

DEPARTMENT OF EDUCATION**National Institute on Disability and Rehabilitation Research; Notice of Proposed Funding Priorities for Fiscal Years 1998–1999 for Certain Centers and Projects**

SUMMARY: The Secretary proposes funding priorities for four Rehabilitation Research and Training Centers (RRTCs) and two Disability and Rehabilitation Research Projects (DRRPs) under the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years 1998–1999. The Secretary takes this action to focus research attention on areas of national need. These priorities are intended to improve rehabilitation services and outcomes for individuals with disabilities.

DATES: Comments must be received on or before January 21, 1998.

ADDRESSES: All comments concerning these proposed priorities should be addressed to Donna Nangle, U.S. Department of Education, 600 Maryland Avenue, S.W., room 3418, Switzer Building, Washington, D.C. 20202–2645. Comments may also be sent through the Internet: comment@ed.gov

You must include the term Disability and Rehabilitation Research Projects and Centers in the subject line of your electronic message.

FOR FURTHER INFORMATION CONTACT: Donna Nangle. Telephone: (202) 205–5880. Individuals who use a telecommunications device for the deaf (TDD) may call the TDD number at (202) 205–2742. Internet: Donna_Nangle@ed.gov.

Individuals with disabilities may obtain this document in an alternate format (e.g., Braille, large print, audiotape, or computer diskette) on request to the contact person listed in the preceding paragraph.

SUPPLEMENTARY INFORMATION: This notice contains proposed priorities under the Disability and Rehabilitation Research Projects and Centers Program for four RRTCs related to: secondary conditions of spinal cord injuries (SCI); neuromuscular diseases (NMD); multiple sclerosis (MS); and community integration for persons with traumatic brain injury (TBI). The notice also contains proposed priorities for two Disability and Rehabilitation Research Projects related to: dissemination and utilization of research information to promote independent living; and supported living and choice for persons with mental retardation.

These proposed priorities support the National Education Goal that calls for every adult American to possess the

skills necessary to compete in a global economy.

The authority for the Secretary to establish research priorities by reserving funds to support particular research activities is contained in sections 202(g) and 204 of the Rehabilitation Act of 1973, as amended (29 U.S.C. 761a(g) and 762).

The Secretary will announce the final 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 a particular project depends on the final priority, 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 this competition will be published in the **Federal Register** concurrent with or following the publication of the notice of final priorities.

Rehabilitation Research and Training Centers

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 that 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.

Description of Rehabilitation Research and Training Centers

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, integrated, 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.

RRTCs disseminate materials in alternate formats to ensure that they are accessible to individuals with a range of disabling conditions.

NIDRR encourages all Centers to involve individuals with disabilities and individuals from minority backgrounds as recipients of research training, as well as clinical training.

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.

Proposed General Requirements

The Secretary proposes that the following requirements apply to these RRTCs pursuant to these absolute priorities unless noted otherwise. An applicant's proposal to fulfill these

proposed requirements will be assessed using applicable selection criteria in the peer review process. The Secretary is interested in receiving comments on these proposed requirements:

Each RRTC must provide: (1) Training on research methodology and applied research experience; and (2) training on knowledge gained from the Center's research activities to persons with disabilities and their families, service providers, and other appropriate parties.

Each RRTC must develop and disseminate informational materials based on knowledge gained from the Center's research activities, and disseminate the materials to persons with disabilities, their representatives, service providers, and other interested parties.

Each RRTC must involve individuals with disabilities and, if appropriate, their representatives, in planning and implementing its research, training, and dissemination activities, and in evaluating the Center.

The RRTC must conduct a state-of-the-science conference in the third year of the grant and publish a comprehensive report on the final outcomes of the conference in the fourth year of the grant.

Priorities

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

Proposed Priority 1: Secondary Conditions of Spinal Cord Injuries

Background

There are approximately 10,000 new cases of SCI each year and the prevalence of SCI is estimated between 183,000 and 230,000 persons (University of Alabama-Birmingham, "Facts and Figures at a Glance," *Spinal Cord Injury Factsheet*, August, 1997). The etiology of SCI has been very well documented and the medical characterization of this condition is well established (Maynard, F. M., et al., "International Standards for Neurological and Functional Classification of Spinal Cord Injury—American Spinal Cord Injury Association" *Spinal Cord*, 35(5), pgs. 266–274, May, 1997). Past medical advances have improved the probability of surviving SCI, and ongoing developments and improvements in clinical care have increased the life expectancy and quality of life of persons with SCI (Ditunno, J. F. and Formal,

C. S., "Chronic Spinal Cord Injury," *New England Journal of Medicine*, 330(8), pgs. 550–556, February, 1994). However, the life expectancy of individuals with SCI is still lower than the general population, and people who are living with SCI continue to be at higher risk than the general population for a number of secondary conditions. For the purposes of this priority, a secondary condition is a condition that is causally related to a disabling condition (i.e., occurs as a result of the primary disabling condition) and that can be pathological, an impairment, a functional limitation, or an additional disability (Pope, A. M. and Tarlov, A. R., "Prevention of Secondary Conditions," *Disability in America*, pgs. 214–241, 1991).

