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Part V

Department of Education

National Institute on Disability and
Rehabilitation Research; Notice

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

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

ACTION: Notice of proposed funding priority for fiscal years 2000–2001 for Model Spinal Cord Injury Centers.

SUMMARY: The Assistant Secretary for the Office of Special Education and Rehabilitative Services proposes a funding priority for Model Spinal Cord Injury Centers under the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years 2000–2001. The Assistant Secretary takes this action to focus research attention on areas of national need. We intend this priority to improve the rehabilitation services and outcomes for individuals with disabilities. This notice contains a proposed priority under the Special Projects and Demonstrations for Spinal Cord Injuries Program.

DATES: Comments must be received on or before January 10, 2000.

ADDRESSES: All comments concerning this proposed priority should be addressed to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW, room 3418, Switzer Building, Washington, DC 20202–2645. Comments may also be sent through the Internet: donna_nangle@ed.gov

You must include the term “Special Projects and Demonstrations for Spinal Cord Injuries” 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:**Invitation to comment:**

We invite you to submit comments regarding this proposed priority.

We invite you to assist us in complying with the specific requirements of Executive Order 12866 and its overall requirement of reducing regulatory burden that might result from this proposed priority. Please let us know of any further opportunities we should take to reduce potential costs or

increase potential benefits while preserving the effective and efficient administration of the program. During and after the comment period, you may inspect all public comments about this priority in Room 3424, Switzer Building, 330 C Street SW., Washington, DC, between the hours of 9:00 a.m. and 4:30 p.m., Eastern time, Monday through Friday of each week except Federal holidays.

Assistance to Individuals With Disabilities in Reviewing the Rulemaking Record

On request, we will supply an appropriate aid, such as a reader or print magnifier, to an individual with a disability who needs assistance to review the comments or other documents in the public rulemaking record for this proposed priority. If you want to schedule an appointment for this type of aid, you may call (202) 205–8113 or (202) 260–9895. If you use a TDD, you may call the Federal Information Relay Service at 1–800–877–8339.

This proposed priority supports 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. 762(g) and 764). Regulations governing this program are found in 34 CFR parts 350 and 359.

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

Note: This notice does not solicit applications. In any year in which the Assistant Secretary chooses to use this proposed priority, we invite applications through a notice published in the **Federal Register**. When inviting applications we designate each priority as absolute, competitive preference, or invitational.

Special Projects and Demonstrations for Spinal Cord Injury

The authority for Model Spinal Cord Injury Centers is contained in section 204(b)(4) of the Rehabilitation Act of 1973, as amended (29 U.S.C. 764(b)(4)). The Secretary may make awards for up to 60 months through grants or cooperative agreements. This program

provides assistance to establish innovative projects for the delivery, demonstration, and evaluation of comprehensive medical, vocational, and other rehabilitation services to meet the wide range of needs of individuals with spinal cord injuries.

Description of Special Projects and Demonstrations for Spinal Cord Injuries

This program provides assistance for projects that provide comprehensive rehabilitation services to individuals with spinal cord injuries and conduct spinal cord research, including clinical research and the analysis of standardized data in collaboration with other related projects.

Each Spinal Cord Injury Center funded under this program establishes a multidisciplinary system of providing rehabilitation services, specifically designed to meet the special needs of individuals with spinal cord injuries. This includes acute care as well as periodic inpatient or outpatient follow up and vocational services. Centers demonstrate and evaluate the benefits and cost effectiveness of such a system for the care of individuals with spinal cord injury and demonstrate and evaluate existing, new, and improved methods and equipment essential to the care, management, and rehabilitation of individuals with spinal cord injuries. Grantees demonstrate and evaluate methods of community outreach and education for individuals with spinal cord injuries in connection with the problems of such individuals in areas such as housing, transportation, recreation, employment, and community activities.

