

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 priorities.

SUMMARY: The Assistant Secretary for Special Education and Rehabilitative Services proposes priorities for one or more Burn Model Systems (BMS) Projects and one Burn Data Center under the Disability and Rehabilitation Research Projects (DRRP) Program of the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal year (FY) 2002. The Assistant Secretary takes this action to focus research attention on an identified national need. We intend this priority to improve the rehabilitation services and outcomes for individuals with severe burn injuries.

DATES: We must receive your comments on or before April 4, 2002.

ADDRESSES: Address all comments about these proposed priorities to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW., room 3412, Switzer Building, Washington, DC 20202-2645. If you prefer to send your comments through the Internet, use the following address:
donna.nangle@ed.gov.

You must include the term Burn Data Projects or Burn Data Center in the subject line of your electronic message.

FOR FURTHER INFORMATION CONTACT: Donna Nangle. Telephone: (202) 205-5880 or via the Internet:
donna.nangle@ed.gov.

If you use a telecommunications device for the deaf (TDD), you may call the TDD number at (202) 205-4475.

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

SUPPLEMENTARY INFORMATION**Invitation to Comment**

We invite you to submit comments regarding these proposed priorities.

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

preserving the effective and efficient administration of the program.

During and after the comment period, you may inspect all public comments about these priorities in room 3412, Switzer Building, 330 C Street SW., Washington, DC, between the hours of 8:30 a.m. and 4 p.m., Eastern time, Monday through Friday of each week except Federal holidays.

Assistance to Individuals With Disabilities in Reviewing the Rulemaking Record

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

General Information

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

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

The proposed priorities refer to the New Freedom Initiative (NFI). The NFI can be accessed on the Internet at: <http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html>.

The proposed priorities also refer to NIDRR's Long-Range Plan (the Plan). The Plan can be accessed on the Internet at: <http://www.ed.gov/offices/OSERS/NIDRR/Products>.

Disability and Rehabilitation Research Projects (DRRP) Program

The purpose of the DRRP Program is to plan and conduct research, demonstration projects, training, and related activities to:

(a) Develop methods, procedures, and rehabilitation technologies that maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities; and

(b) Improve the effectiveness of services authorized under the Act.

The BMS Projects must conduct research designed to improve treatment and service delivery outcomes and must demonstrate excellence in clinical care, rehabilitation research, and relevance to consumers, principally individuals with burn injuries and their families. Each BMS project funded under this program will have an integrated continuum of care to support the rehabilitation of persons with burn injury, with early linkage to trauma centers as well as community-based treatment alternatives. There should be an emphasis on multi-disciplinary treatment and service delivery approaches. Additional information on the BMS program is available on the Internet at: <http://mama.uchsc.edu/pub/nidrr>.

The Department is particularly interested in ensuring appropriate expenditure of public funds. Not later than three years after the establishment of any project, NIDRR will conduct one or more reviews of the activities and achievements of the project to ensure that it is carrying out proposed activities and contributing to the advancement of knowledge. In accordance with the provisions of 34 CFR 75.253(a), continued funding depends at all times on satisfactory performance and accomplishment of stated objectives.

The NFI emphasizes the importance of access to assistive and universally designed technologies, employer and workplace supports, and promoting full access to community-based care. The Plan emphasizes the need for consumer knowledge and information, new techniques and technologies, and advancements in the overall body of scientific knowledge. Focusing on both individual and systemic factors that impact functional capability, the Plan includes the following elements: employment outcomes; health and function; technology for access and function; and independent living and community integration.

NIDRR recently completed summative reviews of its BMS projects. Participants in the program reviews observed that the comprehensive continuum of quality care should continue to be a key requirement for participation in the BMS program. In addition, participants felt that projects must demonstrate the impact on individual outcomes of integrating rehabilitation techniques in burn treatment. Reviewers also noted that uniformly comprehensive, high quality care together with a common data collection system and administrative infrastructure make the BMS program a valuable platform for

various collaborative studies, including multi-center trials of rehabilitation therapies and technologies.

The BMS program has, since its inception, been guided by a committee consisting of the individual project directors. The project representatives will be required to meet annually in Washington, DC, and with NIDRR input and guidance, develop and oversee the policies of the BMS. NIDRR intends to work through the project directors to implement the following recommendations:

- Systematic evaluation of the burn longitudinal data set, with reduction in redundancy of data items and consideration of adoption of a minimal data set;
- Development of guidelines for public use of the data set, ensuring confidentiality of data;
- Continued development of research management mechanisms that ensure rigorous attention to protocols in collaborative studies; and
- Evaluation of the inclusion criteria's impact on the population admitted to the model system.