Pressure ulcers, respiratory complications, urinary tract infections (UTIs), pain, and obesity are commonly reported secondary conditions of SCI (Lemons, V. R. and Wagner, F. C., Jr., "Respiratory Complications After Cervical Spinal Cord Injury," *Spine*, 9(20), pgs. 2315–2320, 1994; Anson, C. A. and Shepherd, C., "Incidence of Secondary Complication in Spinal Cord Injury," *International Journal of Rehabilitation Research*, 19(1), pgs. 55–66, March, 1996). Depression in SCI is also often identified as a secondary condition (Elliott, T. R. and Frank, R. G., "Depression Following Spinal Cord Injury," *Archives of Physical Medicine and Rehabilitation*, Vol. 77, pgs. 816–823, 1996). Continued research efforts directed toward the prevention and treatment of secondary conditions of persons with SCI will improve their health and well-being.

Despite past efforts, pressure ulcers remain a daunting problem with respect to both prevention and treatment. Most approaches to pressure ulcer management emphasize prevention (Ditunno, J. F., op. cit.). There is little systematic evidence on how individuals with SCI manage a pressure ulcer once one develops (Fuhrer, M. J., et al., "Pressure Ulcers in Community-Resident Persons with Spinal Cord Injury: Prevalence and Risk Factors," *Archives of Physical Medicine and Rehabilitation*, 74, pgs. 1172–1177, 1993).

Respiratory-related conditions have now replaced UTIs as the major cause of death in the SCI population, particularly among individuals with cervical level injuries (University of Alabama-Birmingham, op. cit.). Pneumonia continues to be one of the most common secondary conditions. Secretion management is often problematic due to impaired cough (Ditunno, J. F. and Formal, C. S., op.

cit.). The effectiveness of current therapeutic interventions to reduce the incidence of respiratory conditions appears to be marginal (Lemons, V. R. and Wagner, F. C., Jr., op. cit.).

Urinary tract infections are a common secondary condition in SCI. Antibiotic prophylaxis is not generally recommended. Other possible strategies, such as vaccination, immunotherapy, and the use of receptor analogs have been suggested, but there is not yet sufficient data on the effectiveness (Galloway, A., "Prevention of Urinary Tract Infection in Patients with Spinal Cord Injury—A Microbiological Review," *Spinal Cord*, 35(4), pgs. 198–204, April, 1997). There are possible psycho-social-vocational factors that impact bladder management programs (NIDRR 1992 Consensus Statement, "The Prevention and Management of Urinary Tract Infections Among People with Spinal Cord Injuries," *Journal of American Paraplegia Society*, 15(3), pgs. 194–204, July, 1992).

Pain is a secondary condition that affects a significant number of persons with SCI (Yeziarski, R. P., "Pain Following Spinal Cord Injury: the Clinical Problem and Experimental Studies," *Pain*, 68(2–3), pgs. 185–194, 1996). Previous research has resulted in a number of classification schemes for SCI pain; however, there is no standardized classification system, limiting comparability of findings from the literature. The numerous individual variations in pain as a secondary condition accompanying SCI impede research progress in the alleviation of pain (Stover, S. L., et al., "Management of Neuromusculoskeletal System," *Spinal Cord Injury: Clinical Outcomes from Model Systems*, Chapter 8, pgs. 154–155, 1995).

Obesity can contribute to health-related problems in the general population. Obesity in SCI, particularly morbid obesity, is more likely to contribute to health-related problems. This condition is closely tied to nutritional status and the ability to engage in physical activity or exercise. Limitations on the latter are likely to contribute significantly to the problems stemming from this secondary condition (Blackmer, J. and Marshall, S., "Obesity and Spinal Cord Injury: An Observational Study," *Spinal Cord*, 35(4), pgs. 245–247, April, 1997).

