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National Institute on Disability and Rehabilitation Research—Notice of Final Long-Range Plan for Fiscal Years 2005–2009

DEPARTMENT OF EDUCATION

National Institute on Disability and Rehabilitation Research—Notice of Final Long-Range Plan for Fiscal Years 2005–2009

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

ACTION: Notice of Final Long-Range Plan for Fiscal Years (FY) 2005–2009.

SUMMARY: The Assistant Secretary for Special Education and Rehabilitative Services (OSERS) publishes the Final Long-Range Plan (Final Plan) for the National Institute on Disability and Rehabilitation Research (NIDRR) for FY 2005 through 2009. As required by the Rehabilitation Act of 1973, as amended (Act), the Assistant Secretary takes this action to outline priorities for rehabilitation research, demonstration projects, training, and related activities, and to explain the basis for these priorities.

DATES: *Effective Date:* The Final Plan is effective March 17, 2006.

FOR FURTHER INFORMATION CONTACT: Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW., room 6030, Potomac Center Plaza, Washington, DC 20204–2700. Telephone: (202) 245–7462.

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SUPPLEMENTARY INFORMATION:

Background

The Final Plan presents a five-year research agenda anchored in legislative mandate, consumer goals, and scientific initiatives. The Final Plan has several distinct purposes:

(1) To set broad general directions that will guide NIDRR's policies and use of resources.

(2) To establish objectives for research and related activities from which annual research priorities can be formulated.

(3) To describe a system for operationalizing the Final Plan in terms of annual priorities, evaluation of the implementation of the Final Plan, and updates of the Final Plan as necessary.

(4) To direct new emphasis to the management and administration of the research endeavor.

The Final Plan was developed with the guidance of a distinguished group of NIDRR constituents—individuals with disabilities and their family members and advocates, service providers, researchers, educators, administrators, and policymakers, including the Commissioner of the Rehabilitation Services Administration, members of the National Council on Disability, and representatives from the U.S. Department of Health and Human Services.

The authority for the Secretary to prepare the Final Plan is contained in section 202(h) of the Act (29 U.S.C. 762(h)). NIDRR published a Notice of Proposed Long-Range Plan for FY 2005–2009 (Proposed Plan) on July 27, 2005 (70 FR 43522). The Act requires that NIDRR consider all public comments received regarding the Proposed Plan and then transmit the Final Plan to Congress.

The Final Plan is published as an attachment to this notice.

Public Comments

In response to the invitation in the Notice of Proposed Long-Range Plan for FY 2005–2009, NIDRR received 45 comments regarding the Proposed Plan. The majority of the comments were positive and supportive of the Proposed Plan. Comments that suggested changes in the Proposed Plan generally fell into one of two categories. One small group of comments suggested changes to the Proposed Plan that NIDRR does not have the authority to make (*e.g.*, requests to increase funding for NIDRR) or that would result in NIDRR not complying with the Act (*e.g.*, changes to the mandatory set-aside requirements for minority institutions). NIDRR is unable to make these changes.

Another group of comments requested that NIDRR include more references to specific target populations, disability groups, and therapeutic modalities in the Proposed Plan. NIDRR believes that it is unnecessary to make any changes to the Proposed Plan based on these comments because the long-range plan is a strategic plan designed to provide a broad framework for funding research that is consistent with NIDRR's mission, including research that both addresses specific target populations (as defined in 34 CFR § 350.5) and relates to the outcomes described in NIDRR's Logic Model, as presented in the Proposed Plan.

While the Proposed Plan is organized along domains of research (*i.e.*, employment, health and function, technology for access and function, participation and community living, and disability demographics) for the sake of manageability, it also makes clear that disability is a holistic phenomenon that involves many overlapping and cross-domain issues. For example, through the Field-Initiated (FI) Program, which covers all aspects of NIDRR's research domains and addresses all disability populations with a wide range of research approaches, NIDRR encourages applications that address overlapping and cross-domain issues for any relevant populations. In addition, with respect to those programs for which NIDRR establishes annual priorities—Rehabilitation Research and Training Centers (RRTCs), Rehabilitation Engineering Research Centers (RERCs), and Disability and Rehabilitation Research Projects (DRRPs)—NIDRR may require applicants to focus on one or more target populations or issues that cut across domains. Increasingly, NIDRR is asking for cross-disability and multidisciplinary research. For example, NIDRR could establish a research priority in the employment domain that requires applicants to focus on persons with intellectual disabilities and issues related to technology. Given the structure of NIDRR's research programs, therefore, NIDRR believes that the concerns of commenters who seek more attention on specific target populations, disability groups, or therapeutic modalities can be accommodated within the framework of the Proposed Plan.

Changes to Proposed Plan

Following publication of the Proposed Plan, NIDRR realized that it inadvertently had failed to discuss in the Proposed Plan the Disability and Business Technical Assistance Centers (DBTACs) that it supports under its DRRP program and its work on coordinating the Federal response to emergency preparedness and disability based on Executive Order 13347, Individuals with Disabilities in Emergency Preparedness. Commenters also noted the absence of this information in the Proposed Plan. Accordingly, NIDRR has made changes to the Proposed Plan as follows:

DBTAC

The Proposed Plan did not include references to NIDRR's ongoing DBTAC program, which is NIDRR's program for facilitating implementation of the Americans with Disabilities Act of 1990 (ADA). The following language, therefore, has been added as the third paragraph under the heading *Future Agenda* in the section entitled *Knowledge Translation:*

''Knowledge Translation includes the provision of information, technical assistance, and training in areas related to disability policy. The Act assigns to NIDRR the responsibility for those activities in relation to the ADA. NIDRR intends to implement those activities through a national network of regionally-based centers that will provide assistance to disability organizations, individuals with disabilities, businesses, public agencies, and the general public, and that will contribute to research on topics covered under the ADA.''

Individuals With Disabilities in Emergency Preparedness

In recognition of NIDRR's ongoing work in the area of emergency preparedness for individuals with disabilities, NIDRR has made the following changes to the Proposed Plan:

Under the heading *National Policy Context for NIDRR Research* in *Part A: Introduction and Background Introduction,* we have revised the second sentence to reference Executive Order 13347, Individuals with Disabilities in Emergency Preparedness, such that the sentence now reads as follows: ''These include the U.S. Supreme Court's 1999 decision in *Olmstead* v. *L.C.* (527 U.S. 581), the President's New Freedom Initiative (NFI), the report of the President's New Freedom Commission On Mental Health, and Executive Order 13347, Individuals with Disabilities in Emergency Preparedness.'' In addition, at the end of the *National Policy Context for NIDRR Research* section, NIDRR has added the following language:

''On July 26, 2004, President George W. Bush issued Executive Order 13347, 'Individuals with Disabilities in Emergency Preparedness'. This Order establishes a policy that the Federal government appropriately support the safety and security of individuals with disabilities in situations involving both natural and man-made disasters. The Order directs Executive departments and other Federal agencies to include individuals with disabilities in emergency preparedness planning. Also included in the Order was the establishment of an Interagency Coordinating Council (ICC) to coordinate the Federal response to emergency preparedness and disability. The ICC established a research committee, which was co-chaired by NIDRR staff. The ICC concluded, and reported to the President, that it is critical to transition from suggestions and ideas to empirically-based research that provides evidence of what works.''

In addition to the few changes identified in the preceding paragraphs, the Final Plan reflects a number of additional non-substantive and clarifying revisions.

NIDRR appreciates the many thoughtful comments it received regarding the Proposed Plan, and will continue to consider them in updates to the Final Plan and in future priorities.

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Dated: February 7, 2006.

John H. Hager,

Assistant Secretary for Special Education and Rehabilitative Services.

National Institute on Disability and Rehabilitation Research: Long-Range Plan for 2005–2009

Preface

The introductory section of the National Institute on Disability and Rehabilitation Research (NIDRR) Long-Range Plan 2005–009 (Plan) provides basic background about NIDRR. This includes its mission, its administrative location, the legislative and administrative environments in which NIDRR operates, intended beneficiaries of NIDRR research, conceptual overview of the Plan, management and evaluation principles, general highlights of 25 years of NIDRR research, and the structure of the Plan. The first section of the Plan also includes a chapter that defines and describes NIDRR's target population, providing some data on population characteristics. The second section of the Plan presents NIDRR's Logic Model and research domains, and operational strategies to implement the Plan and enhance the accountability and responsiveness of NIDRR. The third section of the Plan delineates each domain of NIDRR research and related activities and the strategies that will be employed to address NIDRR's mission.

Part A: Introduction and Background

I. Introduction

The mission of the National Institute on Disability and Rehabilitation Research (NIDRR or the Institute) is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

The timely convergence of technological breakthroughs and empowerment of people with disabilities has resulted in increased demand for the products of disability and rehabilitation research. These include not only technological devices but also new knowledge about interventions and policies that will further the mission of NIDRR to advance all aspects of life for people with disabilities.

Organizational Context

NIDRR is located within the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education (Department). OSERS has two other components: The Rehabilitation Services Administration (RSA), which administers the State-Federal Vocational Rehabilitation Program, and the Office of Special Education Programs (OSEP), which oversees the implementation of the Individuals with Disabilities Education Act, as amended (IDEA). NIDRR, therefore, is ideally situated to facilitate the transfer of knowledge to consumers, practitioners, and administrators in vocational rehabilitation and special education. NIDRR also has developed extensive linkages to the broader disability and rehabilitation research community through its leadership work chairing the Interagency Committee on Disability Research (ICDR) and through development of significant partnerships with many Federal agencies, research institutions, and consumer organizations. NIDRR values and encourages the collaborative and synergistic nature of its many partnerships, as significant advancements in disability knowledge are achieved through the efforts of many researchers and others over time.

Statutory Mandates

The 1978 amendments to the Rehabilitation Act of 1973, as amended, (the Act) created NIDRR [1] in recognition of both the opportunities for scientific and technological advancements to

[1] Established as the National Institute on Handicapped Research (NIHR) in the 1978 amendments, the Institute's name was changed to the National Institute on Disability and Rehabilitation Research (NIDRR) by the 1986 amendments to the Rehabilitation Act of 1973, as amended.

improve the lives of people with disabilities and the need for a comprehensive and coordinated approach to research, development, demonstration, and information dissemination and training. These amendments charged NIDRR with providing a comprehensive and coordinated program of research and related activities designed to maximize the inclusion and social integration, health and function, employment and independent living of individuals of all ages with disabilities.

In addition to research and development (R&D), the Act authorizes widespread dissemination of research-generated knowledge to rehabilitation service providers, people with disabilities and their families, researchers, and others; promotion of technology transfer; leadership of an Interagency Committee to coordinate Federal disability and rehabilitation research; advanced training in disability and rehabilitation research; and increased opportunities for minority institutions and researchers with disabilities or from minority groups.

To guide rehabilitation research, the Act requires publication of the proposed Plan in the **Federal Register**, public comment on the Plan, and subsequent production of a final Plan. The Act specifies that in developing and implementing the Plan, NIDRR should: outline priorities for NIDRR's activities and provide the basis for such priorities; specify appropriate goals and timetables for covered activities to be conducted under sections 202 and 204 of title II of the Act; develop the Plan in consultation with the Commissioner of RSA, the Commissioner of the Administration on Developmental Disabilities, the National Council on Disability (NCD), and the ICDR; and provide full consideration to the input of people with disabilities and their family members, organizations representing people with disabilities, researchers, service providers, and other appropriate entities. The Plan also must provide for widespread dissemination of the results of funded activities, in accessible formats, to rehabilitation practitioners and individuals with disabilities and their families, including those who are members of minority groups or underserved populations.

This final Plan was developed by NIDRR with extensive input from an expert panel of researchers, service providers, and people with disabilities. Appendix 1 of this Plan contains a list of the expert panel members. In addition, NIDRR actively solicited comments through a Web site and through six national videoconferences. NIDRR also consulted with the ICDR, the NCD, and other Federal partners.

National Policy Context for NIDRR Research

In recent years, several major policy directives have influenced activities and initiatives in disability and rehabilitation research, including implementation of the 1999–2003 NIDRR Long-Range Plan and development of the proposed Plan. These include the U.S. Supreme Court's 1999 decision in *Olmstead* v. *L.C.* (527 U.S. 581), the President's New Freedom Initiative (NFI), the report of the President's New Freedom Commission On Mental Health, and Executive Order 13347, Individuals with Disabilities in Emergency Preparedness. The Americans with Disabilities Act of 1990 (ADA), now in existence for more than a decade, has continued to provide a strong framework for all disability-related activities.

Because maximum community participation for persons with disabilities is the ultimate objective of NIDRR research, the important directives in the *Olmstead* decision resonate with and inform NIDRR's agenda. The *Olmstead* decision stated that Title II of the ADA requires public agencies that provide services to people with disabilities do so in the most integrated settings appropriate to their needs. Moreover, State agencies that provide housing and services must make plans to move individuals from institutions to community environments and to divert others from institutionalization when appropriate. The *Olmstead* decision allows State agencies to take into consideration limited available funds, but does require that they show progress through planning for the implementation of change. Full implementation of this decision eventually will have far-reaching consequences for people with disabilities and the service systems they use.

The *Olmstead* decision affects disability and rehabilitation research as it highlights the need for new, validated strategies; and supports programs, interventions, guidelines, and policies to make living in the community successful for deinstitutionalized individuals or those diverted from potential institutionalization. Individual States are serving as de facto laboratories for research into social policy implementation, and generate a need and an opportunity for the evaluation of best practices. NIDRR will continue its focus on research that addresses effective use of information for people with disabilities and access to appropriate accommodations in society; both are essential components of the Institute's research agenda.

The NFI was announced by President George W. Bush on February 1, 2001, to further the full participation of people with disabilities in all areas of society by increasing access to assistive and universally designed technologies, by expanding educational and employment opportunities, and by promoting full access to community life. Several provisions of the NFI have had a direct impact on NIDRR activities. The NFI included a proposal to increase funding for NIDRR's Rehabilitation Engineering Research Centers (RERCs). Substantial funding was earmarked for the ICDR, which is chaired and staffed by NIDRR, in order to increase coordination of Federal research efforts related to technology and disability. Other aspects of the NFI, such as increased preparedness and more opportunities for employment, telework, universal design, access to assistive technology, increased homeownership, and access to mental health services, also influenced NIDRR's activities and research during much of the preceding four years.

The President's New Freedom Commission on Mental Health (Commission), established through Executive Order 13263 on April 29, 2002, examined the mental healthcare system in the Nation and issued recommendations for change. In July 2003, the Commission issued its final report, ''Achieving the Promise: Transforming Mental Health Care in America.'' The report identified barriers to care within the mental health system and provided examples of community-based care models that have worked successfully to coordinate and provide treatment services. The Commission concluded that the mental health service delivery system in the United States is fragmented and should be substantively transformed. Goals for the transformed system include ensuring that: (1) Americans understand that mental health is essential to overall health; (2) Mental healthcare is consumer and family-driven; (3) Disparities in mental health services are eliminated; (4) Early mental health screening, assessment, and referral to services are common practice; (5) Excellent mental health services are delivered and research is accelerated; and (6) Technology is used to access mental healthcare and information.

The realization of these goals will require the development and transfer of new knowledge about barriers to recovery and community integration, effective treatment interventions and

supports, best practices in services delivery and increasing access to care, technology to support living independently in the community, and accommodations to promote employment. The Commission's final report contains substantial implications for NIDRR's research agenda, as well as those of its Federal partner agencies.

On July 26, 2004, President George W. Bush issued Executive Order 13347, ''Individuals with Disabilities in Emergency Preparedness.'' This Order establishes a policy that the Federal government appropriately support the safety and security of individuals with disabilities in situations involving both natural and man-made disasters. The Order directs Executive departments and other Federal agencies to include individuals with disabilities in emergency preparedness planning. Also included in the Order was the establishment of an Interagency Coordinating Council (ICC) to coordinate the Federal response to emergency preparedness and disability. The ICC established a research committee, which was co-chaired by NIDRR staff. The ICC concluded, and reported to the President, that it is critical to transition from suggestions and ideas to empirically-based research that provides evidence of what works.

Overview of Long-Range Plan Concepts

The proposed Plan builds on the work of the 1999–2003 Long-Range Plan, while responding to new developments in the disability and rehabilitation research field and in government. Both plans stress the importance of NIDRR's significant role as a research institute in the public interest, carrying out scientific research to meet the diverse needs of people with disabilities.

The contextual paradigm of disability and rehabilitation research will continue to frame the NIDRR research agenda. This paradigm overcomes the limitations imposed by a medical model of disability. The new paradigm of disability maintains that ''disability is a product of the interaction between characteristics of the individual (*e.g.*, conditions or impairments, functional status, or personal and social qualities) and the characteristics of the natural, built, cultural, and social environments.'' (NIDRR Long-Range Plan 1999–2003).

The contextual paradigm of disability was explicated in the 1999–2003 NIDRR Long-Range Plan and significantly influenced the design of NIDRR research during the past five years. The contextual paradigm of disability helps to focus NIDRR research on new research issues; new approaches for defining, measuring, counting, and categorizing disability; and new methods for conducting and managing research. Definitions and enumeration of disability are addressed in the subsequent chapter on the characteristics of the target population and in the demographics research chapter. New approaches to measurement issues and research methods will be addressed in each of the chapters on research domains (*e.g.*, participation and community living, health and function, technology for access and function, employment, and demographics), as will new research methods. New research issues will be discussed in the individual chapters on research domains.

The Plan continues the important research areas of universal design and the emerging universe of disability. The new Plan further recognizes the importance of interdependence, not only in its continued emphasis on personal assistance services, but also on supports for family and other informal caregivers, direct care workers, and paraprofessionals in facilitating community living and participation in the community.

The Plan expands NIDRR's emphasis on the major research ''domains'' of employment, participation and community life, health and function, and technology for access and function. In these areas, the Plan continues to emphasize areas of employment incentives and accommodations, access to healthcare, and the preference for supports rather than services as the model for facilitating the community integration of people with disabilities. The previously termed *domain of independent living and community integration* in the 1999–2003 Long-Range Plan has been renamed *participation and community living* to better capture the broad goal of increased participation, which is intrinsic to the NIDRR mission. Additionally, the area of *disability demographics* has been elevated to a major domain. This change recognizes and reinforces the importance of improved disability data for policy, design of services, and future research initiatives.

