the employment status of people aging with SCI and prevent job loss due to premature aging effects.

As people age and their functioning changes, the need for assistance from others (i.e., family, friends, and paid caregivers) increases. Strategies to best assist the caregiver, in turn, to help the person who is aging with SCI need to be developed. Moreover, there is no "typical" caregiver, some are spouses, some are parents, and some are children. Fifty percent of people with SCI receive help exclusively from their families, and an additional 19 percent receive substantial help from their families. Living with family is the most frequently reported living situation, occurring in over 90 percent of cases (Nosek, M.A., "Personal Assistance: Key to Maintaining Ability of Persons with Physical Disabilities," *Applied Rehabilitation Counselor*, Vol. 21, 1990).

Declining or unstable support systems for people aging with SCI are also a major concern. Since parents of aging SCI individuals are often elderly, they are also at risk of poor health or death. Spousal support providers may experience "burn-out" and stress, or develop health problems. There are few alternatives to the informal support system. As individuals with SCI age, access to proper health care, especially with the growing trend toward managed care, is becoming a bigger problem. There is need for research on maintaining independence in the community for people aging with SCI through both the informal and formal systems of care.

Psychological well-being for individuals aging with SCI is also of major concern. Depression is a very important issue requiring additional study because of its bearing on quality of life, its importance for overall health, and its relationship to suicide (Schulz, R., "Long Term Adjustment to Physical Disability: The Role of Social Support Service of Control and Self Blame," *Journal of Personality and Social Psychology*, 5, pgs. 1162-1172, 1985). The research indicates that over 40 percent of people who have sustained functional changes as a consequence of aging with SCI show high levels of distress and depression. Pilot data on treatment are available from the NIDRR-funded centers, but a full treatment procedure for stress and depression needs to be developed.

#### Proposed Priority 4

The Secretary proposes to establish an RRTC for the purpose of conducting research on rehabilitation techniques that assist individuals aging with SCI to maintain employment and independence in the community. The RRTC shall:

(1) Identify, develop, and evaluate interventions that maintain employment for individuals aging with SCI;

(2) Identify, develop, and evaluate rehabilitation techniques that will assist individuals aging with SCI to cope with changes in functional abilities, changes in ADL, and the impact of these techniques on quality of life;

(3) Investigate how formal and informal systems of care could be improved to address the impact of problems associated with long-term caregivers and personal service assistants;

(4) Develop a program of information dissemination and training for individuals aging with SCI and those who provide services to them;

(5) Develop regimens to minimize or take account of the impacts of aging with SCI and develop materials that support these regimens for individuals with SCI, their families, service providers and educators; and

(6) Develop materials for individuals with SCI, their families, service providers and educators that will provide a better understanding of the natural course of SCI as persons age.

In carrying out the purposes of the priority, the RRTC shall coordinate with all other relevant SCI research and demonstration activities, including those sponsored by the National Center on Medical Rehabilitation Research, RSA, Paralyzed Veterans of America, National Spinal Cord Injury Association and NIDRR-funded SCI projects.

#### Knowledge Dissemination and Utilization Projects

Authority for the D&U program of NIDRR is contained in sections 202 and 204(a) of the Rehabilitation Act of 1973, as amended (29 U.S.C. 760-762). Under this program the Secretary makes awards to public and private organizations, including institutions of higher education and Indian tribes or tribal organizations. Under the regulations for this program (see 34 CFR 355.32), the Secretary may establish research priorities by reserving funds to support particular research activities.

#### Priority

Under 34 CFR 75.105(c)(3), the Secretary proposes to give an absolute preference to applications that meet the following priority. The Secretary

proposes to fund under this competition only applications that meet this absolute priority:

#### *Proposed Priority 5: Improving the Utilization of Existing and Emerging Rehabilitation Technology in the State Vocational Rehabilitation Program*

##### Background

One of the more persistent issues in the rehabilitation of individuals with disabilities has been maximizing the use of existing and emerging rehabilitation technology in the service settings of the State Vocational Rehabilitation (VR) programs.

As defined in Section 7(13) of the Rehabilitation Act, as amended (Act), rehabilitation technology means "the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by individuals with disabilities in areas which include education, rehabilitation, employment, transportation, independent living and recreation" and includes "rehabilitation engineering, assistive technology devices, and assistive technology services." Under Section 101(a)(5)(C) of the Act, designated VR agencies must describe in their State plan how the State will provide a broad range of rehabilitation technology services at each stage of the rehabilitation process. As appropriate, rehabilitation technology services are provided to individuals with disabilities served by State VR programs under an Individualized Written Rehabilitation Program.

