

## DEPARTMENT OF EDUCATION

**National Institute on Disability and Rehabilitation Research; Notice of Final Funding Priorities for Fiscal Years 1998–1999 for Certain Centers and Projects**

**SUMMARY:** The Secretary announces final funding priorities for two Disability and Rehabilitation Research Projects (DRRPs) and three Rehabilitation Research and Training Centers (RRTCs) under the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years 1998–1999. The 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.

**EFFECTIVE DATE:** This priority takes effect on August 26, 1998.

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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:** This notice contains final priorities under the Disability and Rehabilitation Research Projects and Centers Program for two DRRPs related to a burn data coordinating project and collaborative research for traumatic brain injury (TBI) model systems. This notice also contains final priorities for three RRTCs related to employment opportunities for American Indians, community integration for persons with mental retardation, and policies affecting families of children with disabilities.

These final 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. 761a(g) and 762).

**Note:** This notice of final priorities does not solicit applications. A notice inviting applications was published in the **Federal Register** on July 2, 1998 (63 FR 36298).

**Analysis of Comments and Changes**

On June 8, 1998 the Secretary published in separate parts two notices of proposed priorities in the **Federal Register**. One notice included two proposed priorities related to a burn data coordinating project and collaborative research for traumatic brain injury (TBI) model systems (63 FR 31320–31321). The second notice included three proposed priorities related to employment opportunities for American Indians, community integration for persons with mental retardation, and policies affecting families of children with disabilities (63 FR 31324–313290). The Department of Education received 17 letters commenting on the notices of proposed priorities by the deadline date. Technical and other minor changes—and suggested changes the Secretary is not legally authorized to make under statutory authority—are not addressed.

**Disability and Rehabilitation Research Projects****Priority 1: Burn Data Coordinating Project**

**Comment:** Three commenters identified qualifications that applicants for the Burn Data Coordination Project should possess. The commenters suggested that applicants for the burn data coordinating project should demonstrate: an understanding of burn care, an understanding of the burn model systems database, and the ability and motivation to collaborate with the database currently being generated by the American Burn Association. In addition, the commenters suggested that applicants should have experience in the development, coordination, and management of multi-center databases and possess the technology to respond to idiosyncratic hardware and software needs and issues that each burn model system brings to the common database.

**Discussion:** An applicant's qualifications are addressed in the peer review process and evaluated on the basis of the competition's selection criteria. The qualifications identified by the commenter will be evaluated in the peer review process. It is unnecessary to include these qualifications in the priority.

**Changes:** None.

**Comment:** The Burn Data Coordinating Project should be affiliated with an institution that is currently operating a Burn Model Systems Project.

**Discussion:** NIDRR recognizes the advantages of having the Burn Data Coordination Project administered by an entity that is affiliated with an institution that is currently operating a

Burn Model Systems Project. However, NIDRR does not believe that this affiliation is a prerequisite qualification and is unwilling to limit eligible applicants to current Burn Model Systems projects.

**Changes:** None.

**Comment:** One commenter suggested that the Burn Data Coordination Project's autonomy and authority should be clearly defined, strict time frames should be required for transmission of data and other summary reports to the model systems from the data center, and the procedures that are currently being developed to use scannable forms and score certain instruments should be continued.

**Discussion:** These suggestions relate to the administration of the Burn Data Coordination Project grant and the project's relationship with the Burn Model Systems Projects. Following the awarding of the grant, NIDRR will work cooperatively with the Burn Data Coordination Project and the Burn Model Systems Projects to address and resolve these issues. It is not necessary to revise the priority in order to address these administrative matters.

**Changes:** None.

**Comment:** Clarification is needed on the requirement for the Burn Data Coordinating Project to collaborate with the Spinal Cord and TBI Model Systems data collection activities.

**Discussion:** NIDRR believes that communication between the Burn, Spinal Cord, and TBI Model Systems data collection projects may result in improved performance of their common data collection activities and could lead to mutually beneficial collaborative activities. In order to provide the project with as much discretion as possible, the priority indicates that this collaboration should be carried out "as appropriate."

**Changes:** None.

**Priority 2: Collaborative Research for Traumatic Brain Injury Model Systems**

**Comment:** The priority should be revised to address the needs of individuals in correctional facilities.

**Discussion:** An applicant could propose to address the needs of individuals with TBI in correctional facilities. The peer review process will evaluate the merits of the proposal. However, NIDRR declines to specify any particular subpopulations of research subjects.

**Changes:** None.

**Comment:** The priority should be revised to require projects to use the TBI Model Systems database.

**Discussion:** NIDRR recognizes the advantages of using the TBI model systems database and expects that a

number of applicants will propose collaborative research projects that use the database. Because there may be highly meritorious collaborative research projects that do not use the database, NIDRR declines to limit the scope of research to only those that use the database.

*Changes:* None.

*Comment:* The priority should be revised to require collaboration with more than one Model System.

