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Monday
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Part IV

Department of Education

National Institute on Disability and Rehabilitation Research; Notice

DEPARTMENT OF EDUCATION

National Institute on Disability and Rehabilitation Research

AGENCY: Department of Education.

ACTION: Notice of Proposed Priorities for Fiscal Years 1997–1998 for Rehabilitation Research and a Knowledge Dissemination and Utilization Project.

SUMMARY: The Secretary proposes priorities for the Rehabilitation Research and Training Center (RRTC) Program and the Knowledge Dissemination and Utilization (D&U) Program under the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years 1997–1998. The Secretary takes this action to focus research attention on areas of national need to improve rehabilitation services and outcomes for individuals with disabilities, and to assist in the solutions to problems encountered by individuals with disabilities in their daily activities.

DATES: Comments must be received on or before May 21,1997.

ADDRESSES: All comments concerning these proposed priorities should be addressed to David Esquith, U.S. Department of Education, 600 Independence Avenue, SW., Switzer Building, Room 3424, Washington, DC 20202–2601. Internet: NPP__D&U@ed.gov

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) 205–2742. Internet: David__Esquith@ed.gov

SUPPLEMENTARY INFORMATION: This notice contains proposed priorities to establish RRTCs for research related to persons who are late-deafened or hard-of-hearing, substance abuse, rural rehabilitation, and medical rehabilitation services and outcomes. In addition there is a D&U project on parenting.

These proposed priorities support 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.

The Secretary will announce the final funding priorities in a notice in the **Federal Register**. The final priorities will be determined by responses to this notice, available funds, and other considerations of the Department. Funding of particular projects depends on the final priorities, the availability of funds, and the quality of the applications received. The publication of these proposed priorities does not preclude the Secretary from proposing additional priorities, nor does it limit the Secretary to funding only these priorities, subject to meeting applicable rulemaking requirements.

Note: This notice of proposed priorities does *not* solicit applications. A notice inviting applications under these competitions will be published in the **Federal Register** concurrent with or following publication of the notice of the final priorities.

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 that 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, to alleviate or stabilize disabling conditions, and to 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 these RRTCs pursuant to the priorities 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 proposes to give an absolute preference to applications that meet one of the following priorities. The Secretary proposes to fund under these competitions only applications that meet one of these absolute priorities:

Proposed Priority 1: Maintaining the Employment Status and Addressing the Personal Adjustment Needs of Individuals Who Are Late-Deafened or Hard-of-Hearing

Background

Individuals whose hearing is impaired, but who can understand conversational speech with, or without, amplification are hard-of-hearing (HOH). Adults who are late-deafened (L–D) become deaf after having experienced hearing as well as speech and language development. Adults who are late-onset HOH and those who are L–D have common and different employment-related and personal adjustment needs. A third group of persons who are considered hearing-impaired are those persons who are prelingually deaf. Because the prelingually deaf have been and continue to be the focus of other NIDRR-funded research, this proposed priority is for research that addresses the needs of adults who are L–D or late-onset HOH.

According to data from the Bureau of the Census, the number of individuals who have a functional limitation in hearing normal conversation is approximately 10.9 million (McNeil, J., ''Americans with Disabilities: 1991–1992,'' *Household Economic Studies*, P70–33, December 1993). The National Center for Health Statistics (NCHS) estimates the number of persons who are HOH ranges from 20 million to 22 million (''National Health Survey,'' Series 10, No. 188, 1994). The NCHS studies use the ''Gallaudet Hearing Scale'' which is self-reporting and quantifies the amount of interference with hearing in ordinary day-to-day situations. According to the Association of Late-Deafened Adults, the number of persons who are L–D is estimated to be between 800,000 and 1.5 million. For 1991 and 1992, of all persons 21 to 64 years old who had some functional limitation hearing normal conversation, 3,335,000 individuals or 63.6 percent were employed, while 189,000 individuals, or 58.2 percent of those who were totally unable to hear normal conversation, were employed (McNeil, J., 1993).

Over the years, NIDRR has supported a number of research efforts to address the problems caused by various hearing impairments. At various times these efforts have included: developing hearing aids and telecommunication devices; enhancing the use and teaching of sign language interpreters; developing interventions for ''low-functioning'' deaf persons with multiple disabilities; developing more effective interventions and service models for hearing impaired vocational rehabilitation clients; and studying mental health issues of persons who are deaf, HOH, or L–D.