The Plan also embraces the concept of disability as a holistic phenomenon by extending this concept into the research field. This is achieved by emphasizing interactions between two or more domains, thus indicating and stressing the important interrelationships among the research domains throughout the Plan.

Accountability, Management, and Evaluation of Research

The Plan introduces major changes in accountability, management, and evaluation of the research portfolio, some of which reflect new standards of accountability for NIDRR as an entity, while others relate to the performance of grantees.

In 1993, Congress passed the Government Performance and Results Act (GPRA), intended to improve accountability of Federal programs through strategic planning and performance assessment. GPRA requires Federal agencies to develop strategic plans for all programs, identifying performance goals and the indicators that would be used to measure progress. In 2002, the President's Management Agenda was announced, emphasizing the use of objective criteria to assess program results for budgeting purposes. The Office of Management and Budget (OMB) developed the Program Assessment Rating Tool (PART) to assess each program's performance. Government-wide policy shifts have resulted in changes in NIDRR management procedures to emphasize standards for assessing its work and that of its grantees. NIDRR has developed its response to the PART document by using a logic model, as presented in the next part of the Plan.

While NIDRR will continue to emphasize the same or similar research areas as those delineated in the 1999–2003 Long-Range Plan (*i.e.*, employment, health and function, technology for access and function, participation and community living, and disability demographics, which are termed *domains* in this Plan), there will be new emphases on stages of knowledge development. These stages relate to the types of objectives and end products that grantees are expected to pursue. These stages include: (1) Discoveries; (2) theories, measures, and methods; and (3) interventions, products or devices, and environmental adaptations.

In program reviews and other evaluations, NIDRR has found that disability and rehabilitation research often lacks validated theories and measures. The degree of deficit varies from one domain to another, and within domains, in relation to certain disability types or other target populations. Equally important is the tendency to sometimes reinvent data collection instruments for each individual study, rather than create a more robust knowledge base by using instruments that already are validated. Validated measurement tools are critical to

evaluating research outcomes, and for determining which research findings are appropriate for dissemination to various constituents. Research projects at the second stage of knowledge development will develop and test the validity of theories, measures, and methods as applied to disability research.

The focus on research stages of knowledge development will enable NIDRR to set more measurable goals and to assess the extent to which grantees have produced relevant outputs and outcomes. For example, whether a particular research topic is appropriate for the interventions, products, and environmental adaptations stage will be an important judgment, and one that NIDRR generally will announce with a published priority. In this third stage of knowledge development, researchers will test the effectiveness of specific interventions or program configurations.

Accomplishments of NIDRR Researchers

NIDRR researchers and representatives of the disability community generally attribute two categories of accomplishments to NIDRR. The first category includes NIDRR leadership in important areas, pioneering inquiries, and general principles. The second category consists of the work of NIDRR-supported grantees in enhancing the knowledge base and disseminating new findings. The two categories are often complementary and interdependent. The Institute has reached its 25th Anniversary, and a backward glance will highlight some important NIDRR achievements.

The need to examine the many dimensions of the new paradigm of disability, also referred to as the contextual paradigm of disability, provided the catalyst for an innovative collaboration between NIDRR and the American Psychological Association (APA). The *Bridging Gaps* research conference examined the impact of the paradigm shift on psychology and rehabilitation research. One presenter at the *Bridging Gaps* conference described the significant effects of the paradigm shift:

NIDRR's new paradigm for conceptualizing disability is a powerful tool for focusing both research and service delivery systems on interactions that can significantly affect outcomes for persons with disability. If we are trying to understand outcomes through research or attempting to influence outcomes by direct intervention, or both, it is critical to understand and apply this paradigm by paying increased attention to the person-environment interactions. As with any good theory, this one illuminates aspects that were in the dark under the older paradigm and suggests ways of thinking that were not intuitively obvious.[2]

Related to the new paradigm are several new directions in research that also have served to lead the field. Among the research issues are universal design, the concept of an emerging universe of disability, and emphasis on accommodations. NIDRR has been a leading international proponent of universal design, which is defined as design for a built environment that can be used by nearly all people—living, working, and playing together. Rather than using design parameters based on idealized measures of human factors that restrict usability to a narrow segment of the population, universal design works to accommodate a wider range of functional abilities through approaches including modular designs that easily can be modified.

The *emerging universe of disability* refers to a disabled population that is shaped by demographic changes in age, immigrant status, and other socioeconomic factors, by new types of potentially disabling conditions, by consequences of treatments of existing conditions, and by differential distribution of conditions and their consequences. The concept of an emerging universe of disability has helped to increase attention in the last five years to the unique needs of this population, and to multiply the research endeavors focusing on cultural and economic factors affecting disability.

NIDRR has pursued a model for addressing obstacles facing people with disabilities that have shifted from service provision to supports that enable self-direction. Supports may include personal assistance services (PAS), assistive technology, civil rights, and peer support, and involving people with disabilities in the conduct and administration of disability and rehabilitation research. Promoting accommodations and assistive technology have been two areas of NIDRR leadership that are reflected in new public policy, including in the ADA and the NFI. Accommodations may be physical, technological or programmatic, and entitlement to accommodations is a cornerstone of the ADA. Accommodations are particularly important in supporting work and education. NIDRR researchers have developed assistive technology devices addressing information technology (IT), communications and speech, and neurological, mobility, and manipulation issues, among other functional areas. Accommodations also encompass changes in program operations to enable people with disabilities to participate fully; these changes may include times and locations, structure of activities, and accessibility.

NIDRR has sponsored research on supports that help individuals with disabilities make their own choices and direct their own lives. Supports include peer-to-peer and family-to-family programs, PAS, self-advocacy skill development, consumer direction, assistive technology, and environmental modifications, all which have been subjects of considerable NIDRR research.

In 1982, NIDRR convened the first meeting of the member agencies of what is now known as the Interagency Subcommittee on Disability Statistics (ISDS), to coordinate and promote the generation of improved statistical knowledge about disability populations. This committee has met monthly for 20 years. The ISDS achievements include: collaborating to publish a book on statistics of disability populations (Thompson-Hoffman, S. Fitzgerald Storck, I. (Eds.), *Disability in the United States: a Portrait from National Data* (1991); and serving as a consultation and review resource for other public and private agencies designing surveys of individuals with disabilities. The ISDS also has facilitated a substantial amount of sharing and exchange of information among member agencies, and joint funding of projects among these agencies.

Structure of the Plan

The Plan is divided into three parts. Part A includes this introduction and a chapter on NIDRR's target population. NIDRR has, by law, a number of target populations, including people with disabilities and their families; individuals who provide vocational rehabilitation, or medical, technological, and direct support services; educators; policymakers; businesses; and the general public. However, people with disabilities clearly are intended to be the ultimate beneficiaries of all NIDRR activities, and the next chapter focuses on defining and describing that population.

Part B (Managing for Success) addresses accountability, management, and evaluation through the use of a

[2] Nirenberg, B., ''A system for bridging the financial and cultural gaps in the well-being of persons with disabilities'', in *Bridging gaps: Refining the disability research agenda for rehabilitation and the social sciences—Conference proceedings*. Menomonie: University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, Research and Training Centers, edited by F.E. Menz and D.F. Thomas, 2003, p. 239 (*http://www.rtc.uwstout.edu/pubs/pubs.htm*).

logic model and a strategy of ''managing for results.'' The NIDRR Logic Model provides a theoretical base for the evaluation of program outcomes, and will serve to ensure consistency throughout a planning and feedback cycle. In ''managing for results,'' NIDRR presents its strategy for making its operations more systematic and responsive to the concerns of all its constituents. The management chapter focuses on setting regular, fixed dates for the steps of annual grants competitions—announcement of priorities and closing dates, peer reviews, and grant award announcements—and establishing standing panels for consistency and expertise in peer review. Additionally, NIDRR will focus on setting priorities that encourage greater leeway for applicants in designing research. NIDRR will be enhancing its monitoring and evaluation processes to provide continuous feedback to improve its research portfolio.

Part C discusses three arenas of outcomes achievement: research and development (R&D), capacity building (C–B), and knowledge translation (KT). The R&D arena is divided according to the domains of NIDRR research—employment; health and function; technology for access and function; participation and community living; and disability demographics.

Each domain of the R&D arena may include a discussion of one or more of the identified stages of knowledge development which include: discoveries; theories, measures and methods; and interventions, products and devices, and environmental adaptations. Under each of these domains, NIDRR will develop a set of implementation strategies that will identify potential research that could address the anticipated outcomes in the given domain. NIDRR will publish these implementation strategies as proposed priorities and, following public comment, final priorities annually, on a combined basis.

In the arena of capacity building (C–B), NIDRR has focused its efforts on the personal and professional development of scientists, advocates, and people with disabilities, and is expanding this approach to include development of the capacity of institutions and organizations, especially those that address the needs of underserved populations.

The *Knowledge Translation* (KT) chapter discusses the arena of KT and introduces reforms in NIDRR's current knowledge dissemination program. The new approach to KT features a process for assessing the scientific validity of findings to be transferred, using consortia and other external organizations for evaluation.

Appendix 1 to this Plan lists the NIDRR 2005–2009 Long-Range Plan expert panel members.

II. The Target Population: Definitions and Characteristics

Definitions of Disability

The ICDR, based on a survey of publicly available documents, identified more than 60 definitions of disability in the Federal government alone, generally related to eligibility requirements for benefits or services, but also reflected in major national surveys that determine the Nation's estimates of disability. NIDRR is governed by the definitions in Title II of the Act. The definition that applies to Title II describes a person with a disability as: ''any person who (i) Has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment'' (29 U.S.C. 705).

NIDRR is required to focus especially on experiences of individuals with the most significant disabilities. The Act defines an *individual with a significant disability* in functional terms, the resulting need for multiple vocational rehabilitation services over an extended period of time, and indicates that the definition includes, but is not limited to, a list of specific conditions (29 U.S.C.705). Multiple services over an extended period of time include accommodations needed during the rehabilitation process and/or during subsequent employment. Under this definition of an individual with a significant disability, NIDRR is concerned with finding research solutions for people with all types of disabilities—mobility and manipulation, sensory, cognitive, and emotional. The target population includes individuals of all ages. Section 21 of the Act requires specific attention to underserved populations, those individuals with disabilities who are additionally marginalized by membership in minority racial or ethnic populations.

Prevailing definitions of disability used by Federal agencies do not reflect the new paradigm of disability concepts because the Federal definitions typically stress limitations and do not mention the potential role of accommodations or environmental conditions. The field of disability and rehabilitation research also continues to lack a widely accepted conceptual framework to identify and measure disability. The newer conceptual frameworks all focus on some continuum that progresses from etiology through disease, impairments, and functional limitations, which, when combined with external or environmental conditions, may cause deficits in the performance of daily activities or desired social roles. The latest proposal for classifying disability is the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO), and last revised in 2001.[3] A diagram of the ICF classification schema can be found at *http://www.cessi.net/longrangeplan/icf.htm.*

The ICF allows one to view disability as a dynamic interaction between the person and the environment. ICF's diagram of its classification schema depicts the multiple interactions of the person with the environment, and the various aspects of the person. The ICF provides a method for organizing measures of function, activity, participation, and environmental context. NIDRR and many of its partner agencies are considering the appropriateness of applying the ICF to U.S. populations, and are engaged in assessments of the necessary measurement tools and data systems. A later chapter of this Plan, *Disability Demographics,* presents a more thorough discussion of the ICF.

Prevalence of Disability

Current figures on the number of people with disabilities in the United States indicate an estimated 54 million individuals have disabilities, based on definitions employed in national surveys, and self-reported responses to them. General definitions and descriptions of the target population, in terms of the domains of NIDRR research—employment, health and function, participation and community living, and technology for access and function—are provided in this section. A later chapter of the Plan includes an analysis of the data in current measurement systems, and identifies gaps to be addressed by future research.

General descriptors of NIDRR's target population, drawn from data about the disabled population, show that disability is closely related to aging and poverty. Persons with disabilities are

[3] The ICF represents a revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was first published by the WHO for trial purposes in 1980. Developed after systematic field trials and international consultation, it was endorsed for international use on 22 May 2001 by the Fifty-fourth World Health Assembly (resolution WHA54.21). *http://www3.who.int/icf/intros/ICF-Eng-Intro.pdf.*

more likely to be elderly, poor, of low educational status, and unemployed than those with no disabilities. People with disabilities are less likely to participate in community and social activities and are more likely to lack adequate transportation. However, persons with disabilities are about as likely as those without disabilities to have health insurance (relying heavily on Medicare and Medicaid) and somewhat more likely to have an identified source of healthcare. The disabled population is not monolithic, and there are many variations based on type of disability and age of onset, for example, as well as on the demographic characteristics mentioned here.

Tables 1 and 2 describe the overall disabled population—its size, age and race distributions, and the frequency of conditions underlying the disabilities. Table 3 includes type of disability in the characterization. These tables are from the U.S. Census Bureau, Census 2000, Summary File 3.

TABLE 1.—PREVALENCE OF DISABILITY BY AGE AND RACE

Race and Hispanic or Latino Origin	Total population aged 5 and older	Percent with a disability			
		5 and older	5 to 15	16 to 64	65 and older
Total	257,167,527	19.3	5.8	18.6	41.9
White alone	195,100,538	18.5	5.6	16.8	40.6
Black or African American alone	30,297,703	24.3	7	26.4	52.8
American Indian and Alaska Native alone	2,187,507	24.3	7.7	27	57.6
Asian alone	9.455,058	16.6	2.9	16.9	40.8
Native Hawaiian and Other Pacific Islander alone	337,996	19	5.1	21	48.5
Some other race alone	13,581,921	19.9	5.2	23.5	50.4
Two or more races	6,206,804	21.7	7.1	25.1	51.8
Hispanic or Latino (of any race)	31,041,269	20.9	5.4	24	48.5
White alone, not Hispanic or Latino	180,151,084	18.3	5.7	16.2	40.4

TABLE 2.—PREVALENCE OF DISABILITY BY AGE AND GENDER

	Total		Males		Females	
	Number	Percent	Number	Percent	Number	Percent
Population 5 years and over	257,167,527	100	124,636,825	100	132,530,702	100
With any disability	49,746,248	19.3	24,439,531	19.6	25,306,717	19.1
Population 5 to 15 years	45,133,667	100.0	23,125,324	100.0	22,008,343	100.0
With any disability	2,614,919	5.8	1,666,230	7.2	948,689	4.3
Population 16 to 64 years	178,687,234	100.0	87,570,583	100.0	91,116,651	100.0
With any disability	33,153,211	18.6	17,139,019	19.6	16,014,192	17.6
Population 65 years and over	33,346,626	100.0	13,940,918	100.0	19,405,708	100.0
With any disability	13,978,118	41.9	5,634,282	40.4	8,343,836	43.0

The following table, Table 3, presents information about three categories of disability—sensory, physical, and mental—by age and gender. The table also includes additional information about major life activities. Thus, these are not unduplicated counts, and the totals exceed the estimated number of individuals who have disabilities.

TABLE 3.—CHARACTERISTICS OF THE CIVILIAN NON-INSTITUTIONALIZED POPULATION BY AGE, DISABILITY STATUS, AND TYPE OF DISABILITY: 2000

	Total		Males		Females	
	Number	Percent	Number	Percent	Number	Percent
Population 5 years and over	257,167,527	100	124,636,825	100	132,530,702	100
With any disability	49,746,248	19.3	24,439,531	19.6	25,306,717	19.1
Population 5 to 15 years	45,133,667	100.0	23,125,324	100.0	22,008,343	100.0
With any disability	2,614,919	5.8	1,666,230	7.2	948,689	4.3
Sensory	442,894	1.0	242,706	1.0	200,188	0.9
Physical	455,461	1.0	251,852	1.1	203,609	0.9
Mental	2,078,502	4.6	1,387,393	6.0	691,109	3.1
Self-care	419,018	0.9	244,824	1.1	174,194	0.8
Population 16 to 64 years	178,687,234	100.0	87,570,583	100.0	91,116,651	100.0
With any disability	33,153,211	18.6	17,139,019	19.6	16,014,192	17.6
Sensory	4,123,902	2.3	2,388,121	2.7	1,735,781	1.9
Physical	11,150,365	6.2	5,279,731	6.0	5,870,634	6.4
Mental	6,764,439	3.8	3,434,631	3.9	3,329,808	3.7
Self-care	3,149,875	1.8	1,463,184	1.7	1,686,691	1.9
Going outside the home	11,414,508	6.4	5,569,362	6.4	5,845,146	6.4
Employment disability	21,287,570	11.9	11,373,786	13.0	9,913,784	10.9
Population 65 years and over	33,346,626	100.0	13,940,918	100.0	19,405,708	100.0
With any disability	13,978,118	41.9	5,634,282	40.4	8,834,836	43.0

TABLE 3.—CHARACTERISTICS OF THE CIVILIAN NON-INSTITUTIONALIZED POPULATION BY AGE, DISABILITY STATUS, AND TYPE OF DISABILITY: 2000—Continued

	Total		Males		Females	
	Number	Percent	Number	Percent	Number	Percent
Sensory	4,738,479	14.2	2,177,216	15.6	2,561,263	13.2
Physical	9,545,680	28.6	3,590,139	25.8	5,955,541	30.7
Mental	3,592,912	10.8	1,380,060	9.9	2,212,852	11.4
Self-care	3,183,840	9.5	1,044,910	7.5	2,138,930	11.0
Going outside the home	6,795,517	20.4	2,339,128	16.8	4,456,389	23.0

Part B: Managing For Success

Preface

This section of the Plan contains two chapters. The first chapter describes NIDRR's logic model for outcomes achievement, which has served as the basis of development of the Plan.