Rehabilitation technology, and information about rehabilitation technology, is generated by a variety of sources including, but not limited to, NIDRR-funded Rehabilitation Engineering and Research Centers, the Assistive Technology program funded under the Technology-Related Assistance for Individuals with Disabilities Act of 1988, ABLEDATA, the Department of Veterans Affairs Research and Development projects, and manufacturers in the private sector. While many of these sources may undertake dissemination activities, too often rehabilitation counselors and related vocational rehabilitation service providers are unaware of existing or emerging rehabilitation technologies, resulting in a number of problems for clients of the State vocational rehabilitation system.

The provision of inappropriate rehabilitation technology can result in nonuse. The nonuse of a device may lead to decreases in functional abilities, freedom, and independence. On a

service delivery level, device abandonment represents ineffective use of limited funds by Federal, State, and local government agencies, insurers, and other provider organizations (Phillips, B. and Hongxin, Z., "Predictors of Assistive Technology Abandonment," *Assistive Technology*, Vol. 5, No. 1, pg. 36, 1993).

If vocational rehabilitation personnel are unfamiliar with an emerging technology, their clients are disadvantaged by not having access to recent developments in the field. These developments may be more effective and economical than existing rehabilitation technology. Because of the costs that can be involved, the decision to utilize a particular rehabilitation technology, even if the technology is outdated, can be difficult to reverse or modify.

Information barriers related to rehabilitation technology also apply to secondary students with disabilities who increasingly complete their education with the help of assistive devices (Everson, J., "Using Person-centered Planning Concepts to Enhance School-to-Adult Life Transition Planning," *Journal of Vocational Rehabilitation*, Vol. 6, 1996). In order to ensure their continued access to technical accommodation as part of their transition to employment and independent living, special education and vocational rehabilitation personnel involved in their transition must have proper training and access to current information.

Assigning inappropriate or outdated rehabilitation technology to consumers can be avoided if vocational rehabilitation personnel are provided with comprehensive and current information on existing and emerging rehabilitation technology. Rehabilitation counselors and related vocational rehabilitation service providers gain

access to information about rehabilitation technology from various sources including, but not limited to, their pre-service and in-service training, memberships in professional organizations, conferences, and more recently through the information superhighway. Because the field of rehabilitation technology is developing rapidly, and because it is a technically diverse and complex field, it has been a challenge for rehabilitation personnel development programs to keep pace with rehabilitation technology. There is a growing need for dissemination of information about rehabilitation technology, including the development of pre-service and in-service resources, in order to promote improved rehabilitation professional training on rehabilitation technology.

#### Proposed Priority 5

The Secretary proposes to establish a knowledge dissemination and utilization project for the purpose of improving the ability of rehabilitation professionals to more effectively use rehabilitation technology in providing services to individuals through the State VR Services program. The proposed D&U project must:

- (1) evaluate the pre-service and in-service rehabilitation professional training materials that address rehabilitation technology and identify strengths and deficiencies in those materials;
- (2) Based on this evaluation, develop training materials that will improve the ability of rehabilitation counselors and related professionals to utilize existing and emerging rehabilitation technology;
- (3) Disseminate these materials to pre-service and in-service rehabilitation professional training programs;
- (4) As needed, provide technical assistance to these pre-service and in-service training programs to maximize the use of the materials; and

(5) Using a variety of strategies, disseminate information about existing and emerging rehabilitation technology to rehabilitation counselors, special educators involved with the transition of secondary students, and related rehabilitation professionals.

In carrying out the purposes of the priority, the proposed D&U project must:

- Coordinate with the Assistive Technology projects to avoid duplication of effort;
- Develop information about existing and emerging rehabilitation technology from a wide variety of sources; and
- On a regular basis, update the information and materials that are developed.

#### Invitation To Comment

Interested persons are invited to submit comments and recommendations regarding these proposed priorities.

All comments submitted in response to this notice will be available for public inspection, during and after the comment period, in Room 3423, Mary Switzer Building, 330 C Street S.W., Washington, D.C., between the hours of 8:00 a.m. and 3:30 p.m., Monday through Friday of each week except Federal holidays. APPLICABLE PROGRAM REGULATIONS: 34 CFR Parts 350, 351, and 352.

Program Authority: 29 U.S.C. 760-762.

Dated: February 27, 1997.

(Catalog of Federal Domestic Assistance Numbers: 84.133A, Research and Demonstration Projects, 84.133B, Rehabilitation Research and Training Center Program, 84.133D, Knowledge Dissemination and Utilization Program)

Judith E. Heumann,

*Assistant Secretary for Special Education and Rehabilitative Services.*

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