Proposed Priorities—Burn Model System Projects and Burn Data Coordinating Center

Background

In 1994, NIDRR established the Burn Injury Rehabilitation Model Systems of Care (Burn Model Systems) by making 36-months awards to three Centers. In 1997, NIDRR continued the Burn Model Systems (BMS) program and funded four projects for 60 months. NIDRR funded a separate Burn Data Coordinating Center in 1998. The BMS projects are committed to developing and demonstrating comprehensive burn care and rehabilitation services, involving all necessary and appropriate disciplines, for children and adults with severe burns, from point of injury to community integration and long-term follow-up. The BMS projects also evaluate the efficacy of the BMS program through the collection and analysis of uniform data on the course of recovery and outcomes following the delivery of a coordinated system of care that includes emergency care, acute care management, comprehensive inpatient rehabilitation, and long-term interdisciplinary follow-up services.

The Burn Data Coordinating Center (BDCC) coordinates the centralized data collection, manages the database, and provides statistical support to the BMS projects. The current data elements may be obtained from: <http://mama.uchsc.edu/pub/nidrr>.

In the past, the use of data from the BMS database has been largely

restricted to the use of BMS researchers. Recent Federal regulations (see March 16, 2000; 65 FR 14416–14418) outline conditions under which outside parties may request access to the data under the auspices of the Freedom of Information Act. In addition, there is increased interest in expanding the use of these data in conjunction with population-based data to further research on burn injury rehabilitation by the larger research community. Both activities require development of guidelines that ensure subject confidentiality, protect the identity of individual projects, and support use of the data in rigorous research efforts.

The American Burn Association (ABA) reports that about 51,000 Americans, one-third under age 20, are hospitalized for severe burn treatment every year. Of this number, 5,500 die (ABA National Burn Repository Report, April 18, 2001; <http://www.ameriburn.org/pub/factsheet.htm>). Burn injuries can have devastating impacts on the ability of an individual to function in the community and to achieve positive long-term outcomes. Early initiation of an aggressive inpatient rehabilitation program in a burn program is critical for restoration of optimal physical and psychological function (De Santi L., Lincoln L., Egan F., Dempling, R., *Development of a burn rehabilitation unit: Impact on burn center length of stay and functional outcome*, Journal of Burn Care and Rehabilitation, Sept.-Oct. 1998; 19(5): 414–9).

In the past, individuals who didn't die from burn shock during the first few weeks following the burn incident often died from wound sepsis in the following weeks. Today, new innovative therapies such as improved antibiotics for wound management and infection control, improved nutritional supports, and advanced surgical skin grafting techniques provide burn survivors greater chances of survival. Acute burn treatment encompasses a number of elements that will affect the rehabilitation process. For instance, research has led to improved biotechnology-based products (i.e., biodegradable bandage or spray-on dressings) that are redefining potential outcomes of severe burn by limiting scarring and increasing potential for regaining function (*Crab shells and healing webs: Burn Therapy's Bright Future*, <http://healthwatch.medscape.com/cx/viewarticle/216114>, Sept. 19, 2001). Treatment to enhance mobility reduces contractures and improves long-term functional outcomes. Nutrition also is critical to wound healing and to

regaining strength and ability to participate in ongoing rehabilitation efforts (Deitch E.A., *Nutritional support of the burn patient*, Critical Care Clinics, July 1995, 11(3): 735–50).

The goal of rehabilitation intervention for burn patients is to maximize function, minimize or prevent secondary complications, and improve long-term outcomes such as return to community, employment, and quality of life. 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, such as disfiguring scars, contractures, chronic open wounds, hypersensitivity to heat and cold, amputation, heterotopic ossification, chronic pain, deconditioning/weakness, and neuropathies. Neuropathy is a common complication of severe burn injury inpatients who are older and critically ill (Kowalske K., Holavanahalli R., Helm P., *Neuropathy after burn injury*, Journal of Burn Care and Rehabilitation, Sept.-Oct. 2001; 22(5): 353–7). Scars may require many surgeries and lifelong management. Many of these impairments may be mitigated by integrating rehabilitation techniques and approaches into the acute treatment setting and continuing with aggressive rehabilitation interventions once the acute phase of treatment is completed.