Projects funded under this program ensure widespread dissemination of research findings to all Spinal Cord Injury Centers, and to rehabilitation practitioners, individuals with spinal cord injury, and the parents, family members, guardians, advocates, or authorized representatives of such individuals. They engage in initiatives and new approaches and maintain close working relationships with other governmental and voluntary institutions and organizations to unify and coordinate scientific efforts, encourage joint planning, and promote the interchange of data and reports among spinal cord injury researchers.

NIDRR requires all Centers to involve individuals with disabilities and individuals from minority backgrounds as recipients of research training, as well as clinical service and 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 Center, 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 Priority for Model Spinal Cord Injury Centers

Estimates of the number of people living with traumatic spinal cord injury (SCI) range from 183,000 to 230,000, with an incidence of approximately 10,000 new cases each year ("Spinal Cord Injury Facts and Figures at a Glance," National Spinal Cord Injury Statistical Center (NSCISC), University of Alabama at Birmingham). Although SCI predominately affects young adults (56% of SCIs occur among people aged 16–30 years), there is an increasing proportion of new SCI cases in the population over 60 years of age (NSCISC, *ibid.*). The true significance of traumatic SCI lies not primarily in the numbers affected, but in the substantial impact on individuals' lives and the associated substantial health care costs and living expenses. A traumatic SCI has far-reaching repercussions on the lives of the injured persons and their families that can be devastating if not addressed effectively. According to a report from the Agency for Health Care Policy and Research (Hospital Inpatient Statistics, 1996, AHCPR Publication No. 99-0034), spinal cord injury is the most expensive condition or diagnosis treated in U.S. hospitals. The estimated lifetime costs for an individual injured at the age of 25 range from \$365,000 for an incomplete injury to more than \$1.7 million for an individual with a high cervical injury (NSCISC, *op cit*).

The Model SCI program was developed in 1970 to demonstrate the value of a comprehensive integrated continuum of care for SCI. Twenty-six sites have been designated, at various times, as Model SCI Centers through funding initially from the Rehabilitation Services Administration, and subsequently from the National Institute on Handicapped Research, and its successor, the National Institute on Disability and Rehabilitation Research (NIDRR). For the period 1995–2000 there are 18 funded Model SCI Centers. (Additional information is available on the World Wide Web at <http://www.ncddr.org/mscis/>). The clinical components of the Model Centers are specified in the program regulations,

and include ". . . emergency medical services, acute care, vocational and other rehabilitation services, community and job placement, and long-term community follow up and health maintenance" (34 CFR 359.11). In addition to demonstrating and evaluating the benefits of such a system the centers are required to contribute data on their patients to the National Spinal Cord Injury Database (NSCID), and engage in research both within the center, and in collaboration with other centers.

During the past 30 years, there have been substantial improvements in outcomes following SCI (Stover, S.L., *et al.*, *Spinal Cord Injury: Clinical Outcomes From the Model Systems*, and Special Issue, *Spinal Cord Injury: Current Research Outcomes from the Model Spinal Cord Injury Care Systems*, *Archives of Physical Medicine and Rehabilitation*, Vol. 80, No. 11, November, 1999). Enhanced emergency medical services have led to increased preservation of neurologic function. Mortality during the first year following injury has continuously declined. Life expectancy, while still below that for those without SCI, has significantly increased for all levels of injury. The ideal of a comprehensive multi-disciplinary system of care for SCI has gained widespread acceptance.

However, significant challenges and opportunities remain for SCI rehabilitation. Recent statistics from the National Spinal Cord Injury Statistical Center (NSCISC) suggest that as the length of stay in rehabilitation settings has progressively decreased (1993–1998), there has been an increase in re-hospitalization during the first year after injury. In addition, mortality after the first anniversary of injury declined continuously from 1973–1992, but now has increased for the period 1993–1998. Secondary medical complications, including, but not limited to, respiratory complications, pressure ulcers and autonomic dysreflexia, continue to be significant problems. Injuries due to interpersonal violence have increased as a proportion of the total SCI incidence and are more likely to be neurologically complete injuries.