Depression is more common among persons with SCI than among the general population. There is some evidence that depression is higher among persons whose SCI is of relatively short duration compared to others who have had a longer time to

adjust (Steins, S. A., et al., "Spinal Cord Injury Rehabilitation: Individual Experience, Personal Adaptation, and Social Perspectives," *Archives of Physical Medicine and Rehabilitation*, Vol. 78, March, 1997). Proper diagnosis and treatment of depression in persons with SCI has not yet been well established (Elliott, T. R. and Frank, R. G., op. cit.). Prevention and treatment for depression and other psychosocial adjustment problems may include increasing opportunities for social interactions through community participation (Rintala, D. H., et al., "The Relationship Between the Extent of Reciprocity with Social Supporters and Measures of Depressive Symptomatology, Impairment, Disability, and Handicap in Persons with Spinal Cord Injury," *Rehabilitation Psychology*, 39(1), pgs. 15-27, 1994).

There is a linkage between maintaining the health of persons with SCI and the prevention of secondary conditions. Health maintenance activities may include, but are not limited to, following accepted medical protocols, proper diet, weight control, and exercise. Persons with SCI are increasingly realizing the importance of and seeking access to health maintenance activities (Edwards, P., "Health Promotion Through Fitness for Adolescents and Young Adults Following Spinal Cord Injury," *SCI Nursing*, 13(3), pgs. 69-73, September, 1996).

Because of the differences in exercise tolerance among different levels of SCI, one uniform exercise protocol can not be applied to all individuals. Exercise options for persons with SCI will be expanded when appropriate exercise protocols are developed for the different levels of injury (Rimmer, J. H., "Fitness and Rehabilitation Programs for Special Populations," Brown & Benchmark, Madison, WI, Chapter 7, 1994). Little is known about the synergistic effects of exercise, diet, and nutrition. Questions remain as to whether and how these lifestyle factors work together to promote health and prevent secondary conditions.

The availability and dissemination of information about this injury tends to be concentrated in speciality areas. This problem can be frustrating to newly-injured individuals and their family members. Rapidly accessing the most up-to-date clinical information can also be problematic for non-specialty health professionals.

Proposed Priority 1

The Secretary proposes to establish an RRTC on Secondary Conditions of Spinal Cord Injuries to improve general

health, well-being, and community integration of persons with spinal cord injury. The RRTC shall:

(1) Investigate and evaluate interventions to prevent and treat secondary medical conditions, including but not necessarily limited to pressure ulcers, respiratory complications, UTIs, pain, and obesity;

(2) Investigate and evaluate interventions to prevent and treat depression; and

(3) Develop and evaluate exercise protocols, stress management techniques and diet and nutrition regimens.

In carrying out the purposes of the priority, the RRTC must coordinate with all other relevant SCI research activities, including the NIDRR-sponsored Model SCI Systems, those sponsored by the National Center for Medical Rehabilitation Research, the Centers for Disease Control, and NIDRR's RRTCs on Aging with A Disability, Personal Assistance Services, and Managed Care.

Proposed Priority 2: Neuromuscular Diseases

Background

Neuromuscular disease is a taxonomic category that describes diseases of the peripheral neuromuscular system, both acquired and hereditary. This category encompasses diseases such as amyotrophic lateral sclerosis, post-polio, Guillan-Barre, muscular dystrophy, myasthenia gravis, and other muscular atrophies and myopathies. NMDs affect approximately 400,000 children and adults in the United States (LaPlante, M., et al., *Disability in the United States: Prevalence and Causes*, 1992). Conditions associated with these disorders include progressive weakness, limb contractures, spine deformity, and impaired pulmonary function. Cardiac involvement and intellectual impairment occur with some NMDs. The progression of these degenerative diseases takes three stages: ambulatory, wheelchair, and prolonged survival (Bach, J. R. and Lieberman, J. S., "Rehabilitation of the Patient with Disease Affecting the Motor Unit," *Rehabilitation Medicine: Principles and Practice*, pg. 1099, 1993). Past research efforts have focused on documenting the impairment and disability profiles of neuromuscular disease as well as on mitigating the functional consequences of NMD. Functional independence and community integration continue to challenge persons with NMDs.

Among the functional independence issues that affect persons with NMD are preserving respiratory function, maintaining muscle strength, assuring

good nutrition, and combating muscle fatigue. Respiratory insufficiency due to progressive muscle wasting is one of the leading causes of illness and death among persons with NMDs (Bates, D., *Respiratory Function in Disease*, pgs. 371-379, 1989). For persons with NMDs, maintaining or improving muscle strength is a major functional concern. The relationships among conditioning exercise, functional strength, and fatigue is not well understood in this population. For example, exercise has been shown to be effective in improving strength and endurance at particular points in the disease progress, but many questions remain and the optimal use of exercise across different NMD categories is not known (Brinkmann, J. R., and Ringel, S. P., "Effectiveness of Exercise in Progressive Neuromuscular Disease," *Journal of Neurological Rehabilitation*, Vol. 5, pgs. 195-199, 1991). Finally, feeding problems in patients with NMDs are frequently underestimated and poorly analyzed (Willig, T. N., et al., "Swallowing Problems in Neuromuscular Disorders," *Archives of Physical Medicine and Rehabilitation*, Vol. 75, No. 11, pgs. 1175-1181, 1994).

