

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

**AGENCY:** Department of Education.

**ACTION:** Notice of Proposed Funding Priority for Fiscal Years 1996–1997 for Rehabilitation Research and Training Centers.

**SUMMARY:** The Secretary proposes a funding priority for Rehabilitation Research and Training Centers (RRTCs) under the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years 1996–1997. The Secretary takes this action to focus research attention on an area of national need identified through NIDRR's long-range planning process. This proposed priority is intended to improve outcomes for individuals with disabilities.

**DATES:** Comments must be received on or before May 22, 1996.

**ADDRESSES:** All comments concerning this proposed priority should be addressed to David Esquith, U.S. Department of Education, 600 Independence Avenue, S.W., Switzer Building, Room 3424, Washington, D.C. 20202–2601.

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

**SUPPLEMENTARY INFORMATION:** This notice contains one proposed priority under the RRTC program. The proposed priority is for research related to health care for individuals with disabilities.

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

The Secretary may make awards for up to 60 months through grants or cooperative agreements. The purpose of the awards is for planning and

conducting research, training, demonstrations, and related activities leading to the development of methods, procedures, and devices that will benefit individuals with disabilities, especially those with the most severe disabilities.

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

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

NIDRR is in the process of developing a revised long-range plan. The priority proposed in this notice is consistent with the long-range planning process.

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

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

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

RRTCs provide training, including graduate, pre-service, and in-service training, to assist individuals to more effectively provide rehabilitation services. They also provide training including graduate, pre-service, and in-service training, for rehabilitation research personnel and other rehabilitation personnel.

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

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

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

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

**General**

The Secretary proposes that the following requirements will apply to all of the RRTCs pursuant to the priority:

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

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

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

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

## Priorities

Under 34 CFR 75.105(c)(3) the Secretary gives an absolute preference to applications that meet the following proposed priority. The Secretary will fund under this competition only applications that meet this absolute priority:

**Proposed Priority: Health Care for Individuals with Disabilities—Issues in Managed Care**

### *Background*

Individuals with disabilities have a vital interest in high quality health care, and important interests in the reshaping of the health care delivery system. To begin, they are higher than average users of health services (NMES, 1987), and are more likely to be dependent on quality health care services to prevent secondary disabilities and maintain quality of life. Individuals with disabilities are more likely to be insured under public programs—Medicare and Medicaid—and thus are particularly concerned with the directions of public policy in these programs (LaPlante, 1996). Individuals with disabilities are more likely to be dependent on their health care programs for a wide range of services intended to assure their quality of life and independence, particularly as health care insurers usually control access to funding for personal assistance services and assistive technology.

The central health care issue for individuals with disabilities is access to appropriate, high quality health care. Appropriate care must be timely, of high quality, in sufficient quantity, and accessible both physically and programmatically. For individuals with disabilities, appropriate care also generally implies an integrated continuum of care as necessary, and consumer involvement in the care decisions and implementation. A comprehensive continuum of care, including primary care, acute care, rehabilitation, and long-term care, is key to any health care delivery system for individuals with disabilities.

The health care needs of individuals with disabilities differ from those of the general population in many important aspects (DeJong, 1995). They are at greater risk of acquiring certain medical conditions, often experience these conditions differently, and may require a more extensive therapeutic intervention. Individuals with disabilities often are vulnerable to secondary conditions that may exacerbate the original disability. For this reason, as well as for costs related to the original impairment, persons with disabilities are likely to need more

health care and thus to be particularly affected by cost constraints that may affect the volume or quality of services available.

In recent years there has been a significant change in the way health care is delivered and reimbursed. Historically, most of the insured population (including individuals with disabilities) received their health care through fee-for-service health care plans. However, various forms of managed care increasingly are the typical mode of organizing and delivering health care in the private sector, and segments of the Medicaid and Medicare populations have been enrolled in managed care plans. There are many varieties of managed care, ranging from the model of a case manager in a fee-for-service system, through preferred provider arrangements, to the HMO. Regardless of how managed care is operationalized, the essential features are that it is a cost-driven model paid for by a capitation method with strict controls on the volume and costliness of services to be provided to an individual with a given diagnosis. While traditional fee-for-service systems were said to reward the provider in direct proportion to the amount of services rendered, i.e., more services given equals more fees collected, managed care operates with an opposite set of incentives, often rewarding the provider for such things as low average costs, or fewer than average patient visits per diagnostic category. The provider in turn manages the care of the patient through gatekeeping practices that individuals with disabilities fear may limit access to specialists or higher-cost services. One challenge in improving health care for all individuals is to change the incentive-reward systems for gatekeepers, and all providers, from those based on cost savings to those based on quality of outcomes achieved.

