

DEPARTMENT OF EDUCATION

National Institute on Disability and Rehabilitation Research—Disability and Rehabilitation Research Projects and Centers Program—Rehabilitation Research and Training Centers

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

ACTION: Notice of proposed priority for children with special health care needs.

SUMMARY: The Assistant Secretary for Special Education and Rehabilitative Services proposes one funding priority for the National Institute on Disability and Rehabilitation Research's (NIDRR) Disability and Rehabilitation Research Projects and Centers Program, Rehabilitation Research and Training Centers (RRTC) program. The Assistant Secretary may use this priority for competitions in fiscal year (FY) 2005 and later years. We take this action to focus research attention on areas of national need. We intend this priority to improve rehabilitation services and outcomes for individuals with disabilities.

DATES: We must receive your comments on or before May 18, 2005.

ADDRESSES: Address all comments about this proposed priority to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW., room 6030, Potomac Center Plaza, Washington, DC 20204-2700. If you prefer to send your comments through the Internet, use the following address: donna.nangle@ed.gov.

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

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

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

SUPPLEMENTARY INFORMATION:

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 proposed priority in room 6030, 550 12th Street, SW., Potomac Center Plaza, Washington, DC, between the hours of 8:30 a.m. and 4 p.m., Eastern time, Monday through Friday of each week except Federal holidays.

Assistance to Individuals With Disabilities in Reviewing the Rulemaking Record

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

We will announce the final 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 using additional priorities, subject to meeting applicable rulemaking requirements.

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

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

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

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

Note: NIDRR supports the goals of President Bush's New Freedom Initiative (NFI). The NFI can be accessed on the Internet at the following site: <http://www.whitehouse.gov/infocus/newfreedom>.

The proposed priority is in concert with NIDRR's 1999-2003 Long-Range Plan (Plan). The Plan is comprehensive and integrates many issues relating to disability and rehabilitation research topics. The reference to the topic of this priority may be found in the Plan, Chapter 2, Health and Function. The Plan can be accessed on the Internet at the following site: <http://www.ed.gov/rschstat/research/pubs/index.html>.

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

Rehabilitation Research and Training Centers

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

General Requirements of Rehabilitation Research and Training Centers

RRTCs must—

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

representatives, providers, and other interested parties.

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 RRTC. In accordance with the provisions of 34 CFR 75.253(a), continued funding depends at all times on satisfactory performance and accomplishment of approved grant objectives.

Priorities

Background

This priority focuses on children with disabilities who have special health care needs. For purposes of this priority, the term “children with special health care needs” is defined as children who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson *et al.* 1998. A New Definition of Children with Special Health Care Needs. *Pediatrics* 102(1)). A new study using this definition estimates that 9.3 million, or one in eight, children under the age of 18 in the United States have special health care needs (van Dyke *et al.* 2004. Prevalence and Characteristics of Children with Special Health Care Needs, *Archives of Pediatrics and Adolescent Medicine*, 158:9).

Exactly how many children with special health care needs have disabilities is unclear. Estimates differ depending on the source of the data and how the populations are defined. However, data from a number of sources suggest that there is a substantial proportion of children with special health care needs who have disabilities. For example, according to the National Survey of Children with Special Health Care Needs, 23 percent—nearly one-quarter—of children with special health care needs are affected in their ability to do the things other children do usually, always, or a great deal. The sources also note that income, race, and ethnicity are important factors in a child’s experience of disability. (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville,

Maryland: U.S. Department of Health and Human Services, 2004; U.S. Department of Education, Office of Special Education Programs, Data Analysis System; and Americans with Disabilities: Household Economic Studies. U.S. Census Bureau, 1997. Issued February 2001.)

The U.S. Supreme Court, in its 1999 *L.C. v. Olmstead* decision, held that title II of the Americans with Disabilities Act prohibits unjustified isolation or segregation of qualified individuals with disabilities through institutionalization. The President issued Executive Order 13217, “Community-based Alternatives for Individuals with Disabilities,” which requires Federal agencies to implement the Olmstead decision. The U.S. Department of Health and Human Services reported that children with special health care needs face barriers to community integration that include, but are not limited to, a lack of access to comprehensive, family-centered, community-based care; affordable health care; and transition services to adulthood (U.S. Department of Health and Human Services, Delivering on the Promise, Self-Evaluation to Promote Community Living for People with Disabilities. Report to the President on Executive Order 13217, 2002). Additional difficulties include fragmentation in health care service delivery, and unequal access to care based on factors such as race, ethnicity, income, and the availability of health insurance (Mayer *et al.*, 2004. Unmet Need for Routine and Specialty Care: Data from the National Survey of Children with Special Health Care Needs. *Pediatrics*, 133(2)).