Persons with NMDs must maintain functional independence to maximize their ability to participate in home, work, educational, recreational, and other community activities. For instance, respiratory problems often require mechanical ventilation. Home ventilation has been shown to be useful for a growing number of patients with NMDs (Winterholler, M., et al., "Recommendation of Bavarian Muscle Centers of the German Neuromuscular Disease Society for Home Ventilation of Neuromuscular Diseases of Adult Patients," *Nervenarzt*, Vol. 68, No. 4, pgs. 351-357, 1997). Despite its technical simplicity, home ventilation leads to a number of social, medical and infrastructural problems (*Paraplegia*, Vol. 31, pgs. 93-101, 1993).

Many persons with NMDs have had limited opportunity for educational and work experiences. Research has demonstrated the "alteration of cognitive functions" in some NMD diagnoses, creating special challenges to pursuing education (Fardeau-Gautier, M. and Fardeau, M., "Socioeconomic Aspects of Neuromuscular Diseases," *Myology: Basic and Clinical*, 1994). Previous research found a significant relationship between psychosocial adjustment and unemployment for some persons with NMD (Fowler, W. M., Jr., "Employment Profiles in Neuromuscular Diseases," *American Journal of Physical Medicine &*

Rehabilitation, Vol. 76, No. 1, pgs. 26–37, 1997).

In addition to issues of functional capacity and community integration, there is an emerging policy issue related to diagnosis of NMDs. Rapid development in genetic knowledge and technologies has increased the ability to test asymptomatic NMD individuals for late-onset diseases, disease susceptibilities, and carrier status. Genetic criteria may be replacing diagnostic and clinical classification systems as a method of identifying NMDs (Fowler, W. M., Jr., "Impairment and Disability Profiles of Neuromuscular Diseases," *American Journal of Physical Medicine & Rehabilitation*, Vol. 74, No. 5, pg. S61, 1995). These developments raise ethical, legal and financial issues related to appropriate timing for tests and communication of results ("American Society of Human Genetics and American College of Medical Genetics Report—Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents," *American Journal of Human Genetics*, Vol. 57, pgs. 1233–1241, 1995).

Because of the number of very rare diseases that are included in the proposed World Federation of Neurology Classifications of NMD and the low incidence and prevalence of the more well-known NMDs, the availability and dissemination of information about these diseases is problematic. This difficulty is characteristic of cases where there is both a limited amount of information and a very small audience. This problem can be frustrating to newly-diagnosed individuals and their family members. Rapidly accessing the most up-to-date clinical information can also be problematic for the non-specialist physicians, as evidenced by the well-known difficulty in diagnosing these diseases (Swash, M. and Schwartz, M. S., *Neuromuscular Diseases: A Practical Approach to Diagnosis and Management*, pg. 3, 1988).

Proposed Priority 2

The Secretary proposes to establish an RRTC on NMDs to promote the functional independence and community integration of persons with NMDs. The RRTC shall:

- (1) Investigate and evaluate interventions to preserve functional capacity;
- (2) Investigate and evaluate techniques for enhancing community integration;
- (3) Examine the risks and benefits related to the use of genetic testing; and

- (4) Establish and maintain a clearinghouse on NMDs.

In carrying out the purposes of the priority, the RRTC shall coordinate with research activities by the National Institute on Neurological Disorders and Stroke, and other related NIDRR-funded projects relevant to the priority.

Proposed Priority 3: Multiple Sclerosis Background

Multiple sclerosis is a disease capable of producing significant disability, particularly in the young adult population. The most frequent age of onset is between 20 and 45 years, with a mean onset age of 33. The female to male ratio is nearly 2:1 and the white to non-white ratio is also nearly 2:1. The total population of individuals with MS in the United States is estimated at 250,000–350,000. The causes of MS are unknown, although autoimmune, viral, genetic, and environmental factors are considered to have potential causal significance (Smith, C. & Schapiro, R., "Neurology," *Multiple Sclerosis*, pg. 7, 1996).