The second chapter details the systematic approaches NIDRR intends to pursue to advance the management of the Institute's operations. A central feature is a move toward a fixed competition schedule. The second chapter also describes efforts to enhance NIDRR's scientific review process, and the emphasis on outcomes evaluation.

I. NIDRR Logic Model

Introduction

NIDRR has based the development of the Plan on its mission statement. The mission statement emphasizes participation in the community by persons with disabilities as the overall objective of NIDRR's investment activities. NIDRR's mission statement was derived from the enabling legislation for NIDRR. In developing its research agenda, NIDRR drew upon accountability guidelines from the Department and OMB, which focus on outcomes of research activities.

To provide a theoretical framework for the Plan and guide its implementation, NIDRR developed its program Logic Model (see Appendix 2), which represents graphically the different types of short-term and intermediate outcomes that NIDRR's investments in R&D are designed to produce or contribute to and the interrelationships among these intended outcomes. The Logic Model also serves as the framework for depicting NIDRR's planned performance assessment and outcomes evaluation processes, which are key to demonstrating the Institute's accountability for research results. The width and density of the upward-directed arrows, at the bottom of the Logic Model diagram, indicate that the degree of accountability and hence intensity of NIDRR efforts in assessment and evaluation is greatest for the short-term outcome arenas.

How the NIDRR Logic Model Contributes to the Long-Range Plan

The value of any logic model is that it provides:

- A tool for outcomes planning and performance management that depicts the ''chain of events'' linking outcome goals to outputs, activities and inputs.
- A vehicle for communicating program goals and guiding program improvement and evaluation.
- A graphic representation or ''blueprint'' of the key elements of a program or intervention, and how these elements will work under certain conditions to ''solve'' identified problems.

Definitions of Components of the NIDRR Logic Model Situation

The uppermost block in the Logic Model, labeled ''situation,'' highlights the gaps in knowledge, skills, policy and practice that hinder attainment of parity in employment, health and function, and participation for people with disabilities compared to the non-disabled population (*see* Appendix 2). The Logic Model depicts the short-term and intermediate outcomes that NIDRR seeks to achieve directly and indirectly through its investments in research and related activities to eliminate these gaps and inform needed changes in policy, practice, behavior, and system capacity. These advancements and changes, in turn, contribute to the long-term outcome of improving the lives of people with disabilities.

Major Domains of NIDRR Mission

The substantive focus of NIDRR's investment activity is R&D applied to maximizing the participation of people with disabilities. This activity is centered on the three major life domains of interest to NIDRR: (a) Employment, (b) participation and community living, and (c) health and function. In the Logic Model, interlocking circles represent these inter-related domains (*see* Appendix 2). The achievement of goals related to the three major life domains is facilitated by technology, which addresses both access and function, and knowledge of disability demographics, including characteristics and trends in the population of people with disabilities. Policymakers, service providers, researchers, and disability advocates are the principal users of demographic data. NIDRR is uniquely positioned to address these inter-connected domains.

The *employment* circle of the Logic Model represents research on employment-related activities and strategies to improve employment outcomes and labor force participation. Lack of parity in employment remains one of the greatest barriers to independence for people with disabilities. Research is needed on strategies to enable Americans with disabilities to access careers, integrate into the workforce, and participate as full citizens in the economic marketplace. Employment, although an integral part of community participation, is treated as a separate domain because of NIDRR's statutory relationship with the Federal-State vocational rehabilitation program, and because of its overwhelming significance to people with disabilities and society.

The *participation and community living* circle of the Logic Model represents the interaction with the social and built environment in a way that maximizes full inclusion and integration of people with disabilities. This domain focuses on direct supports that increase the availability of acceptable options and opportunities to make choices and enhance participation in everyday activities. For the promise of full participation and community living to become a reality, people with disabilities need safe and affordable housing; access to transportation; access to the political process; and access to the services, programs, and activities offered to all members of the community at public and private facilities.

The *health and function* circle of the Logic Model represents individual

factors such as the structure and function of the human body, as well as strategies to prevent, identify, assess, or resolve causes and consequences of disability. In this domain, as in the others, NIDRR stresses the importance of individual choice—choosing providers, services and objectives. The health and function domain encompasses research to achieve outcomes at the individual level—improved functioning, fitness, and health, including mental health. This domain also addresses goals at the system level, such as more effective service delivery systems, better access (financial and logistical) to healthcare services, and the assessment of rehabilitation effectiveness.

The outer ring of the Logic Model includes two additional domains: *technology for access* and *function and disability demographics.* Technology for access and function is essential to community integration, employment, and health and function, and plays a major role in enabling a good fit between individuals with disabilities and the environment. The domain of disability demographics emphasizes describing and characterizing people with disabilities to provide a better understanding of the phenomenon of disability. Improved statistics on disability and participation are critical to developing policies and strategies that will be effective in addressing barriers to participation faced by individuals with disabilities, and in assessing the Nation's progress in improving life outcomes for individuals with disabilities.

Long-term Outcomes

Generally, outcomes refer to anticipated or actual changes in a target system that occurs from carrying out program activities and outputs. Long-term outcomes are the desired end-results of a program at the societal level; long-term outcomes are indicated by changes in overall conditions of the target population. Given their scope, long-term outcomes go beyond the direct or indirect influence and control of any one agency. Because of this, NIDRR is not accountable for producing, by itself, societal level improvements in the overall conditions of people with disabilities. Rather, the Institute's long-term outcomes, which focus on eliminating disparities in employment, participation and community living, and health and function, serve as critical anchor points guiding all strategic planning and research management efforts. Consistent with the Act, NIDRR's span of accountability centers on generating, romoting, and disseminating short-term outcomes that consist of new knowledge resulting from the combined accomplishments of its grantees. These short-term outcomes, when combined with KT activities, can be used to inform policy, change practice and behavior, and expand system capacity, which in turn will contribute to improving the lives of individuals of all ages with disabilities.

Short-Term Outcome Arenas

Short-term outcomes refer to advancements in understanding, knowledge, skills, and learning systems that result from the successful implementation of program activities and the use of R&D related outputs. Within the Logic Model and in the context of disability and rehabilitation research, there are three short-term outcome arenas, corresponding to NIDRR's investments in three functional programs. These functional arenas are: (1) C–B; (2) R&D; and (3) KT, corresponding to NIDRR's three strategic goals (*See* Part C). Given its centrality to the NIDRR mission, the R&D arena is further divided to reflect three stages of knowledge development. The three stages recognize that advancements in knowledge may occur through (a) Discoveries, (b) new or improved theories, measures, and methods, or (c) interventions, products, devices, and environmental adaptations. The generation of new knowledge in this short-term outcomes block is the primary area of direct responsibility for which NIDRR holds itself accountable.

Although the three strategic goals are discussed separately in Part C of the Plan, they are inextricably intertwined, in that research is supported by C–B and feeds KT, but the process is not linear. Inevitably, the generation of new knowledge raises new questions, calls for new skills and leads to further discoveries, theories, and interventions, multiplying the efficacy of NIDRR's investment.

Research and Development

R&D is divided into three generally sequential, but closely related, outcome arenas, corresponding to stages in knowledge development. Characteristically, research begins with significant discoveries (stage one) and moves through theory, measure, and method development (stage two) ultimately to enable the development of effective new and improved interventions, products and devices, and environmental adaptations (stage three). In this context, a product may be a new device or technique. An adaptation may include methods to improve physical, behavioral, or virtual environments.

The first two stages—discoveries and new or improved theories, measures, and methods—provide the critical foundation for new ideas, information, analyses, and scientific tools (*i.e.*, theories, measures, methods) upon which to base the conduct of valid and reliable research and development activity. NIDRR will shape future priorities based on considerations of the state of knowledge development in a particular subject area to determine, for example, if an adequate theoretical basis exists upon which an intervention can be developed.

Capacity Building

NIDRR will focus its specific C–B activities primarily on the need to train new investigators to enable them to pursue topics of importance to NIDRR's research agenda, and to otherwise increase the capacity of the system to carry out complex studies. The Institute's training agenda includes cross-training of individuals already skilled in other disciplines in topics relevant to disability issues, and training of promising young investigators, with particular emphasis on underrepresented groups and persons with disabilities to facilitate their participation in the research process. In addition, NIDRR specifically supports institutional C–B through targeted initiatives. Finally, NIDRR plays an active leadership role throughout the Department and the Federal government in raising awareness of the needs of people with disabilities and issues of equity.

Knowledge Translation

Equally critical to NIDRR's mission is the ability to effectively translate and transfer the knowledge and products generated through R&D activities. NIDRR must successfully disseminate this information for use by intended target audiences, including individuals with disabilities and their families and caregivers. Indeed, NIDRR will include an assessment of the potential for translation of knowledge gained through the project to the target audiences in considering new projects for support. KT includes the important work of technology transfer that directly promotes the widespread commercialization and utilization of research results. Previously referred to as the ''Knowledge Dissemination and Utilization (KDU)'' component of NIDRR's agenda, this arena has been renamed KT to reflect the evolution of translation science as a field and increased emphasis in the Federal

government on the importance of systematic review and synthesis of R&D results.

Intermediate Beneficiaries

This component refers to the immediate intended beneficiaries of NIDRR products and services as well as the recipients of the outputs and outcomes generated by NIDRR-funded grantees. This array of recipients includes individuals with disabilities and family members, researchers, clinicians and engineers, educators, service providers, product developers, policy experts and decision-makers, Federal and non-federal partners, industry representatives, employers, media, and consumer advocates.

Intermediate Outcome Arenas

Intermediate outcomes refer to changes in policy, practice, behavior, and system capacity that occur in part as a result of the external use or adoption of NIDRR-funded outputs and advances in knowledge. Unlike short-term outcomes, intermediate outcomes are under the indirect influence of program activities and outputs and consist of changes in decision-making and societal action. Because of the multiple influences on these intermediate outcomes, NIDRR can only partially influence these outcomes, and thus cannot be held accountable to the same degree as for short-term outcomes.

Intended Beneficiaries

The intended beneficiaries of NIDRR's overall investments are people with disabilities and their families. These individuals may benefit either directly, or more likely, indirectly through changes in policy, practice, behavior, and system capacity brought about through NIDRR's investments. The of purpose of NIDRR's activities, as described above in discussing the *Long-term Outcomes,* is the elimination of disparities in employment, participation and community living, and health and function. Intended beneficiaries include people with impairments or limitations in mobility, communications, cognition, and behavior.

Performance Assessment & Outcomes Evaluation

The last component of the NIDRR Logic Model depicts NIDRR's multi-level evaluation system. The intensity of the assessment and evaluation efforts is proportional to the thickness of the arrows of the Logic Model, and is greatest for short-term outcomes (*see* Appendix 2). Performance assessment takes place annually and is focused on evaluating grantee progress and the quality and relevance of the aggregate of R&D findings and accomplishments. Moreover, the performance assessment identifies the strengths and weaknesses of portfolio areas, which are defined as clusters of projects in NIDRR's domains and the Institute's program funding mechanisms. Data from these annual performance assessment and portfolio reviews are used to satisfy GPRA and PART requirements and inform program improvement efforts. Outcomes evaluation, in contrast, occurs periodically and is focused primarily on a retrospective assessment of the long-term achievements in a portfolio area relative to both short-term and intermediate outcomes, as well as any contributions at the societal level toward improving the overall condition of people with disabilities. Both types of evaluations are performed by independent review panels comprised of scientists, engineers, clinicians, service providers, policy analysts, industry representatives, consumer advocates, individuals with disabilities, and family members.

Contextual Factors

Some of the factors that may change the activities implemented by NIDRR, both directly and indirectly, are called ''contextual factors'' and are shown at the base of the Logic Model (see Appendix 2). Changes may be mandated directly in changing policies or indirectly in a changing environment that might require new strategies. The contextual factors include variable funding, scientific and technological advancements, societal attitudes, economic conditions, changing public policies, and coordination and cooperation with other government entities.

II. Managing for Results

A. Overview

In this chapter, NIDRR presents the management agenda for implementing its disability and rehabilitation research portfolio. Management of NIDRR research programs and projects encompasses many distinct aspects: provision of a results-oriented planning environment, selection and scheduling of priorities, operation of program mechanisms to carry out research and related activities, organization and monitoring of projects, and support for interagency and international research efforts.

To further advance the management of research and related activities, NIDRR is developing plans to improve its grant-making procedures and to expand the scope and enhance the effectiveness of its standing peer review panels. The Plan delineates and clarifies the processes of decision-making, and includes a new emphasis on research portfolios and research clusters, which use the different program mechanisms to integrate disparate research projects in a given topical area. Over the lifetime of the Plan, NIDRR will systematically evaluate all aspects of its management activities.

B. Results-Oriented Planning Environment

To facilitate advancements in rehabilitation and disability and rehabilitation research, NIDRR will delineate and plan strategic goals, identify specific program options for achieving the goals over time, and manage a wide range of projects derived from priorities based on these goals and program decisions. GPRA requires that all Federal managers link resources to results through use of outcome performance measures.

NIDRR research comprises a diverse portfolio of projects. As is true of overseeing and directing any sizeable portfolio of investments, management must set criteria for choices, time investments, execute decisions, monitor returns, evaluate outcomes, rebalance as necessary, and report results. NIDRR anchors its portfolio management and performance evaluation systems in the legislative mandate set forth in the Act. As described in the previous chapter, NIDRR translates the legislative mandate into its mission and strategic goals through continually assessing performance, measuring project progress and short-term outcomes, tracing intermediate outcomes as the target systems use the projects' results, and identifying long-term outcomes as depicted in the NIDRR Logic Model.

Within the accountability goals established by GPRA and PART, NIDRR is responsible for measuring and reporting the progress of its many research projects. NIDRR managers and program stakeholders face the continuing challenge of delineating longer-term achievements, as these will improve the use of scarce resources, advance outcome measures, and provide feedback on strategic goals.

Priority Planning

NIDRR, like all Federal agencies, must plan and schedule its decision-making for portfolio management over a multi-year time frame. At any given time, NIDRR is engaged in implementing and managing ongoing projects, conducting grant competitions and making new awards, planning for the next immediate budget cycle, and assessing the

consequences of multi-year funding decisions for subsequent funding cycles. Table 4 presents time frames and descriptions of activities for the management of NIDRR research.

TABLE 4.—TIME FRAMES FOR PLANNING AND IMPLEMENTING MANAGEMENT IMPROVEMENTS

Time horizon	Process	Description of activities	Product
36–24 months prior to start of fiscal year (FY).	Pre-planning	Review Plan, strategic and performance goals, portfolio of existing projects to address emerging opportunities and ongoing needs.	Potential priority areas in broad terms.
24–18 months prior to start of FY	Planning	Initial environmental scan, identification of potential projects.	Refined list of priorities.
9 months prior to start of FY through start of FY.	Program Priority Choices	Based on budget and identified goals and criteria, establish specific priorities and issue announcements.	Priorities.
During FY	Pre-Award Decision and Award	Make award decisions based on peer review and program considerations.	Projects chosen for award based on peer review and extent to which proposed activities match Plan.
1 to 5 years post-award	Post-Award Management	Throughout project periods, monitor progress, assess trends, feed back data for planning and portfolio decisions.	Data on project and center operations.
3–10 years post-award	Performance evaluation	Review goal measurements, programs, and combinations of projects for outputs, outcomes, and impacts.	Documented outcomes.

Timeline

This Plan describes a number of important changes that will improve the way NIDRR manages its multiple responsibilities to constituencies, grantees and potential grantees, and the public. These changes will take five years or longer to be fully realized. The timeline for completion of these efforts is identified in Table 5.

TABLE 5.—TIMELINE FOR MANAGEMENT ACHIEVEMENTS

Item	Description/Implication	Timeframe
Regulation changes	Update selection criteria and legislative references; implement small grant authority; describe procedures for resubmission; establish proposal content.	1 year.
Fixed competition schedule	Annual announcement of priorities; notices inviting applications, peer reviews, and grant awards at regular dates.	3 years.
Standing panels for competition review	Enhance expertise of standing panels	3 years.
Evaluate clusters	Using expert panels, review topical project clusters	5 years.
GPRA panels	Establish standing panels for annual review of quality of outputs, research rigor, short-term outcomes.	3 years.
Environmental scan	Establish procedures for conducting comprehensive studies of relevant technological, scientific and policy changes with implications for disability.	4 years.
Independent Expert review	Conduct comprehensive review by independent panel of status of research on disability.	3 years.

To accomplish a number of goals, NIDRR plans to initiate efforts to change regulations governing the management of its research portfolio. NIDRR will make changes to selection criteria that will improve the quality of its peer review and provide for more consistent evaluation. Moreover, the initiation of a streamlined, systematic process for resubmission of applications would be useful for grantees and peer reviewers. The establishment of elements needed for a standardized proposal narrative would facilitate a more consistent review. The following steps are intended to advance NIDRR research management:

- NIDRR will implement a regular, fixed competition schedule. This will facilitate the recruitment and retention of standing panels of reviewers.
- NIDRR will undertake a rotating review of all major components of its research portfolio.
- In order to meet the obligations of GPRA, NIDRR will establish expert panels to conduct an annual review of its clusters of projects. Data for this evaluation will be drawn from existing (or planned) data sources to the maximum possible extent, *e.g.*, using the Annual Performance Report (APR) as one source document.
- NIDRR intends to institute systematic ''environmental scans'' to help ascertain elements of technology, science, or policy that may impact research to be conducted in the future. These scans shall be carried out by NIDRR staff, making use of all available data sources, and may involve experts and other stakeholders as needed.
- As part of the ongoing evaluation of the appropriateness of the NIDRR research portfolio, NIDRR will, together with other Federal partners, initiate an

external study of disability research and related topics.

Funding Mechanisms and Strategies

NIDRR operates a number of program mechanisms to support research and related activities. These mechanisms vary in purpose, duration, and resource allocation. Rehabilitation Research and Training Centers (RRTCs) and the Rehabilitation Engineering Research Centers (RERCs) are primary recipients of NIDRR resources and carry out many of NIDRR's major research efforts.

