

Rehabilitation Research and Training Centers (RRTCs)

RESEARCH THAT IMPACTS THE LIVES OF AMERICANS WITH DISABILITIES

RRTC Highlights of Accomplishments



**RRTCs ARE FUNDED BY GRANTS FROM THE
NATIONAL INSTITUTE ON DISABILITY
AND REHABILITATION RESEARCH (NIDRR)**

**OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES
U.S. DEPARTMENT OF EDUCATION**

Overview

The National Institute on Disability and Rehabilitation Research (NIDRR) has been funding Rehabilitation Research and Training Centers (RRTCs) since its inception. RRTCs are centers of excellence that are national and regional resources for individuals with disabilities, their family members and advocates, as well as for providers.

The network of NIDRR's Rehabilitation Research and Training Centers represent the flagships of this nation's investment in disability and rehabilitation research. Over the past 25 years, the investment in these programs has produced significant new knowledge that has:

- impacted the lives of people with disabilities and expanded our understanding of the nature and experience of disabilities;
- led to the creation of whole new service systems, created and disseminated new programs of services and support at the local level;
- discovered and empirically validated new treatment techniques;
- trained a large cadre of new researchers, policymakers and practitioners; and
- contributed to the efforts of people with disabilities to improve their own lives and communities.

RRTCs conduct programs of research targeted toward improving rehabilitation service delivery, increasing our understanding of disabling conditions, and facilitating the social and economic independence of individuals with disabilities. In addition, RRTCs provide graduate, pre-service, and in-service training, laying the groundwork for increasing the infrastructure of rehabilitation personnel as both service providers and researchers.

In addition, RRTCs recognize research results that remain “on the shelf” do not produce benefits for a wide range of Americans in need. Therefore, RRTCs serve as active information and technical assistance resources to service providers, as well as to the full network of those who advocate for individuals with disabilities. The RRTC concept is unique among federal agencies that fund health services research as they thematically integrate research, training, dissemination, technical assistance, and utilization. The size of the grants, the scope of work, and the five-year time frame allow centers to accomplish three

About this Publication

Our purpose is to highlight selected achievements of NIDRR's RRTCs that demonstrate the variety of ways RRTC program activities are making a difference in meeting the real-world needs of persons with disabilities. This is accomplished by carefully planning and implementing high quality research designs and systematically disseminating research-based applications to those that can most benefit from them. This publication outlines the RRTCs pursuit of excellence by moving science into services for Americans with disabilities.

significant aims.

First, building capacity. The RRTC approach allows us to recruit and retain researchers at various stages in their careers, ranging from newly-minted graduates to established health care researchers making a change in research interests. With the assurance of comparatively long-term funding, people are more likely to be willing to relocate and commit to rehabilitation/disability research.

Second, developing and exploring new research topics in the disability arena. Seeking the answers to research questions invariably leads to new research questions that could not have been foreseen at the start of a project. The five-year period gives RRTCs the opportunity to explore and answer some of these second-generation questions right away, instead of waiting two or three years for additional funding. In addition, this allows RRTCs to do the preliminary studies that are critical to the development of sophisticated research that will increase the evidence-based foundation of rehabilitation services and our knowledge of disability.

Third, training and technical assistance. By directly integrating training into research, RRTCs are far in advance of other programs, which fund “translating research into practice” separately. NIDRR’s RRTC approach does not build in a lag time of years between research findings and application. The RRTCs include consumer and provider training from the very start of projects and research is immediately translated from “the bench” to practice.

This report highlights selected impacts and benefits of research sponsored by NIDRR’s RRTC program, the place of RRTCs in NIDRR’s portfolio and the nation’s current commitment to addressing issues of importance to people with disabilities.

RRTC Program of Research

RRTCs pursue programmatic research that produces:

- Data that enlightens us about needs, status, effects, and changes in consequences of disabilities and informs-public policy and decision making;
- Cumulative knowledge and guidance on ways to meet individual, family, community, and social effects resulting from disability; and
- Instrumentation and practices useful with individuals and systems-that-can affect the consequences of disabilities.

Highlights of Selected Outcomes

In responding to the needs of individuals with disabilities, RRTCs have addressed critical practical and theoretical issues. Examples of selected outcomes of the RRTC's research program are summarized and itemized, in terms of six questions that Corrigan (1994) suggests as the basis for quality of life decisions often raised by people with disabilities.

How Long Will I Live?