Multiple Sclerosis randomly attacks the central nervous system and may manifest itself over several decades in a wide range of disabilities including, but not limited to, inability to walk, loss of bowel and bladder control, blindness, mild alteration of sensation, paralysis of limbs, impaired speech, sexual dysfunction, extreme fatigue, poor coordination, spasticity, and cognitive dysfunction. The course of MS is unpredictable. The disease may wax and wane. Significant manifestation can be brought on by heat, overwork, or a common cold and followed by return to a state with little evidence of active disease. Sometimes there are manifestations with no apparent trigger. A small group of those with the disease experience continued evolving neurological deficits. Generally, progression, severity and specific symptoms cannot be foreseen.

Various interventions may alleviate some of the manifestations. While medications may slow the disease course, there is no cure for MS. Coping and planning can be difficult and exhausting for those who make continual adjustments in daily activity. Work schedules or family plans may be disrupted by the sudden onset of fatigue. Driving and independent activity may be difficult due to MS-related impairments. Bladder difficulties may cause a person to avoid activities.

Maintaining healthy lifestyle habits can assist persons with MS to maintain maximum function despite the disease.

Exercise can strengthen muscles when possible or can help maintain muscle tone for those that are affected, although the potential for overexercise must be understood. Adequate rest is critical for persons with MS and relaxation techniques can be aids as well (Chan, A., "Physical Therapy," *Multiple Sclerosis*, pg. 87, 1996). Various diets have been suggested, as have vitamin and nutritional supplements. However, the evidence supporting the value of those measures is inconclusive. Alcohol or substance abuse can be problems for persons with the disease whose neurological deficits have caused decreased tolerance. Any substance that places extra strain on the already-impaired nervous system must be used with extreme caution. Drug interactions can be a danger if the person is on prescribed medication (Lechtenberg, R., *Multiple Sclerosis Fact Book*, pg. 171, 1989).

It is difficult to assess the employment status of persons with MS. This is due in part to the nature of the disease and its variable impact on individuals' ability to work. Information on the employment status of persons with MS may be available through a secondary analysis of databases such as the 1994–95 National Health Interview Survey Disability Supplement. Persons with MS may require unique work accommodations such as sustained cooler environments, rest breaks, and flexible work schedules.

Rehabilitation techniques are available to assist the person with MS in daily life, including at the workplace. Medications can be effective for treating fatigue, bladder, bowel, or sexual difficulties. Physical therapists commonly recommend mobility aids and devices to help with visual impairments or difficulties using the hands. At times, as when mobility impairments occur, there may be hesitation or unwillingness on the part of the person with MS, physicians, or health care coverage providers, to use assistive technologies, believing that the problem will go away (Iezzoni, L., "When Walking Fails," *The Journal of the American Medical Association*, Vol. 276, No. 19, pg. 1609, 1996).

While the life expectancy for persons with MS is nearly identical to that of healthy individuals, various manifestations of MS can be expected over the course of decades. As a person with MS ages, depression, cognitive dysfunction, and other emotional or physical health problems may play increasingly larger roles. Treatment and rehabilitation modalities may be different if a manifestation is caused by aging, as opposed to MS.

NIDRR is particularly interested in receiving public comments on whether this RRTC should pursue two research questions related to rehabilitation interventions: (1) the extent to which women with MS require unique rehabilitation interventions, and (2) whether alternative models of providing rehabilitation interventions may be needed for persons of different cultural, economic, minority, ethnic or geographic backgrounds.

Proposed Priority 3

The Secretary proposes to establish an RRTC on MS to promote the health and wellness, and improve the functioning and employment status of persons with MS. The RRTC shall:

- (1) Identify, develop, and evaluate health promotion and wellness activities, including those that address substance abuse.
- (2) Identify, develop, and evaluate rehabilitation techniques to manage and improve functioning, including those that address coping with the uncertain course of MS and depression, stress, and cognitive dysfunction;
- (3) Investigate the employment status of persons with MS;
- (4) Identify, develop, and evaluate workplace accommodations; and
- (5) Investigate the interaction between aging and MS.

In carrying out the purposes of the priority, the RRTC shall collaborate with the Consortium of MS Centers and the RRTC on Substance Abuse.

Proposed Priority 4: Community Integration for Persons with Traumatic Brain Injury

Background

Each year approximately 1.9 million Americans experience traumatic brain injuries (Collins, J. F., "Types of Injuries by Selected Characteristics: US 1985-1987," National Center for Health Statistics, *Vital Health Stat*, 10 (175), 1990). Brain injury is frequently a childhood injury, and incidence is highest among youth and young adults, particularly males (NIDRR Rehabilitation Research and Training Center, University of California, San Francisco, *Disability Statistics Abstract*, No. 14, November, 1995). The number of people surviving brain injuries has increased significantly over the last 25 years due to improved emergency medical services and advances in acute care.