NIDRR support of RRTCs is specified in the Act. RRTCs are funded to conduct coordinated and advanced programs of research, training, and information dissemination in priority areas that are specified by NIDRR. RRTCs are expected to be multidisciplinary; involve people with disabilities and their families; provide advanced research training, as well as training for rehabilitation practitioners, consumers, and families; and provide undergraduate education. RRTCs are designed to be national centers of scientific research and resources for the disability and rehabilitation field, providing information and technical assistance to a broad constituency. Each RRTC typically is funded for five years.

RERCs also are specified in the Act, and conduct engineering and technological research to design, develop, and test equipment, technologies, assistive devices, and methods that will remove environmental barriers and provide innovative models for rehabilitation technology service delivery.

The Act also provides for discrete research projects and other related work. These undertakings are carried out either through Disability and Rehabilitation Research Projects (DRRPs) that are directed toward solving specific problems identified by NIDRR, or through the Field-Initiated (FI) Program.

A program of investigator-initiated research was created by NIDRR in 1984, under its R&D authority. This FI program supplements NIDRR's directed research portfolio by addressing diverse research issues in promising and innovative ways. FI research projects cover all aspects of NIDRR's domains, including employment, independent living, medical rehabilitation, and development of new technologies, and address all disability populations with a wide range of research approaches.

The Act also provides for two C–B programs—Fellowships and Advanced Rehabilitation Research Training Grants (ARRTs). Fellowships are awarded to individuals in various stages of their careers to support one year of independent research in a selected area. ARRTs are awarded to institutions of higher education to support advanced training in research in any discipline investigating issues of disability and rehabilitation. ARRTs, which typically are funded for five years, provide stipends to trainees and funding for mentoring, instruction, hands-on research experience, and opportunities for presentation and publication.

NIDRR also supports service demonstration and research programs to develop and evaluate improved methods and systems of rehabilitation care for individuals with spinal cord injury, traumatic brain injury, and burns.

Fixed Competition Schedules

NIDRR will move toward a fixed schedule for competitions that will enable potential grantees to better plan application efforts, facilitate NIDRR's work with reviewers, and increase efficient grant-making operations at NIDRR. Fixed schedules will maintain consistent dates for key activities in the competition process, including announcements of final priorities, application due dates and award dates. These goals are consistent with the Department's overall management directions. To accomplish these goals, NIDRR intends to publish all of its proposed priorities and, following public comment, final priorities annually, on a combined basis. This will allow NIDRR's constituents to view the overall scope of NIDRR's planned priorities and to evaluate and submit comments on these priorities at one time rather than at different times throughout the year.

Managing for Results at NIDRR

NIDRR research management will be guided by many elements and will employ several research planning and decision-making principles in its work. These principles include:

- NIDRR will implement its research portfolio through use of ''clusters'' of projects that address common subject matters and employ various funding mechanisms. This management approach will be used for specified types of R&D activities and will be grouped around the domains of the NIDRR Logic Model. Portfolio management will utilize strategies that organize and review clusters or groups of related projects. The organization of program analysis by common elements, including subject and the target population that will benefit, improved collaborations, sequencing of activities and related methods will encourage collaboration among researchers. Management will facilitate communication among related projects through meetings, technical assistance, research compilations, and related activities.
- To establish the context for its research, NIDRR will assess portfolio investments and opportunities by applying criteria that ascertain the importance of proposed activities in relationship to NIDRR's mission and authority; past, current, and emerging projects; scientific advances; and work of research partners in the U.S. and abroad. Distinguishing the context for a NIDRR initiative may include identifying the legal basis for action, determining partner agency needs, capitalizing on opportunities to respond to new discoveries, continuing effective research, or supporting a national initiative.
- NIDRR will communicate decisions clearly and understandably to a wide range of audiences. The complex interrelationships inherent in disability and rehabilitation research require that NIDRR's decision making process be clear and understandable to a wide range of audiences. Success will be attained through increasing public input to planning; holding regularly scheduled competitions; and continually assessing the quality of communications with stakeholders.
- NIDRR will make choices regarding resource allocation using the best available evidence. NIDRR will ensure that explanations of directed activities are clear to external observers in reviews of funding opportunities and actual awards. Portfolio decisions will reflect advisory input such as scientific conferences, literature reviews and public comments. NIDRR will provide explanations for the use of ''directed'' versus ''non-directed'' (*i.e.*, NIDRR priorities vs. FI) research.
- NIDRR will allocate resources across program clusters to achieve the best relationship of costs and benefits. Factors for consideration may include the anticipated size of the investment; available funds; congruence with NIDRR's Logic Model; and risks of failure to act, including lost value and expertise.
- NIDRR will build on current capacity and promote the development of new capacity to anticipate future needs. C–B has two important dimensions in NIDRR's management framework. First, NIDRR strives to assess readiness of potential applicants to address the specific research topics. Second, some NIDRR program activities have as their primary purpose the enhancement of future disability and

rehabilitation research efforts through improved resources.

For both dimensions, NIDRR management must assess the ways in which investments support not only new research areas, but also the development of methods and measures that improve outcome assessment and evidence-based practices, and the investment in people to improve research capacity. NIDRR also has responsibilities to address areas of special need, such as improving services and opportunities for racial and ethnic minority populations (see section 21 of the Act); research capacity to address specific geographic issues; and training for individuals with disabilities and their families.

• Quality program management at NIDRR will require the further development of internal and external controls to provide knowledge of ongoing and completed research and its utility to stakeholders.

Internal and external controls will assist in assessing program progress in implementing the Plan. High-quality scientific peer review with preeminent peers will ensure high quality research. Participation of people with disabilities at all stages of NIDRR-funded work also will contribute to quality outcomes. Monitoring of project and research activity will ensure that funds are spent wisely, efforts are on target, effective feedback is provided, and best practices are identified. Formative and summative ''in-process'' peer reviews will continue to establish quality mechanisms for evaluating and disseminating research findings.

Peer Review Processes

Application review is central to efforts that ensure the integrity and validity of the research agenda. This review provides both face and content validity to the research portfolio. Thus, it is imperative that this process be as effective as possible.

As mandated by the Act, NIDRR continues its commitment to a review of its research portfolio by a fully representative audience that includes both researchers and consumers. NIDRR envisions a standardized peer review process across NIDRR's research portfolio, with standing panels servicing many program funding mechanisms.

NIDRR will establish standing panels as part of an overall revision of program operations. By providing standing panels, NIDRR anticipates achieving a more consistent review of applications, thereby encouraging continued growth and improvement in those applications. A fixed competition schedule, as described above, will allow panelists to reserve time for the reviews and enable a higher percentage of individuals to complete their term of service. Such consistency should increase reviewer familiarity and skill with NIDRR research programs, allow effective role modeling by panelists, and ensure more effective training efforts. NIDRR will provide training to all panelists to optimize their effectiveness in reviewing proposals.

Monitoring

As is depicted in the NIDRR Logic Model (Appendix 2), NIDRR will evaluate the outcomes of its grantee research efforts; measures of success will vary by goal and topic. NIDRR will use the results of outcomes research to judge projects for productivity gains, economic value, practitioner satisfaction, and end user satisfaction. Product indicators will measure how a new or improved tool contributes to better rehabilitation technologies. Citations and bibliometrics on a grantee's research efforts will be applied to identify widespread use of a new or improved theory, measure, or method.

Historical tracing—examining research to outcome, or backward from outcome to contributing research—will be employed to identify key times when a theory, measure, or method advanced the state of a particular field.

NIDRR is developing a systematic tracking of instruments developed by grantees (Tools List), which, along with patent counts, will serve to verify outcomes of research methods and products. Systematic reviews or meta-analyses will be used to evaluate aggregated research outcomes. NIDRR will employ survey techniques to indicate widespread or specialized use of a tool or measure. Qualitative studies of social and behavioral dimensions of research activities indicate the benefit gained from improved tools. NIDRR also works with professional groups to identify increased use of new measures in research and practice guides. The Federal government requires that interventions research adhere to standards for Human Subjects Protection, privacy, and data safety monitoring; such standards are monitored in conjunction with appropriate Department officials.

Research Cooperation

As a leading Federal agency involved in disability and rehabilitation research, NIDRR works closely with numerous other Federal agencies. These working relations are fostered through memoranda of understanding and other interagency agreements that facilitate joint projects. These agreements have resulted in research jointly sponsored with the Substance Abuse and Mental Health Services Administration, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the National Institutes of Health, and other components of the Department of Health and Human Services (HHS). NIDRR also conducts employment research jointly with the U.S. Department of Labor and conducts NFI-related activities with the Office on Disability of HHS, through memoranda of understanding.

Another avenue for interagency cooperation is participation in groups such as the Washington Research Evaluation Network (WREN), a partnership of Federal agencies that serves as a forum for the R&D evaluation community in exploring new approaches that will improve the management of science and technology organizations. These efforts will assist NIDRR as it examines and implements performance measures to assess the quality, effectiveness, and utility of its R&D investment.

Interagency collaborations can facilitate addressing mutual and individual concerns in research areas. A major mechanism for fostering such collaboration is the ICDR.

Interagency Committee on Disability Research

The ICDR, authorized by the Act, will continue to promote coordination and cooperation among Federal departments and agencies that conduct disability and rehabilitation research programs. NIDRR is the administrative home of the ICDR, and the Director of NIDRR chairs this committee. Representatives of more than 35 Federal entities regularly participate in the ICDR. In addition to the full committee, five subcommittees address specific issues: Disability Statistics, Medical Rehabilitation, Technology (including Technology Transfer), Employment, and the NFI).

The goals of the ICDR and its subcommittees are to increase public input to ensure that research efforts lead to solutions for identified needs, to improve the visibility of Federal disability research in general, and to increase collaboration among agencies. The ICDR meets quarterly, and subcommittees meet either quarterly or more frequently. As required by the Act, the ICDR submits an annual report of its work to the President and Congress. Under the NFI, funds are allocated to support the ICDR in coordinating Federal disability research programs relative to technology. The Plan proposes to support the continued work and accomplishments of the ICDR;

information on the ICDR can be accessed on the Internet at: *http://www.icdr.us*.

International Research Program

The magnitude of the overall Federal R&D effort directed to disability and rehabilitation research is relatively small, compared to R&D efforts in other areas. Thus, international cooperation and exchange has been viewed as an important mechanism by which the critical mass of disability and rehabilitation research can be increased. Section 204(b)(6) of the Act states that the Director of NIDRR is authorized to: ''* * * conduct a program for international rehabilitation research, demonstration, and training * * *'' and many nations look to the U.S. as a model for disability and rehabilitation research in technology.

NIDRR has funded the international exchange of information and experts. NIDRR projects have demonstrated the value of international collaboration in developing technology for individuals with disabilities in prosthetics development—for example, a sand casting system that greatly facilitates prosthetic socket fabrication. Additionally, addressing the issues concerning Web accessibility continues to be mutually beneficial to NIDRR's constituents and its international partners.

NIDRR also has funded research in the multicultural aspects of disability and rehabilitation research and in understanding how cultural perspectives affect the development and implementation of intervention strategies and the interpretation and analysis of disabilities.

Thus, there is a compelling reason for NIDRR to continue its work on projects with an international scope, including issues of concern for individuals with disabilities in the Middle East, Asia/Pacific, Africa, Europe/North America, Latin America, and Caribbean regions. There is a possibility for creating further collaborations through the Department and the United States-Mexico Binational Commission. NIDRR supports the United Nations Educational Scientific and Cultural Organization (UNESCO) Flagship activities to ensure the inclusion of children with disabilities in UNESCO's Education for All (EFA) plans. NIDRR is interested in developing closer relationships with funding agencies in other nations. A potential avenue for this would be the United States-European Union (US-EU) Science and Technology Agreement signed in 1997. NIDRR could operate under this agreement to expand cooperation with a comparable governmental agency in the European Commission (EC). The possibility of coordinated calls for research on both sides of the Atlantic could greatly increase the critical mass of research and development of technology, further improving the lives of people with disabilities in the United States and other nations.

Part C: Addressing Outcomes Through Research and Development, Capacity Building, and Knowledge Translation

Preface

NIDRR has built its program of funded activities around the three arenas of R&D, C–B, and KT. For each of these arenas, there are strategic goals and objectives. This part of the Plan presents NIDRR's Strategic Goals and Objectives, and then presents more detailed chapters on R&D, C–B, and KT.

Strategic Goals and Objectives

Strategic goals are broad statements of a program's aims, whereas strategic objectives specify the means by which the goals will be carried out. These strategic goals and objectives are intended to communicate NIDRR's main themes and directions, and not to serve as measurable operational objectives. NIDRR has developed the following set of comprehensive strategic goals and objectives that reflect the program's mission and align with both the targeted outcome arenas depicted on the Logic Model (see Appendix 2) and the Institute's GPRA performance measures.

Advance Knowledge Through Research and Related Activities

Generate scientific knowledge, technologies, and applications to inform policy, change practice, and improve outcomes.

- Objective 1a: Contribute evidence-based theories, information, and analyses to increase understanding and enhance knowledge of disability and rehabilitation related concepts, issues, and emerging trends and developments.
- Objective 1b: Provide new and improved measures and methods to strengthen the scientific basis of disability and rehabilitation related research, policy, and practice and increase the generalizability of findings and utility of products.
- Objective 1c: Develop new and improved interventions, programs, products, devices, and environmental adaptations to guide decision-making, change practice, and enhance access, function, and opportunities for full participation.

Goal 2: Advance Knowledge Through Capacity-Building

Increase capacity to conduct and use high quality and relevant disability and rehabilitation research and related activities designed to guide decision-making, change practice, and improve the lives of individuals with disabilities.

- Objective 2a: Promote productive partnerships with other Federal agencies and non-federal organizations and facilitate improvements in R&D infrastructure to strengthen the research portfolio, support clinical trials, and increase the effectiveness of KT efforts.
- Objective 2b: Encourage multidisciplinary applications representing a broad array of relevant fields and from diverse individuals and underrepresented institutions to balance the research portfolio and strengthen the capacity to solve problems in a creative, state-of-the-art manner.
- Objective 2c: Enhance opportunities for cross-disciplinary and advanced research training in disability and rehabilitation-related fields and improve the quality of training provided to qualified individuals, including students with disabilities and from minority backgrounds.

Goal 3: Advance Knowledge Translation

Promote the effective use of science-based knowledge, technologies, and applications to inform disability and rehabilitation policy, improve practice, and enhance the lives of individuals with disabilities.

- Objective 3a: Promote external review of the quality of NIDRR funded research and related activities through participation in independent scientific collaborations (e.g., Campbell and Cochran Collaborations) and registries.
- Objective 3b: Develop tools and methods to facilitate effective accumulation, translation, dissemination and transfer of disability and rehabilitation related knowledge, technologies, and applications to relevant stakeholders.

These strategic goals and objectives are addressed in the following three chapters: I. Research and Development, II. Capacity Building, and III. Knowledge Translation.

I. Research and Development

At the heart of NIDRR's mission is supporting research to improve the lives of people with disabilities. The associated strategic goal for this is to generate science-based knowledge, technologies, and applications to inform policy, change practice, and thereby improve overall conditions for people with disabilities. This section focuses

attention on the major domains as seen in the Logic Model, beginning with employment of people with disabilities, which is a major concern of the Department and of NIDRR. Similarly, NIDRR is interested in maximizing choices for persons with disabilities as they select their dwellings, transportation, and life activities. Health and function are essential components of such life choices. A focus on technology that supports these choices is of central importance to NIDRR.

As NIDRR establishes goals and priorities for effective resource allocation, the Institute is interested in improving knowledge about people with disabilities, including the nature and duration of disability, where they live, and what kinds of jobs they have.

The future research agenda for NIDRR rests on the strategic goals and objectives defined above and on the long-term outcomes depicted in the Logic Model, which call for eliminating disparities in employment, participation and community living, and healthcare between people with disabilities and the general population. However, because achieving this desired end-result requires changes in the overall condition of people with disabilities that go beyond the reach of the Institute's mission, it is necessary to articulate an additional set of more operational performance goals. Unlike long-term outcomes, performance goals, which may be output or outcome-oriented, lie within a program's span of accountability and consist of tangible, measurable objectives, against which actual accomplishments and achievements can be compared.

Within the NIDRR research agenda, performance goals are formulated separately for each of the major domains of the Institute's mission. However, it is important to note that because of differences in the needs of consumers and levels of knowledge and methodological development across domains, the number of articulated performance goals may differ among the domains. NIDRR will publish specific implementation strategies in the form of proposed priorities and, following public comment, final priorities annually, on a combined basis.

A. Employment

Overview

For many people with disabilities, employment that is challenging, fulfilling, and fairly and adequately compensated is the ultimate rehabilitation outcome. For those individuals interested in workforce participation, employment shapes the lives of individuals with disabilities at all stages of life. Successful workforce participation requires supports and partnerships of employers, service providers, workers, and often a network of family, friends, and community entities. At the individual and systems level success is often measured in terms of acquisition, improvement, and enhancement of skills, productivity, earnings, job retention and advancement, and benefits. NIDRR advances employment-related innovations that contribute to success at work and subsequent improvements in quality of life in education, home, and community.

Research can be used to strengthen the scientific basis of disability-related employment policy and practice. Studies provide validated information that improve understanding of employment policy and practice as it affects the workforce and society. Moreover, research findings related to career planning, job entry, advancement, and retention can assist individuals with disabilities, particularly those with significant disabilities, in moving from dependency on public benefits to self-sufficiency, or from underemployment into work that is consistent with the individual's strengths, abilities, and interests. Examples include workplace assistance, methods, and techniques developed from productivity studies, and accommodations improve on-the-job outcomes.

Employment research supported by NIDRR for people with disabilities strives to identify proven job enhancements and career building blocks to sustain them in the workforce. NIDRR supports studies to improve knowledge of societal, environmental, individual, and behavioral factors that serve as barriers or facilitators for employment.

The Context for Research on Employment

The employment policy environment has changed dramatically in recent years. Laws such as the Ticket to Work and Work Incentives Improvement Act (TWWIIA) and other initiatives were designed to erase some of the disincentives to work that current public policy and programs present for beneficiaries. Sound research at the systems and individual levels is necessary to evaluate the impact of long-standing policies and programs, and to assess new developments as they are considered for national implementation, modification, or elimination.