A number of rehabilitation techniques are used with burn survivors. These include psychological treatments to deal with problems of self-image and depression, physical therapy to facilitate muscle use and strengthening, occupational therapy to assist with activities of daily living (e.g., dressing), and assistive devices. Complementary and alternative therapies (e.g., massage therapy) may be useful tools in relieving post-burn itching, pain, and psychological symptoms. Wellness programs such as aerobic exercise can be effective in increasing muscular strength and functional outcome (Cucuzzo N.A., Ferrando A., Herndon D.N., *The effects of exercise programming vs. traditional outpatient therapy in the rehabilitation of severely burned children*, Journal of Burn Care and Rehabilitation, May-June 2001; 22(3): 214–20). Advancing technology has the potential to enhance access and function for individuals with burns such as the expanded use of virtual reality for reducing pain during burn therapy sessions (Hoffman H.G., Patterson D.R., Carrougher G.J., Sharar S.R., *Effectiveness of virtual reality-based pain control with multiple treatments*, Clinical Journal of Pain, Sept. 2001; 17(3): 229–35). Assistive

devices such as orthotics or prosthetics may reduce the likelihood of secondary complications in burn injuries and maximize residual function for persons who acquired limb loss because of the burn. Telerehabilitation programs may provide services for people with burn injuries who live in rural areas (Massman N.J., Dodge J.D., Fortmark K., Schwartg K.J., Solem L.D., *Burns follow-up: An innovative application of telemedicine*, Journal of Telemedicine and Telecare, 1999; 5 Supplement 1:S52-4).

Rehabilitation for burn survivors includes efforts by social workers and psychologists who work with the individuals to deal with the psychological aftermath of severe burn and issues such as sexuality, family emotional status, and long-term behavioral adjustment of pediatric burn survivors. Strategies such as peer support begun early in the rehabilitation process may enhance return to participation in the community. Support groups can provide an opportunity to communicate with others going through the same unsettling changes. Rehabilitation goals include community reintegration and burn survivors face many obstacles in reaching this goal. For instance, a number of environmental factors, such as alcohol dependency, drug abuse, psychiatric treatment, heat/cold hypersensitivity or preexisting physical disability may impact vocational rehabilitation, community and workplace integration (Fauerbach J.A., Engrav L., Kowalske K., Brych S., Bryant A., Lawrence J., Li G., Munster A., de Latour B., *Barriers to employment among working-aged patients with major burn injury*, Journal of Burn Care and Rehabilitation, Jan.-Feb. 2001; 22(1): 26-34; Horn W., Yoels W., Bartolucci A., *Factors associated with patient's participation in rehabilitation services: a comparative injury analysis 12 months post-discharge*, Disability and Rehabilitation; May 20, 2000; 22(8): 358-62).

Priorities

Priority 1—Burn Model System Projects

The Assistant Secretary proposes to fund an absolute priority for one or more Burn Model System projects for the purpose of generating new knowledge through research to improve treatment and service delivery outcomes for persons with burn injury. A BMS project must:

(1) Establish a multidisciplinary system that begins with acute care and encompasses rehabilitation services specifically designed to meet the needs

of individuals with burn injuries. This system must encompass a continuum of care, including emergency medical services; acute care services; acute medical rehabilitation services; post-acute services; psychosocial/vocational services; and long-term community follow-up.

(2) Participate as directed by the Assistant Secretary in national studies of burn injuries by contributing to a national database and by other means as required by the Assistant Secretary; and

(3) Conduct significant and substantial research in burn injury rehabilitation, ensuring that each project has sufficient sample size and methodological rigor to generate robust findings that will contribute to the advancement of knowledge in accordance with the NFI and the Plan. Applicants may develop up to three site-specific projects and develop up to two projects to be done in collaboration with other BMS projects.

In proposing research studies, applicants must demonstrate their potential impact on rehabilitation goals and objectives. Applicants may select from the following research directives related to specific areas of the NFI and the Plan:

- *Integrating Persons with Disabilities into the Workforce:* (1) Assess intervention strategies for improving employment outcomes of persons surviving severe burns; (2) Identify environmental factors that either enable or impede community and workplace integration.