A managed care system, particularly one without the funding constraints typically imposed by capitated managed care, has ideal elements of a system of care for individuals with disabilities. These elements include case management, with an opportunity for the primary care provider or case manager to become familiar with the needs of the individual consumer; coordination of interventions of a variety of specialists; often a single location that increases the physical accessibility of a variety of services and specialists; preventive health care; health education; coordination of medications; a frequent preference for alternative or holistic therapies (such as stress reduction, nutritional education,

or exercise) over more invasive procedures that many consumers resent; and a central focus for quality assurance and consumer input.

The American Hospital Association has stated that, managed care is based on the premise that the majority of the health care services delivered in the United States are most appropriately delivered and managed by primary care physicians (HIAA, 1993). While this is not an exact description of the existing practices, it is an indicator of the importance of the primary care provider in the managed care model. The primary care physician (or nurse, physicians' assistant, or other triage personnel) determines the need for primary care and makes referrals as specialized care or hospitalization are needed, and thus controls not only the delivery of primary care but entry into other services.

However, individuals with disabilities have long been concerned about a lack of appropriate primary care, and are increasingly apprehensive about effects of capitated systems on the quantity and quality of care that will be available to them. As managed care becomes more frequent as a mechanism for delivering health care, primary care providers become even more critical to the disabled individual because of their typical roles in the managed care system, determining referrals to specialists as well as delivering primary care.

Batavia and others have written about the practice of individuals with disabilities educating primary care providers in the medical implications of their impairments, and have discussed the generally unsatisfactory nature of the primary care available to individuals with disabilities (Batavia, DeJong, Halstead, and Smith, 1989).

The role of the gatekeeper—usually the primary care provider—in managed care is a critical one for individuals with disabilities. That manager not only may have an incentive to limit access to services, but also may lack competence in assessing the needs of disabled individuals with various impairments or chronic conditions.

At present, most insured individuals with disabilities are enrolled—under Medicaid or Medicare—in fee-for-service programs, where they have some latitude in choosing providers and may often elect to see rehabilitation specialists for routine and preventive care. Within this market system, it has become common for rehabilitation medicine specialists, and rehabilitation hospitals, to provide primary care. Many disabled individuals choose to return to rehabilitation specialists who

are familiar with their conditions and have wide experience in the treatment of individuals with similar conditions for both routine preventive care and for treatment of occasional illnesses or injuries. Of course, not all disabled individuals seek primary care from rehabilitation specialists and teaching hospitals.

Similarly, it must be noted that not all individuals with disabilities require special health care arrangements different from those of the general population. It is also probable that special requirements of many groups of disabled individuals can be met by accommodations and attention to accessibility within mainstream programs. At present, there is no satisfactory method for identifying, or even accurately estimating the numbers of, those disabled individuals in the total population whose health care needs cannot be met through standard managed health care plans. Most studies of managed care for individuals with disabilities are based on SSI or SSDI recipients who are enrolled in Medicaid. However, Medicaid eligibility is not a satisfactory proxy for the target population of this Center, which is addressing all individuals with disabilities who require alternative health care delivery approaches. Identifying the target population based on high volume service usage is also unsatisfactory because many individuals with disabilities may use few medical services, but still require special knowledge or accommodations when they do access the health care system.

Individuals with disabilities, as potential plan enrollees, are concerned about cost containment strategies such as capitation, which have the financial incentive to deliver fewer services. There are also incentives to avoid high-risk enrollees, and to establish policies and practices that discourage the enrollment of high users. Examples of these practices discussed by Kronick (1995) in his concise description of this problem include: screening for pre-existing conditions, designing service packages to discourage potential enrollees with certain conditions, terminating of subscribers, discouraging service use by making access difficult, and encouraging disenrollment. Kronick proceeds to list a series of strategies designed to compensate for the intensely risk averse nature of managed care programs, and these techniques are deserving of thorough evaluation in a variety of settings.

There are at present a number of alternative models for the delivery of health care services to populations with

special health care needs other than the traditional fee-for-service approach. These include the social HMOs; managed care carve outs; centers of excellence and university-based medical centers; special demonstration programs that may be conducted in connection with centers for independent living or other disability organizations; designation of rehabilitation medicine specialists as primary care providers or case managers; so-called disease management models designating special elements of care based on diagnostic category; model systems of comprehensive care; special education efforts directed at primary care providers; and more traditional limited risk models based on principles of reinsurance. The suitability of these alternative models may vary by the type of impairment, age of the consumer, geographic location, and many other factors. In recent years there have been many innovative delivery models tested (Community Medical Alliance in Boston, extensively documented by Alan Meyers and Robert Masters; the On Loc project in San Francisco for elderly medically fragile and chronically ill persons; and the PACE project, for example). However, more needs to be done to investigate the applicability of a variety of models to a range of populations, especially to working age adults, to disabled individuals who are employed, and to those covered by private health insurance.

Finally, individuals with disabilities are concerned about the physical and programmatic accessibility of health care and with their own roles in maintaining health. Individuals with disabilities, and their organizations, are learning to take an active role in the choice and management of the services they receive. Health care is one of the most critical areas for individuals with disabilities to be informed consumers. In some cases, individuals with disabilities will have a choice among benefit plans or service providers under managed care. In all cases they need the option of an informed and active role in their individual health care, including understanding of risks and benefits, choice of optional treatments, and an opportunity to provide care system. A second focus group identified a number of issues in managed care from the perspective of individuals with disabilities.