Both individuals and employers are intended beneficiaries of NIDRR employment research. For individuals, employment research can develop and improve interventions for and measures of individual function and task performance at all stages of life. NIDRR's employment research may be general across disabilities or specific to certain target populations. Many employment issues, particularly those related to economic and social policies, have similar impacts on people with different disabilities. However, some aspects of employment research, such as accommodations at the work site or applications of technology, may be specific to persons with physical, communication, cognitive, or psychiatric disabilities and NIDRR will address their specific needs as appropriate.

Employers are important targets for NIDRR research. Research addresses methods to integrate unique needs of employers and disability populations to improve employment outcomes across the life span. NIDRR research can lead to more accessible work environments. R&D activities seek to address employer concerns about costs of accommodations and generate innovative approaches to alleviate obstacles to accommodations. Research defining employer perspectives on hiring and retaining people with disabilities is in early stages. Continued research will help in understanding how economics, legal issues, healthcare, functional status, and attitudes drive employer practices with regard to people with disabilities. Employer-oriented, or demand-side, research will help policymakers, employers, and service providers develop better strategies for meeting the employment needs of people with disabilities and hiring entities.

Employment researchers must overcome significant challenges in their work, including: Diverse employment settings and service systems; limited access to work settings to test interventions; inadequate research methods and measures; unsatisfactory models for designing new employment initiatives; difficulty in arranging cooperation of service partners and employers; and work disincentives. Consequently, it is critical for NIDRR to sponsor studies that pose significant research questions, use sound methods, and produce results that are generalizable to large numbers of people with disabilities.

Disability and rehabilitation researchers explore methods, costs, and results of services of rehabilitation programs or supported employment, including studies of natural supports at work as they relate to employment

outcomes. Researchers address PAS challenges and solutions for work. PAS aids an individual with a disability in performing activities of daily living on or off the job. Rehabilitation technology and universal design require systematic application of products, environmental adaptations, and engineering. Technological innovations support enhanced personal function and address the barriers confronted by people with disabilities in many areas, including employment.

For a person with a disability, personal and environmental factors such as health, age, work incentives and disincentives, accommodations, functional capacity, education, PAS, housing and transportation influence labor force participation. Policy and societal changes, including technological advancements, continually change the questions that must be asked about labor force participation, earnings, and work.

NIDRR employment research addresses a culturally diverse population across age, gender, ethnic, disability, and socioeconomic groups. In addition to addressing the general population of people with disabilities, NIDRR develops strategies for targeted services for subpopulations. For example, research identifies needs of persons who are blind or visually impaired, or who are deaf or hard of hearing. To assist another subpopulation of people with disabilities, NIDRR works with the Center for Mental Heath Services in HHS on the employment needs of persons with mental illness. NIDRR works with the Social Security Administration on disability criteria for benefits, return-to-work, and the TWWIIA.

Research relates transitions across the life span to employment outcomes for people with disabilities. Transition services promote movement from educational settings and post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community-based services to participation in the labor force. Activities address individual student needs, taking into account individual preferences and interests. NIDRR's employment research addresses the lifelong challenges and opportunities of transitions in employment of people with disabilities.

Accomplishments in Employment Research

Research on theories, measures and methods for employment has:

- Developed, at the University of North Carolina, a method to analyze administrative complaints and lawsuits filed under the employment discrimination mandates of the ADA. Findings describe people with disabilities and show that the Equal Employment Opportunity Commission's mediation program has increased settlements.
- Simplified and reorganized demographic data resources on employment, income, and poverty status of persons with disabilities. The online statistical resource, provided by Cornell University, is readily available to all in need of accurate disability statistics.
- Developed, at the University of Montana RRTC on rural disability, an improved measures and methods for assessing transportation, housing, employment, independent living services, health and wellness facilities, and community planning activities for people with disabilities in rural communities.
- Developed, at the University of Missouri, a model designed to ensure students with disabilities access to accommodations, mentoring, and information technology upon graduation.

Research on new and improved interventions, products, devices, and environmental adaptations for employment has:

- Demonstrated an input-intervention-outcome model for vocational rehabilitation services to deaf or hard of hearing consumers under the Workforce Investment Act (WIA) and the Rehabilitation Act.
- Investigated State employment services to people with disabilities to improve outcomes within welfare-to-work initiatives.
- Developed employment-related assistance services for individuals who are blind or severely visually impaired receiving services under the WIA.
- Investigated incentives, disability management, return-to-work, and telecommuting to improve employment outcomes and benefit employers.
- Developed approaches to help ensure that students with disabilities access technology resources, mentoring, and advanced IT in school and obtain related jobs upon graduation.
- Developed a prototype computer software program that provides the opportunity for job seekers who are deaf or hard-of-hearing to practice interviewing skills for employment.

Research Agenda

Within the domain of employment research, NIDRR will focus on increasing useful theories, measures, and methods to improve the scientific validity of employment research and on research to increase the availability of validated interventions, products, devices, and environmental adaptations.

Theories, Measures and Methods

Tested theories, measures, and methods to increase the scientific validity of employment research will enable end users to sustain quality employment for individuals with disabilities by improving:

- Understanding of employment trends for individuals with disabilities in relation to macroeconomic, legislative and societal changes, and demographic trends.
- Services and policies that impact work-related needs of individuals with disabilities and employers.
- Tools that measure multiple dimensions of employment for individuals with disabilities and the employment industry.

Valid theories for investigating employment phenomena and measures of the specific needs of subpopulations should enable researchers to map pathways from knowledge advances to target systems, and to identify the determinants of labor force participation, lost earnings, and recovery of employment.

Interventions, Products, Devices, and Environmental Adaptations

Research on interventions, products, devices, and environmental adaptations will serve to develop strategies that will:

- Successfully support transitions into employment and within the employment setting across the lifespan.
- Effectively increase access to and quality of vocational rehabilitation and individualized employment services, workplace supports, and job accommodations; successfully reduce barriers to hiring while enhancing work skills, job acquisition, job retention, and career advancement.
- Effectively contribute to program eligibility determinations, design of program components, and assessment of program outcomes.
- Effectively address the employment needs of individuals with intellectual or cognitive disabilities, mental illness or psychiatric disabilities, and episodic disabilities of all etiologies. These interventions must be sensitive to changing demographics.
- Respond to employment needs in high growth and rapidly changing industries.

• Improve work opportunities for individuals with disabilities from diverse interest, knowledge, language, and cultural backgrounds.

• Assist employers and policymakers to provide employment opportunities for people with disabilities.

• Create tools that match the needs of employers and individuals with disabilities for workplace accommodations.

• Improve employment outcomes for specific disability populations, including individuals with behavioral, physical, psychiatric, cognitive, and sensory disabilities.

Thus, NIDRR's research agenda in the area of employment is designed to:

• Strengthen the scientific basis of disability and rehabilitation-related research and practice by increasing the availability of validated theories, measures, and methods to improve measurement, data sources and estimates, and enhance identification, evaluation and prediction of the factors that facilitate successful labor force participation and work-related transitions across the life span.

• Strengthen the scientific basis of disability-related employment policy, practice, and research by providing evidence-based information and analyses that improve understanding of employment trends; specific job industries and changes within industries; individual labor force participation and school-to-work transitions; and that enhance knowledge of the rapidly changing societal developments that affect employment opportunities and outcomes across the life span.

B. Participation and Community Living

Overview

Like employment, participation and community living are at the heart of NIDRR's mission to develop knowledge that will ''improve substantially the options for disabled individuals to perform activities in the community, and the capacity of society to provide full opportunities and appropriate supports for its disabled citizens.'' In this Plan chapter, NIDRR will use the term ''participation'' to represent all three concepts of participation, community integration, and independent living (IL). The central question of the *Olmstead* decision is whether people with disabilities are physically living in the community. This enriched term ''participation'' will help NIDRR and the applied rehabilitation research community to focus on the extent to which people with disabilities are participating in the community in a manner that is meaningful to them.

NIDRR's focus on participation follows the stated purpose of IL programs under the Act. That purpose is ''to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.'' People with physical disabilities historically have employed the term ''independent living'' to indicate a philosophy, movement and service system that work toward a goal of meaningful participation in society. Similarly, the term ''community integration'' has been used to represent a concept, movement, and service delivery system that encompasses the ultimate goal of full societal participation of people with cognitive or psychiatric disabilities. Thus, incorporation of the IL and community integration terms within the term of participation will allow NIDRR to focus on the ultimate outcome sought by all people with disabilities. This chapter mainly addresses general research needs related to achieving societal participation for people with all types of disabilities. Where necessary, the Plan presents research topics that are specific to promoting participation among particular subpopulations of people with disabilities.

Research enhances the scientific basis for a wide range of policies and practices aimed at promoting the societal participation of individuals with disabilities. Research may include evaluation of specific participation-promoting programs, interventions and products, as well as development of methods, measures and theories to enhance the scientific rigor of these evaluations. NIDRR sponsors research to improve knowledge of individual- and societal-level factors that may serve as barriers to, or facilitators of, participation among all people with disabilities.

The Context for Research on Participation and Community Living

The current policy context for research that promotes full participation of people with disabilities is supportive and encouraging. There are two major components of this context. The first is the *Olmstead* decision, which upholds the integration mandate from Title II of the ADA, requiring public entities to provide services ''in the most integrated setting appropriate to the needs of qualified individuals with disabilities.'' Just as encouraging is the 2003 report of the President's New Freedom Commission on Mental Health, which makes recommendations that would enable adults with serious mental illnesses and children with serious emotional disturbance to live, work, learn, and participate fully in their communities.

The *Olmstead* decision holds that States must place people with disabilities in community settings rather than institutions whenever appropriate. This decision and subsequent efforts by States to abide by it have spotlighted the many barriers to meaningful community participation of people with disabilities. These barriers include, but are not limited to: (1) A shortage of affordable and accessible housing in the community, (2) a shortage of personnel to serve as personal assistants in the community, (3) a lack of accessible and appropriate community-based health and dental care, (4) a lack of accessible transportation, (5) problems and gaps in the mental health service delivery system, and (6) a persistent bias in Medicaid-funded long-term care programs that channels resources away from communities and into institutions. Many States are models of effective planning for *Olmstead* implementation. Full implementation of these thoughtful plans could lead to enhanced integration and participation of people with disabilities.

Future research on community integration, IL and participation of people with disabilities also will be influenced by the 2003 report of the President's New Freedom Commission on Mental Health, ''Achieving the Promise: Transforming Mental Health Care in America.'' The report provides six major goals for our nation's mental health efforts that are directly related to the participation of individuals with psychiatric disabilities. These goals are (1) Americans understand that mental health is essential to overall health, (2) mental healthcare is consumer and family driven, (3) disparities in mental health services are eliminated, (4) early mental health screening, assessment, and referral to services are common, (5) excellent mental healthcare is delivered and research is accelerated, and (6) technology is used to access mental healthcare and information.

The above-mentioned report shows a mental health system in disarray. For children and adults with psychiatric disabilities, the service delivery systems, policies, finances, and

treatment options are fragmented, confusing, and inadequate. Unnecessary institutionalization remains a problem, as do the practices of seclusion, restraint, and forced treatment. Stigma remains a major obstacle to treatment, and suicide continues to be a major public health problem. People with psychiatric disabilities are overrepresented in the homeless population and in the juvenile and criminal justice systems. Existing policies frequently force parents of children with psychiatric disabilities to relinquish custody to ensure that their children receive adequate mental healthcare.

To respond to the challenges described in the preceding paragraphs, NIDRR research in the area of participation develops and evaluates strategies for services, interventions, products, and modifications to the built and social environment that would allow individuals with all types of disabilities to live and participate in their communities. These services, interventions, products, and environmental adaptations differ for specific subgroups of people with disabilities. NIDRR-funded researchers are among the vanguard of measurement experts seeking to develop new and improved theories and measures of participation and community living so that the impact of these specific strategies and interventions can be more accurately determined.

Accomplishments in Participation and Community Living Research

NIDRR-sponsored research has been associated with a number of significant outcomes related to the participation of people with disabilities. These accomplishments are categorized as related to (1) theories, measures, and methods or (2) interventions, products and devices, and environmental adaptations.

Research on Theories, Measures, and Methods Has

- Addressed the full range of independent living issues, from the development of conceptual frameworks to policy research, to research addressing the management needs of centers for independent living (CILs).
- Led to the acceptance of the concept of consumer-direction and control among a broad population of people with disabilities. This concept originated among working-age individuals with physical disabilities, but more recently has been accepted by leadership in both the aging and developmental disability communities.
- Led to the development of new measures of participation and community integration among people with disabilities. Measures developed in the past include the Community Integration Questionnaire and the Craig Handicap Assessment and Reporting Technique (CHART).

Research on Interventions, Products, Devices, and Environmental Adaptations has:

- Led to the development and expansion of a range of services and programs designed to directly support individuals with disabilities in their communities.
- Helped determine that, from the consumer perspective, consumer-directed PAS are delivered in a manner that is no less safe than traditional agency-directed services.
- Increased the knowledge base about PAS programs and best practices among a wide variety of stakeholders, including local, State and Federal-level policymakers, service-providers, and disability advocates.
- Clarified the extent of PAS use, as well as the unmet need for PAS in the United States.
- Led to advances in treatment options and community-based supports for individuals with mental illness and psychiatric disability. These advances include recovery-oriented services and practices; psychiatric rehabilitation; peer supports and other natural supports in community and employment settings; supported education services in higher education, employment services that integrate mental health and vocational rehabilitation services; psychosocial rehabilitation; services that are provided by mental health consumers, and systems of care and wraparound services in children's mental health.
- Led the Alzheimer's Association and the Arc of the United States to use recommendations derived from NIDRR-funded research to promote constructive approaches to community care for people with intellectual and developmental disabilities affected by dementia.
- Promoted participation by creating the concept of universal design, which holds that all products and environments can be created for use by all people, regardless of their physical or mental abilities.
- Promoted participation by applying universal design principles to create accessible voting kiosks, ATMs, computers, and other mass-market products that allow people with disabilities to participate in their communities.
- Promoted participation through the development of disability-accessibility guidelines for the World Wide Web.
- Promoted participation through design and application of a wide variety of technological products that allow easier navigation of indoor and outdoor environments by people with sensory disabilities. For example, ''Talking Signs®'' technology allows individuals with low vision to travel more independently in all environments. This remote infrared technology has been deployed in numerous cities throughout the U.S., Europe, and Asia. Other NIDRR-sponsored research-based advances include wayfinding applications, combinations of global positioning technologies with Braille capabilities, audio descriptions in theaters, and closed-captioning in public spaces.

Research Agenda

The expected outcome of NIDRR's research efforts, at the individual level, is the development of new knowledge that can be used to increase the capacity of people with disabilities to plan and direct their own lives, choosing among options for maintaining the levels of independence and social involvement that they desire.

The expected outcome of NIDRR's research efforts, at the systems level, is the production of knowledge that can be used to improve options and services for achieving independence and social involvement, and the supports necessary to realize those options.

Theories, Measures, and Methods

Effective theories, measures and methods to achieve optimal levels of participation among individuals with disabilities are important because they:

- Improve understanding of the wide range of activities that may be associated with enhanced participation among people with disabilities.
- Improve tools that measure multiple dimensions of participation among individuals with disabilities.
- Improve the ability to scientifically identify and evaluate effective services and policies that impact the participation levels of individuals with disabilities.

By bolstering understanding of the complex meaning of participation and employing new and improved measures that adequately reflect this concept, NIDRR will build a stronger foundation of research-based knowledge upon which participation-focused services and policies can be based.

NIDRR will continue to promote research that develops and strengthens theories for understanding and

promoting community integration, IL and participation, as well as new methods for measuring these ultimate outcomes. NIDRR will continue to lead the way in the development of participation and community living measures. Current measures of participation and community integration largely have been developed by researchers working in the context of medical rehabilitation, and have been applied to populations of people with physical disabilities. Measurement of participation and community living among people with intellectual or cognitive disabilities requires emphasis on the development and testing of measures designed to be applied to populations of people with these types of disabilities. NIDRR will sponsor research to construct reliable and valid theories and measures for participation and community integration of individuals with intellectual, cognitive, or psychiatric disabilities. These advances will provide a foundation for high quality research on these issues.

NIDRR also plans to pursue research to develop advanced theories of disability and participation to capture the complex interaction of environmental and individual factors. That will require improvements in the ability to measure the influence of environmental factors on participation levels of people with disabilities. An increased understanding of the environment's role will sharpen understanding of the specific physical or social barriers to be addressed, and the facilitators on which to build enhanced participation.

Interventions, Products, Devices and Environmental Adaptations

New and improved interventions, products, devices, and environmental adaptations are important because they:

- Improve participation outcomes for all individuals with disabilities. Improved participation outcomes would include quantitative increases in the number of individuals with disabilities living and interacting in the community, as well as qualitative improvements in the nature and quality of that social involvement.
- Provide access to individualized services and supports to promote participation among all people with disabilities.
- Apply conceptually sound theories of societal participation for specific subgroups of people with disabilities.
- Can be tailored to the specific needs of individuals with physical, sensory, cognitive, or psychiatric disabilities to reduce environmental barriers to participation.

NIDRR is interested in promoting rigorous research based on well-developed theories, using validated measures and appropriate methods that examine the efficacy and effectiveness of interventions and programs designed to promote community integration. These interventions may include Federal, State, and local programs, or improved environmental adaptations or devices that enhance the ability of individuals to live independently in the community. NIDRR is especially interested in sponsoring research on programs and interventions that will (1) Promote participation in educational opportunities over the life span, (2) enhance access to recreation and transportation, (3) enhance access to PAS and direct-care providers, (4) promote the availability of accessible, affordable housing for people with disabilities, (5) enhance asset-accumulation practices among people with disabilities, and (6) enhance participation and integration of parents with disabilities, and families with children with disabilities.

NIDRR intends to place particular emphasis on research related to direct supports and services that will enable individuals with disabilities to have options for participation and to implement their choices in their environments. The aim of this research would be to develop best practices for providing supports for people with disabilities living in the community.

