

**DEPARTMENT OF EDUCATION****National Institute on Disability and Rehabilitation Research; Notice of a Final Funding Priority for Fiscal Years 1996–1997 for a Rehabilitation Research and Training Center**

**AGENCY:** Department of Education.

**SUMMARY:** The Secretary announces a final funding priority for the Rehabilitation Research and Training Center (RRTC) Program 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 areas of national need. This priority is intended to improve rehabilitation services and outcomes for individuals with disabilities.

**EFFECTIVE DATE:** This priority takes effect on August 8, 1996.

**FOR FURTHER INFORMATION CONTACT:** Betty Jo Berland, U.S. Department of Education, 600 Independence Avenue, S.W., Switzer Building, Room 3424, Washington, D.C. 20202–2601. Telephone: (202) 205–9739. Individuals who use a telecommunications device for the deaf (TDD) may call the TDD number at (202) 205–8133. Internet: Betty-Jo-Berland@ed.gov.

**SUPPLEMENTARY INFORMATION:** This notice contains a final funding priority to establish an RRTC for research related to managed health care for individuals with disabilities.

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

Note: This notice of final funding priority does not solicit applications. A notice inviting applications under this competition is published in a separate notice in this issue of the Federal Register.

On April 22, 1996, the Secretary published a notice of proposed priority in the Federal Register (61 FR 17818–17821). The Department of Education received nineteen letters commenting on the notice of proposed priority by the deadline date. Three additional comments were received after the deadline date and were not considered in this response. Technical and other minor changes—and suggested changes the Secretary is not legally authorized to make under statutory authority—are not addressed. All of the comments

supported the need for the proposed RRTC, and some made suggestions for modifications to the Rehabilitation Research and Training Center (RRTC) in managed care.

**Analysis of Comments and Changes**

The following paragraphs first discuss those comments that pertain to the priority as a whole, and then discuss those that address the specific activities, or “bullets”, within the priority.

**General Comments**

*Comment:* One commenter suggested that the center grant be awarded to an institution that specializes in serving the health care needs of children, and another suggested that the health care of children with disabilities should be a central focus of the RRTC.

*Discussion:* The Secretary cannot limit the field of eligible applicants beyond that authorized by the statute and program regulations, which permit any organization operating in affiliation with an institution of higher education or a provider of rehabilitation or other appropriate services to apply for the Center grant. Furthermore, because the Bureau of Maternal and Child Health in the Department of Health and Human Services (HHS) has developed an extensive agenda for research on managed health care for children with disabilities, the Center to be funded under this priority is directed toward health care needs of adults.

*Changes:* None.

*Comment:* A number of commenters urged that the priority require the Center to include a focus on certain subpopulations of individuals with disabilities, such as children or adolescents, the elderly, residents of rural areas, or persons with specific types of disabling conditions.

*Discussion:* The Secretary believes that this should be a cross-disability study, with a unique emphasis on working age adults. Applicants are not precluded from addressing the health care needs of any groups of individuals with disabilities, but due to the scope and complexity of the issue of managed care, and the need to respond to unanticipated developments in health care delivery, the Secretary elects not to require all applicants to structure research programs that focus on particular subgroups.

*Changes:* None.

*Comment:* Several commenters suggested the addition or further specification of various requirements to the work scope of the Center, including: studies of specific health care services; educational programs for specific categories of professional service

providers; focus on rural health care delivery; models for services to individuals with comorbidities; transition from pediatric to adult care; and examination of comparable benefits between health care and vocational rehabilitation funding streams.

*Discussion:* The Secretary believes that many of the suggested additional requirements are important studies, but points out that this RRTC will not have unlimited resources, and that researchers should have flexibility to choose the optimum approach to addressing the general challenges of the priority, as well as addressing the other specific requirements of the priority. The Secretary believes that many of these specific suggestions could be addressed by an applicant in responding to this priority, but the Secretary declines to require them of all applicants.