*Discussion:* NIDRR recognizes the advantages of collaboration with more than one Model System. However, there may be highly meritorious research projects that involve only one Model System. NIDRR declines to require that applicants collaborate with more than one Model System in order to provide applicants with as much discretion as possible.

*Changes:* None.

*Comment:* The meaning of collaboration should be clarified.

*Discussion:* The selection criteria on collaboration (see 34 CFR 350.54(k)) provide all applicants with guidance on the meaning of collaboration for the purpose of the priority. No further guidance is necessary.

*Changes:* None.

*Comment:* Any non-Model System applicant should demonstrate equivalent levels of data quality control as achieved by the Model System.

*Discussion:* The peer review process will evaluate the merits of the research that applicants propose, including the level of data quality control. It is not necessary to revise the priority in order to address the quality of the data that applicants' propose to collect.

*Changes:* None.

*Comment:* The priority should be revised to include collaborative projects on costs of rehabilitative interventions and their relationship to the effects of those interventions.

*Discussion:* An applicant could propose to address the costs of rehabilitative interventions and their relationship to the effects of those interventions. The peer review process will evaluate the merits of the proposal. However, NIDRR has no basis for requiring all applicants to carry out this research.

*Changes:* None.

*Comment:* In the Background statement to the priority, one of the examples of the collaborative research that could be carried out under the priority is assessment and treatment of persons with mild TBI. Individuals with mild TBI are not currently captured by the Model System database. Collaborative research on this topic, though very important, would involve a

brand new effort, and one for which existing Model Systems offer no special advantages.

*Discussion:* The fact that assessment and treatment of persons with mild TBI was one of a number of examples included in the Background statement does not bind or encourage applicants to propose this research.

*Changes:* None.

*Comment:* The priority should be revised to acknowledge need for an assessment tool to measure community integration of persons with TBI.

*Discussion:* An applicant could propose to carry out research contributing to the development of these tools. The peer review process will evaluate the merits of the research. However, NIDRR has no basis for requiring all applicants to carry out this research.

*Changes:* None.

#### *Rehabilitation Research and Training Centers*

##### *Priority 1: Employment Opportunities for American Indians*

*Comment:* The fourth activity should be revised to require the RRTC to provide a technical assistance training program to counseling staff from community based service programs, American Indian Vocational Rehabilitation Projects supported under Section 130 of the Rehabilitation Act, and State VR agencies that serve American Indians.

*Discussion:* In part, the general RRTC training requirement specifies that the RRTC must provide training to persons with disabilities and their families, service providers, and other appropriate parties in accessible formats on knowledge gained from the Center's research activities. No further requirements are necessary for the RRTC to carry out the training suggested by the commenter.

*Changes:* None.

*Comment:* The priority should be expanded to include two new activities: (1) analyzing existing data to determine the specific risk factors for severe disabilities among American Indian people, and developing primary and secondary prevention strategies that address these risk factors in order to achieve long-term reduction in lifestyle risk factors that contribute to disability; and (2) developing and evaluating a model Independent Living Service program.

*Discussion:* NIDRR acknowledges the importance of the suggested activities, however, the purpose of this RRTC is to improve the employment status of American Indians with disabilities. The

suggested activities are not sufficiently related to the purpose of the RRTC to be added to the priority. Also, adding them to the priority is not feasible in light of the resources available to the RRTC.

*Changes:* None.

*Comment:* It would be interesting to assess whether American Indians with disabilities seek seasonal subsistence employment such as ricing, fishing, hunting, shepherding, and berrypicking. The priority should include culturally-specific strategies for employment such as subsistence employment.

*Discussion:* An applicant could propose to carry out research on subsistence employment. The peer review process will evaluate the merits of the research. However, NIDRR has no basis for requiring all applicants to carry out this research.

*Changes:* None.

*Discussion:* The RRTC is expected to be national in scope and address the needs of American Indians with disabilities in all parts of the country.

*Changes:* None.

##### *Priority 2: Community Integration for Persons With Mental Retardation*

*Comment:* Recreation and leisure should be included in the RRTC's efforts in studying effective and cost-beneficial approaches for community integration.

*Discussion:* An applicant could propose to integrate recreation and leisure into the research activities of the RRTC. The peer review process will evaluate the merits of the research. However, NIDRR has no basis for requiring all applicants to integrate recreation and leisure into the research activities of the RRTC.

*Changes:* None.

#### *Disability and Rehabilitation Research Projects*

Authority for Disability and Rehabilitation Research Projects (DRRPs) is contained in section 202 of the Rehabilitation Act of 1973, as amended (29 U.S.C. 761a). DRRPs carry out one or more of the following types of activities, as specified in 34 CFR 350.13–350.19: research, development, demonstration, training, dissemination, utilization, and technical assistance. Disability and Rehabilitation Research Projects develop methods, procedures, and rehabilitation technology that maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities, especially individuals with the most severe disabilities. In addition, DRRPs improve the effectiveness of services authorized

under the Rehabilitation Act of 1973, as amended.