NIDRR also will sponsor research to determine the ways in which people with disabilities can use applications of universal design to reach their participation goals. This research will illuminate the barriers to, and facilitators of product utilization, and will guide future dissemination and marketing of state-of-the-art technologies. Thus NIDRR's research agenda in the domain of participation and community living is designed to:

- Strengthen the scientific basis of policies and practices aimed at enhancing participation among people with disabilities by providing information and analyses that improve understanding of participation levels among individuals with disabilities and the multiple barriers to and facilitators of their participation.
- Strengthen participation-related research and practice by increasing the availability of validated theories, measures, and methods. These theories, measures, and methods will improve data sources and estimates, and will enable better identification, evaluation, and prediction of the factors that facilitate or impede participation and community living. These improvements will enhance the credibility of research and thus increase the utilization of research findings.

C. Health and Function

Overview

Maximizing health and function among people with disabilities is critical to the achievement of NIDRR's mission and the associated higher-order goals of employment and community participation. Functional ability reflects the complex interaction between individuals and the environments in which they live. Accordingly, NIDRR conceptualizes and examines issues of health and function at the systems and the individual levels.

At the systems level, NIDRR-supported research focuses on the structure, organization, and delivery of healthcare and medical rehabilitation services. Individual level research focuses on the development and testing of new interventions that improve functional and health outcomes for individuals. At the systems level, NIDRR also studies access to healthcare and rehabilitative medicine, and the complex delivery systems used for those services.

In conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR posits a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

The Context for Research on Health and Function

NIDRR sponsors research to improve the health and function of individuals with disabilities, as well as to understand and improve the system of healthcare services delivery, including the delivery of medical rehabilitation services.

Individual Level: Ongoing research and clinical efforts have produced a wide variety of programs, interventions, and products aimed at enhancing the health and function of individuals with disabilities. The scope of research in medical rehabilitation is as broad as the numerous conditions that result in disablement, and may focus on the onset of new conditions, the exacerbation of existing conditions, or the development of coexisting conditions. Accordingly, there are important opportunities for advancements in a range of body systems.

Over the course of the last several decades, neurobiologists have been advancing the understanding of the

central nervous system and the complex mechanisms by which cells and neurons are able to compensate for and potentially heal injuries and lesions. NIDRR is well positioned to capitalize on these basic science findings by funding research to develop rehabilitative interventions that are based on the expanding knowledge of neurobiological processes. There is continuous research on prevention of secondary conditions among people with disabilities. Conditions such as pain, muscle weakness, obesity, cardiovascular de-conditioning, and depression are especially prevalent for persons with disabilities, to a great extent because of their sedentary lifestyles. Studies have indicated that persons with disability are more susceptible to earlier age-related functional declines when compared to their non-disabled counterparts.

NIDRR will continue to sponsor research that examines the impact of exercise and activity on the functional independence and overall health status of individuals with both newly diagnosed and long-term disabling conditions. Related to this research on the impact of physical activity on the health and function of people with disabilities are recent findings on the impact of complementary and alternative therapies. Interventions such as yoga, acupuncture, martial arts, and reflexology have enhanced effects on rehabilitation outcomes when coupled with conventional rehabilitation treatment modalities.

There is also a growing body of research on the use of pharmacological interventions to improve health and functional outcomes. There are several examples in treating symptoms of major brain injuries, including new uses for existing drugs that may be effective in treating agitation and fatigue and addressing states of minimal consciousness. New drugs now in testing may show promise for managing spasticity in spinal cord injury (SCI) and multiple sclerosis (MS) and pain management in the arthritis population. Research in medical rehabilitation must remain attuned to pharmacological advances and be prepared to examine their use with rehabilitative interventions.

Research on health and function also involves research on new technologies that improve diagnosis and measurement of disabling conditions, as well as devices to support enhanced function. Under investigation is the extent to which home-based telerehabilitation interventions meet current clinical standards. Researchers are looking at multimedia and virtual reality technologies to minimize pain in burn treatment and to provide cognitive retraining for individuals after traumatic brain injury (TBI) or stroke. Examples of other emerging technological interventions aimed at enhancing individual function include microelectronic connections between the central nervous system and muscle groups affected by injury or disease, and artificial intelligence to enable walkers and wheelchairs to navigate varied terrains.

All of these research-based innovations that have developed over the course of the last decade provide the context and foundation for continuing advances in theories, interventions, and products that will help promote the health, wellness, and community participation of people with disabilities.

Systems Level: The complex, ever-evolving healthcare delivery system in the U.S. plays a major role in the promotion and maintenance of health by all people, including people with disabilities. People with disabilities should have access to an integrated continuum of healthcare services, including primary care and health maintenance services, specialty care, medical rehabilitation, long-term care, and health promotion programs.

While health services researchers are increasingly attuned to racial and ethnic disparities in healthcare, less attention and fewer resources are devoted to disability-related disparities and the innovations in policy and practice that might reduce them. Physically inaccessible offices and equipment, abbreviated appointments, and physician attitudes are significant barriers to the use of appropriate preventive services by people with disabilities. The relative lack of access to healthcare services by people with disabilities is likely to become an increasingly serious problem as the full implementation of the *Olmstead* decision shifts some individuals out of institution-based healthcare into mainstream health services.

People with a range of disabilities disproportionately experience depression and other mental health conditions, and there is a substantial amount of unmet need for mental health services. The NFI strongly promotes improvements to the Nation's mental healthcare delivery system for individuals with severe mental illness. People with all different types of disabilities—not just psychiatric disabilities—may benefit from increased access to mental health services.

The population of people with disabilities is heterogeneous in terms of type of disabling condition, sociodemographic characteristics, and specific healthcare needs. Researchers must make concerted efforts to sample and collect data from the wide diversity of people with disabilities, including racial and ethnic minorities and people in low-income categories. The healthcare experiences of these doubly underserved populations are different than the experiences of white, middle-income people with disabilities.

The relatively small number of studies focusing on healthcare delivery for people with specific types of disability, sociodemographic backgrounds, and healthcare coverage, makes it difficult to piece together a coherent picture of the impact of the healthcare delivery system on health and wellness of people with disabilities. Given the relative lack of research resources in this important area, researchers must work together to synthesize this work to create a coherent body of knowledge that delineates specific practices and policies that are either beneficial or harmful to the health and wellness of people with disabilities. In addition to this synthesis of studies into a coherent mosaic, there is a need for large-sample, longitudinal research projects to determine the impact of healthcare systems on the health and wellness of the diverse population with disabilities. This endeavor will require increased inter-agency cooperation on health services research for people with disabilities.

Accurately and appropriately measuring the health status of individuals with disabilities is critical to our understanding of the impact of the healthcare delivery system on their health and wellness. One barrier to accurate measurement of the health status of individuals with disabilities is the tendency of widely used measures to conflate functional ability with health. Functional capacity and health are distinct concepts; disability is not the same as poor health. NIDRR-funded research has demonstrated that people with lower levels of functional capacity are, in the aggregate, less likely to report positive levels of health. Despite this association, a substantial number of individuals with low functional levels report that their health is good or excellent. Researchers need measures of health that do not rely on estimates of functional capacity. The SF–36, developed by RAND to assess outcomes of medical care, is the most widely used health status measure in the world. Its holistic conceptualization of health is generally appropriate, but it is widely criticized by disability researchers for its tendency to conflate functional ability with health status.

Over the course of the last two decades, NIDRR's investment has been instrumental to the development of appropriate and effective measures of health and function for people with disabilities. NIDRR-funded research led directly to the development of the current standard for measuring functional independence in rehabilitation settings, the Functional Independence Measure (FIM).

There has been considerable discussion about the problems of classifying specific interventions in medical rehabilitation, which is characterized by its overlapping teamwork approach practiced by physical therapists, occupational therapists, and other allied health professionals. NIDRR is funding groundbreaking research in this area. However, the lack of consensus on how to define and measure the multitude of interventions that take place within the ''black box'' of rehabilitation is a persistent barrier to a more rigorous and targeted evaluation of rehabilitation outcomes. The robustness of outcomes research findings requires that the intervention be delineated specifically so that it can be replicated or adapted by researchers or practitioners.

Accomplishments in Health and Function Research

Research on theories, measures, and methods has advanced the field of medical rehabilitation at both the individual and systems levels. At the level of the individual, NIDRR has supported research on theories, measures, and methods that has:

- Supported the development of the Functional Independence Measure (FIM), the most commonly used functional assessment tool in rehabilitation medicine.
- Promoted the conceptual analysis of disability and functional outcomes as the interaction of the individual with his/her environment. NIDRR-funded researchers developed, tested, and implemented the use of the Craig Hospital Inventory of Environmental Factors (CHIEF) instrument to quantify a variety of environmental factors that promote or hinder functional independence and community participation.
- Developed computer-assisted methods for efficiently assessing health and functional status outcomes for individuals with disabilities.
- Developed, tested, and implemented widespread use of instruments such as the Craig Handicap Assessment Research Tool (CHART) and the Community Integration Questionnaire (CIQ) to measure community participation following medical rehabilitation.
- Supported development of quality of life measurements that take a person-centered perspective in evaluating long-term outcomes of disability.
- Developed instruments such as the Walking in Spinal Cord Injury (WISCI) to measure specific functional activities and mobility after SCI. This measure has been adopted by the European Clinical Trials Group in SCI.
- Developed information resources such as the Center for Outcomes Measurement in Brain Injury (COMBI), which provides detailed reliability, validity, and instructions for using the major outcomes assessment tools in TBI.

NIDRR research on theories, measures, and methods also has made many advances that inform the future agenda at the systems level:

- Documented that individuals with disabilities use a disproportionate amount of services from across the healthcare spectrum and incur higher per capita medical expenditures than do people without disabilities.
- Documented a persistent lack of consistent access to a broad spectrum of healthcare services by people with disabilities, including some cancer screenings, primary care, specialty care, and medical rehabilitation services.
- Described and documented a number of systematic Barriers to healthcare for people with disabilities, as well as the consequences of those barriers for individuals' health, wellness, functional ability, and social participation.
- Determined that there are a number of healthcare quality factors that are unique to the population with disabilities, and that these factors are not reflected in population-based health care quality tools that are in current use.
- Improved the ability of State service agencies and education departments to meet the needs of children with mental health disorders by influencing changes in policy and practice regarding parent participation, and improving State financing mechanisms for children's mental health.
- Developed the conceptual, empirical, and technological base of the field of psychiatric rehabilitation and promoted widespread adoption of psychiatric recovery-oriented systems, services, and practices.
- Promoted access to mental health services, including alcohol and drug treatment services, for adults and children with physical and/or psychiatric disabilities.
- Supported the ongoing translation of the ICF classification system into the next generation of post-acute measures of function, performance of activities, and participation.
- Supported applications of state-of-the-art statistical modeling techniques and computer adapted testing methods for bringing increased efficiency and accuracy to the process of outcomes data collection.

Achievements in research on interventions, products, devices, and environmental adaptations have created a basis at the individual level from which to direct future research. This research has:

- Established and maintained model systems programs in SCI, TBI and burn rehabilitation. These programs have collected longitudinal data to characterize the population and outcomes of individuals with these injuries as well as developed new evidence-based interventions to improve long-term functional, vocational, cognitive, and quality of life outcomes.
- Developed specific exercise protocols designed to strengthen and enhance flexibility among individuals with severe arthritis. These protocols have been adopted for use in both the clinic and home-based setting, but require further evaluation.
- Led to the development of novel methods of treating a number of secondary conditions associated with SCI, including urinary tract infections, dyslipidemia, cardiovascular disease, and pressure ulcers.
- Developed new computerized technology for the proper alignment of leg prostheses, to improve the mobility of individuals with foot amputations.
- Developed and tested therapeutic interventions focused on enhancing functional capacity following stroke. Further, NIDRR-funded stroke rehabilitation researchers have systematically documented the natural history of stroke impairment, short- and long-term disability, and the implications of these findings for rehabilitation practice and quality of life after stroke.
- Developed and disseminated an effective health behavior education curriculum that is being used by agencies in the U.S. and internationally to improve the physical activity and recreational skills of people with intellectual and developmental disabilities.
- Developed the conceptual, empirical, and technological base of the field of psychiatric rehabilitation, and promoted widespread adoption of psychiatric recovery oriented systems, services, and practices, including alternative health practices.

• Identified best practices in comprehensive burn care, focusing on early intervention of rehabilitation to improve psychological well-being, functional status, and employment status of burn survivors.

• Generated descriptive findings about the nature and etiology of a wide variety of disabling conditions that have set the stage for testing innovative interventions and rehabilitative treatments.

• Documented the elevated propensity for persons aging with disability to encounter issues such as onset of new chronic conditions, decline of functional ability as a result of changed health status, diminished psychological well-being and quality of life, and diminished family and social supports.

• Described and documented the dynamic psychosocial factors that affect community integration and participation of people with multiple sclerosis.

• Developed numerous assistive devices to improve the health and functional abilities of individuals with disabilities. Examples of these devices include prostheses, orthoses, communication aids, and mobility aids.

• Supported development of repetitive motion techniques on the treadmill, to improve stability and mobility of individuals with SCI and other mobility impairments.

• Developed and implemented telehealth and telerehabilitation initiatives to expand the ability of the organized healthcare and rehabilitation systems to diagnose, treat, and monitor ongoing needs of individuals with disabilities.

• Developed technological advances such as pressure garment materials to prevent contractures among burn survivors.

• Examined the use of portable hand-held devices to support cognitive functioning for individuals with TBI and other neurological conditions.

• Developed a product to support gait recovery in individuals with stroke that has been commercialized and is now sold in the U.S. and Japan.

Research on interventions, products, devices, and environmental adaptations at the systems level has:

• Demonstrated that a substantial number of people with disabilities who need medical rehabilitation services and/or assistive equipment have difficulty accessing them, regardless of whether they are covered by managed care or fee-for-service health plans. This body of research consistently indicates that access difficulties occur most frequently among those reporting the most severe disabilities, those in the poorest health, and those with the fewest monetary resources.

• Demonstrated that a substantial percentage of individuals with moderate to severe disabilities do not have systematic access to preventive medicine and screening services.

• Led to the adoption of a new policy statement by the Medical Advisory Board of the National Multiple Sclerosis (MS) Society, which recommends rehabilitation as a necessary component of quality healthcare for people with MS at all stages of the disease.

• Led to the adoption of the ''Living Well with a Disability'' health education curriculum by a large health plan in California that serves 9,500 individuals with disabilities.

• Increased the interest and commitment among some State Departments of Mental Health to adopt recovery-oriented rehabilitation systems for persons with mental illness.

Research Agenda

At the individual level, NIDRR will fund research that supports the development and evaluation of new interventions, products, devices, and environmental adaptations aimed at improving the health status and functional abilities of people with a wide range of disabling conditions. Many of these new interventions will address the needs of people who are aging with disability, with particular emphasis on minimizing secondary conditions. To aid in the evaluation of these new interventions, NIDRR also will fund research that leads to the development of the next generation of valid and reliable measures of health and functional status among people with disabilities.

These new measures will be applicable in a wide variety of clinical and community settings, and will incorporate consumer perspectives in order to assess the extent to which health status and functional capacity relate to the ability to perform valued activities in the community. NIDRR will conduct research that identifies effective methods for translating data from these new outcomes measures into information that can be used to inform decisions made by consumers, payers, provider organizations, and clinicians.

At the systems level, NIDRR will fund research that will generate new knowledge about the systematic causes and consequences of substandard access to rehabilitation, healthcare, and mental healthcare services for people with a wide range of disabling conditions. This research will identify and evaluate the effectiveness of specific service delivery approaches and reimbursement models aimed at minimizing physical, social, and economic barriers to the full spectrum of health, mental health, and rehabilitation services that are needed by people with disabilities.

Thus, NIDRR's research agenda in the area of health and function is designed to:

• Increase the number of validated new or improved methods for assessing function and health status.

• Increase the number of interventions, products, and devices demonstrated to be efficacious in improving health and function outcomes in targeted disability populations.

• Increase understanding of the underlying structures and processes that facilitate or impede equitable access to rehabilitation and physical and mental healthcare by people with disabilities.

D. Technology for Access and Function

Overview

Everywhere, Americans are using technology to make their lives easier, more enjoyable, and more productive. Americans with disabilities, however, depend upon technology for much more than convenience or a competitive edge. Technology plays a vital role in the lives of millions of Americans with disabilities by helping them to overcome physical, cognitive, and sensory functional deficits, thus enabling them to lead more independent, secure, and productive lives. In the past, persons with significant disabling conditions often were considered to lack potential for habilitation or rehabilitation and were subsequently consigned to institutions or segregated facilities such as nursing homes, denying them the opportunity to live full and meaningful lives. In 2004, barely three decades after the birth of rehabilitation engineering, individuals with significant disabilities are able to live, often independently, in their own homes, and to participate in society in meaningful and productive ways.

Advances in science and engineering have had an extraordinary impact on all areas of disability and rehabilitation. Research has emerged from a period focused primarily on impairment to a period that focuses on a broad range of issues of function and access. NIDRR's leadership in rehabilitation engineering and assistive technology development has played a major role in creating technology for use in rehabilitation services, for use by individuals with disabilities to conduct their daily lives, and to inform policy and adapt environments to meet the needs of persons with disabilities.

NIDRR's Logic Model depicts technology as encircling the goals of sustaining health and function, employment, and participation, because technology is a critical contributor to successful outcomes for persons with disabilities in all these areas. This section of the Plan discusses the societal and scientific contexts of disability technology research, and describes its applications at the individual and systems levels. At the individual level, the primary focus is on assistive technology devices; at the systems level, the areas emphasized include environmental adaptations and accessible IT. Also included are instruments for use in medical and rehabilitative interventions, such as tools for diagnoses, assessments, and therapeutic interventions.