There is a growing body of research on issues of managed health care for persons with disabilities being conducted by various Federal agencies, and there are other ongoing or planned studies that may provide appropriate venues for addressing many of these additional questions. The Secretary reminds potential applicants that some of these problems may be addressed, with appropriate coordination with the RRTC, in discrete studies under NIDRR's Field-Initiated Research program.

*Changes:* None.

*Comment:* One commenter suggested that the proposed RRTC should be a resource for disseminating new health policy analysis methods from other medical specialties into the rehabilitation medicine specialty.

*Discussion:* The Secretary does endorse the use of the best and most appropriate methods of health care analysis in the field of medical rehabilitation. However, the Secretary points out that the primary purpose of this Center is not the improvement of medical rehabilitation, but rather the improvement of the managed care delivery system, with a focus on primary care, acute care, and long-term care, as well as on rehabilitative care. NIDRR currently funds an RRTC on medical rehabilitation research and expects to announce a competitive priority to continue research in this area in fiscal year 1997. Therefore, the Secretary believes that this activity would not be an appropriate use of resources in this Center.

*Changes:* None.

*Comment:* One commenter suggested that NIDRR use the term “significant disability” and the definition of that term contained in the Americans with

Disabilities Act to define the target population of this Center.

*Discussion:* NIDRR is authorized and funded under the Rehabilitation Act of 1973, as amended and therefore must relate its activities to persons who have disabilities as defined by the Rehabilitation Act.

*Changes:* None.

*Comment:* Two commenters expressed the opinion that the Background statement did not make it clear that psychiatrists provided primary care by default, and not because of a professional mission or obligation to do so.

*Discussion:* The Secretary intended that the priority convey the relationship between the lack of informed primary care for individuals with disabilities and the demand for rehabilitation medicine professionals to fill this void. Provision of primary care by rehabilitation medicine providers, including psychiatrists, has been, at least to date, by default rather than by design. However, because the information was contained in the Background statement as descriptive information, and would not affect directly the activities to be performed under the grant, no changes are made.

*Changes:* None.

*Comment:* One commenter suggested that the priority should focus on older as well as working age adults with disabilities, because of the similarity of health care concerns in areas such as prevention of secondary conditions and quality of life.

*Discussion:* The Secretary agrees that managed care for older individuals with disabilities is an important area. However, as the priority states, there is considerable research supported by HHS on managed care in elderly populations, most of whom are enrolled in Medicare. Working age individuals with disabilities have some unique concerns with the health care delivery system, for example, the availability of coverage and the scope of services covered by commercial insurance. These individuals are more likely to need family coverage or support for technologies and services related to employment. Thus, the Secretary believes that the needs of working age disabled persons should be the primary focus of this Center. The health care needs of working age disabled persons under managed care is an area that is not adequately addressed at present. In addition, this is an area in which NIDRR has unique responsibilities and the ability to make a significant contribution to the overall managed health care policy debate.

*Changes:* None.

*Comment:* Several commenters discussed the significance of the ways in which "auxiliary" services such as technology, personal assistance services (PAS) or long-term care, transportation, and housing are handled in a health services plan, and urged focus on this issue.

*Discussion:* The proposed priority does reference the continuum of care, PAS, and access to technology as components of a health care system for individuals with disabilities. The Secretary believes that the priority is explicit in requiring attention to a comprehensive continuum of care.

*Changes:* None.

*Comments:* One commenter, representing the Administration on Aging (AoA), stated that the AoA sponsored only a limited amount of research on managed care, rather than the "significant program" referred to in the Background statement.

*Discussion:* The Secretary agrees to describe the research program of the AoA in the terms suggested by that agency.

*Changes:* The AoA has been dropped from the listing of agencies that are establishing significant programs of research into managed care, and a separate sentence has been added stating that "managed care research also is being conducted by the Administration on Aging."

