

## DEPARTMENT OF EDUCATION

### National Institute on Disability and Rehabilitation Research; Notice of Proposed Funding Priorities for Fiscal Years (FY) 2000–2001 for Rehabilitation Research and Training Centers (RRTCs)

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

**SUMMARY:** The Assistant Secretary for the Office of Special Education and Rehabilitative Services proposes funding priorities for three Rehabilitation Research and Training Centers (RRTCs) under the National Institute on Disability and Rehabilitation Research (NIDRR) for FY 2000–2001. This notice contains proposed priorities for one RRTC related to rehabilitation for persons with long-term mental illness and two RRTCs related to independent living. The Assistant Secretary takes this action to focus research attention on areas of national need. These priorities are intended to improve rehabilitation services and outcomes for individuals with disabilities. The proposed priorities refer to NIDRR's Long Range Plan (the Plan). The plan can be accessed on the World Wide Web at: <http://www.ed.gov/legislation/FedRegister/other/1999-12/68576.htm>

**DATES:** Comments must be received on or before March 24, 2000.

**ADDRESSES:** All comments concerning these proposed priorities should be addressed to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, S.W., room 3414, Switzer Building, Washington, D.C. 20202–2645. Comments may also be sent through the Internet: [Donna\\_Nangle@ed.gov](mailto:Donna_Nangle@ed.gov)

You must include the term "Disability and Rehabilitation Research Projects and Centers" in the subject line of your electronic message.

**FOR FURTHER INFORMATION CONTACT:** Donna Nangle. Telephone: (202) 205–5880. Individuals who use a telecommunications device for the deaf (TDD) may call the TDD number at (202) 205–4475. Internet: [Donna\\_Nangle@ed.gov](mailto:Donna_Nangle@ed.gov)

Individuals with disabilities may obtain this document in an alternate format (e.g., Braille, large print, audiotope, or computer diskette) on request to the contact person listed in the preceding paragraph.

#### SUPPLEMENTARY INFORMATION:

#### Invitation To Comment

We invite you to submit comments regarding these proposed priorities.

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

During and after the comment period, you may inspect all public comments about this priority in room 3414, Switzer Building, 330 C Street, SW., Washington, DC, between the hours of 9 a.m. and 4:30 p.m., Eastern time, Monday through Friday of each week except Federal holidays.

#### Assistance to Individuals With Disabilities in Reviewing the Rulemaking Record

On request, we will supply an appropriate aid, such as a reader or print magnifier, to an individual with a disability who needs assistance to review the comments or other documents in the public rulemaking record for these proposed priorities. If you want to schedule an appointment for this type of aid, you may call (202) 205–8113 or (202) 260–9895. If you use a TDD, you may call the Federal Information Relay Service at 1–800–877–8339.

These proposed priorities support the National Education Goal that calls for every adult American to possess the skills necessary to compete in a global economy.

The authority for the Secretary to establish research priorities by reserving funds to support particular research activities is contained in sections 202(g) and 204 of the Rehabilitation Act of 1973, as amended (29 U.S.C. 762(g) and 764). Regulations governing this program are found in 34 CFR part 350.

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

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

#### Rehabilitation Research and Training Centers

The authority for the RRTC program is contained in section 204(b)(2) of the Rehabilitation Act of 1973, as amended (29 U.S.C. 764(b)(2)). 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 Assistant 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.

#### Description of Rehabilitation Research and Training Centers

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, integrated, 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.

RRTCs disseminate materials in alternate formats to ensure that they are accessible to individuals with a range of disabling conditions.

NIDRR encourages all Centers to involve individuals with disabilities and individuals from minority backgrounds as recipients of research training, as well as clinical training.

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.