Community integration is the primary aim of rehabilitation after serious trauma. For the purposes of this priority, community integration is defined as integration into home-like

settings, social networks, and productive activities such as employment, school, or volunteer work (Willer, B., et al., "Assessment of Community Integration for Traumatic Brain Injury," *Journal of Head Trauma Rehabilitation*, Vol. 8, No. 2, pgs. 75-87, June, 1993). Living independently, pursuing avocational activities, volunteering, educational endeavors, employment, and participation in social activities outside the home are important community integration outcomes.

Sequelae to TBI include problems of cognition resulting in memory and learning difficulties and personality and behavior problems, including irritability and impulsivity, that impact on community integration outcomes. In addition, individuals with severe TBI often experience fatigue, limited attention span, information processing problems, visual perception difficulties, and depression. Furthermore, alcohol use at the time of injury, as well as pre- or post-injury heavy drinking, has been related to worse post-injury outcomes (Kreutzer, J. S., "A Prospective Longitudinal Multi-center Analysis of Alcohol Use Patterns Among Persons with TBI," *The Journal of Head Trauma Rehabilitation*, Vol. 11, No. 5, pg. 58, October, 1996).

Persons who experience the physical and mental consequences of TBI require a variety of programs and services to be successfully reintegrated in the community. These resources may include schools, libraries, recreation centers, health facilities, drug treatment programs, housing, transportation, and police and law enforcement services. Often these programs and services are not fully accessible to this population because their needs are not known or recognized.

The sequelae of TBI contribute to significant difficulties obtaining and retaining employment post-injury. Because of the demographics of head injury, some of the survivors may not have worked prior to the injury. Those who were employed face challenges in seeking to return to work. Despite increasing emphasis on vocational rehabilitation, investigation of long-term outcomes has indicated unemployment rates ranging from 34 percent to 75 percent at two to 15 years after injury. A recent longitudinal investigation revealed unemployment rates for rehabilitation patients as high as 76 percent during the first four years after injury (Sander, A. M., "Neurobehavioral Functioning, Substance Abuse, and Employment after Brain Injury: Implications for Vocational Rehabilitation," *Journal of Head*

Trauma Rehabilitation, 12 (5), pgs. 28-41, 1997). Past research has examined the efficacy of supported employment and other strategies for improving employment outcomes for individuals with TBI. Successful strategies consider the structure and culture of the workplace in linking these to the needs of individuals with TBI to succeed in employment settings (Wehman, P. H., et al., "Return to Work for Persons with Severe Traumatic Brain Injury: A Data-based Approach to Program Development," *Journal of Head Trauma Rehabilitation*, 10 (1), pgs. 27-39, 1995).

The prevalence of TBI in children is documented by the National Pediatric Trauma Registry located at the RRTC on Rehabilitation and Childhood Trauma. Most injured children are one to 14 years of age. Children with disabilities face numerous problems transitioning from rehabilitation to educational settings. Educators may be unaware of the impact of TBIs on school performance and uncertain of effective educational programming. Establishing a stronger link between hospitals and school professionals is an essential step toward improving educational and functional outcomes (Farmer, J. E., et al., "Educational Outcomes in Children with Disabilities: Linking Hospitals and Schools," *NeuroRehabilitation*, Vol. 5, No. 1, pgs. 49-56, 1995).

Families of people with TBI exhibit high levels of distress, depression and anxiety. As a result, they may experience isolation and diminished social interaction and diminished ability to make decisions regarding medical, ethical, and financial issues. Even 15 years post-injury, family members of persons with TBI report tension, friction, and distress (Gervasio, A. H., "Kinship and Family Members' Psychological Distress after TBI: A Large Sample Study," *The Journal of Head Trauma Rehabilitation*, 12(3), pgs. 14-16, 1997).

Because of improved treatment and increased survival rates, many more people with TBI are living to middle age and beyond. For people with TBI who live with their families, both their aging and that of the caregivers may create problems. This is especially true for those people who live with their parents following head injury. Shortages of affordable and accessible housing, personal assistance services, and respite care may pose threats to community integration and require additional community resources.