#### *Comments on the First Required Activity*

*Comment:* Two commenters expressed the opinion that the first prescribed activity of developing a method to identify individuals whose health care needs require special approaches under managed care would be difficult to accomplish. At the same time, several commenters suggested that the priority could be strengthened by adding an evaluation of the experiences of individuals with diverse types of disabilities under various models of managed care and fee-for-service care. Another commenter suggested that coordination with the National Committee on Vital and Health Statistics (NCVHS), which is leading an effort to develop voluntary standardized sets of disability descriptors for health encounters, would be useful to the Center in its efforts to develop methods to identify individuals with disabilities who need special health care approaches.

*Discussion:* The Secretary believes that a prerequisite to designing a comprehensive health care system is an understanding of what populations of disabled individuals are likely to need special arrangements under managed

health care, and to have some parameters for describing and identifying that population. The Secretary agrees with the commenters that a definitive understanding of the pertinent experiences of individuals with disabilities under various types of managed care as well as under traditional approaches would be useful to the Center in determining the characteristics of persons likely to need special managed care arrangements.

*Changes:* The first bullet has been revised to encompass an assessment of managed care and fee-for-service care experiences of individuals with disabilities, and to include coordination with the NCVHS and other large-scale efforts to routinize the collection of disability-related information in health care records.

#### *Comments on the Second Required Activity*

*Comment:* One commenter stated that the requirement in the second bullet to use existing data may be unrealistic, due to the absence or unavailability of the types of data that might be needed. The commenter suggested a revision to require the use of existing data only "where possible." One commenter suggested that the priority should require the center, working with other researchers and government agencies, to develop both qualitative and quantitative research examining the impact of managed care arrangements on quality of care, cost of care, and access to specialty providers, and to identify gaps in training as well as gaps in research, as currently required.

*Discussion:* The Secretary suggested the use of existing data as a means of achieving economy and efficiency. The Secretary agrees that applicants should not be restricted in their approach to answering important research questions, as long as they demonstrate that they are using the most efficient means. The Secretary believes that the parameters of quality, cost, and access to specialists are critical elements in assessing the impact of managed care on individuals with disabilities, and that coordinated activity is desirable in studying these factors.

*Changes:* The second bullet has been revised to include the words "where possible", and to stress coordinated qualitative and quantitative research on the impact of managed care.

#### *Comments related to the third required activity*

*Comment:* Several commenters suggested a stronger emphasis on the involvement of consumers, particularly in the development of quality indicators

for managed health care programs and providers. Two commenters also pointed out that there are current efforts of the National Committee for Quality Assurance (NCQA), the Robert Wood Johnson Foundation (RWJ), and the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (ASPE) in this area, and urged that the Center be required to coordinate with those efforts.

*Discussion:* The Secretary agrees that individuals with disabilities and their families, where appropriate, must be involved in all phases of the Center's activities and further agrees to emphasize the need for this involvement in the development of quality indicators, and also that coordination with other national efforts is essential.

*Changes:* The third priority requirement has been revised to include an emphasis on consumer involvement and also coordination with other national efforts in the development of standards.

#### *Comments on the fourth required activity*

*Comment:* One commenter suggested that this activity should emphasize the involvement of consumer and organizations representing consumers in the development of these educational programs, while another commenter stated that the priority should state explicitly that the educational programs should also be implemented. A third commenter suggested that the training programs should be based on an evaluation of the factors likely to influence health plan decision-making by individuals with disabilities. One commenter suggested that the Center should work with NIDRR and other Federal planning and demonstration offices in designing consumer education programs.

*Discussion:* The Secretary agrees that consumers must be involved in the development of the educational programs, as in all phases of the Center's activities, and also that they should be involved in the implementation. The Secretary also agrees that the educational program should be knowledge-based, but declines to specify what type of research should be conducted to ascertain the necessary knowledge. The Secretary emphasizes that the Center will be required to work with NIDRR and with a range of Federal planning agencies and their grantees on all phases of the Center's activities, and does not want to suggest that it is more important on this particular bullet.

*Changes:* The fourth bullet is revised to note the need to involve consumers and their organizations in the development of the training, and the need to implement the training with their involvement. The bullet also requires that the educational programs be based on a knowledge of consumer training needs.