RRTCs have:

- Designed, evaluated, and refined a health promotion program for people with disabilities that has, to date, been replicated in 16 states.
- Designed the first program for persons with spinal cord injury that includes proper combination of diet, exercise, and behavioral modification techniques proving successful for weight loss and subsequent improved health outcomes.
- Focused national policy expertise on far-ranging specific issues and recommendations for meeting the health-related needs of individuals with disabilities.
- Developed a comprehensive community-based health promotion program for adults with developmental disabilities in response to research showing this audience experiences health challenges including earlier aging, high incidence of obesity, and low fitness levels, and limited use of health screenings.
- Established that people who have survived a traumatic brain injury experience a high incidence of endocrine problems, concomitant depression, and anxiety disorders.
- Created a drug prevention program for school-aged youth in special education programs in the public schools.
- Conducted state-of-the-art webcasts on health and wellness practices and resources targeted expressly to the needs of people with disabilities.
- Developed training curricula for healthcare professionals to use in meeting the health and wellness needs of teenagers with disabilities.

- Developed a Web-based interactive outreach program for people with disabilities to promote physical activity.
- Demonstrated an effective stress management program that reduces psychological and health status concerns of people with rheumatoid arthritis and identified associated effective pain management strategies that reduce pain and improve function.
- Produced research findings that document several barriers to access to healthcare and its consequences among people with arthritis.
- Produced research findings showing positive effects of exercise for people with arthritis and developed a corresponding model for a community exercise center supporting physical fitness of people with arthritis.
- Conducted one of the only studies of the use by people with mental illness of alternative and complementary medicine.

What Will I Live On?

RRTCs have:

- Collaborated in analyzing the experiences of over 100,000 individuals in moving from short-term disability status, to long-term disability status, to Social Security Disability Insurance benefit receipt.
- Conducted the first research examining the experience of people with disabilities under HMO and fee-for-service medical insurance plans. This research showed that people in managed care plans have lower access to care and equipment but that access to preventive care is slightly better in managed care plans. Regardless of payer type, access to specialty care, therapy, and Durable Medical Equipment (DME) is much lower than for people without disabilities.
- Developed a set of predictors of vocational outcomes for persons with psychiatric disabilities used by the U.S. Social Security Administration to revise its evaluation procedures with persons with psychiatric disabilities.
- Developed a model for small, rural communities to identify and provide vocational supports needed by youth with disabilities in successfully transitioning from school to community life including community-based employment.

What Will I Live On?
continued

-
- Developed a dynamic model of Social Security Disability Insurance (SSDI) application following the onset of a disability that shows the importance of employer accommodation on workplace retention.
 - Established that economic resources play a much stronger role in hindering or encouraging participation in social-recreational life for people with traumatic brain injuries than for others without an injury.
 - Aggregated and customized Current Population Survey (CPS) and National Health Interview Survey (NHIS) data for use by researchers and advocates in tracking the employment and economic well-being of people with disabilities.
 - Developed a Web-based entrepreneurs' resource, "Next Level," to facilitate use of self employment models by people with disabilities.
 - Convened a national audience of experts in a state-of-the-science conference to build consensus regarding the facilitation of employment for people with substance abuse and co-existing disabilities.

Where Will I Live?

RRTCs have:

- Produced the first national estimate of the extent of caregiving provided to Americans living in the community – 57 hours of help per week on average. Approximately 85 percent of this help is provided by family members and half of those receiving help are non-elderly.
- Produced the first national estimate of unmet need for caregiving help of Americans with over one million adults needing caregiving help than receive it.
- Developed the concept of supported employment, which served the U.S. Department of Health and Human Services' efforts in implementing the U.S. Supreme Court's Olmstead Decision.
- Conducted the first longitudinal study providing systematic descriptions of children with serious emotional disturbances and their families served by the public mental health system.