There is a need to identify, evaluate, and eliminate barriers in the natural, built, cultural, and social environments to enable people with SCI to achieve the goal of fully reintegrating into their community. Particular focus is required to address the needs of minority and underserved populations. Although employment for the U.S. population is at historically high levels, employment for the SCI population remains low. Individuals with SCI due to inter-

personal violence have an employment rate approximately half of the average for all individuals with SCI (NSCISC, *op cit*).

NIDRR shares the concerns of the rehabilitation community about the impact of changes in health care delivery and financing upon the continuum of care for SCI. People with SCI often have more difficulty in obtaining adequate primary health care than non-disabled individuals. The unique needs of women with SCI in cardiac rehabilitation, reproductive health, and early cancer screening are special issues that need to be addressed.

There are also new and developing opportunities for improving SCI care. Medical and pharmacological therapies show promise for preserving and enhancing function. There is a need to identify and evaluate therapeutic interventions, including prevention and wellness programs, and complementary and alternative therapies using evidence-based evaluation protocols.

Advancing technology has the potential to enhance access and function for individuals with SCI. There is a need to develop and evaluate service delivery models incorporating telerehabilitation strategies and technologies to provide services for people with SCI. Assistive technologies may reduce the likelihood of secondary complications in SCI. For example, improved wheelchair and seating systems may reduce musculoskeletal trauma associated with long term wheelchair use. Technological advancement has the promise of providing greater accessibility to information, telecommunications, and employment. The adoption of universal design methodologies will enhance access to the built environment as well as rapidly developing electronic and information technologies.

The development of strong collaborations by SCI centers with community and social support organizations has the potential to impact positively the independence and community integration for individuals with SCI. Peer support beginning early in the rehabilitation process may enhance return to participation in the community. The causes of unemployment in SCI include lack of education and skills, lack of prior work experience, and policy disincentives. Pending changes in legislation and policy to permit retention of some medical insurance during employment, together with the high demand for skilled individuals in the workforce, represents an opportunity to foster education and employment of individuals with SCI.

NIDRR has published a Long-Range Plan (the Plan) that is based upon a new paradigm for rehabilitation that identifies disability in terms of the relationship between the individual and the natural, built, cultural, and social environments (63 FR 57189–57219). The Plan focuses on both individual and systemic factors that have an impact on the ability of people to function. The elements of the Plan include employment outcomes, health and function, technology for access and function, and independent living and community integration. As part of the Plan to attain the goals in these areas, NIDRR is committed to capacity building for research and training, and to ensure knowledge dissemination and utilization. Each area of the Plan includes objectives at both the individual and system levels. For example, the health and function objectives include research to improve medical rehabilitation interventions, as well as research to ensure access to an integrated continuum of quality health care services that address the unique needs of persons with disabilities. It is clear that the challenges and opportunities for SCI care reflect all of the priority areas of the Plan.

NIDRR has recently completed Program Reviews of all current Model SCI Centers. Based upon presentations by the Centers, and discussion with the external reviewers, NIDRR has concluded that the value of a comprehensive integrated system of care for SCI has been demonstrated. Because this conclusion is widely accepted, NIDRR is shifting the focus of the program from demonstration, to place a greater emphasis upon research. Participants in the Program Reviews observed that the comprehensive continuum of quality care should continue to be a requirement for participation in the Model SCI Centers Program. There is significant diversity among the Centers, however, in research interests and capacities. This diversity extends across the priority areas of the Plan, and represents the strength of the program.

Reviewers noted that uniformly comprehensive, high quality care, together with a common data collection system and administrative infrastructure makes the Model SCI Centers Program a valuable platform for various collaborative studies, including multi-center trials of therapies and technologies. To further the enhancement of the research mission, participants recommended a separate competition for the collaborative research portion of the program. A separate competition will facilitate

focused, considered proposals, a higher level of scientific review, and the development of significant research projects in the Model SCI Centers. The competition for collaborative research projects will be conducted subsequent to the identification of the Model SCI Centers, and funds will be reserved for that purpose.