**Priorities:** Under 34 CFR 75.105(c)(3), the Secretary gives an absolute preference to applications that meet the following priorities. The Secretary will fund under this competition only applications that meet one of these absolute priorities.

**Priority 1: Burn Data Coordinating Project**

**Background.** In 1994 NIDRR established the Burn Injury Rehabilitation Model Systems of Care (Burn Model Systems) by awarding three 36-month projects. In 1997 NIDRR reestablished the Burn Model Systems with the award of four 60-month projects. These projects develop and demonstrate a comprehensive, multidisciplinary model system of rehabilitative services for individuals with severe burns, and evaluate the efficacy of that system through the collection and analysis of uniform data on system benefits, costs, and outcomes. The projects study the course of recovery and outcomes following the delivery of a coordinated system of care including emergency care, acute care management, comprehensive inpatient rehabilitation, and long-term interdisciplinary follow-up services.

The Burn Model Systems projects serve a substantial number of patients, allowing the projects to conduct clinical research and program evaluation. In addition, the Burn Model Systems projects utilize a complex data collection and retrieval program with the capability to analyze the different system components and provide information on project effectiveness and benefits. The projects are intended to establish appropriate, uniform descriptors of rehabilitation care. Information is collected throughout the rehabilitation process. Systematic burn injury care permits long-term follow-up on the course of injury and the identification of continuing needs and results in areas such as functional outcome, health and rehabilitation services, procedures for cost-reimbursement and billing and community integration. The Burn Model Systems projects serve as regional and national models for program development and as information centers for consumers, families, and professionals.

In order to take full advantage of the data collected by individual Burn Model System projects, there is a need for a project to assist the projects in their research efforts and establish and maintain a combined database for short- and long-term outcome evaluations

(functional, health, psycho-social and vocational status measures) and financial assessments (rehabilitation, professional and hospital charges) for various burn care and injury rehabilitation strategies.

**Priority 1:** The Secretary will establish a Burn Data Coordinating Project for the purpose of maintaining a common database of burn care and injury rehabilitation information compiled by the Burn Model Systems projects supported by NIDRR. The project shall:

(1) Establish and maintain a common database through the data collection, entry, transfer, editing, quality control, issues resolution, and integration efforts of NIDRR's Burn Injury Rehabilitation Model Systems' projects;

(2) Provide technical assistance to the Burn Model Systems projects in the compilation of common data values from each Burn Injury Model System into a single quality information database for both joint and site specific management reporting, center evaluations and research analyses;

(3) Develop management reports on each Burn Injury Model System project's database-related activities and on trends that can be combined with and compared to other national data systems for evaluation of burn injury outcomes;

(4) Provide technical assistance to the Burn Model System projects in the preparation of scientific articles by providing statistical and analytical support;

(5) Provide technical assistance to the Burn Model Systems projects in the design, implementation, and analysis of specialized clinical studies that assess new burn injury rehabilitation methodologies; and

(6) Provide technical assistance to the Burn Model Systems projects in the clinical and systems analysis studies by collecting and analyzing data on patient characteristics, diagnoses, causes of injury, interventions, outcomes, and costs within a uniform standardized database.

In carrying out these purposes, the project must:

- As appropriate, collaborate with other model systems (such as spinal cord and traumatic brain injury model systems) data collection activities; and
- Link Burn Injury Model Systems, NIDRR Staff, and the project as required to facilitate database interactions and information dissemination opportunities.

**Priority 2: Collaborative Research for Traumatic Brain Injury Model Systems**

**Background.** In 1987 NIDRR funded four research and demonstration

projects to establish the Traumatic Brain Injury Model Systems of Care (TBI Model Systems) for individuals in need of comprehensive, multidisciplinary rehabilitative services. At present NIDRR supports five TBI Model Systems projects to study the course of recovery and outcomes following the delivery of a coordinated system of care including emergency care, acute neuro-trauma management, comprehensive inpatient rehabilitation, and long-term interdisciplinary follow-up services.

The TBI Model Systems projects collect and analyze uniform data from projects on system benefits, costs, and outcomes.

The TBI Model Systems projects serve a substantial number of individuals, allowing the projects to conduct clinical research and program evaluation, and maximize the potential for project replication. In addition, the systems have a complex data collection and retrieval program with the capability to analyze different system components and provide information on cost effectiveness and benefits. Information is collected throughout the rehabilitation process, permitting long-term follow-up on the course of injury, outcomes, and changes in employment status, community integration, substance abuse and family needs. The TBI Model Systems projects serve as regional and national models for program development and as information centers for consumers, families, and professionals.