#### *Comments on the sixth required activity*

*Comment:* One commenter suggested that the Center be required to attend the two-day National Conference on Managed Care and People with Disabilities that will be sponsored by the Department of Health and Human Services, and integrate the conference's research and training recommendations into its goals and directions. One commenter suggested that the Department of Veterans Affairs be added to the list of coordinating agencies, while others recommended coordination with the Robert Wood Johnson (RWJ) foundation and with offices of HHS in addition to those named in the priority. A commenter suggested that the Center be required to coordinate with NIDRR's Model Systems in Spinal Cord Injury, Traumatic Brain Injury, and Burns to make use of information available from those systems. One commenter suggested that parents and family care givers should be represented on the Advisory Board.

*Discussion:* The Secretary agrees that all of these are excellent suggestions. The Secretary has the flexibility to address the issue of attendance at the National Conference in the negotiation of the grant award. However, the Secretary does not want to prescribe the ways in which the Center must meet the requirements to represent consumers on the advisory board, and prefers to permit each applicant to propose how it will meet that requirement. With respect to other Federal agencies, the Secretary believes that the Department of Veterans Affairs will be a source of information, as will many units of HHS in addition to those named in the priority. Among private sector sponsors of health care research, the RWJ Foundation merits special inclusion because of its extensive body of research on managed care and disability and on consumer directed activities of personal assistance services and independent living. However, the Secretary believes that the priority as written, along with this discussion, provides sufficient guidance to applicants on the need to develop a substantial advisory committee with a wide scope of interests. The Secretary believes that each applicant should have the freedom within that framework to

propose and defend an Advisory Committee on its own choosing.

*Changes:* None.

#### *Rehabilitation Research and Training Centers (RRTCs)*

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.

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.

#### *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 following requirements apply to this RRTC pursuant to the priority unless noted otherwise:

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 priority. The Secretary will fund under this competition only applications that meet this absolute priority:

##### *Priority: Health Care for Individuals with Disabilities—Issues in Managed Health 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 with 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 designated 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 care 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 systems. 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, and the Office of the Assistant Secretary for Planning and Evaluation (ASPE), are establishing significant programs of research into managed care for vulnerable populations. The Administration on Aging also conducts research on managed care: 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 of 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 funding 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 funding 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 funding 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 intends 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 carrying out activities to fulfill this general purpose, the RRTC shall:

- Conduct a study assessing the impact of managed care on individuals with disabilities, by type of disability and social and demographic characteristics, examining such factors as quality of care, costs of care, access to specialty providers, service utilization, and preventive care, and develop, using the findings of this study, a method for identifying those individuals with disabilities whose health care needs require special approaches under managed care;
- Using existing data where possible, analyze 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, in cooperation with efforts sponsored by the NCQA, ASPE, and the Robert Wood Johnson Foundation, existing or emerging industry quality assurance standards in relation to the needs of individuals with disabilities, and develop and recommend quality indicators for this population, involving individuals with disabilities in this effort;

- Design, based on new or existing research about consumer training needs, and with the involvement of individuals with disabilities, programs to prepare individuals with disabilities to be educated consumers of health care, and implement these training programs, 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 national conferences on emerging issues in research on managed care for individuals with disabilities, researchers, and service providers; 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, including ASPE, HCFA, AoA, and the Public Health Service, and the Department of Veteran's Affairs), foundations such as RWJ, key managed care representatives from the private sector, individuals with disabilities, and other NIDRR centers and projects addressing related issues.

Program Regulations: 34 CFR Parts 350 and 352.

Program Authority: 29 U.S.C. 760-762.

(Catalog of Federal Domestic Assistance Number: 84.133B, Rehabilitation Research and Training Center Program)

Dated: July 3, 1996.

Judith E. Heumann,

*Assistant Secretary for Special Education and Rehabilitative Services.*

[FR Doc. 96-17456 Filed 7-8-96; 8:45 am]

BILLING CODE 4000-01-P-M