### **Proposed Priority 1: Long-term Mental Illness**

#### *Background*

The Surgeon General estimates that approximately 20 percent of the U.S. population experience a mental disorder in any given year, that 9 percent of the adult population have a diagnosable major mental illness, and that a subpopulation of 5.4 percent of the population is considered to have a significant mental illness (Kessler, *et al.* 1994, 1996). The costs to society of mental illness are substantial. The indirect costs of mental illness in 1990, stemming from lost productivity at work, school, or home, were estimated at \$78.6 billion (Rice and Miller, 1996). As the population grows, the needs of a growing number of individuals with a significant mental illness are not being met. Only one in four adults with a diagnosable mental disorder receives treatment and one third of children and adolescents needing mental health services are treated (Manderscheid & Henderson, 1998). The lives of individuals with long-term mental illnesses are complicated by inadequate community resources, lack of access to new medications and psychosocial treatments, unemployment, and lack of options for long-term care. Many individuals also experience homelessness, family disruptions, chronic medical conditions, alcohol and substance abuse, incarceration, and

social isolation, as well as the potential for periodic exacerbation.

Quality is an important factor in the delivery of effective mental health services. Defining quality services is not an easy task, nor is there ready consensus on all components of the concept. The Institute of Medicine states that quality of services is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (Marder, 1999). However, measuring the quality of services provided to individuals with significant mental illness, as well as measuring outcomes, present numerous challenges because of the periodic and chronic nature of the illness, and the ongoing need for intensive therapeutic services and long-term support. Practitioners, policy makers, and consumers continue to ask questions about how to adequately meet the multifaceted needs of individuals with significant mental illness.

Generally, family members and consumers want community-based support services and treatment programs that are accessible and designed to meet long-term needs. The potential for individuals with serious mental illness to be maintained in the community rather than in institutions, work productively, live independently, and participate in rehabilitation planning is increased when a comprehensive support system is available in community settings. Research on consumer participation and community-based programs has provided evidence that there is a positive relationship between the level of consumer participation and therapeutic outcomes (Kent & Read, 1998).

Proponents of community-based service programs and support systems long have advocated that consumers be empowered to participate in the decisionmaking process. However, one reason individuals with disabilities have limited opportunities to participate in decisions about their services are related to the lack of consensus on a definition for self-determination. Self-determination is defined and implemented differently (Ward, 1999) depending on the program, philosophy, and purposes for implementing a self-determination model. However, there are some common concepts in the definitions for self-determination; NIDRR includes factors such as consumer control, choice, self-direction, empowerment, leadership, and self-advocacy (Ward & Roger, 1999) as potential elements of self-direction.

While most mental health professionals support the concept of self-determination, not all agree that individuals with psychiatric disabilities should have control over or participate in planning and decisionmaking activities (Kent & Read, 1998).

Individuals with psychiatric disabilities are not yet full participants in the disability self-determination movement. It is widely alleged that professionals in the psychiatric disabilities community continue to use medical compliance as a control mechanism and as a determining factor for awarding patients certain privileges. The right to choose among treatment options is often regarded as a privilege that is earned through medical compliance (Chamberlain & Powers, 1999).

Obstacles to the development and implementation of self-determination efforts include controversy over whether severe mental illness is a lifelong process or whether recovery is possible. Some discussants of this issue suggest that the need for extensive, lifelong support and the severity of the illness preclude using a self-determination approach. In addition, the impact of self-determination approaches on quality of services are unknown. Methodologies, indicators, and standards for measuring quality of care within self-determination models would facilitate understanding the impact of this approach on rehabilitation outcomes. In particular, research that addresses questions about the ability of individuals with serious mental illnesses to make decisions about treatment and medication management is lacking. Traditionally, program planning and treatment decisions in the mental health field have been made by clinicians, and often involve maintaining patients on medication without consumer input or choice.

Policies and service systems tend to be based on a paternalistic model that restricts consumer control and input. However, there is evidence that consumer and family involvement in decisionmaking and program planning have the potential to foster higher quality services and responsiveness from providers. The effectiveness service models incorporating self-determination and their relationship to rehabilitation outcomes has not been evaluated. There has not been adequate study of the impact of elements of self-determination models on the rehabilitation process. Similarly, there have not been adequate studies of the impact of the various components of self-determination models on the rehabilitation process.

Better understanding of the implications of self-determination for rehabilitation outcomes potentially will answer questions related to competency, patient rights, recovery, outcomes, and policies. Research addressing these issues, describing standards for quality, and establishing outcome measures for consumer driven decisions is lacking in the research literature. Studies evaluating self-determination will potentially further the understanding of the rehabilitation process for individuals with significant mental illness, and identify strengths, weaknesses, and needed improvements in the existing models.