The Context for Research on Technology for Access and Function

NIDRR is well positioned to continue its leadership in rehabilitation engineering and assistive technology research. NIDRR maintains an environment in which rehabilitation engineering and assistive technology research are parts of an institutionalized continuum that includes related medical, clinical, public policy, psychological, economic, vocational and social research. NIDRR continues to promote the value of rehabilitation engineering and assistive technology research while raising the national conscience about the value of research relating to people with disabilities.

Advances in basic biomedical science and technology have resulted in new opportunities to enhance the lives of people with disabilities. Recent advances in biomaterials research, composite technologies, information and telecommunication technologies, nanotechnologies, micro electro-mechanical systems (MEMS), sensor technologies, and the neurosciences provide a potential wealth of opportunities for individuals with disabilities and should be incorporated into research focused on disability and rehabilitation.

NIDRR supports technology-related research at both individual and systems levels. At the individual level, assistive technology is used to enhance the physical, sensory, and cognitive abilities of people with disabilities and to assist them to participate in and function more independently in the home, at work, in recreational settings, and at cultural and religious events. At the systems level, technology R&D activities are applied in ways that enhance community integration, independence, productivity, competitiveness, and equal opportunity by mitigating or eliminating barriers found in large social systems such as public transportation, telecommunications, IT, and the built environment.

Assistive technology often is described as either ''high tech'' or ''low tech''. High tech devices generally are complex and often expensive to produce and use, while low-tech devices often can be made at home or in a hobbyist's workshop, are simple to create and operate, and are usually less costly. One NIDRR researcher frequently states that what is needed is ''not high tech or low tech, but the right tech'' to meet the needs of a specific individual.

Most assistive technology for people with disabilities falls into the category of orphan technology because of the specialized nature, limited demand, and consequent limited markets. This translates into reduced economic rewards for manufacturers. Strategies to address the problem of small markets include universal design and capitalizing on the growing recognition that many improvements intended for people with disabilities serve similar functions for others. For example, closed captioning is useful to all in noisy environments like airports, and in improving English literacy; curb cuts improve access for people pushing baby carriages or luggage; and voice recognition technologies are used throughout the Nation's telecommunications systems.

Consumer participation in rehabilitation engineering and assistive technology research is vitally important. Without end-user input, products tend to be developed in a vacuum; invariably, such products miss critical elements of design that facilitate adoption and successful use by persons with disabilities. The incidence of abandonment of assistive devices has been distressingly high throughout the history of the field. There appears to be a variety of reasons for abandonment, including: Poor fitting; mismatch to the user's needs; inadequate training in use of the device; equipment failures; objection to size, appearance or cumbersomeness of the device; and individual or cultural beliefs and values. Inherent in poor design and mismatch, in particular, is the paucity of customer reference or consumer involvement at each level of product development. In order for products to gain widespread acceptance and adoption, there must be detailed and exacting analysis of user feedback at each stage of product evolution, especially during the earliest stages of development. To continue use of the device, the consumers must find that the functional gains brought by the device outweigh the various inconveniences.

In sum, the principal function of technology research is to support the end-user outcome of participation, including employment, community integration and independent living, and the maintenance of health and function.

Accomplishments in Technology for Access and Function Research

The outputs of recent NIDRR-supported research, along with recent advancements in the field of technology as a whole, serve to describe the state-of-the-science and to indicate the most promising areas for future NIDRR investments.

Universal design principles have been incorporated into IT systems to create accessible public information kiosks, electronic voting systems, ATMs, postal kiosks, and airport information systems. Universal design principles can be applied to the built environment, IT, telecommunications, transportation, and consumer products. These systems are basic to community integration, education, employment, health, and economic development. The application of universal design principles at each step of the R&D process would incorporate the widest range of performance on human engineering factors into technological systems. Universal design applications may result in the avoidance of costly retrofitting, a wider market base, and cost stability or reduction over time. NIDRR has taken a leadership role with regard to the development and promulgation of universal design principles that can be applied to the built environment, telecommunications, IT, transportation, consumer products, and the World Wide Web.

The IT revolution is fundamentally altering the way Americans work, purchase goods and services, communicate and play. Today, one can access information using any number of electronic devices and networks, including computers connected to ''plain old telephone lines'' (POTS), televisions connected to cable or digital satellite networks, cellular telephones, or wireless hand-held personal digital assistant devices. Unlike earlier information technologies (*i.e.*, print, radio, telephone, television and telefax), mobile communications networks, the Internet, and the World Wide Web did not seep into our daily lives gradually—rather, they exploded onto the scene. While the economic impact of this transformation has not been fully evaluated at either the individual or systems level, it is significant. The

ubiquitous nature of IT brings with it a host of opportunities as well as challenges—especially for people with disabilities.

NIDRR, through its network of grantees, has provided critical expertise and leadership for policy, regulatory and standards development related to wheelchairs, wheelchair restraint systems, and wheelchair seating systems. Specifically, NIDRR-sponsored researchers have created standards for wheelchair safety in motor vehicles, for docking devices for public transit, and for measuring and testing wheelchair seating component strength, seating posture, and cushion design. Other NIDRR-sponsored research resulted in the development of a manual entitled ''Landmarking Manual for 3–D Anthropometry'' to enhance and expand a prototype database of individuals who use both powered and manual wheelchairs.

NIDRR researchers identified problems with reproducibility of the standard measure (ANSI C.63.19) used by the Federal Communications Commission (FCC) as a basis for its rule on wireless phones and hearing aids, and developed consumer guidance for hearing aid wearers. NIDRR-sponsored research resulted in a consumer-tested tool for evaluation of TTY error rates over digital wireless phones. This tool has been transferred to industry, where it is now the industry standard measurement tool. The first web guidelines (Mosaic Access Guidelines, Unified HTML Accessibility Guidelines) were developed and adopted by the World Wide Web Consortium (W3C) as the starting point for their Web Content Accessibility Guidelines work. Representatives from several RERCs have been working with the International Committee for Information Technology Standards (INCITS) on the development of the V2 interoperability standards for augmentative and alternative communication, assistive technology, and IT.

Related to technology for hearing, NIDRR researchers developed instrumentation for the objective measurement of certain types of tinnitus. The rate of growth of evoked otoacoustic emissions with input signal level is abnormal in the frequency region of the tinnitus. Differences in the growth functions provide a means for identifying and measuring different forms of tinnitus. The instrument can be used to obtain objective measurements of tinnitus generated in the auditory periphery.

NIDRR's technology research is well situated to contribute to the realization of goals in the three outcome areas. Research on technology to support employment has led to the creation of a system for applying ergonomic technologies to accommodate disabled and elderly workers, developed tools for evaluating workers and jobs, and developed ergonomic solutions for disabled workers.

Research on technology to support health and function led to a simple yet highly functional prosthetic hand for children, and a novel transtibial prosthetic socket fabrication technology that greatly reduces the time and money needed for manufacture of prostheses. Other research has produced novel phone features such as ''Touch One to Call'' and ''Flip to Call'', which allow individuals who have significant cognitive impairments to use mainstream phones; an instrument for cost-effective early detection of hearing loss based on evoked otoacoustic emissions in the ear canal; and a technique for in situ measurements of hearing aid distortion, internal noise and other forms of interference in a hearing aid.

Research on technology to support participation and community living resulted in the design of an affordable universally designed kitchen, an adjustable height bathroom vanity, universally accessible laboratory furniture, and an easy to use screen door handle; and also created the first cross-disability accessible building entry system. Implemented first in public housing in San Francisco, that system allows access to the building directory and entrance security by individuals with low vision, blindness, physical disabilities, hearing impairments, deafness, and reading disabilities.

Research Agenda

NIDRR will continue to further the development and application of universal design principles to promote the full participation of people with disabilities in mainstream society. As the American population ages and the associated prevalence of disability increases over the course of the next 20 years, the importance and visibility of universal design applications will be greatly enhanced. These applications will include universally designed homes, buildings, vehicles, communication devices, media interfaces, entertainment venues, and other advances related to all aspects of life. These products and environmental adaptations will be universally designed for use by people of all ability levels, so that people can continue to lead active lives in their communities following the occurrence of trauma or age-related disabilities.

NIDRR will sponsor research to improve and build upon disability-specific products and environmental adaptations that have been developed to enhance participation and community integration. That will include the improvement of current augmentative communication technology so that it is smaller, easier to use, and provides a more life-like human voice for its users.

NIDRR research will address the principal function of technology—to support the end user outcome of participation. This requires research on techniques to enhance use and reduce abandonment by emphasizing consumer investment at each level of product development, including studies that illuminate potential population-specific factors (*e.g.*, behavioral patterns, cultural and societal values, or other variables). Because most assistive technology for disabled individuals falls into the category of orphan technology and is of a specialized nature, researchers often do not consider this cost-effective product development and employers sometimes do not consider this as a cost-effective mechanism for retaining injured workers or accommodating potential employees.

NIDRR will sponsor research that builds upon an understanding of the impact of economic factors on technology development, production, availability, and use, including studies that enhance understanding of the determinants of technology development and transfer, and use within specific industries or community environments. All of these factors must be considered within the realm of technology R&D, and in some instances across other areas of the NIDRR research agenda. Increasingly R&D researchers will be required to pay attention to environmental issues, societal factors, and cultural norms during the research and product development process, particularly in an environment where globalization influences outcomes for the technology market and changing demographics dictate technology needs. NIDRR intends to benefit from this international research agenda by providing the opportunity for researchers around the world to collaborate on product development and to examine technology needs through the lens of the international community. This creates a critical mass with related scientific expertise, leading to possibilities for new discoveries and information that otherwise would not benefit people with disabilities in this Nation.

NIDRR's research agenda in the area of technology for access and function is designed to:

• Strengthen the science basis of rehabilitation engineering and assistive technology through the development of theories, validated measures, and appropriate research methods for the identification and solution of problems to be addressed through technology.

• Increase the number and availability of empirically validated products, devices, or environmental adaptations that promote increased mobility, interactive control and manipulation of relevant features of the environment as well as access to information and technological communications systems by people with disabilities to promote independence in the home, community, and workplace.

• Increase the number of empirically based standards for products and devices and the built environment to ensure safety, accessibility, and usability by and for people with disabilities.

E. Disability Demographics

Overview

In carrying out its statutory mandate to work with other Federal agencies to produce demographic and statistical data describing the population of Americans with disabilities, NIDRR has continued to support important research in disability demographics. Good demographic data are a critical component of NIDRR's broader mission of supporting research that contributes to improvements in the lives of people with disabilities.

Demographic data contribute to NIDRR's mission by helping to:

• Allocate NIDRR resources among competing topical areas.

• Inform policy within NIDRR and within the Federal government as a whole.

• Identify potential changes in the characteristics and needs of the disabled population.

• Understand changes over time in disablement.

• Inform service delivery.

• Plan research to address current and emerging needs.

• Inform consumers and their families and advocates.

NIDRR researchers strive to understand the processes by which individuals vary in participation and, when appropriate, to foster strategies or interventions that may help bridge the gap between preference and feasibility in an existing environment. The dynamic nature of ability and the continuing advances in technology, policy, and human resources practices offer great promise toward maximizing participation of individuals with disabilities in all areas of life.

This chapter clarifies NIDRR's work in the context of disability demographics; and describes past activities and achievements in demographic studies. Examples of achievements in this area include: the establishment of a Disability Statistics Center; elucidation of the complex concept of an ''emerging universe of disability'; and delineation of problems and gaps in the current disability demographics effort. The chapter further identifies target areas for priority attention and presents a future agenda for NIDRR.

The Context for Research in Disability Demographics

Many organizations continue to collect important information about individuals with disabilities. At least five major national surveys are in existence, along with untold numbers of minor surveys and databases related to the use of specific programs and surveys.

An overarching concern in disability demographics is the assessment of the intersection of the individual and the environment. At the individual level, one may note varying degrees of function, variation in demographic factors, and variation in preferences. National datasets focus on measurements that allow one to describe the individual in isolation from his or her surroundings. At the environmental level, researchers are beginning to explore measures of barriers and facilitators to participation. Measures of participation vary, although sources such as the National Health Interview Survey/Disability (NHIS-D) and the Survey on Income and Program Participation (SIPP) move toward evaluating the gestalt of social performance.

A lack of standardized definitions, terminology, coding, classification, and measurement of disability and functioning often limits generalization of research findings. Extending use of research findings or population trends to inform policy or clinical interventions is limited due to the difficulty of extrapolating knowledge about disabilities from a disparate range of data sources, classification and coding systems, and measures of disability. For example, it is important to estimate future potential demands on rehabilitation systems, but existing population data sources do not adequately provide for planning, development, and evaluation of rehabilitation services and population trends. The ICF, which is described elsewhere in this plan, is a coding system that promises to allow the assessment of disability as a dynamic interaction between the person and the environment.

NIDRR's mission and its measurement tools are complicated by the interaction of static and dynamic variables that describe the background of disabilities. For example, people age, health changes, economic circumstances vary, and accidents occur. Point-in-time data sources may describe facets of disability, if enough questions are asked, but the environmental context often is absent.

A range of researchers and consumers of data have noted the problem in obtaining valid and reliable data about disability prevalence and its consequences. For policy purposes, the Census is a critical resource, as is the American Community Survey (ACS). Federal, State, and local planning underscore the role of the Census. Nonetheless, as noted by the NCD, there are methodological problems with the measures used in the Census.

Descriptions of the Population With Disabilities From Existing Surveys

Due to the variety of measurement tools for disability, there is no simple answer to the question of how many people with disabilities are living in the United States. Overall estimates of the prevalence of disability in key national data sources range from five or six percent up to more than 20 percent. For planning purposes, policymakers, advocates, and the media often cite the figure of 54 million Americans with disabilities.

Measures of disability in Federal surveys reflect a variety of needs across agencies for gathering such data. The ACS and the SIPP of 2002, both produced by the U.S. Census Bureau, reported that the prevalence of disability among males from 18 to 64 years of age ranges from 13.5 percent (ACS) to 14.8 percent (SIPP). Also, for example, the prevalence of disability among females from 18 to 64 years of age ranges from 13.4 percent (ACS) to 20.1 percent in the SIPP. For females 65 years of age and older, the ACS reported a disability prevalence rate of 43.5 percent while the SIPP reported a 50.4 percent rate. Males age 65 and older had a 41.0 percent rate of disability according to ACS data and 40.4 percent according to the SIPP.

It must be noted that each of the national surveys is tied to a program mandate other than the estimation and characterization of disability, especially as it is presented in the NIDRR paradigm. Major data collections

generally are related to health status, employment status, benefits recipient status, and program usage. Thus, it is understandable that they use varying definitions of disability and sample parameters.

Measures of severity of disability are critical for purposes of the Act. Each of the national datasets can be used to estimate the prevalence of significant disability. Generally, limitations in activities of daily living (ADLs)—for example, bathing, eating, and getting dressed—reflect the greatest severity, with limitations in instrumental activities of daily living (IADLs)—cooking, shopping, and managing money—and in working also are components of severity. For working-age adults, working at a job or business is often a major life role, and work limitation figures show the impact of disability on the ability to work. Overall trends regarding employment and disability have emerged from various data sources. Generally, disability is associated with lower labor force participation and earnings.

Review of the NHIS, SIPP, and Census indicates variations in estimates, reflecting methodological differences such as question wording, data collection, and coverage. These three data sources were examined for prevalence estimates of need for help with ADLs or IADLs and work limitations among adults aged 18 through 69. In 2000, the NHIS estimated 1.8 percent of the population needed help with ADLs, the SIPP reported 3.8 percent and the Census reported 9.0 percent. For IADLs, the NHIS estimated 4.2 percent of the population needed help, the SIPP estimated 6.2 percent and the Census estimate was 9.8 percent. Looking at limitations on work, the NHIS provides estimates of limitations in ability to carry on work and other age-appropriate major activities. The SIPP and the Census also measure what are frequently called work limitations, with the Current Population Survey (CPS) sometimes being used as a source of numbers on ''work disability.'' Again, there is variation in the questions on these surveys. Prevalence estimates for work limitation from the NHIS, the SIPP, and the Census were 2.6 percent, 8.6 percent, and 11.9 percent, respectively.

Measures of self-care, and the need for personal assistance or technologies, provide rich data for understanding more severe disability. Exploration of such needs also highlights cultural and socioeconomic variations in access to help. Across data sources that measure need for help with personal care, such as the NHIS and the SIPP, there are consistent trends showing that increasing age is a key factor in need for assistance. Thus, aging is strongly correlated with disability and with the need for functional supports including technology and environmental access. Predicted changes in the demographics of the general population will have substantial impact on the distribution of disability and the need for specialized technologies to assist individuals with disabilities. The U.S. Census Bureau has projected substantial increases during the next several decades in the percentage of the general population ages 65 and older.

Emerging Universe: Population Demographics and Disability

In its 1999–2003 Long-Range Plan, NIDRR noted a phenomenon it called an ''emerging universe of disability.'' The emerging universe was defined by changes in the distribution of disability according to demographic characteristics. This ''universe'' encompassed changes in the age, ethnic composition, income, education, and immigrant status of the population, as well as the appearance of new impairments, and different etiologies and consequences of existing disabilities. Research supported by NIDRR has tended to validate this construction, and to provide a description of the emerging universe.

As noted earlier, certain trends are common across national data systems that measure disability. Individuals with disability are more likely to be older, less educated, unemployed or out of the labor market, reliant on public as opposed to private health insurance, poor or near poor, and black or Native American as opposed to white or Asian. In addition, there is a geographic imbalance, with disability rates highest in the South.

Poverty as both an input to disability and an outcome of disability requires better understanding. As an underlying variable, poverty may discourage full social participation by people who are from minority backgrounds and have disabilities. As Fujiura and his colleagues write, ''across all ethnic/racial and age cohorts, rates of disability were higher among low income households; above the low income threshold, group differences were greatly attenuated. Black and Hispanic children with a disability lived disproportionately in low-income, single-parent homes.'' (Fujiura, 2000) One must disentangle economic, health, and social risks and policies to fully understand the impact of disability on persons from diverse backgrounds. The flux of the general population, due to increasing diversity, immigration, the growth of the Hispanic population, and the graying of the baby boom generation, presents challenges to existing service systems. Emergent health conditions are yet another factor that introduces complexity. Ultimately, NIDRR researchers will need to evaluate the impact of all of these factors on the equalization of access, opportunity, and successful outcomes for people with disabilities in fulfilling a range of social roles.