As the population ages, as people recover from serious illness with hearing impairments, and as environmental factors contribute to the incidence of hearing loss, it has become clear that there is a growing population of persons who experience disabling hearing loss as adults. The time of onset is likely to be in older adulthood, but this population is distinguished by the fact that the hearing loss occurs after the person has developed spoken language, has completed substantial formal education, and may have worked, married, had children, or developed social relationships—as a hearing person with ''normal'' speech.

These individuals face major adjustment problems in all phases of their lives, and may undergo depression and disruption in family or community life, as well as in their ability to perform their work and maintain their career. Such individuals need to learn ways to maintain communication skills—both receptive and expressive—and frequently need interventions to enable them to maintain speech quality (i.e., volume, modulation, articulation). Because they socialize and work with colleagues, family, and friends in a hearing and speaking environment, and because of their age, they are not likely to make a transition to deaf culture even if they do learn some sign language. Most will depend on lip-reading, amplification, or written communication. Multiple personal adjustment and work performance issues confront these individuals ranging from safety (e.g., driving and traffic noise, fire alarms, public announcement warning systems) to following instructions at work, to communicating with doctors, dentists, and therapists about their health and medications.

The impact of partial or complete hearing loss may have compound effects on the work status of individuals who are L–D or HOH. In addition to the functional impact of the hearing loss on an employee's performance, the employee may be unfamiliar with his or her civil rights and concerned about disclosing his or her condition for fear of dismissal, demotion, or loss of potential career advancement. This fear of disclosure not only produces additional anxiety, but also may delay or prevent the employee from obtaining needed assistance. Even if the employee discloses his or her condition, human resource personnel, family counselors, and other employment and social service providers may not be familiar with the sundry impacts that hearing loss and impairment can have on work performance and personal life. The inability of human resource personnel, family counselors, and others to provide effective services can increase the individual's sense of isolation and anxiety.

Factors such as early identification, family support, and the provision of reasonable accommodations can play an important role in enabling the individual to adjust to the hearing impairment and maintain employment, family, and community status. Providing such individuals with appropriate assistive technology (e.g., assistive listening devices, realtime computer assisted captioning) in a timely manner can make a significant difference in job performance and morale.

The onset of a hearing impairment or the increased loss of hearing ability also can have a significant impact on the personal life of an individual who is L–D or HOH. It is not uncommon for those individuals to experience feelings of disorientation and alienation and to withdraw from family and friends. That

withdrawal reinforces the individual's isolation and can, in extreme instances, lead to secondary complications such as alcohol and drug abuse.

Proposed Priority 1

The Secretary proposes to establish an RRTC for the purpose of conducting research on the maintenance of employment status and personal adjustment of persons who are L–D or HOH. The RRTC will:

(1) Identify and analyze the factors that negatively impact the employment status and the personal life of persons who are L–D or HOH;

(2) Develop and disseminate interventions that address these employment and personal adjustment problems, including early identification, reasonable accommodations, counseling, and assistive technology;

(3) Develop information materials on effective interventions and disseminate those materials to employers, human resource organizations, appropriate counseling organizations, and organizations representing persons who are L–D or HOH;

(4) Identify materials that address the rights of persons who are L–D or HOH under the ADA, and other disability rights laws, disseminate these materials to organizations representing those persons, and inform those organizations about opportunities to receive training and technical assistance from entities such as the Disability and Business Technical Assistance Centers (DBTACs); and

(5) Develop training and technical assistance materials and provide training and technical assistance to employers, human resource organizations, appropriate counseling organizations, and organizations representing persons who are L–D or HOH to enable them to address effectively the employment and personal adjustment problems experienced by persons who are L–D or HOH.

In carrying out the purposes of the priority, the RRTC shall:

- Identify and address the employment and personal adjustment issues that are common to both persons who are L–D and those who are HOH, as well as those issues that are unique to each population; and
- Coordinate with NIDRR's other research projects addressing individuals who are L–D or HOH, the DBTACs, and the Assistive Technology Projects.

Proposed Priority 2: Improving Vocational Rehabilitation Outcomes for Individuals Who Are Substance Abusers

Background

In 1993, NIDRR funded the establishment of a three-year RRTC on Substance Abuse and Disability to address the vocational rehabilitation needs of two major categories of eligible individuals served by the State Vocational Rehabilitation (VR) Services program. The two categories of VR eligible individuals were: (1) Those whose substance abuse has resulted in a work disability; and (2) those who have some other disability but whose substance abuse interferes with their ability to benefit from vocational rehabilitation services.

In addition, the 1993 priority authorizing the RRTC limited the scope of substance abuse to substances other than alcohol abuse (although the presence of alcohol abuse in conjunction with other substance abuse was within the scope of the RRTC). For the purposes of this priority, NIDRR is proposing to expand the scope of the priority to include alcohol abuse with or without the presence of other substance abuse. NIDRR is particularly interested in receiving public comments on expanding the scope of substance abuse addressed by the RRTC.