- *Maintaining Health and Function:* (1) Study interventions to improve rehabilitation potential in the acute care setting such as nutritional support, early therapeutic exercise to increase mobility, treatment for scar tissue, or the prevention and treatment of secondary conditions; (2) Develop and evaluate rehabilitation treatment/interventions for persons surviving severe burns; or (3) Design and test service delivery models that provide quality rehabilitation care for burn survivors under constraints imposed by recent changes in the health care financing system.

- *Assistive and Universally Designed Technologies:* (1) Evaluate the impact of selected innovations in technology (e.g., assistive devices, biomaterials) on outcomes such as function, independence, and employment of individuals with burn injuries; or (2) Investigate the impact of national telecommunications and information policy on the access of persons with burn injuries to related education, work, and other opportunities.

- *Full Access to Community Life:* Assess the value of peer support and early onset of services from community and social support organizations to improve outcomes such as independence, community integration, employment, function, and health maintenance.

- *Associated Areas:* Develop and refine measures of treatment effectiveness in burn rehabilitation to incorporate environmental factors in the assessment of function.

(4) Provide widespread consumer-oriented dissemination activities to other burn projects, rehabilitation practitioners, researchers, individuals with burn injuries and their families and representatives, and other public and private organizations involved in burn care and rehabilitation.

In carrying out these purposes, the projects must:

- Involve consumers, as appropriate, in all stages of the research and demonstration endeavor;
- Demonstrate culturally appropriate and sensitive methods of data collection, measurements, and dissemination addressing needs of burn survivors with diverse backgrounds;
- Demonstrate the research and clinical capacity to participate in collaborative projects, clinical trials, or technology transfer with other BMS projects, other NIDRR grantees, and similar programs of other public and private agencies and institutions; and
- In conjunction with other BMS projects, plan and conduct a State-of-the-Science conference on "New Trends in Burn Injury Rehabilitation" and publish a comprehensive report on the final outcomes of the conference. The report must be published by the end of the fourth year of grant.

Proposed Priority 2—Burn Data Coordinating Center

The Assistant Secretary proposes to fund an absolute priority for a Burn Data Coordinating Center for the purpose of managing and facilitating the use of information collected by the BMS projects on individuals with burn injury. The BDCC must:

(1) Establish and maintain a database repository for data from BMS projects while providing for confidentiality, quality control, and data retrieval capabilities, using cost-effective and user-friendly technology;

(2) Ensure data quality, reliability, and integrity by providing training and technical assistance to BMS projects on data collection procedures, data entry methods, and use of study instruments;

(3) Provide consultation to NIDRR and to directors and staff of the BMS

projects on utility and quality of data elements;

(4) Support efforts to improve the research findings of the BMS projects by providing statistical and other consultation regarding the national database;

(5) Facilitate dissemination of information generated by the BMS projects, including statistical information, scientific papers, and consumer materials;

(6) Evaluate the feasibility of linking and comparing BMS data to population-based data sets or other available burn data and provide technical assistance for such linkage, as appropriate; and

(7) Develop guidelines to provide access to BMS data by individuals and institutions, ensuring that data are available in accessible formats for persons with disabilities.

In carrying out these purposes, the center must:

- Demonstrate knowledge of culturally appropriate methods of data collection, including understanding of culturally sensitive measurement approaches; and

- Collaborate with other NIDRR-funded projects, e.g., the Model Spinal Cord Injury and Traumatic Brain Injury Model System Data Centers, regarding issues such as database development and maintenance, center operations, and data management.

Applicable Program Regulations: 34 CFR part 350.

Electronic Access to This Document

You may review this document, as well as all other Department of Education documents published in the **Federal Register**, in text or Adobe Portable Document Format (PDF) on the Internet at the following site: www.ed.gov/legislation/FedRegister.

To use PDF you must have Adobe Acrobat Reader, which is available free

at this site. If you have questions about using PDF, call the U.S. Government Printing Office (GPO), toll free, at 1-888-293-6498; or in the Washington, DC, area at (202) 512-1530.

Note: The official version of this document is the document published in the **Federal Register**. Free Internet access to the official edition of the **Federal Register** and the Code of Federal Regulations is available on GPO Access at: <http://www.access.gpo.gov/nara/index.html>.

(Catalog of Federal Domestic Assistance Number 84.133A, Disability Rehabilitation Research Project)

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Dated: February 27, 2002.

Lorretta L. Petty,

Acting Assistant Secretary for Special Education and Rehabilitative Services.

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