During the Program Reviews, there was considerable discussion of the National SCI Database (NSCID). It is clear that the database is a valuable resource and that participation in the NSCID is an essential element for the Model SCI Centers. For the purpose of the present competition, the data collection activities will be maintained without change. NIDRR expects that applicants will include historical documentation of numbers of patients as well as expected new patients and expected annual follow-up submissions based on current eligibility criteria for the NSCID. However, it is anticipated that, through discussion among the newly identified Model SCI Centers, NIDRR staff, and external reviewers, details of data collection may be modified following the award. This process should not result in increased data collection workloads above current levels.

Proposed Priority

The Assistant Secretary proposes to establish Model Spinal Cord Injury Centers for the purpose of generating new knowledge through research, development, or demonstration to improve outcomes for SCI through improved interventions and service delivery models. A Model Spinal Cord Injury Center must:

- (1) Establish a multidisciplinary system of providing rehabilitation services specifically designed to meet the special needs of individuals with spinal cord injury (SCI), including emergency medical services, acute care, vocational and other rehabilitation services, community and job placement, and long-term community follow up and health maintenance;
- (2) Participate as directed by the Assistant Secretary in national studies of SCI by contributing to a national database and by other means as required by the Assistant Secretary; and
- (3) Conduct a significant and substantial research program in SCI that will contribute to the advancement of knowledge in one of the goal areas of the NIDRR Long Range Plan. Applicants may select one of the following research objectives related to specific areas of the Plan:

- (Chapter 3, Employment Outcomes): Either (1) Assess the impact

of legislative and policy changes on employment outcomes; or (2) Test direct intervention strategies for improving employment outcomes.

- (Chapter 4, Maintaining Health and Function): Either (1) Study interventions to improve outcomes in the preservation or restoration of function or the prevention and treatment of secondary conditions; or (2) Design and test service delivery models that provide quality care under constraints imposed by recent changes in the health care financing system.

- (Chapter 5, Technology for Access and Function): Either (1) Evaluate the impact of selected innovations in technology and rehabilitation engineering on service delivery; or (2) Evaluate the impact of selected innovations in technology and rehabilitation engineering on outcomes such as function, independence, and employment.

- (Chapter 6, Independent Living and Community Integration): Assess the value of peer support and early onset of services from community and social support organizations to improve outcomes such as independence and community integration, employment function, and health maintenance.

(4) Provide for the widespread dissemination of research and demonstration findings to other SCI centers, rehabilitation practitioners, researchers, individuals with SCI and their families and representatives, and other public and private organizations involved in SCI care and rehabilitation. In carrying out these purposes, the SCI center must:

- Incorporate culturally appropriate methods of community outreach and education in areas such as health and wellness, housing, transportation, recreation, employment, and other community activities for individuals with diverse backgrounds with spinal cord injury;

- Demonstrate the research and clinical capacity to participate in collaborative projects, clinical trials, or technology transfer with other model SCI centers, other NIDRR grantees, and similar programs of other public and private agencies and institutions; and

- Demonstrate the likelihood of having a sufficient number of individuals with SCI, including newly injured persons, to conduct statistically significant research.

Proposed Selection Criteria

The new emphasis on research and NIDRR's Long-Range Plan, plus the importance of the NSCID, require some modifications to the selection criteria for this program. The Secretary proposes

to redistribute points to reflect the increased emphasis on research, and to add references to the Plan and NSCID.

The Secretary proposes to use the following criteria to evaluate applications under this program. The maximum score for all the criteria is 100 points.

(a) *Project design* (30 points). The Secretary reviews each application to determine to what degree—

(1) There is a clear description of how the objectives of the project relate to the purpose of the program and the NIDRR Long Range Plan;

(2) The research is likely to produce new and useful information;

(3) The need and target population are adequately defined and are sufficient for meaningful research and demonstration;

(4) The outcomes are likely to benefit the defined target population;

(5) The research hypotheses are sound; and

(6) The research methodology is sound in the sample design and selection, the data collection plan, the measurement instruments, and the data analysis plan.