Proposed Priority 4

The Secretary proposes to establish an RRTC on Community Integration of Persons with TBI to assist families to

cope, and to improve community resources, employment outcomes, and educational programming. The RRTC shall:

- (1) Identify and evaluate model programs and services that support community integration;
- (2) Identify, develop, and evaluate strategies to improve employment outcomes, including obtaining initial employment and successful return-to-work;
- (3) Identify and evaluate effective practices that link rehabilitation and education professionals to facilitate identification and appropriate educational programming for children;
- (4) Identify and evaluate techniques to assist families to cope; and
- (5) Investigate the impact of aging on community integration;

In carrying out the purposes of the priority, the RRTC must:

- Coordinate research efforts with the TBI Model Systems projects, other NIDRR TBI projects and centers, and the RRTC on Substance Abuse; and
- Address the needs of persons with TBI who are substance abusers.

Disability and Rehabilitation Research Projects

Authority for Disability and Rehabilitation Research Projects (DRRPs) is contained in section 202 of the Rehabilitation Act of 1973, as amended (29 U.S.C. 761a). DRRPs carry out one or more of the following types of activities, as specified in 34 CFR 350.13—350.19: research, development, demonstration, training, dissemination, utilization, and technical assistance. Disability and Rehabilitation Research Projects develop methods, procedures, and rehabilitation technology 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. In addition, DRRPs improve the effectiveness of services authorized under the Rehabilitation Act of 1973, as amended.

Proposed Priority 5: Improving Research Information Dissemination and Utilization to Promote Independent Living

Background

One of the persistent concerns in the area of knowledge dissemination and utilization is the gap between information generated from disability and rehabilitation research and its utilization by persons with disabilities in their efforts to live independently in

the community. Persons with disabilities can draw from a wealth of information derived from research, such as universal design concepts, consumer-directed personal assistance strategies, the availability of assistive technology, peer counseling techniques, housing options, and self-care techniques. This information can help provide persons with disabilities with the knowledge to exercise control over their lives, reduce their reliance on others in making decisions, perform everyday activities, and participate more fully in community life.

To generate baseline data on information dissemination related to independent living, the National Center for the Dissemination of Disability Research (NCDDR) conducted a nationwide survey asking persons with disabilities about their perceptions of the usefulness of research-based disability information, their knowledge of where to obtain that information, and their current modes of receiving information. Seventy-two percent of survey respondents affirmed that disability research information is useful to them. Twenty percent reported that they do not know if it is useful to them, and eight percent responded that the information is not useful. The survey also asked the respondents if they knew how to find information from disability research. Forty-eight percent responded they did, and 32 percent responded that they did not know how to find the information (NCDDR, "Research Exchange," Vol. 2, No. 4, 1997).

Even if research information is in the public domain, it may not be accessible to persons with disabilities. Highly technical language, obscure journal articles, and under-publicized or prohibitively expensive conference presentations exemplify some of the barriers that persons with disabilities face in their efforts to access research information. There may also be physical barriers when research information is not available in alternate formats (e.g., braille, large print, tape recording) for persons with sensory disabilities.

NIDRR has funded information dissemination and utilization efforts related to living independently in the community, using a variety of techniques, media, and dissemination strategies. NIDRR also disseminates information through national information databases and dissemination programs, such as the National Rehabilitation Information Center (NARIC) and ABLEDATA, a database that contains information on more than 22,000 assistive devices. Many Centers for Independent Living (CILs) provide information and referral

activities both in person, in print, and electronically. In addition, there are fully established consumer-run publications, television networks, electronic bulletin boards, and world wide web pages that provide independent living information.

The Internet is a primary medium for the dissemination of disability information. The Internet allows this information to be available to persons with disabilities in daily life settings, rather than requiring travel to workshops and conferences. The NCDDR survey showed that over 50 percent of the persons with disabilities living independently indicated that they have never used the Internet to obtain information, 25 percent reported using it often or very often.

Although many persons with disabilities do not currently own computers or contract with Internet provider services themselves, many institutions, such as public libraries, churches, or places other than employment or educational sites are increasingly providing alternate points of free access. Also, the decreasing costs of web TV and other accessing equipment are expected to make this resource more universally available in the future.

Proposed Priority 5

The Secretary proposes to establish a DRRP on Improving Research Information Dissemination and Utilization to Promote Independent Living. The DRRP shall:

- (1) Using the NCDDR survey results as baseline information, further assess the use of research information to promote independent living;
- (2) Identify the barriers to increased use of research information by persons with disabilities;
- (3) Based on the input of persons with disabilities, identify research that promotes independent living;
- (4) Develop and implement strategies to disseminate research information to promote independent living, using a variety of innovative methods and media;
- (5) Develop and disseminate strategies that other information providers, such as CILs, NIDRR-funded grantees, and consumer publications, can use to increase the utilization of research to promote independent living, and provide technical assistance to those entities to increase the dissemination and utilization of this information; and
- (6) Develop and implement strategies to assist persons with disabilities to increase their use of existing and future information technologies such as the Internet.