Individuals with a disability that results in a substantial impediment to employment and who can benefit from VR services, including those individuals whose disabling condition is due to substance abuse, are eligible for services through the State Vocational Rehabilitation (VR) Services Program, authorized under Title I of the Rehabilitation Act. Program data for fiscal year 1995 show that substance abuse was reported as the primary disabling condition for 51,339 eligible individuals who exited the program in that year. Of the 51,339 individuals with a primary disability of substance abuse, 22,708 persons' primary disabling condition was alcohol abuse and 28,631 persons' primary disabling condition was drug abuse. Of the 40,766 eligible individuals with a primary disabling condition of substance abuse who received services before exiting the program, 21,718 (53 percent) achieved an employment outcome (Rehabilitation Services Administration, Caseload Services data, 1995).

There are also individuals with disabilities served by the State VR program for whom substance abuse is a co-existing, and sometimes hidden, condition. In addition to those individuals who exited the VR program in 1995 for whom substance abuse was reported as the primary disabling condition, another 33,808 individuals were reported to have a secondary disability of substance abuse. Findings from a State-wide survey of alcohol, tobacco, illicit drugs, and medication among applicants for vocational rehabilitation services from Michigan Rehabilitation Services indicate that while alcohol use patterns approximate the general population, the percent of applicants who report current tobacco use or lifetime use of illicit drugs appear considerably higher than the general population (Moore, D. and Li, L., ''Substance Abuse Among Applicants for Vocational Rehabilitation Services,'' *Journal of Rehabilitation,* Vol. 60, No. 4, pgs. 48–53, 1994).

Unrecognized or untreated substance abuse as a co-existing condition can be a greater barrier to employment than the primary disability. Chief among those barriers are complications of psychological and social adjustment to the disability, impaired learning processes, decreased chances for vocational preparation and employment, and increased risk of adverse medical effects from the intersection of abused substances with treatment medications.

One of the primary modes of transmission of HIV is through injection drug use when an HIV-infected syringe is shared between individuals. The higher incidence of intravenous drug abuse in socio-economically depressed communities means that resultant HIV is concentrated among individuals who lack health care, have low education and little prior work experience, and lack access to transportation, assistive technology, and other community supports that facilitate vocational rehabilitation and job maintenance. Substance abuse also leads to more high risk sexual behaviors, further increasing the incidence of HIV infection in this population. The presence of HIV infection can be a complicating factor in the vocational rehabilitation of substance abusers. There is a need for research on the specific vocational rehabilitation needs of substance abusers with HIV.

The need for an expanded understanding of the relationship between vocational rehabilitation, substance abuse, and disability has been further underscored by recent changes in legislation, including welfare reform and discontinuance of Social Security Insurance and Social Security Disability Insurance benefits for individuals who previously were eligible based on addictions to alcohol and other drugs. The removal of substantial numbers of substance abusers from income supports

and medical assistance is likely to cause strains on the vocational rehabilitation service delivery system by increasing the demand for services, decreasing the ''comparable benefits'' dollars available for VR services, decreasing access to general health care during rehabilitation, and increasing client financial instability. Changes in the management and financing of health care in both the public and private sector, including managed care, may also have an impact on VR agencies' financial arrangements with third party payers and access to comparable benefits for substance abuse treatment.

Although there is an increasing prevalence of substance abuse among a diverse population of individuals undergoing rehabilitation, many service providers communicate that they have an inadequate understanding about substance abuse and co-existing disability and that this adversely impacts their ability to address the problem effectively (Heinemann, A. W., ''An Introduction to Substance Abuse and Physical Disability,'' *Substance Abuse and Physical Disability*, New York: The Haworth Press, 1993). Practitioners in a growing number of disciplines within the rehabilitation field need information about substance abuse and co-existing disability, including rehabilitation educators, vocational rehabilitation counselors, health care providers, independent living specialists, community-based rehabilitation providers, rehabilitation administrators, chemical dependence counselors, and directors of State vocational rehabilitation programs.

In order to address this need and because there are other Federal agencies that focus significant resources on individuals whose sole or primary disability is substance abuse, NIDRR is proposing that this RRTC focus its efforts, although not exclusively, on issues affecting individuals with co-existing disabilities. Particular emphasis would be given to VR eligible individuals for whom substance abuse is not their sole or primary disabling condition, but whose substance abuse interferes with their ability to benefit from vocational rehabilitation services. NIDRR is particularly interested in receiving public comments on this emphasis.