On January 21, 1998, NIDRR published a notice in the **Federal Register** inviting applications to establish 10 additional TBI Model Systems projects (63 FR 3240). In conjunction with the establishment of these new TBI Model Systems projects, NIDRR is establishing collaborative research projects to broaden knowledge and encourage multi-institutional studies of outcomes, rehabilitation interventions and service delivery system innovation for individuals with traumatic brain injury. The following are examples of collaborative research topics that the proposed project could carry out: evaluation of emerging pharmacologic interventions; examination of the effects of specific type and intensity of rehabilitative treatments; aging with TBI; secondary conditions of TBI; assessment and treatment in mild traumatic brain injury; impact of environmental factors on long term outcomes; impact of substance abuse on memory; and implications of managed care on availability and type of care for persons with TBI.

**Priority 2:** The Secretary will establish collaborative research projects for the

purpose of improving the knowledge about rehabilitation outcomes in order to improve the lives of persons with TBI, their families, and caregivers. A collaborative research project shall:

(1) Investigate rehabilitation interventions or service delivery issues; and

(2) Disseminate information based on that investigation to TBI Model Systems projects and other appropriate rehabilitation settings.

In carrying out the purposes of the priority, the project must:

- Collaborate with one or more of the 17 NIDRR TBI Model Systems projects that are directed by the following individuals: (1) Dr. Thomas Novack, University of Alabama—Birmingham, AL, (205) 934-3454; (2) Dr. Karyl Hall, Santa Clara Valley Medical Center—San Jose, CA, (408) 295-9896; (3) Dr. Gale Whiteneck, Craig Hospital—Englewood, CO, (303) 789-8204; (4) Dr. Anthony Stringer, Emory University—Atlanta, GA, (404) 712-5667; (5) Dr. Mel B. Glenn, The Spaulding Rehabilitation Hospital—Boston, MA, (617) 720-6821; (6) Dr. Mitchell Rosenthal, Wayne State University/Rehabilitation Institute of Michigan—Detroit, MI, (313) 745-9769; (7) Dr. James F. Malec, Mayo Foundation—Rochester, MN, (507) 255-5199; (8) Dr. Mark Scherer, Mississippi Methodist Rehabilitation Center—Jackson, MS, (601) 364-3490; (9) Dr. Brick Johnstone, University of Missouri—Columbia, MO, (573) 882-6290; (10) Dr. Mark V. Johnston, Kessler Medical Rehabilitation Research and Education Corporation—West Orange, NJ, (973) 414-4734; (11) Dr. Flora Hammond, Charlotte-Mecklenburg Hospital Authority—Charlotte, NC, (704) 355-4300; (12) Dr. John Corrigan, Ohio State University—Columbus, OH, (614) 293-3830; (13) Dr. Randall M. Chestnut, Oregon Health Services University—Portland, OR, (503) 494-4314; (14) Dr. John Whyte, Moss Rehabilitation Research Institute—Philadelphia, PA, (215) 456-9597; (15) Dr. Walter High, Jr., The Institute for Rehabilitation and Research—Houston, TX, (713) 666-9550; (16) Dr. Jeffrey S. Kreutzer, Medical College of Virginia—Richmond, VA, (804) 828-9055; and (17) Dr. Sureyya S. Dikmen, University of Washington—Seattle, WA, (206) 685-7529; and

- Once a year, participate in the TBI Model Systems project directors' meeting.

#### *Rehabilitation Research and Training Centers*

The authority for RRTCs 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.

#### *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.

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.

*General Requirements:* The following requirements apply to these RRTCs pursuant to these absolute priorities unless noted otherwise. An applicant's proposal to fulfill these requirements will be assessed using applicable selection criteria in the peer review process:

The RRTC must provide: (1) applied research experience; (2) training on research methodology; and (3) training to persons with disabilities and their families, service providers, and other appropriate parties in accessible formats on knowledge gained from the Center's research activities.

The RRTC must develop and disseminate informational materials based on knowledge gained from the Center's research activities, and disseminate the materials to persons with disabilities, their representatives, service providers, and other interested parties.

The RRTC must involve individuals with disabilities and, if appropriate, their representatives, in planning and implementing its research, training, and dissemination activities, and in evaluating the Center.

The RRTC must conduct a state-of-the-science conference and publish a comprehensive report on the final outcomes of the conference. The report must be published in the fourth year of the grant.

*Priorities:* Under 34 CFR 75.105(c)(3), the Secretary gives an absolute preference to applications that meet the following priorities. The Secretary will fund under this competition only applications that meet one of these absolute priorities.