In carrying out the purposes of the priority, the DRRP must:

- Include information and activities that feature concepts of consumer choice, independence, personal autonomy and self-direction; and
- Coordinate activities with the NCDDR.

Proposed Priority 6: Supported Living and Choice for Persons With Mental Retardation

Background

Personal autonomy and choice are primary rehabilitation goals for persons with mental retardation. Supported living has emerged as a viable approach toward achieving these goals. In order for the potential impact of supported living to be realized, information on supported living must be provided to a wide array of parties involved with promoting choice and community living for persons with mental retardation.

Based on the National Health Interview Survey on adults living in the general household population and surveys of people in formal residential support programs, about .78 percent or 1,250,000 of the adult population of the U.S. can be identified as being limited in a major life activity and having a primary or secondary condition of mental retardation.

NIDRR has supported research and demonstrations in the area of mental retardation and developmental disabilities since 1965. Throughout this time, researchers have addressed issues involving deinstitutionalization, mainstreaming, transition from school to work, supported employment and the overall supports persons with mental retardation and developmental disabilities need to live as independently as possible in the community.

Supported living refers to the development and provision of assistance, including natural supports, to enable persons with mental retardation to live in settings and participate in activities that contribute to their personal goals and quality of life (Abery, B. H., et al., "Research on Community Integration of Persons with Mental Retardation and Related Conditions: Current Knowledge, Emerging Challenges and Recommended Future Directions," Prepared for the NIDRR Long Range Planning Process, pg. 4, May, 1996). Supported living intends to increase control and choice of services and supports that persons with mental retardation receive.

Access to community services and community supports varies greatly by

State. Information on trends in supported community living and innovative models of successful community living can assist States to initiate and improve effective services. In addition to parents and family members, direct service personnel such as group home staff, foster family members and job coaches, are primary sources of support and services for persons with mental retardation living in the community.

In the past decade, there has been growing concern about recruitment and retention of direct service personnel. Research has shown high turnover rates of between 55 percent and 73 percent annually (Braddock, D., & Mitchell, D., "Residential Services and Developmental Disabilities in the United States: A National Survey of Staff Compensation, Turnover, and Related Issues," American Association on Mental Retardation, Washington, DC, 1992). In order to attract and retain competent direct service personnel, service providers must provide staff with information and training on effective and innovative approaches to promote independence. Agency trainers and managers require information about effective training techniques that teach support providers how to encourage self advocacy and choice making to persons with mental retardation. In addition, public awareness activities that educate both the public and policymakers on the importance of direct service workers can enhance the image of community workers and the individuals with developmental disabilities they assist (Larson, S. A., et al., "Residential Services Personnel: Recruitment, Training and Retention," *Challenges for a Service System in Transition*, pg. 321, 1994).

Recent developments in two major Federal programs significantly affect the nature and extent of community-based services for persons with mental retardation: the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (welfare reform) and Medicaid. Recent welfare reforms provide States with increased flexibility in the delivery of community-based public services. The Medicaid program is the primary source of payment for both health care and community-based long term care services for persons with mental retardation and their families. Providing training and technical assistance on supported living to policymakers and services providers involved in the administration of welfare and Medicaid programs will enable them to take advantage of new opportunities to shape integrated and

flexible programs for persons with mental retardation.

Proposed Priority 6

The Secretary proposes to establish a Dissemination, Training, and Technical Assistance Project to promote supported living and choice for persons with mental retardation. The Project shall:

- (1) Identify and synthesize research findings on state-of-the-art models of supported living;
- (2) Develop and disseminate materials based on the synthesis and provide training and technical assistance to consumers, families, service providers, State policy makers and State agencies; and
- (3) Develop and disseminate training materials for direct service staff with input from consumers and family members.

In carrying out the purposes of the priority, the Project shall disseminate materials and coordinate training activities with relevant units of the Department of Health and Human Services, State public and private managed care representatives, individuals with disabilities and other NIDRR Centers addressing related issues.

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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 3424, Switzer Building, 330 C Street S.W., Washington, D.C., between the hours of 9:00 a.m. and 4:30 p.m., Monday through Friday of each week except Federal holidays.

Applicable Program Regulations

34 CFR parts 350 and 353.

Program Authority: 29 U.S.C. 760–762.

(Catalog of Federal Domestic Assistance Number 84.133A, Disability and Rehabilitation Research Projects, and 84.133B, Rehabilitation Research and Training Centers)

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