Proposed Priority

The Secretary proposes to establish an RRTC for the purpose of improving vocational rehabilitation outcomes for VR eligible individuals whose substance abuse has resulted in a work disability, or who have some other disability that results in a substantial impediment to employment but whose substance abuse interferes with their ability to benefit from vocational rehabilitation services. The RRTC shall:

(1) Conduct epidemiological studies to advance the understanding of the relationship between substance abuse and disability among individuals who are eligible for the State Vocational Rehabilitation Services program, including determining the relative prevalence of substance abuse among persons with more severe disabilities; (2) Develop, identify, and evaluate information about effective methods for providing vocational rehabilitation services to individuals who are substance abusers;

(3) Investigate the impact of recent legislative changes (including welfare reform and SSA eligibility) and changes in health care management and financing of substance abuse treatment on the provision of vocational rehabilitation services to individuals who are substance abusers; and

(4) Disseminate informational materials and provide technical assistance and training to VR eligible individuals whose substance abuse has resulted in a work disability, or who have some other disability that results in a substantial impediment to employment but whose substance abuse interferes with their ability to benefit from vocational rehabilitation services, vocational rehabilitation personnel, and related rehabilitation disciplines concerning effective strategies for providing vocational rehabilitation services.

In carrying out the purposes of the priority, the RRTC shall:

- Give special emphasis to issues affecting the vocational rehabilitation of individuals with co-existing disabilities, particularly issues affecting VR eligible individuals for whom substance abuse is not their sole or primary disabling condition, but whose substance abuse interferes with their ability to benefit from vocational rehabilitation services.
- Address the vocational rehabilitation needs of individuals with HIV/AIDS who are VR eligible individuals whose substance abuse has resulted in a work disability, or who have some other disability that results in a substantial impediment to employment but whose substance abuse interferes with their ability to benefit from vocational rehabilitation services;
- Where appropriate, address the needs of transitioning special education students who may have substance abuse problems, their special education teachers, and administrators; and
- Coordinate with projects on substance abuse supported by the Substance Abuse and Mental Health Services Administration and with NIDRR centers and projects on vocational rehabilitation and emerging disability populations.

Proposed Priority 3: Improving Employment and Independent Living Outcomes for Persons With Disabilities in Rural Areas

Background

Between 11 and 15 million persons living in rural areas have a chronic or permanent disability, a higher per capita rate of disability than exists in cities with populations over 50,000 (Young, C. and O'Day, B., ''Issues in Rural Independence: Funding,'' *Rural Monograph Series*.'' Compared to their counterparts in metropolitan areas, persons with disabilities in rural areas have higher rates of activity limitation (16.4% versus 14.6%), work limitation (14.2% versus 10.9%), and personal care limitation (4.7% versus 3.8%) (LaPlante, M. et al., ''Disability Statistics Report #7,'' *Disability in the United States: Prevalence and Causes, 1992*, Institute for Health and Aging, University of California, San Francisco, July, 1996). Persons with disabilities in rural areas face challenges that are quite different from their peers living in and around metropolitan areas. The quality of life for many people with disabilities residing in rural America is characterized by:

(1) Limited job opportunities; (2) inadequate health care; (3) isolation and inadequate transportation; (4) lack of accessible housing; and (5) underfunded social services.

For many rural areas, social and economic vitality hinges on overcoming the problems posed by remoteness from urban centers—such as the lack of easy access to advanced education, medical knowledge, and enterprise development opportunities. People with disabilities living in rural communities often live a long distance from vocational rehabilitation (VR) agencies, independent living centers (ILCs), and other social service agencies. Although these resources have great potential for reducing the impact of disability, service delivery challenges limit their availability in rural areas.

Currently, Federal, State, and local initiatives such as Empowerment Zones (EZ) or Enterprise Communities (EC) are addressing community and economic development in rural areas. The Federal government, working across agency lines and in a new partnership with State and local government and the private sector, has provided distressed communities with the tools they need

and flexibility they desire, in the form of block grants, tax breaks and waivers. In return, EZ/EC communities—residents, community leaders, businesses, State and local governments and schools—must demonstrate that they are taking responsibility for their own futures by developing and implementing a plan to utilize these tools. The U.S. Department of Agriculture (USDA) is authorized to designate three rural EZs and thirty ECs.

These projects are intended to demonstrate that innovative economic development and service delivery approaches can make a difference for people with disabilities living in rural areas. It is important for individuals with disabilities living in rural communities participate in long-range community development planning. Their involvement is crucial to ensure that the unique needs of people with disabilities for employment, economic self-sufficiency, transportation, affordable and accessible housing, and access to generic community facilities are addressed. Research is needed to study current approaches, and to develop new models, for increasing their participation in public and private economic development and services improvement initiatives.