### Priority 1: Employment Opportunities for American Indians

**Background.** On August 1, 1997, the U.S. population of American Indians, including Alaskan Native and Aleut, was 2.3 million. This population has the highest rate of disability of any racial or ethnic group. One in three American Indians aged 15 and over reports having a disability; about one in seven reports having a "severe" disability. One in two American Indians aged 65 or over has a severe disability (U.S. Department of Commerce, Bureau of the Census, *Census Facts For Native American Month*, October, 1997). American Indians have the highest unemployment rates, the lowest family incomes, and highest percentage of people living below the poverty level (U. S. Department of Commerce, Bureau of the Census, *Current Population Reports, Special Studies Series*, P 23-189, pg. 51, July, 1995). The nation's several hundred reservations have a 50 percent average unemployment rate (Kalt, J. "Development Strategies for American Indians," *Social Policy Research Bulletin*, pg. 21, fall, 1996).

In addition, American Indians have the most severe health problems of all U.S. groups, including the shortest life expectancy and highest infant mortality rate. American Indians experience alcohol and substance abuse, sensory impairment, diabetes mellitus, learning disabilities, fetal alcohol syndrome, and accidents and injuries at alarming rates when compared to the general population (U.S. General Accounting Office, *Indian Health Service, Basic Services Mostly Available; Substance Abuse Problems Need Attention*, GAO/HRD-93-48, April, 1993). American Indians have the nation's highest school dropout rates and the lowest postsecondary attainment rates. Only 66 percent of American Indians have high school diplomas, compared to a 78 percent rate for whites and Asian-Americans (U. S. Department of Education, Office of Educational Research and Improvement, *National Assessment of Vocational Education, Final Report to Congress, Volume IV Access to Programs and Services for Special Populations*, pg. 70, July, 1994).

Although some data on employment and on disability are available, there is little specific information on employment of American Indians with disabilities. In addition, although general disability rates are available for this population, there is little information on the distribution of disability within the population. Many factors may have an impact on the employment status of, and the delivery

of, employment services to American Indians with disabilities. These factors include, but are not limited to health status, poverty, educational level, and availability of culturally relevant vocational rehabilitation services.

State vocational rehabilitation (VR) agencies provide employment services to American Indians with disabilities who meet the eligibility criteria for the Vocational Rehabilitation Services Program authorized by the Rehabilitation Act of 1973 (the Act). In 1996, VR agencies assisted approximately 1600 American Indians with disabilities to achieve an employment outcome. However, data from the Rehabilitation Services Administration (RSA) indicate that American Indians served under the program achieve employment outcomes at a lower rate compared to other populations receiving vocational rehabilitation services (*RSA Case Service Reports, RSA-911*, 1991-1996).

Geographic, cultural, language, and political factors affect the ability of State agencies to deliver services to this population, particularly those individuals residing on reservations. Approximately, one-third of American Indians live on reservations or trust lands. Most reservations have populations of less than one thousand and are located in rural areas. Many of these Indian communities are in isolated areas where poor roads and populations spread out over many miles. In addition, tribes are often sovereign political entities with specific powers of self-governance, thus affecting access to populations on reservations.

In recognition of this problem, Congress amended the Act in 1978 to authorize grants for American Indian Vocational Rehabilitation Service Projects (Section 130 Projects) to support tribal vocational rehabilitation programs. These discretionary grant projects, also administered by RSA, are awarded to the governing bodies of Indian tribes located on Federal and State reservations to provide VR services for American Indians who are individuals with disabilities residing on reservations. There are currently 39 such projects.

Nearly two-thirds of American Indians live in urban areas. Much of the urban Indian population is assimilated and dispersed throughout urban census tracts, making it difficult for Vocational Rehabilitation agencies to identify and serve this population (The National Urban Indian Policy Coalition, *Report to the White House Domestic Policy Council*, April, 1995). The lack of culturally sensitive definitions of

disability in national data collection efforts, such as the National Health Interview Survey or the Survey of Income and Program Participation, further complicates this problem.

Cultural and language barriers significantly impede delivery of employment services, including vocational rehabilitation programs. There are 557 federally recognized tribes, speaking about 200 languages and dialects. Cultural barriers affect knowledge, understanding, and acceptance of disability and contemporary medical and health practices. In addition, concepts such as self-sufficiency, self-determination and self-advocacy may have very different meanings across Indian cultures.

**Priority 1:** The Secretary will establish an RRTC to improve the employment status of American Indians with disabilities. The RRTC shall:

(1) Investigate and analyze existing data, demographic and other, relevant to disability and employment outcomes and recommend methodological improvements to enhance the usefulness and comprehensiveness of such data for the purpose of planning and evaluating employment services, including vocational rehabilitation services (as set forth in 34 CFR 361.48), for Indians with disabilities;

(2) Analyze existing employment and vocational rehabilitation service strategies for American Indians with disabilities and identify those that have produced successful employment outcomes, taking into consideration the actual employment opportunities that exist on and off the reservation, and examine how these strategies might be applied to the Section 130 Projects;

(3) Develop and evaluate model employment services, including vocational rehabilitation services, for American Indians with disabilities, incorporating best practices from the review of existing services, taking into account cultural issues and reflecting needs of American Indians on and off the reservations as well as the Section 130 Projects; and

(4) Disseminate both the recommendations for data collection improvements and the results of the evaluation of model employment services to a range of relevant audiences, using appropriate accessible formats.