The Plan emphasizes the importance of independent living and community integration. Central to independent living is the recognition that each individual has a right to independence that comes from exercising maximal control over his or her life. These activities include making decisions involved in managing one's own life, sustaining the ability and opportunity to make choices in performing everyday activities, and minimizing physical and psychological dependence on others. Independent living is a concept that also emphasizes participation and equity in the right to share in the opportunities, risks, and rewards available to all citizens.

#### **Proposed Priority 1: Improving Service and Supports for Individuals with Long-Term Mental Illness**

The Assistant Secretary, in collaboration with the Substance Abuse and Mental Health Services Administration and the Center for Mental Health Services, proposes to establish an RRTC for the purpose of improving services and supports for individuals with long-term mental illness. In carrying out these purposes, the Center must:

- (1) Develop measures that can be applied to evaluate self-determination activities in terms of rehabilitation outcomes, quality of services, and availability of community resources;
- (2) Identify and assess self-determination direction theories, models, and activities, as well as the barriers to participation in self-determination activities for individuals with disabilities;
- (3) Develop and evaluate management tools to enable service providers to support self-determination;
- (4) Develop, conduct, and evaluate, training on self-determination and consumer choice to improve understanding and support of self-determination; and

(5) Assess policies of service providers and payers in terms of their implications for fostering or impeding self-determination, and identify strategies for policy improvements.

In addition to the activities proposed by the applicant to carry out these purposes, the RRTC must:

- (1) Conduct in the third year of the grant, a state-of-the-science conference on self-determination for persons with significant and persistent mental illness and publish a comprehensive report in the fourth year of the grant; and
- (2) Address in its research the specific needs of minority populations with LTMI.

#### **Two Proposed Priorities on Independent Living**

##### *Background*

The mission of NIDRR emphasizes developing knowledge that will "improve substantially the options for disabled individuals to perform regular activities in the community, and the capacity of society to provide full opportunities and appropriate supports for its disabled the Plan, published on December 7, 1999 (64 FR 68575))." Much of NIDRR's work reflects the components of the Independent Living (IL) philosophy: consumer control, self-help, advocacy, peer relationships and peer role models, and equal access to society, programs, and activities. NIDRR has funded subject-specific RRTCs in IL since 1980 and supports other projects that incorporate principles of IL.

Most recently, NIDRR has funded one RRTC on Centers for Independent Living (CIL) management and services and a second on IL and disability policy. The last year of the five-year project period for the awards was 1999. In light of the research agenda established in the Plan, and input obtained from the Rehabilitation Services Administration (RSA) and other Federal agencies and constituents, in various meetings that addressed related themes, NIDRR has identified critical issues in independent living to be addressed at this time. There is a continuing need to fund two Centers that study independent living and community integration.

Living independently and achieving community integration to the maximum extent possible are issues at the crux of NIDRR's mission. NIDRR is committed to the creation of a theoretical framework with measurable outcomes that is based upon the experiences of individuals with disabilities. The new paradigm of disability embodied in the Plan requires analysis of the extent to which socioenvironmental factors help

or hinder individuals with disabilities in attaining full participation in society. Questions as basic as defining independent living in the context of diverse socioeconomic factors must be addressed. Current challenges to independent living derive from the changing characteristics of both the IL service system and the disability population.

Substantial administrative, advocacy, strategic and service-delivery issues affect the daily activities of Centers for Independent Living (CILs). Critical issues include funding and resource management, quality staffing, and relationships with other agencies key to the success of CILs. The issue of financial management of CILs calls for a balanced approach to identify existing policies, regulations, models, and programs that serve to hinder or help in establishing sound fiscal operation. Financial management requires expertise in fiscal analysis, budgeting, understanding grant requirements and program rules, accounting, auditing, and fundraising.

CILs, which spend substantial amounts of money on personnel, are subject to staffing problems typical of human service organizations and small businesses, including recruitment problems, training and competency development, and retention problems. Staffing problems may impede the ability of CILs to deliver individualized information and support services. An essential step in strengthening continuity in services is to recruit, train, and retain first line managers.