The health problems experienced by people with disabilities living in rural areas are complicated by the burden of travelling long distances and the general shortage of primary health care providers. As a result, people with disabilities living in rural areas may experience a high rate of secondary conditions each year such as pressure sores, physical deconditioning, urinary tract infections, depression and pain (Seekins, T. *et al.*, ''A Descriptive Study of Secondary Conditions Reported by a Population of Adults with Physical Disabilities Served by Three Independent Living Centers in a Rural State,'' *Journal of Rehabilitation*, Vol. 60, No. 2, pgs. 47–51, 1994). Proper education, support delivered by health clinics and independent living centers, and utilization of telemedicine can dramatically improve the health of adults with disabilities and reduce medical service utilization.

The USDA's Rural Utilities Service, which funds telecommunications infrastructure in many rural areas, provides grants to link rural health clinics with larger hospitals to better serve rural residents. The U.S. Department of Health and Human Services' (DHHS') Health Care Financing Administration funds Rural Telemedicine Grants which demonstrate and collect information on the feasibility, costs, appropriateness, and acceptability of telemedicine for improving access to health services for rural residents and reducing the isolation of rural practitioners. The intended beneficiaries of these grants are rural health care providers, patients, and rural communities which gain from this program.

Changes in health care policy, such as managed care, are significantly affecting the lives of people with disabilities living in rural areas. For example, managed care emphasizes primary care and control of access to specialized services. Persons with significant disabilities in rural areas, however, have difficulty obtaining primary care and often need extensive services and access to highly specialized providers to prevent death or further disability (''Medicaid Managed Care: Serving the Disabled Challenges State Programs,'' *U.S. General Accounting Office (GAO)/ Health, Education, and Human Services-96–136).*

The use of telecommunications technologies may be a critical element in efforts to provide social services as well as maintain and foster economic development. Advanced telecommunications technologies—the Internet, videoconferencing and high-speed data transmission—offer rural areas the chance to overcome some of the problems they face as a result of their geographic isolation. These technologies can link rural areas with other communities and expertise to improve medical services, create new jobs, and increase rural residents' access to education (''Rural Development: Steps Toward Realizing the Potential of Telecommunications Technologies,'' *GAO/Resources, Community, and Economic Development-96–155*).

Interactive technology can link isolated rural settings with comprehensive services at distant facilities. With these linkages, the distant facility can review X-rays, CAT scans, and other medical evidence to diagnose an illness and prescribe treatment without having the patient make long, and sometimes difficult, trips to the larger institution. Colleges and schools can offer classes, and even degree programs, to students in remote locations. Large businesses can establish or maintain branch offices in rural areas by using videoconferencing or on-line access to hold meetings and conduct business. There is a need to design ways to apply these emerging interactive technologies on the lives of people with disabilities living in rural areas, particularly as Federal and other public and private programs expand their uses of interactive technology.

Proposed Priority 3

The Secretary proposes to establish an RRTC for the purpose of examining means to improve the employment status and ability of persons with disabilities to live independently in rural areas. The RRTC shall:

(1) Identify, analyze and evaluate the impact of rural economic development strategies in improving the employment outcomes and economic status of people with disabilities living in rural communities;

(2) Identify and examine issues of access to health care for persons with disabilities living in rural areas, particularly those issues contributing to the onset of secondary conditions;

(3) Develop and evaluate strategies to increase the participation of people with disabilities in local public planning for community development;

(4) Identify, develop, and evaluate strategies to improve rural transportation, accessible housing, and access to generic community facilities services for people with disabilities;

(5) Identify and evaluate strategies to improve the use of telecommunications technologies for the delivery of health, employment, education, and social services to people with significant disabilities living in rural communities; and

(6) Develop training and informational materials and provide training and information to persons with disabilities, and providers of health care, vocational rehabilitation, and independent living services, on effective strategies for improving the employment, health, and independent living outcomes of people with disabilities living in rural areas.

In carrying out the purposes of the priority, the RRTC shall:

- Coordinate with NIDRR-funded research, training and demonstration activities on delivery of rehabilitation and independent living services in rural areas, including those sponsored by RSA and the RRTC on managed care;
- Where appropriate, address the needs of transitioning special education students and their special education teachers and administrators;
- Coordinate with rural projects affecting persons with disabilities funded by USDA and DHHS; and
- Address the needs of persons with disabilities in rural communities in all parts of the country, including persons from ethnic and racial minority backgrounds.