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

- As appropriate, carry out separate analyses for Indians with disabilities who live on the reservation and for those who live off the reservation; and
- Collaborate with the Section 130 Projects, and coordinate with the

Rehabilitation Services Administration, the Bureau of Indian Affairs and the Indian Health Service, the RRTC on Disability Statistics, and other entities carrying out related research or training activities.

#### Priority 2: Community Integration for Persons With Mental Retardation

**Background.** Since 1965, NIDRR has supported research and demonstrations in the area of developmental disabilities, particularly in the area of mental retardation. During these years, researchers have addressed issues involving deinstitutionalization, special education, transition from school to work, supported employment and the overall supports persons with mental retardation need to live in the community.

Based on the 1994-1995 National Health Interview Survey-Disability Supplement on adults living in the general household population and surveys of people in formal residential support programs, about .78 percent or 1,250,000 of the population of the U.S. can be identified as being limited in a major life activity and having a primary or secondary condition of mental retardation. Until the Disability Supplement survey was conducted, information was not available about individuals with mental retardation who are not participants in specialized programs, but live in the community with their families or on their own.

Many persons with mental retardation and their families receive long-term services and supports through State developmental disability authorities (SDDAs) that are funded primarily by the State or Federal Medicaid program. According to the results of a recent membership survey conducted by the National Association of State Directors of Developmental Disabilities Services (NASDDS), many SDDAs are currently designing or launching large scale system change initiatives. This is due, in part, to Medicaid reforms, managed care initiatives and budget constraints. Seventy-one percent of the respondents said that cost containment is a major factor prompting system change. The initiatives differ in their specifics but share several common themes: decentralizing authority to local managing entities; shifting to less categorical budgeting; promoting greater flexibility in the purchase and provision of community services and supports; and embracing self determination to define a new relationship between the system and individuals and their families (NASDDS, *Community Services Reporter*, pg. 3, Jan, 1998).

Since 1981, the Medicaid Home and Community Based Services (HCBS) waiver has facilitated flexibility and service innovation. HCBS waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid eligible individuals in facilities such as nursing homes. The HCBS waiver program recognizes that many individuals at risk of being placed in a long-term care facility can be supported in their own homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care. Services that may be provided in HCBS waiver programs are case management, homemaker services, home health aide services, personal care services, adult day health services, habilitation, and respite care. Other services States may request include transportation and meal services. States have the flexibility to design each waiver program and select the mix of waiver services that best meet the needs of the population they wish to serve. HCBS waiver services may be provided statewide or may be limited to specific geographic subdivisions.

However, in the last several years, States have attempted to contain Medicaid spending through the application of managed care approaches. Long-term care services, including Medicaid-funded intermediate care facilities for persons with mental retardation and HCBS waiver services for persons with mental retardation, account for 35 percent of all Medicaid spending. Programs serving persons with mental retardation are not likely to be exempt from these cost containment measures (Center on Human Policy, *Information Package on Managed Care and Long-term Supports for People with Developmental Disabilities*, pg. 3, June, 1997).

There is little information available on the use and outcomes of managed care practices in providing long-term supports to persons with mental retardation. Currently, States are implementing various models to consolidate health and long-term care services under one managed care organization. This approach is intended to be cost-effective and improve service coordination. Under some of these models, support networks for persons with mental retardation that now stand alone, could become subspecialty branches of larger care delivery systems (Ashbaugh, J. and Smith, G., "MCARE Policy Brief," *Integration of Health and Long-term Care Services: A Cure in Search of and Illness*, No. 1, pg. 12, 1997). Some observers have voiced concern that the use of consolidated

models may lead to reduced funding for services. Organizations representing persons with mental retardation have proposed integrated models that combine under a single umbrella organization, health and long-term supports in a configuration uniquely suitable for this population.

Emerging practice suggests that people with mental retardation should play leading roles in determining the substance of their lives and that services should be developed as needed to support their preferences. For example, some current service delivery models may provide new options for individuals and their families to self manage their chosen services through vouchers, individual budgets or cash. The field is moving past traditional service delivery approaches to become more responsive to the demands of service recipients and to promote self determined lifestyles. Services developed around the specific needs and choices of an individual may produce better outcomes and cost savings.

There are a number of emerging models for system redesign. Participant driven managed supports refer to a variety of strategies for administering systems to increase their effectiveness and efficiency, while maintaining a commitment to community integration and self determination (Agosta, J., et al., "MCARE Policy Brief," *Developmental Disability Services at the Century's End: Facing the Challenges Ahead*, No. 2, pg. 4, 1997). The consumer managed care approach assumes that consumers with limited budgets will spend more prudently in order to get the most value for their money and increase their use of natural supports in lieu of public supports. Accordingly, consumer choice will spawn a competitive market economy where those providers representing the most value to all consumers will survive (Smith, G. and Ashhbaugh, J., *Managed Care and People with Developmental Disabilities: A Guidebook*, pg. 8, 1996).