-
- Conducted research indicating that approximately 60 percent of U.S. counties are served by a Center for Independent Living (CIL); provision of universal access services in the remaining 40 percent of primarily rural counties would cost an additional \$71.5 million.
 - Conducted the first study of personal assistance services among working age and older adults indicating that 13.2 million people receive 21.5 billion hours of help per year, valued at over \$200 billion.
 - Encouraged change in the common practice of limiting parent-child contact as a behavior management technique in residential treatment facilities, and facilitated changes in the 2003 Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards prohibiting group punishments and requiring individualization of behavior management techniques.
 - Facilitated development of more than 75 issues of The Institutes on Rehabilitation Issues to assist a variety of rehabilitation professionals in dealing with a wide range of emerging issues and concerns of national significance. It is estimated that over 100,000 copies have been printed and have been used in training more than 300,000 people.
 - Conducted a longitudinal study of adults with developmental disabilities in nursing homes and discovered long-term health, adaptive behavior, and community integration benefits of transitioning out of nursing homes into community settings.
 - Promoted relaxation of Medicaid regulations to allow personal use assistance services outside the home from all family members except spouses or parents of dependent children, with non-physician referral.
 - Developed and demonstrated viability of a rural transportation voucher model that has been adopted by the State of Arkansas for demonstration use in the Mississippi Delta region. It is also being used by the Rehabilitation Services Administration (RSA) as a model in ten additional states.
 - Fostered mentorship through development and implementation of programs to bring under-represented university student groups into research professions by facilitating scholarships and admissions into doctoral programs, employment on university-based research project staffs, nurturing the development of relationships with statewide advocacy and support
-

organization leaders, and planning and achieving career path objectives in the research field.

- Validated a protocol instrument that facilitates vocational planning for people with severe brain injuries by combining information regarding medical, psychological, social, personal, and vocational readiness dimensions in community-based rehabilitation program settings.
- Collaborated with the American Association on Mental Retardation to develop a new operational definition of mental retardation emphasizing the individual's need for assistance/supports rather than functional deficits.
- Developed an accessible Independent Living Management resource database containing operational management documents, policies and procedures, job descriptions and resources for Independent Living Center directors and managers.

What Will I Do?

RRTCs have:

- Analyzed data that suggests during the 1990s people with disabilities' employment opportunities improved – faring especially well in growth industries and in larger businesses more able to offer accommodations under the Americans with Disabilities Act. At the same time, however, the proportion of Americans with disabilities who could not work went up. And the overall employment rate remained unchanged.
- Demonstrated a strong positive relationship between postsecondary education and employment for persons with disabilities; for example, only 15.6 percent of persons with disabilities with less than a high school diploma participate in the labor force while 50.3 percent of those completing four years of college are employed.
- Provided data to policymakers and advocates resulting in the 1998 change in Medicaid regulations that expanded access to Medicaid funds for supported employment services, and the change in vocational rehabilitation regulations that eliminate extended employment as a Status 26 Closure.
- Documented significant incidence of “hidden” brain injury in the U.S. population, with strong implications for addressing problems of

underachieving schoolchildren, individuals in substance abuse programs who also are challenged by brain injuries, and for other groups where an unidentified injury to the brain may be leading to unnecessary social failure. In response, the RRTC designed and is validating a screening instrument to detect hidden brain injury in children and in adult populations.

- Compared the efficacy of supported and sheltered employment options for persons with disabilities, resulting in significant shifts in national disability policies, including discontinuation of extended sheltered employment as an approved employment outcome by the Rehabilitation Services Administration.
- Pioneered development of the concept of supported employment that in the last 20 years has served millions of Americans with severe disabilities, as well as those in over 30 countries around the world.
- Pioneered development of the first U.S. employment-related program to serve the needs of individuals with alcohol, drug, and/or mental health concerns, as well as a severe co-existing disability.
- Developed and validated a protocol to integrate medical, psychological, social, personal, and vocational planning with individuals who have sustained severe brain injuries, which is now in wide use in non-profit, community-based rehabilitation programs across the United States.
- Implemented school-wide systems of behavioral support in more than 250 schools in two states.
- Demonstrated that approximately 25 percent of all state general vocational rehabilitation consumers experience significant problems with alcohol or drug dependency.
- Designed and developed a tool for those searching for research-based information about disability on the Internet through its “eResearch: Finding and Evaluating Internet-Based Information.”
- Developed and implemented a distance learning system that reaches direct service personnel in 8,000 community-based rehabilitation programs across America.