Proposed Priority 4: Medical Rehabilitation Services and Outcomes

Background

Medical rehabilitation services are provided to individuals with disabilities to restore maximum function and independence. Traditionally, these services were provided by physicians, nurses, and allied health professionals in hospitals and rehabilitation centers. Medical rehabilitation service consumers comprise a wide range of diagnostic groups including individuals with stroke, orthopedic conditions, brain injury, spinal injury, and neurologic conditions. The need for medical rehabilitation services for persons with disabilities is expected to continue to grow in the coming decades because of increased chances of survival after trauma, disease, or birth anomaly, increased prevalence of disability related to the general aging of the population, and the increased incidence of individuals with disabilities acquiring secondary disabilities or chronic conditions as a result of increased longevity. Despite large growth projections, the impact of the projected increase in need for medical rehabilitation has not been extensively investigated in relation to long-term costs and outcomes.

Changes in the organization and delivery of health services issues are having a significant impact on the delivery and outcomes of comprehensive medical rehabilitation services. Recent trends, such as decreased length of stay associated with the high costs of inpatient care, have contributed to the growth of rehabilitation programs in sub-acute facilities, such as skilled nursing homes, and increased use of outpatient and home health care. Many rehabilitation hospitals, as well as medical rehabilitation programs within hospitals, have been influenced significantly by program consolidations, changes in ownership, third-party reimbursement provisions, and related factors that have decreased the number of beds and the average length of patient stay. At the same time, demand is increasing for sub-acute rehabilitation and general outpatient physical medicine (''Adapting to a Managed Care World: The Challenge for Physical Medicine and Rehabilitation,'' Lewin-VHI Workforce Study, American Academy of Physical Medicine and Rehabilitation, 1995).

The effectiveness of the treatments and therapeutic interventions that are generally used in clinical practice are, for the most part, not evaluated in terms of their impact on long-term functional outcomes or their cost. The cost-effectiveness and impact of alternative rehabilitative strategies should be evaluated rigorously in order to obtain information that will contribute to cost-effective, rational, and fair decisions regarding the provision of treatment and services. Medical rehabilitation services need an enhanced validated outcome measurement system to inform decisions in management issues facing health care consumers, providers, and insurers. Increasingly, payers are seeking to base decisions of whether to provide coverage for selected services or interventions on the basis of proven efficacy or cost-effectiveness as determined by rigorous scientific evidence such as that gained through randomized controlled trials.

Functional Assessments (FAs) can be used to evaluate an individual's ability to carry out activities of daily living and instrumental activities of daily living such as eating, bathing, moving from place to place, dressing, doing household chores or other necessary business, and taking care of personal hygiene. Data from FAs also are used to predict post-rehabilitation functioning, and to evaluate rehabilitation services. Improving rehabilitation practices and outcomes requires an ability to assess the status and changes in function in many areas. Multiple measures of function and activities of daily living are needed in all rehabilitation settings, including in the home and community. The increased use of telemedicine and multimedia technology is rapidly changing the manner in which functional assessment measures are generated and shared among members of the rehabilitation team. Functional outcome measures are of increasing importance in medical economics, benefits planning, managed care, and program evaluation (Ikegami, N., ''Functional Assessment and Its Place in Health Care,'' *New England Journal of Medicine*, Vol. 332, pgs. 598–599, 1995).

There is a need to collect and analyze data to determine the organization and delivery of rehabilitative care, including such parameters as facility and program sizes (i.e., economies of scale) and the number and mix of health care providers needed to serve various disability groups. Few data are available to define optimal strategies for outpatient services, nor are there methods to apply FAs or gather patient outcome data in non-hospital settings.

Improving rehabilitation medicine and ensuring that disabled individuals will have access to needed medical rehabilitation in the future requires: an ability to assess functional status and changes in status in many functional areas; the ability to evaluate rehabilitation outcomes for individuals with various diagnoses, characteristics, and interventions; and the ability to apply these measures in health services policy research in order to affect policy and funding decisions in the health care delivery context.

In the past, NIDRR has supported the development and application of the ''Functional Independence Measure'' (FIM), a criterion-referenced scale that has been widely accepted in inpatient rehabilitation settings, and also the development of the ''Craig Handicap Assessment and Reporting Technique'' (CHART), which contains scales for assessing the World Health Organization (WHO) dimensions of handicap, and is currently being refined to measure cognitive components of handicap. NIDRR currently supports an RRTC on Functional Assessment that has contributed to the scientific measurement of medical rehabilitation through applications of the FIM, refinement of the CHART, and management and analysis of the Uniform Data System (UDS), a collection of data from the application of FIM measures in many institutions.