Coupled with States' efforts toward containment of long-term care costs, most States have long waiting lists for services. Waiting lists are expected to grow in the future due to increased longevity and higher expectations of families. After examining state-by-state data regarding the status of requests for residential, day care, vocational and other community support services, a 1997 Arc study found that 218,000 requests for community based support services remained unanswered. In addition to individuals living in institutions and nursing homes, these waiting lists include students exiting

from special education programs and individuals living at home with caregivers. There is a need to understand the methods and procedures that States are using to provide community based services, as well as to identify ways in which service systems can be redesigned to better respond to the needs of persons with mental retardation and their families.

Residential direct care providers (e.g., group home staff members, foster family members, roommates in supported living arrangements) are the primary providers of support, training, supervision and personal assistance to persons with mental retardation in home and community settings (Larson, S. A., et al., "Residential Services Personnel," *Challenges for a Service System in Transition*, pg. 313, 1994). In community residential settings, there have been few attempts to study the effects of staff orientation and in-service training programs on important outcomes for persons with mental retardation as well as on direct service personnel (Larson, S. A., *ibid.*, pg. 326). As the service delivery system changes, training for these providers will be essential. In addition, it will be important to determine what training efforts contribute to the desired outcomes of fuller community participation and autonomy for persons with mental retardation.

**Priority 2:** The Secretary will establish an RRTC to improve community integration outcomes for individuals with mental retardation. The RRTC shall:

(1) Investigate effective and cost-beneficial approaches to assist families to support members with mental retardation at home, or in homes of their own;

(2) Describe and analyze efforts to redesign policy and services in selected state systems serving persons with mental retardation and their families;

(3) Identify and analyze State policies and practices in the management of Medicaid resources that foster or impede access to supports and services;

(4) Identify and analyze policies that foster or impede (e.g., result in individuals being placed on waiting lists for community-based services) the full participation and integration of persons with mental retardation into their communities;

(5) Analyze the outcomes of the implementation of consumer-controlled services, personal assistance, and individual control-of-service purchasing in areas of quality of life and cost effectiveness; and

(6) Identify outcomes of training for residential direct care providers and the

long-term costs and benefits of specific training strategies.

In carrying out the purposes of the priority, the RRTC must coordinate with research and demonstration activities sponsored by the Health Care Financing Administration, the Administration on Developmental Disabilities, the Office of Disability, Aging, and Long-term Care Policy in the Department of Health and Human Services, and other entities carrying out related research or training activities.

#### Priority 3: Policies Affecting Families of Children With Disabilities

**Background.** The 1992 National Health Interview Survey (NHIS) estimates that 4 million children and adolescents, or 6.1 percent of the U.S. population under 18 years of age, have disabilities. The NHIS broadly defines disability to include any limitation in activity due to a chronic health condition or impairment. Among children under age five, 2 percent are limited in play activities and among children 5-17, 5.5 percent have school related disabilities. In addition, the NHIS estimates that 3.8 million families, or 5.5 percent of all families, contain one or more children with disabilities.

Families of children with disabilities must interact with at least three large service systems: health care, human and social services, and educational systems. It is often difficult to assess the impact of policies, service systems, and service delivery practices because the organizational structures and the services provided under the auspices of public and private institutions vary. The integration and coordination of these systems can be inferred from the patterns of interagency relationships involving client referrals, information flows and resource exchanges (Morrissey, J. P., et al., "Methods for System-Level Evaluations of Child Mental Health Service Networks" *Outcomes for Children and Youth with Behavioral and Emotional Disorders and Their Families: Programs and Evaluation Best Practices*, pg. 299, 1998). For the purposes of this priority, the policies affecting families of children with disabilities include, but are not limited to, those in the areas of health care (including mental health), human and social services (including legal systems such as juvenile services), and public and private education.

Families who have children with disabilities often need assistance with accessing and financing services, information about caring for their child, support from other families, community based respite care, and case management services. Case management

services are intended to ensure that services are delivered in an effective and efficient manner. Numerous models of case management currently exist. However, there is little extant research on the effectiveness, either at the family or system level, of case management services for families who have children with disabilities.

Numerous methodological problems limit the study of the complex service systems surrounding children with disabilities and their families. Current methods of measuring service coordination and examining roles in service delivery systems are not structured to assess the needs of children and their families (Koren, P. E., et al., "Service Coordination in Children's Mental Health: An Empirical Study from the Caregivers Perspective," *Journal of Emotional and Behavioral Disorders*, 5(3), pg. 164, 1997). Measurement issues become even more complex when the focus of a study moves from the individual and family level to the State and local service system level or when policy analysis is required. There is currently a shortage of methods for assessing the interrelationship between Federal, State, and local policy, service systems, and outcomes for families of children with disabilities. The limited availability of data and methodological tools needed for scientific measurement of the impact of systemic and policy reforms on families of children with disabilities serves as a barrier to increasing our understanding of the relationship between policy and outcomes. Recent major changes in Federal policies for social services, child care, family preservation and support services, and related educational and health care services may be having profound impacts upon these families.