What Will I Do?
continued

-
- Produced research results that reliably define how people with significant disabilities achieve supported and non-supported employment type outcomes.
 - Initiated the first Web-based National Directory of Community-based Rehabilitation Providers to establish search and access capabilities for individuals and families seeking community-based rehabilitation and employment outcomes.
 - Developed and evaluated “best practice” models of community-based rehabilitation programs for people with severe traumatic brain injuries and psychiatric disabilities.
 - Consulted with the President’s New Freedom Commission on Mental Health to prepare a series of briefings for Commission members on employment of people with mental illness and advised the Commission on a variety of policy recommendations that will be included in the Commission’s official report to President Bush.
 - Gathered, analyzed, and shared data to facilitate program development, refinement, and policy adjustment at the national level in a variety of areas including children’s mental health and family-related issues.
 - Designed and maintained a Web site featured in Parents magazine that highlights research-based information on children’s mental health issues.
 - Conceptualized, researched, and disseminated one of the first holistic models to understand how people with severe mental illness recover and go on to lead productive lives.
 - Completed one of the only studies of persons with mental illness who are employed as managers and professionals, suggesting that individuals with severe mental illness can and do hold higher level jobs than than previously thought.
 - Developed a tailored curriculum to address needs after identifying high levels of cigarette smoking among students in special education and finding a similar circumstance among adults with disabilities.
 - Assisted policy makers, researchers, disability advocates and other services providers through conferences and analysis of large databases to understand the low employment rate for people with disabilities and its implications.

Whom Will I Love?

RRTCs have:

- Prompted state-level legislation and policy to reduce custody relinquishment issues created when insurance coverage fails to pay for intensive services needed by families with a child with a severe emotional, behavioral, or mental health disorder.
- Developed an assessment tool to measure quality of life experienced by people with disabilities that allows each measured person's values and preferences to define what is a "good" life, rather than assuming that an outsider – such as a researcher – can define goodness on their behalf.
- Developed a model program in which 'veterans' of disability provide mentoring to peers who are 'newer' to disability. As strong benefits were demonstrated – both for those providing and those receiving mentoring – the program is now being exported to other areas of the U.S. through technical assistance.
- Designed and tested an assistive technology/environmental intervention program for adults with developmental disabilities to improve long-term community living and participation outcomes.
- Developed informational materials addressing reproductive healthcare disparities, issues, and access of women with disabilities.
- Developed tools to aid parents, service providers, and professionals in analyzing the efficacy of policies and programs to meet needs in terms of quality of family life; parameters of family, provider, and professional partnerships; and core concepts of disability policy affecting families.

How Much Choice Will I Have?

RRTCs have:

- Produced findings showing that some 6.7 million Americans have a mental health disability, the third ranking cause of disability in America following musculoskeletal and circulatory disorders.

**How Much Choice
Will I Have?**
continued

-
- Conducted longitudinal studies to better understand career attainments and life adjustment of people with deafness 1 to 15 years after closure of vocational rehabilitation services.
 - Developed a series of training curricula and interventions to help older adults with developmental disabilities learn to make choices in later life, advocate for themselves, and provide leadership in advocating for the rights of people with disabilities.
 - Provided national leadership on statistical information about people with disabilities including the content of the Year 2000 Census and other national surveys, generating information ranging from demographics to employment and participation in society.
 - Discovered that a majority of persons with hearing loss consider their hearing loss to have a significant impact on their employment and career, but they are very unlikely to disclose the hearing loss with employers or co-workers for fear of adverse consequences.
 - Developed the System of Care Model, being used to structure each state's mental health plan for children as well as the basis for the largest federal children's mental health grant program to date.
 - Developed a comprehensive report and searchable Web site on the economics of public programs and policies that influence the employment of people with disabilities for use by the disability advocacy community.
 - Developed guidelines for the media in writing about and reporting on people with disabilities that have been used by the Associated Press and the American Psychological Associations' Publication Manual (Fourth and Fifth Editions).
 - Coordinated a collaboration of consumers and organizations to establish the National Association on Alcohol, Drugs, and Disability (NAADD), the first national consumer-controlled association of its kind.



This report was prepared by the
National Center for the Dissemination of Disability Research



Southwest Educational Development Laboratory

211 East Seventh St., Room 448
Austin, Texas 78701-3281

Voice/Text Telephone: 800-266-1832 or 512-476-6861
Fax: 512-476-2286

funded by



National Institute on Disability and Rehabilitation Research

U.S. Department of Education
Office of Special Education and Rehabilitative Services (OSERS)

This publication was produced in collaboration with



The NCDDR is operated by the Southwest Educational Development Laboratory (SEDL). SEDL is an Equal Employment Opportunity/Affirmative Action Employer and is committed to affording equal employment opportunities for all individuals in all employment matters. Neither SEDL nor the NCDDR discriminate on the basis of age, sex, race, color, creed, religion, national origin, sexual orientation, marital or veteran status, or the presence of a disability. This document was developed in part under grant H133A990008-A from the National Institute on Disability and Rehabilitation Research (NIDRR) in the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS). However, these contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal government.

Available in alternate formats upon request.