Current measurement systems, such as the FIM and the UDS, have made significant contributions, but need modifications to increase their utility and applicability in the new environment of rehabilitation care. For example, many practitioners and theorists have suggested that the FIM does not make adequate provision for the role of assistive technology in attaining functional levels. Like the FIM, most functional assessment measurement systems were designed for use in an inpatient setting. These systems need to be evaluated and modified to measure functional status and functional change outside of hospital and clinical settings, either in community-based facilities or in real-world environments of daily living. The FIM, for example, needs further refinement to address the social and environmental dimensions of disablement. The UDS at present contains data on a limited number of disabilities, and those measurements again are not community-based.

NIDRR also has supported a center on medical rehabilitation services that has looked at such factors as supply and demand for rehabilitation facilities and practitioners, financing, and evaluation of the outcomes of rehabilitation medicine. This center has also addressed the changing context for the delivery of medical rehabilitation and access to medical rehabilitation by various population groups. Both of these

centers have made contributions to the maturing of the field of medical rehabilitation and its ability to evaluate and document its interventions and outcomes.

However, it is now clear that the field needs a larger and more integrated effort to refine measures of functional ability, changes in ability over the lifespan or in response to medical rehabilitation interventions, and to apply the measurement system in the changing environment in which medical rehabilitation is delivered. NIDRR therefore is proposing a large-scale effort to involve significant leaders in the classification and measurement of function, the evaluation of rehabilitation interventions, and the broader application of knowledge to the organization and management of medical rehabilitation services in today's environment.

Proposed Priority 4

The Secretary proposes to establish an RRTC for the purpose of examining the impact of changes in the field of rehabilitation medicine and developing improved measures for assessing individual function and the impact of medical rehabilitation services. The RRTC shall:

(1) Identify and evaluate validated functional outcome measures that can be used or modified for assessing the impact of medical rehabilitation services in a wide range of rehabilitation settings, with particular emphasis on measures that can be adapted for use in outpatient and community-based settings, including those that use telemedicine and multimedia technology;

(2) Develop or improve measures to assess the impact of the social and physical environment in achieving quality rehabilitation outcomes, including the use of assistive technology in attaining functional outcomes;

(3) Identify or develop uniform database elements and standards based on validated individual measures at the person level for determining the cost-effectiveness and functional impact of specific rehabilitation interventions used by medical rehabilitation and allied-health disciplines across multiple settings and disability populations;

(4) Identify obstacles to the use of validated functional outcomes measures in a wide range of settings in which medical rehabilitation services are provided, and in decisions to provide and assess the effectiveness of medical rehabilitation treatments, and develop strategies and evaluate pilot projects to overcome those obstacles;

(5) Identify strategies for determining the long-term results of medical rehabilitation care, including use of assistive technology;

(6) Analyze how models for the organization of medical rehabilitation services affect outcomes and costs, and how the demographic, economic, and presenting conditions of consumers affect their utilization of rehabilitation services and the outcomes that are achieved; and

(7) Develop an information dissemination and training program to enable consumers, providers, researchers, policy makers, and relevant others in health and rehabilitation settings to assess the quality of medical rehabilitation services.

In carrying out the purposes of the priority, the RRTC shall:

- Coordinate with rehabilitation medicine research and demonstration activities sponsored by NIDRR, the National Center on Medical Rehabilitation Research, Veterans Affairs, and the Health Care Financing Administration; and
- Support two National Conferences as follows: (1) A conference on the use of functional outcome measures to improve medical rehabilitation practices and interventions, and (2) a conference on improving validity and reliability in the measurement of rehabilitation outcomes.

Knowledge Dissemination and Utilization Projects

Authority for the D&U program of NIDRR is contained in sections 202 and 204(a) 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. Under the regulations for this program (see 34 CFR 355.32), the Secretary may establish research priorities by reserving funds to support particular research activities.

Priority

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

Proposed Priority 5: Parenting With a Disability Technical Assistance Center

Background

Approximately one in eleven families with children at home includes one or more parents with a disability (LaPlante, M., ''Disability in the Family,'' presented at the annual meeting of the American Public Health Association, Atlanta, GA, 1991). This proportion can be expected to increase as a correlate of the gains that persons with disabilities have achieved in their efforts to live and work independently in the community. In the course of becoming parents and rearing children, persons with disabilities may encounter a variety of attitudinal, physical, medical, and legal barriers. They may also find misinformation or an absence of information regarding advances in fields that address issues related to parenting.