The primary Federal responsibility for health care services and research is with the Department of Health and Human Services (HHS). Several units of HHS, particularly the Public Health Service, the Health Care Financing Administration, the Office of the

Assistant Secretary for Planning and Evaluation (ASPE), and the Administration on Aging are establishing significant programs of research into managed care for vulnerable populations. NIDRR plans to continue collaboration with HHS, and expects any Center funded under this priority to work closely with HHS grantees.

However, NIDRR also has had a long history of support for medical rehabilitation research and demonstrations of model systems of care. In addressing its research mission, NIDRR has been impressed by the importance of health care to rehabilitation and independence, as well as by the high value individuals with disabilities attach to access to comprehensive, high-quality, consumer-responsive health care. In 1991, NIDRR supported a planning conference to set a long-term agenda for medical and health research in NIDRR. The conferees recommended four areas of focus: trauma care; medical rehabilitation; primary care; and long-term care.

Consistent with this agenda, NIDRR is supporting a number of RRTCs that address research issues related to trauma care, medical rehabilitation, and long-term care. In order to identify significant research issues related to primary care for individuals with disabilities, NIDRR convened a focus group of researchers, consumers, and service providers. Within the context of primary care, the group's most significant area of concern was managed care, including the role of primary care and of medical rehabilitation in the managed care system. A second focus group identified a number of issues in managed care from the perspective of individuals with disabilities.

NIDRR's proposed priority on issues in managed care focuses on accessibility, consumer-responsiveness, the role of consumers and consumer organizations (e.g., Independent Living programs) in health maintenance and in the evaluation of managed care plans, and the role of rehabilitation medicine. In addition, the priority expands the target population of related research efforts that focus primarily on publicly financed systems to include individuals covered by private health plans and individuals without health care coverage. The research undertaken by this Center is expected to complement, supplement, or confirm studies sponsored by HHS.

The Secretary is interested in research that will identify the characteristics of a managed health care system that is responsive to the needs of individuals with disabilities, including research on

the effects of managed care on individuals with disabilities. For the purposes of this proposed priority, an individual with a disability is defined as one who has a physical or mental impairment that substantially limits one or more major life activities (Rehabilitation Act of 1973, section 7(8)(B)). One function of the proposed RRTC will be to develop a definition and parameters to identify those individuals whose disabilities necessitate special health care arrangements in a managed care system.

#### *Priority*

The Secretary proposes to establish an RRTC to conduct research that will contribute to the development of consumer-responsive managed health care that encompasses the continuum of care needed by individuals with disabilities whose health care needs require special attention under managed care and will provide information and training to service providers and individuals with disabilities on new developments in managed care systems and their implications for individuals with disabilities.

In addition to activities proposed by the applicant to fulfill this general purpose, the proposed RRTC shall:

- Develop a method for identifying those individuals with disabilities, using diagnostic and functional criteria,

whose health care needs require special approaches under managed care;

- Analyze existing data related to alternative health delivery approaches, including carve out models, disease management models, and models combining acute and long-term services in order to: (1) identify critical elements (such as capitation formulas, incentive rewards, or service packages) that enhance the application of traditional managed care models to individuals with disabilities; and (2) identify gaps in the data to be addressed by future research;

- Review existing or emerging industry quality assurance standards in relation to the needs of individuals with disabilities, and develop recommended quality indicators for this population;

- Design programs to prepare individuals with disabilities to be educated consumers of health care, using consumer organizations in this effort;

- Serve as a center of information for policy makers, researchers, and individuals with disabilities about new developments in managed care, integrating the perspective of individuals with disabilities into the national discussion of managed care, and conduct at least two conferences on emerging issues in research on managed care for individuals with disabilities; and

- Establish and work with an Advisory Committee whose members include relevant Federal and other public agencies (e.g., relevant units of the Department of Health and Human Services and the Public Health Service), key managed care representatives from the private sector, individuals with disabilities, and other NIDRR centers addressing related issues.

#### *Invitation to Comment*

Interested persons are invited to submit comments and recommendations regarding these proposed priorities. All comments submitted in response to this notice will be available for public inspection, during and after the comment period, in Room 3423, Mary Switzer Building, 330 C Street S.W., Washington, D.C., between the hours of 8:00 a.m. and 3:30 p.m., Monday through Friday of each week except Federal holidays.

Applicable Program Regulations: 34 CFR Parts 350 and 352.

Program Authority: 29 U.S.C. 760-762. (Catalog of Federal Domestic Assistance Program Number 84.133B, Rehabilitation Research and Training Centers)

Dated: April 5, 1996.

Howard R. Moses,

*Acting Assistant Secretary for Special Education and Rehabilitative Services.*

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