The American Academy of Pediatrics has called for medical care that is “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective” (American Academy of Pediatrics, 2002. Policy Statement: The Medical Home. *Pediatrics*, 110(1)). Similarly, the March 2004 NIDRR-funded State of the Science Conference, Accessing Care: Building Capacity of Service Delivery Systems for Children and Youth with Disabilities and Special Health Care Needs, concluded that the most optimal way to provide appropriate services to children with disabilities and special health care needs is through a service delivery system that is interconnected, flexible, collaborative, responsive, and that includes provider, family, and child participation. Additionally, access to, funding for, and provider familiarity with assistive technologies and other specialized rehabilitative services are critical for appropriate care.

The Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs notes that almost half of a million children with special health care needs transition into adulthood every year in the United States, and that the goal of health care transition is to “maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood” (American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine, 2002. *Pediatrics*, 11(6): 1304).

Proposed Priority

The Assistant Secretary proposes a priority for one RRTC that must focus on children with disabilities and special health care needs. Applicants must demonstrate how their research and development activities will meet the needs of individuals from traditionally underserved populations including, but not limited to, children from low-income backgrounds.

The RRTC must conduct at least two, but not more than four, of the following research activities:

- Identify, develop, and evaluate models and strategies for implementing effective community-based practices for children with disabilities who have special health care needs;
- Identify, develop, and evaluate models and strategies for effective transition of children and adolescents with disabilities who have special health care needs to adulthood, including access to adult health care services, personal assistance services, and full participation in community life;
- Identify and evaluate strategies for maximizing family partnership and decision-making related to access to and use of home- and community-based services for children with disabilities who have special health care needs;
- Identify and evaluate innovative and effective strategies for facilitating access to service delivery for children with disabilities who have special health care needs, including health care reimbursement, assistive technology, and other specialized rehabilitative services (*e.g.*, physical therapy, occupational therapy, telehealth); and
- Identify and evaluate innovative and effective models for establishing coordination within the service delivery system for children with disabilities who have special health care needs.

In addition to the activities proposed by the applicant to carry out this priority, each RRTC must—

- Conduct a state-of-the-science conference on its respective area of research in the third year of the grant cycle and publish a comprehensive report on the final outcomes of the conference in the fourth year of the grant cycle. This conference must include materials from experts internal and external to the RRTC;
- Involve individuals with disabilities in planning and implementing its research, training, and dissemination activities, and in evaluating the RRTC;
- Coordinate on research projects of mutual interest with relevant NIDRR-funded projects as identified through consultation with the NIDRR project officer; and
- Identify anticipated outcomes (*i.e.*, advances in knowledge and/or changes and improvements in policy, practice, behavior, and system capacity) that are linked to the applicant's stated grant objectives.

Executive Order 12866

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

The potential costs associated with the notice of proposed priority are those resulting from statutory requirements and those we have determined as

necessary for administering this program effectively and efficiently.

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

Summary of Potential Costs and Benefits

The potential costs associated with this proposed priority are minimal while the benefits are significant. Grantees may incur some costs associated with completing the application process in terms of staff time, copying, and mailing or delivery. The use of e-Application technology reduces mailing and copying costs significantly.

The benefits of the RRTC program have been well established over the years in that similar projects have been completed successfully. This proposed priority will generate new knowledge and technologies through research, development, dissemination, utilization, and technical assistance projects.

Another benefit of this proposed priority is that the establishment of a new RRTC will support the President's NFI and will improve the lives of persons with disabilities, in particular children with disabilities and special health care needs. The new RRTC will generate, disseminate, and promote the use of new information that will improve the options for individuals

with disabilities to perform regular activities in the community.

Applicable Program Regulations: 34 CFR part 350.

Electronic Access to This Document

You may view 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: <http://www.ed.gov/news/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.gpoaccess.gov/nara/index.html>.

(Catalog of Federal Domestic Assistance Number 84.133B Rehabilitation Research and Training Centers Program.)

Program Authority: 29 U.S.C. 762(g) and 764(b)(2).

Dated: April 12, 2005.

John H. Hager,

Assistant Secretary for Special Education and Rehabilitative Services.

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