NIDRR has been addressing the physical barriers and reproductive issues faced by parents with disabilities through a variety of research and development projects. Since 1993 NIDRR has supported a Rehabilitation Research and Training Center on Families in which one or more adult parent or guardian has a disability. The Center has investigated a wide range of parenting issues, including the assistive technology needs of parents with disabilities, training obstetricians to deal with the needs of women with disabilities, and needs of mothers with visual disabilities. The Center has created and identified a wide range of valuable information for parents and professionals. In addition, over the last ten years, NIDRR has supported research projects on the design and development of new adaptive equipment for parents with physical disabilities and parenting assessment techniques. A wide array of parenting equipment has been developed, for example, a lifting harness and an adapted baby bathing cart. Information is also available on the social service needs of parents with disabilities. As a result of these and other research, training, and development efforts, a substantial body of knowledge now exists related to parenting with a disability.

Persons with disabilities who want to become, or remain parents, may need information and technical assistance. A NIDRR-sponsored focus group on women and disabilities held in 1994 recommended that NIDRR explore issues related to sexuality, reproductive health, pregnancy and parenting for women with disabilities, including ''the level of information that women have about these topics'' (''Focus Group on Women and Disabilities,'' unpublished ''Report of Proceedings,'' NIDRR, pg. 8, July, 1994). Parents with disabilities and prospective parents with disabilities need information about related advances in the field of assistive technology and medicine, public policy

and legal developments, and parenting resources.

One source of information and valuable experience is persons with disabilities who are parents. These individuals have a wealth of knowledge and can not only share their experiences and practical information, but also serve as uniquely qualified sources of support. Currently, this ''parent to parent'' networking is primarily informal and limited in scope.

Persons with disabilities may encounter substantial attitudinal and legal barriers in their efforts to become pregnant, gain or maintain custody, or adopt children. Barbara Faye Waxman, an expert on reproductive rights, notes that laws allowing sterilization of persons with disabilities remain on the books in some States and that social service agencies are often too quick to put the non-disabled children of parents with disabilities up for adoption (Mathews, J., ''The Disabled Fight to Raise Their Children,'' *Washington Post Health Section*, August 18, 1992). Most States treat disability as prima facie evidence of parental unfitness and a possible detriment to the child (Conly-Jung, C., ''The Early Parenting Experiences of Mothers with Visual Impairments and Blindness,'' Dissertation, California School of Professional Psychology, Alameda, CA, pg. 21, May, 1996). One important strategy in the effort to overcome these attitudinal and legal barriers is providing social service, legal, and medical professionals with information that dispels stereotypes and describes advances in the related fields that enable persons with disabilities to provide a safe and nurturing environment for their children.

Proposed Priority 5

The Secretary proposes to establish a center for the purpose of providing technical assistance and disseminating parenting information to persons with disabilities and to social service, medical, and legal service providers. The technical assistance center will:

(1) Identify and disseminate technological, legal, and medical information on parenting, pregnancy, custody, and adoption to parents, and prospective parents with disabilities, and service providers in related field of social services, law, and medicine;

(2) Develop training materials on parenting with a disability and disseminate those materials to organizations and institutions of higher education that provide pre-service and in-service training to professionals in related fields of social services, law, and medicine, as well as to organizations representing persons with disabilities;

(3) Provide technical assistance on parenting with a disability to persons with disabilities and service providers, including making referrals and serving as a clearinghouse of technical information; and

(4) Develop and establish a parent-to-parent network that enables experienced parents with disabilities to voluntarily provide information and support to persons with disabilities interested in becoming or remaining parents.

In carrying out the purposes of the priority, the technical assistance center shall:

- Collect and synthesize information from other NIDRR-funded projects and centers that could be relevant to parenting with a disability including, but not limited to, the Assistive Technology Projects;
- Collaborate with other NIDRR and OSEP-funded projects and centers that address issues related to parenting and to disability rights of persons with disabilities; and
- Establish a national toll-free telephone hotline and publish a quarterly newsletter.

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 3424, Mary Switzer Building, 330 C Street S.W., Washington, D.C., between the hours of 9:00 a.m. and 5:00 p.m., Monday through Friday of each week except Federal holidays.

Applicable Program Regulations

34 CFR Parts 350, 352, and 355.

Program Authority: 29 U.S.C. 760–762.

(Catalog of Federal Domestic Assistance Numbers: 84.133B, Rehabilitation Research and Training Center Program, 84.133D, Knowledge Dissemination and Utilization Program)

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Judith E. Heumann,

Assistant Secretary for Special Education and Rehabilitative Services.

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