(b) *Service comprehensiveness* (20 points). The Secretary reviews each application to determine to what degree—

(1) The services to be provided within the project are comprehensive in scope, and include emergency medical services, intensive and acute medical care, rehabilitation management, psychosocial and community reintegration, and follow up;

(2) A broad range of vocational and other rehabilitation services will be available to severely handicapped individuals within the project; and

(3) Services will be coordinated with those services provided by other appropriate community resources.

(c) *Plan of operation* (10 points). The Secretary reviews each application to determine to what degree—

(1) There is an effective plan of operation that ensures proper and efficient administration of the project;

(2) The applicant's planned use of its resources and personnel is likely to achieve each objective;

(3) Collaboration between institutions, if proposed, is likely to be effective;

(4) Participation in the National Spinal Cord Injury Database is clearly and adequately described; and

(5) There is a clear description of how the applicant will include eligible project participants who have been traditionally underrepresented, such as—

(i) Members of racial or ethnic minority groups;

(ii) Women;

(iii) Individuals with disabilities; and

(iv) The elderly.

(d) *Quality of key personnel* (10 points). The Secretary reviews each application to determine to what degree—

(1) The principal investigator and other key staff have adequate training or experience, or both, in spinal cord injury care and rehabilitation and demonstrate appropriate potential to conduct the proposed research, demonstration, training, development, or dissemination activity;

(2) The principal investigator and other key staff are familiar with pertinent literature or methods, or both;

(3) All the disciplines necessary to establish the multidisciplinary system described in § 359.11(a) are effectively represented;

(4) Commitments of staff time are adequate for the project; and

(5) The applicant is likely, as part of its non-discriminatory employment practices, to encourage applications for employment from persons who are members of groups that traditionally have been underrepresented, such as—

(i) Members of racial or ethnic minority groups;

(ii) Women;

(iii) Individuals with disabilities; and

(iv) The elderly.

(e) *Adequacy of resources* (5 points). The Secretary reviews each application to determine to what degree—

(1) The facilities planned for use are adequate;

(2) The equipment and supplies planned for use are adequate; and

(3) The commitment of the applicant to provide administrative and other necessary support is evident.

(f) *Budget/cost effectiveness* (5 points). The Secretary reviews each application to determine to what degree—

(1) The budget for the project is adequate to support the activities;

(2) The costs are reasonable in relation to the objectives of the project; and

(3) The budget for subcontracts (if required) is detailed and appropriate.

(g) *Dissemination/utilization* (10 points). The Secretary reviews each application to determine to what degree—

(1) There is a clearly defined plan for dissemination and utilization of project findings;

(2) The research results are likely to become available to others working in the field;

(3) The means to disseminate and promote utilization by others are defined; and

(4) The utilization approach is likely to address the defined need.

(h) *Evaluation plan* (10 points). The Secretary reviews each application to determine to what degree—

(1) There is a mechanism to evaluate plans, progress, and results;

(2) The evaluation methods and objectives are likely to produce data that are quantifiable; and

(3) The evaluation results, where relevant, are likely to be assessed in a service setting.

Within this absolute priority, we will give the following competitive preference under 34 CFR 75.105(c)(2)(i), to applications that are otherwise eligible for funding under this priority:

Up to ten (10) points based on the extent to which an application includes effective strategies for employing and advancing in employment qualified individuals with disabilities in projects awarded under this absolute priority. In determining the effectiveness of such strategies, the Secretary will consider the applicant's success, as described in the application, in employing and advancing in employment qualified individuals with disabilities in the project.

For purposes of this competitive preference, applicants can be awarded up to a total of 10 points in addition to those awarded under the published selection criteria for this priority. That is, an applicant meeting this competitive preference could earn a maximum total of 110 points.

Applicable Program Regulations: 34 CFR part 359.

Program Authority: 29 U.S.C. 762(b)(4).

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(Catalog of Federal Domestic Assistance Numbers 84.133N, Special Projects and Demonstrations for Spinal Cord Injuries)

Dated: December 6, 1999.

Judith E. Heumann,

Assistant Secretary for Special Education and Rehabilitative Services.

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