CILs lack documentation of the competencies required for IL management. Awareness of competency needs is key to developing successful recruitment strategies and staff development programs. For example, innovative recruitment strategies are needed to attract youth with disabilities who are transitioning from school to independent living to work in CIL service programs. Creative efforts to attract young persons entering the job market as employees could assist the CILs in understanding the needs of youth with disabilities as consumers as well. Career development, with pathways to more responsible positions in CILs, can be a key to the retention of competent staff.

CILs exist in a framework of public agencies, nonprofit organizations, and the local business sectors. The ability to form effective partnerships and cooperative working relationships with appropriate entities is essential to successful CIL operation. Historically, relationships with State Vocational Rehabilitation agencies, Statewide

Independent Living Councils, and State Consumer Advocacy Organizations have been at the heart of CIL operations and responsibilities. Recent developments in the area of employment services and entitlement benefits for individuals with disabilities pose additional challenges for CILs by introducing new actors, new clients, and new rules. Passage of the Workforce Investment Act of 1998 and the Work Incentives Improvement Act of 1999 might provide new opportunities for CILs to play a role in the process of vocational rehabilitation.

A challenge to facilitating independent living and community integration is the changing universe of disability. Demographic, social and environmental trends affect the prevalence and distribution of various types of disability as well as the demands of those disabilities on social policy and service systems. Within the universe of disabilities are: (1) changing etiologies for existing disabilities; (2) growth in segments of the population with higher prevalence rates for certain disabilities; (3) the consequences of changes in public policy and in health care services and technologies; and (4) the appearance of new disabilities.

The CILs and consumer organizations can prepare to address changing needs of diverse populations with attention to the infrastructure of resource availability and management strategy. At the same time, there is a need to frame the history and role of the independent living movement within the context of theories of society and social movements and organizational and group structure. Such a framework could identify ways to: (1) reach out to underserved populations, (2) collaborate with key organizations that might not be perceived as traditional disability advocates, and (3) recognize the role of environmental factors on successfully living independently and achieving community integration. A sound theoretical base can be drawn upon to develop policy and service-delivery models that can help maximize social participation for individuals with disabilities.

Researchers have identified an association between disabilities and poverty, especially among youth (Fujiura G et al., "Disability Among Ethnic and Racial Minorities in the United States," *Journal of Disability Policy Studies*, Vol. 9, No. 2, pgs. 112-130, 1998). The growing number of individuals aging with long-standing disabilities, as well as the increase in the population of older persons who acquire disabilities as they age, is another aspect of a changing disability population. Newer etiologies of

disability, such as HIV/AIDS, multiple chemical sensitivity and environmental illness, challenge IL concepts, services, and research. CILs and other organizations can serve as a resource to teach youth, aging persons, and underserved populations about independent living. There may be an opportunity for CILs to develop strong alliances with parent information training centers and schools (from pre-school through postsecondary programs) and with the aging and underserved populations through appropriate partnerships.

As an example of the role of demographic factors, disability has a disproportionate impact upon African Americans, Hispanic Americans, and American Indians. An array of culturally-sensitive service-delivery models, community organizations, and other resources is necessary to provide services to individuals from minority backgrounds. Organizations with grassroots orientations, including CILs, are in a unique position to help identify the specific needs of individuals from those affected populations. Model strategies in other countries might be adapted to reach unserved and underserved populations in the United States.

Physical environment, including the built environment, can pose numerous obstacles that confound living independently. Individuals with disabilities living in rural communities may be isolated from CILs and vocational rehabilitation services. Isolation resulting from distance, lack of available transportation, lack of monetary resources to support social services, limited job opportunities, lack of a health care delivery system, and unavailability of accessible and affordable housing can be problems for rural Americans. Similar problems may confront persons from minority backgrounds in inner cities and remote areas, persons who are homeless, and migrants. For all populations, and for all salient issues that affect independent living and community integration, the social and economic costs and benefits of various strategies must be evaluated.