Changes at the Federal level may be having an impact at the State and local level. However, little is known or documented about the effects of Federal policy changes on State and local service systems and families of children with disabilities.

Under new Federal and State legislation, States have more flexibility to administer human service programs. Policymakers and legislators have new opportunities to shape integrated and flexible programs to better serve the needs of families and their children with and without disabilities. Some States are experimenting with a decategorization of State and Federal funding streams so that local communities can reshape their service systems through the use of vouchers. Some State and local agencies are conducting demonstrations of family



support programs that decentralize public services for families of children with disabilities.

The impact of devolution from a system with authority at the Federal level and management of public services at the State level, to a system of both authority and management at the local level has not been documented. Information is needed on these practices and other interventions, the family benefits associated with these policies and practices, and the consequences of practice and policy change in order to facilitate implementation of policies and programs that are sensitive to the needs of families of children with disabilities and to promote effective models of care for families of children with disabilities.

In addition to policy changes in the social services arena, health care systems are changing rapidly the way they provide services to consumers. Families of children with disabilities, and the health care providers that serve them, are facing many challenges that differ from the coverage and access issues that are present for the general population. Even families of children with disabilities that use few medical services often require special knowledge or accommodations when they do access the health care system. Many States have little or no experience in assuring that their health care providers meet the specialized needs of families of children who have disabilities. These challenges are further complicated by the high cost of services for children with disabilities.

Among children enrolled in Medicaid, the average per-person health care costs in 1992 were seven times higher for disabled than nondisabled children. Compared with nondisabled children in the general population, some disabled children use twice as many physician visits and five times as many ancillary services, such as physical therapy. Under current policies and practices, the potential exists to use medical necessity standards to prevent disabled children from receiving therapy or equipment when they need it to maintain existing levels of functioning (U.S. General Accounting Office, *Medicaid Managed Care: Serving the Disabled Challenges States Programs*, (GAO/HEHS Publication No. 96-136) pg. 16, 1996). Research is needed on health care policies and service delivery practices in order to develop long-term strategies to remove service delivery barriers that exist in the health care system and to facilitate establishment of policies that support access to services for families of children with disabilities.

Frequently, children with disabilities who are participating in special education programs and their families have needs that are addressed by health care or social service agencies. As public schools' regular and special education programs restructure, opportunities may arise to expand successful service delivery strategies and develop new ones to fill in existing gaps in the service delivery systems. The development of integrated, community-based services for children with disabilities and their families is an essential component of this reform effort (Duchnowski, A. J., et al., "Integrated and Collaborative Community Services in Exceptional Student Education," *Special Education Practice: Applying the Knowledge, Affirming the Values and Creating the Future*, pgs. 177-188, 1997).

Many communities have begun initiatives to create more responsive family-centered service delivery systems. Mechanisms for interagency coordination at the State and local levels are necessary to ensure optimal service delivery conditions. Service coordination should involve linkages between education agencies, health care systems, and social services systems. In addition, due to the changing demographics of society, little is known about the influence of culture, ethnicity and socioeconomic on how families seek and receive services for their children with disabilities.

Basic information sharing, coordination and collaboration between agencies that provide services to families of children with disabilities is limited. There is a need to evaluate current best practices in service delivery coordination and collaboration, develop a methodology for analyzing collaboration among agencies, establish principles for coordination and collaboration, and develop performance indicators that foster partnerships.

**Priority 3:** The Secretary will establish an RRTC to assess the impact of policies on service delivery and outcomes for families of children with disabilities. The RRTC shall:

(1) Develop an analytical framework, including tools for assessing: family characteristics and policies, structure of service systems, service delivery processes, interagency coordination and collaboration, and outcomes for families with disabled children;

(2) Using the methodology developed above, determine the effectiveness of specific policies, implementation strategies, service delivery procedures, and coordination practices in meeting the needs of families of children with disabilities;

(3) Identify the impact of specific characteristics of interagency collaboration and coordination on families of children with disabilities; and

(4) Assess the impact of specific policies on access to services of families from diverse cultural, linguistic, ethnic and socioeconomic backgrounds.

In carrying out these purposes, the RRTC must:

- Disseminate materials and coordinate research and training activities with the Maternal and Child Health Bureau, the Administration on Developmental Disabilities, the Office of Policy and Planning in the Department of Health and Human Services, the Office of Special Education, the Federal Interagency Coordinating Council, and other entities carrying out related research or training activities; and
- Establish practical statistical methodologies and measurement tools that specifically assess the policies affecting families of children with disabilities.

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