The Plan discusses research on physical inclusion, including the identification and evaluation of models that facilitate housing that are consistent with consumer choice. In addition to physical and economic accessibility, model housing approaches must maximize community integration and ability to participate in a range of normative activities.

## **Proposed Priority 2: Improved Management of CIL Programs and Services**

The Assistant Secretary proposes to establish an RRTC on IL management, services and strategies that will conduct research and training activities and develop and evaluate model approaches to enhance the capacity of CILs to operate and manage effective advocacy and service programs and maintain effective external partnerships. In carrying out this purpose, the Center must:

(1) Develop a database of existing CIL funding and economic resources, and identify innovative and best practices in creating secure economic foundations for CILs;

(2) Working in collaboration with appropriate entities, design and test several options for generating funding from alternative sources, including business development strategies and analyze policy-related and programmatic consequences of various funding options, especially those independent of public financing;

(3) Identify best practices and develop and test programs for CILs in expanding services to youth with disabilities and their families, including those from diverse cultural backgrounds, and in interfacing with education and transition programs to prepare children and youth for independent living;

(4) Develop and test strategies to enable CILs to benefit from management models of other successful community-based organization or organizations. Develop and test innovative models of cost-effective training to improve core competency skills in geographically dispersed and culturally and linguistically diverse CIL staff, including but not limited to those from Indian tribes and tribal organizations, and evaluate strategies for improved recruitment and retention of CIL staff from diverse backgrounds;

(5) Review CIL and vocational rehabilitation agency policies related to collaborations, and design strategies for innovative partnerships to promote employment outcomes for individuals with disabilities;

(6) Coordinate activities with and provide instruments, curricula, methodologies, and resource guides, as well as research findings, including but not necessarily limited to distance learning and web-based technologies, to the RSA training and technical assistance provider under Part C of Title VII of the Rehabilitation Act; and

(7) Provide training and information for CILs, policy makers, administrators, and advocates on research findings and identified strategies.

In carrying out these purposes, the Center must coordinate with other NIDRR and OSERS grantees and community-based organizations that focus upon independent living and with the National Center for the Dissemination of Disability Research. The RRTC on improved management of CIL programs and services will be funded jointly by NIDRR and RSA and will be required to work closely with the RSA grantee providing training, technical assistance, and transition assistance to CILs and Statewide Independent Living Councils under Part C of Title VII of the Rehabilitation Act.

### **Proposed Priority 3: IL and the New Paradigm of Disability**

The Assistant Secretary proposes to establish an RRTC on IL and the New Paradigm of Disability that will facilitate the development of innovative independent living strategies to meet the challenges of the 21st century. This Center will promote an understanding of independent living concepts and practices in the context of the physical and social environments noted in the new paradigm of disability, including assessment of the application of independent living to the changing universe of disability. In carrying out these purposes, the Center must:

(1) Develop an analytical framework for research on living independently that incorporates the definition of IL, the contextual framework of disability and an accessible community, and the

changing universe of disability as articulated in the Plan, and is grounded in social science theory and methods;

(2) Identify and evaluate strategies to promote accessible cost-effective advocacy and generic community services for individuals with significant disabilities, and address specifically at least one changing universe population;

(3) Evaluate the use of peer networks and communication channels to assist individuals with disabilities to maintain wellness, access community services, and participate in community life;

(4) Assess the concept and application of independent living for diverse populations of cultural and linguistic minorities, including but not limited to those from Indian tribes and tribal organizations, and identify and evaluate culturally appropriate independent living approaches and strategies to assist individuals within these groups to attain self-determined independent living goals; and

(5) Provide training and information for CILs, policy makers, administrators, and advocates on research findings and identified strategies.

In carrying out these purposes, the project must coordinate with other NIDRR and OSERS grantees and community-based organizations that focus on independent living, the Center on Emergent Disability, the National Center for the Dissemination of Disability Research, and the RSA training and technical assistance provider under Part C of Title VII of the Rehabilitation Act.

*Applicable Program Regulations:* 34 CFR Part 350.

*Program Authority:* 29 U.S.C. 760–762.

Electronic Access to This Document.

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

Dated: February 17, 2000.

**Curtis L. Richards,**

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

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