Accomplishments in Disability Demographics Research

- *Disability Statistics Center (DSC)*—NIDRR has long funded a DSC as a resource for researchers, policymakers, service providers, consumers, and others. That investment has yielded a number of key reports about the status of individuals with disabilities and their lives. In addition, through its investment in a statistics center, NIDRR has played a significant role in C-B by encouraging disability researchers to understand and analyze demographic data.
- *Emerging Universe of Disability*—Description and increased understanding of the emerging universe of disability, which refers to a disabled population that is shaped by several elements including demographic changes in age, immigrant status, and other socioeconomic factors; new types of conditions; consequences of treatments of existing conditions; and differential distribution of conditions and their consequences. NIDRR researchers' work in examining and explaining this phenomenon has helped to increase attention in the last six years on the unique needs of this ''emerging universe,'' including a focus on cultural and economic factors affecting disability.
- *Publications of Disability Data*—In addition to reports from its DSC, NIDRR has funded a series of Chartbooks that present important data in formats that are accessible to those who are not researchers. Most recently, NIDRR has published a Chartbook on Mental Health and Disability.
- *Improved Measurement*—NIDRR has been a key player in the development, dissemination, and adoption of the shift in conceptualization of disability from a medical to a sociomedical model. As part of that work, NIDRR grantees have contributed to the development of improved survey questions that measure issues of health, well-being, and participation as they relate to individuals with disabilities. In addition, NIDRR has played a

significant role in the development of the ICF that offers potential to facilitate better understanding of individuals with disabilities across a variety of disparate data sources.

• *Primary data collection*—NIDRR supports data collection in a variety of venues. Through its model systems, NIDRR collects data that addresses the efficacy of a variety of rehabilitation methods. NIDRR grantees have collected population-based data that describe specific populations such as individuals with MS or other conditions. Recently, NIDRR designed and funded a national survey regarding the use of and need for assistive technologies.

• *Interagency collaboration*—Through its leadership in the ISDS and other mechanisms, NIDRR has been a leader in promoting the collection of data about individuals with disabilities using a variety of Federal surveys. NIDRR has provided both financial and intellectual support for such efforts.

Research Agenda

NIDRR's performance goals in disability demographics are intended to increase the ability to describe the characteristics and circumstances of people with disabilities and their family members by:

• Improving the ability to collect disability data through the joint development of a standard nomenclature and methodological standards, including sampling, in collaboration with other Federal and non-Federal entities.

As a key objective, NIDRR will continue to support efforts that utilize multiple sources to examine the current state of affairs and trends that allow the projection of future needs. Existing data sources are sometimes contradictory, suggesting an intermediate need to evaluate the reasons for the inconsistencies. No one current source can provide all the important information needed about key inputs such as PAS, assistive technology, environmental facilitators and barriers, and their interactions. In the absence of a valid and reliable national disability survey, meta-analysis threads together the best available sources of topic-specific data.

In conjunction with other Federal partners, NIDRR will support the methodological work that yields the tools needed to implement a national survey of disability across the life span. The 1994–95 NHIS on Disability is a good model for future efforts, with the necessary addition of consumer experts to evaluate the content areas. Of note is that efforts to develop a national disability survey will be of great value even if such a large survey cannot be fielded in the foreseeable future. Each component of a cohesive national survey will have utility in surveys that are agency or mission specific. Resolution of complex sampling issues will benefit any survey that must include a representative proportion of individuals with disabilities. Development of topical modules with reliable and valid measures will yield instruments that can be used in a variety of data collections so that information is available about varying subgroups or the interaction of a variety of factors.

• Enhancing the understanding of the number and characteristics of people with disabilities through targeted studies of existing data.

Through much of its research portfolio, NIDRR will continue to support secondary analyses that lead to understanding of the basic life-cycle events and experiences of people with disabilities. Parsing the population of people with disabilities through cross-tabulation with other demographic variables will continue to be a focus. Linking the national and smaller data sources will be a priority. In the near and mid term, NIDRR will continue its work to evaluate and analyze existing data.

• Improving the science of disability demographics by developing and/or improving the measures of the interaction between technology and the physical environment, the social environment, and social policy as they affect people with disabilities.

NIDRR will stimulate the development of new measures of the interaction between technology and the physical environment, the social environment, and social policy. Such data are important for evaluating policies, including those enumerated in the NFI. Researchers must develop measures and indicators to assess the impact of environmental barriers and facilitators and encourage widespread use of these measures to evaluate how technology enables people with disabilities to succeed in school, work, and community and lead more productive and rewarding lives.

The ultimate goal of NIDRR's disability demographics effort is to generate new information that can be used by intermediate and intended beneficiaries who are working to identifying and eliminate disparities in employment, participation and community life, and health and function. Personal care, work, culture, and health are several of the rich areas that NIDRR and its grantees have studied. First, the concern with data threads through virtually all components of the study of disability. In order to understand needs and impacts, and to evaluate outcomes, quantitative analyses play a key role. In addition, one must often consult multiple sources of data to develop range estimates or compare trends. NIDRR has long funded studies that mine data to address the full range of social, health, and economic facets of disability and that compare findings across data sources. There are significant correlates with disability, such as aging, and there are a variety of links between disability and culture, race, and ethnicity. Supporting multiple sources for examining the current state of affairs for people with disabilities will provide important data that can be used to advance many areas of disability and rehabilitation research.

Research has identified gaps in data, such as the sparse measurement of the interface between individual and environment. NIDRR will nurture the methodological work that will address those gaps. Along with improved measures, there is much to be done to address problems in sampling and data collection. Research must document and evaluate the effects of long-term impacts of interventions to facilitate participation. In particular, research must address geographically and ethnically diverse populations to ascertain differences in needs and effects.

To be useful for policy, research, programs, and services, data must be grounded in an appropriate organizational framework, such as the ICF. The ICF is a scheme organized around function, activity, participation, and environmental context. To evaluate the potential uses of the ICF, a variety of measurement tools and data systems must be examined in addition to further evaluation of the implications of the classification system for U.S. populations.

II. Capacity Building

Overview

This chapter addresses a critical research building block, C–B, recognized as one of the three short-term arenas through which NIDRR achieves its goals. An important function of this chapter is to define C–B and its key dimensions in a context that reflects NIDRR's mission. The following sections describe the multidimensional aspects of C–B, provide a brief review of selected NIDRR C–B accomplishments, and discuss future directions and specific goals and objectives in C–B.

Definition of Capacity Building

As illustrated in the Logic Model (see Appendix 2), C–B is foundational for NIDRR's agenda. NIDRR C–B includes three major components: (1) Improving and building a larger and better quality supply of individuals to conduct research, (2) building a research infrastructure at institutions to carry out research and related activities, and (3) increasing the ability of consumers to interpret and use research and to play an active role in the research process.

At the individual level, NIDRR focuses on C–B to ensure a source of researchers to carry out the research agenda, and to enhance researchers' ability to generate useful knowledge. NIDRR historically has sought to increase the number of individuals from underrepresented groups in this effort, particularly those with disabilities. At the organizational or systems level, NIDRR C–B supports the framework for carrying out individual level research work. At a systems level, all NIDRR programs may be said to involve C–B, in that NIDRR funding is intended to increase the capacity of the field to conduct high quality research directed at the long-term goals and objectives identified in the Logic Model. Another important dimension of NIDRR C–B is the development of strategies to assist individuals with disabilities and their families, as well as practitioners, to use research findings to assist with choices of interventions and improve consumer involvement in the research process. This process begins with research design and extends to implementation, evaluation, and dissemination.

Context for Capacity Building

NIDRR's principal statutory mandate for training is to support advanced instruction for researchers and service providers. Consistent with this mandate, the 1999–2003 NIDRR Long-Range Plan defined C–B as multidimensional and involving training for those who participate in all aspects of the disability research field, including scientists, service providers, and consumers. NIDRR also has a mandate, strengthened in the 1992 amendments to the Act, to train peer reviewers, particularly consumers, and to train consumers to apply new research knowledge and to use assistive technology.

Individual Level

At the individual level, NIDRR's current C–B activities focus primarily on support for individuals, most of who already have selected research as a career, and have completed doctoral studies. Both the Fellowship program and the ARRT program provide support to individuals who fall within this category. While this support assists with developing careers of young investigators, it may not be optimal for supporting other research C–B, particularly with regard to recruitment and career development for individuals with disabilities or those from underrepresented racial and ethnic populations. NIDRR acknowledges the need for supporting increased development of research as a career at the secondary school and undergraduate educational levels, particularly focusing on students with disabilities and those from diverse cultural groups. NIDRR will look for opportunities to partner with other Federal agencies on research initiatives in this area.

Systems Level

NIDRR has several program mechanisms by which it funds C–B. The programs include the ARRT program, Fellowship program, NIDRR Scholars, Minority Development/Section 21 program, RRTCs, and RERCs.

ARRTs provide research training that integrates disciplines, teaches, and enhances research methodology skills, and trains researchers in disability and rehabilitation science. These training programs operate in interdisciplinary environments and provide training in rigorous scientific methods.

The Fellowships augment scholarly careers in the field, and function in an integrative capacity to define new frontiers of disability and rehabilitation research. This program provides opportunities for interaction among the fellows and for exposure to established researchers and policymakers. Additionally, fellows have the opportunity to participate in an annual research dissemination program where their findings are presented and discussed with research experts.

The NIDRR Scholars program recruits undergraduates with disabilities to work in NIDRR-funded research centers and to participate in research activities that expose them to disability and rehabilitation research issues, while at the same time providing work experience and income. This program is an innovative approach aimed at generating interest in research careers for individuals with disabilities and other underrepresented populations.

The Minority Development program focuses on research C–B for minority entities such as Historically Black Colleges and Universities (HBCU) and institutions serving primarily Hispanic, Asian, and American Indian students. Program administration activities include strategies to assist minority entities with networking activities focusing on collaboration, exchange of expertise and advanced training.

Training activities conducted by funded entities such as those participating in the RRTC and RERC programs capitalize on the existing critical mass of expertise and knowledge to provide:

- Experiential and academic training for researchers and clinicians at the undergraduate, graduate, and post-graduate levels, including continuing education activities.
- In-service training for rehabilitation practitioners.
- Training for consumers, their families, and representatives in implications and applications of new research-based knowledge.

Accomplishments in Capacity Building

NIDRR has built capacity for research in a number of ways. Most obvious is its investment in C–B programs to increase the skills of qualified researchers in the disability and rehabilitation field. The NIDRR-supported programs also have had the effect of increasing the numbers of disability researchers who are individuals with disabilities or members of minority populations. The ARRT program, while intended to promote research contributions in the long term, focuses primarily on increasing the number of individuals qualified to conduct rehabilitation research. These may include professionals in clinical settings who wish to sharpen their research skills through institution-based training programs. NIDRR has funded 29 programs under this rubric since 1992. The Fellowship program, while encouraging individuals to increase their expertise in research through the fellowship experience, focuses directly on promoting contributions to the knowledge base. There have been more than 200 fellows funded since the inception of this program with the first ''class'' in 1983. The fellowship experience allows for an intensely focused one-year research activity that is investigator-initiated and involves independent research. This fellowship program has resulted in numerous peer-reviewed journal articles, books and book chapters, as well as refinements in instruments originally developed in other settings.

Most of those who have received funding under these two programs have remained in the disability and rehabilitation research field. In recent years, there has been a ''progression'' from those who received structured mentoring under the ARRT program to their place as full-fledged principal

investigators in NIDRR centers or other programs. However, the fellowship opportunity allows for the support of individual researchers, including those not based at universities, and the flexibility of this approach and the camaraderie engendered in this program have received considerable praise from former participants.

NIDRR has made a major investment in the infrastructure of research through development of the model systems programs in SCI, TBI, and burn. These model systems have made major advancements in the capacity to conduct care for individuals with these conditions. Models systems also have contributed to C–B by putting into place a system for conducting multicenter trials.

Future Agenda

The capability to conduct first-rate research depends on a commitment to providing opportunities for learning the multiple skills required for designing scientifically sound studies, selecting appropriate research methods, analyzing data, and interpreting and reporting findings. NIDRR intends to support C–B activities that incorporate training in the application of research findings to the real-world needs of people with disabilities and the entities that impact their lives, including policymaking. Training aimed at transferring research findings into practical use is critical for C–B at the organizational and individual levels. However, the training must take into account scientific advancements across relevant disciplines, the state-of-the-science, the emerging universe of disability, cultural diversity, and the changing demographic profile of the Nation; otherwise this training is no longer relevant and cannot contribute effectively to research C–B.

NIDRR supports diversification initiatives and training that will attract and increase the participation of researchers, particularly individuals with disabilities and those from diverse cultural backgrounds, and will provide them with high level preparation. NIDRR will place increased emphasis on institutional C–B and building research infrastructure, in addition to developing a plan of evaluation of C–B. NIDRR C–B will extend to increased training for KT of research and the expansion of multidisciplinary research.

NIDRR has invested in C–B programs to increase the number and skills of researchers qualified to work in the disability and rehabilitation field. There are a number of external factors that may affect the success of an effort to build capacity in research, including the anticipated availability of funding for research; the potential for increased attention to preparation for service delivery at the expense of research knowledge and skill building; and the changing demographic profile of the student, professional, and disability communities. Understanding these issues via research activities can inform training and practice needs, and help to ensure that policies are sensitive to these concerns.

Thus, NIDRR intends to:

- Enhance the capacity to solve problems in creative, state-of-the-art ways by encouraging researchers from different cultural, racial, and academic backgrounds to conduct culturally-competent research in new settings that represent the contextual experiences of individuals with disabilities and stakeholders.
- Enhance cross-disciplinary and advanced research training opportunities in disability and rehabilitation-related fields for rehabilitation professionals and qualified individuals, including individuals with disabilities and individuals from minority backgrounds.
- Increase the capacity of persons with disabilities, family members, and advocates to understand and use research findings through training and participatory research experiences.
- Strengthen its research portfolio by increasing the number and type of partnerships with Federal and non-federal research and development agencies that conduct clinical trials and experiment with innovative approaches to R&D infrastructure development.

Various projects have been funded to study the cultural and contextual nature of disability experiences. These projects may help in training the field to design its research efforts using a framework different than the traditional view of disability, but also may put forth new ways in which disability research is conducted. For example, a recent research priority focused on generating greater emphasis on promoting collaboration between minority and non-minority entities and examining the implications of traditional methods, models, and measurement for traditionally underrepresented populations. The changing profile of the disabled population will require intercultural competence, and engaging collaborative research is one approach to meeting those needs. Essential to this process of improving collaboration is the necessity to identify factors that are effective in facilitating collaborative research endeavors across disciplines and the research community, including partnerships between minority and majority entities and relevant disciplines. The community-based research initiative, which fosters partnerships between academic institutions and disability organizations and advocates, illustrates this point.

Other priorities in examining the contextual nature of disability include studies that illustrate the influence of the intersection of the person and environment; exploration of context and culture with regard to specific disability populations; and topics such as assistive technology, disability rights, health promotion, family relationships, and community reintegration. Adding research that examines the evolutionary processes of policy, science, practice, and business or clinical culture can be an important element in creating a better understanding of the factors that shape both professional and disability experiences. Preparing researchers to examine environments where advanced technology, emerging disabilities, economics, and other factors influence training, practice and rehabilitation outcomes can help to improve the development, planning, implementation, and evaluation of programs to promote disability rights, health maintenance, family relationships, and community reintegration. NIDRR anticipates continued leveraging of the strong base of activity of NIDRR's RRTCs and RERCs serving as centers of excellence in rehabilitation research, to further enhance programmatic C–B through these centers.

III. Knowledge Translation

Overview

The KT process actively engages disability researchers, researchers from other disciplines, service providers, policymakers, and persons with disabilities and their families in the interchange, synthesis and application of rehabilitation research knowledge. KT activities are a central part of NIDRR's mission and provide an important pathway for improving the quality of life for individuals with disabilities. Outlining a central role for KT in this Plan is consistent with NIDRR's authorizing statute as well as the expressed interests of stakeholders collected throughout the long-range planning process. It also builds upon the strong history of KDU activities conducted by NIDRR and its grantees. NIDRR will focus its specific KT activities in the domains of employment, participation and community living, health and function, and technology.

Definition of Knowledge Translation

For NIDRR, the definition of KT refers to the multidimensional, active process of ensuring that new knowledge gained through the course of research ultimately improves the lives of people with disabilities, and furthers their participation in society. The process is active, as it not only accumulates information, but it also filters the information for relevance and appropriateness, and recasts that information in language useful and accessible for the intended audience. KT includes transfer of technology, particularly products and devices, from the research and development setting to the commercial marketplace to make possible widespread utilization of the products or devices.

NIDRR is particularly focused on ensuring that disseminated information is of high quality and based on scientifically rigorous research and development. To advance its dissemination of high quality research, NIDRR may analyze aspects of successful procedures used for review, synthesis and dissemination of research findings by other agencies for potential usefulness in NIDRR KT activities. NIDRR is especially interested in using models that encourage a thorough discussion of research findings among researchers, with emphasis on rigor and application possibilities. NIDRR also wants to ensure that potential end users of information will have the information they need to judge the quality of research and development findings and products, from NIDRR and other agencies, and the relevance of these findings and products to their particular needs.

The most appropriate target audience for KT will be determined in large part by the domain and the stage of knowledge development under consideration. For example, research on theories, measures and methods will find a primary audience among researchers and practitioners, whereas the primary target for activities related to new and improved products and environmental adaptations will be people with disabilities and service providers. The scope of KT as envisioned in this Plan covers a wide range of activities and involves a variety of mechanisms, including publication of research results, determination of the effectiveness of research applications, development of targeted materials, and the transfer of technology.

The Context for Knowledge Translation

The Institute has had a mission to disseminate its research findings, and promote their utilization with a range of audiences, since its establishment. As NIDRR expanded its conceptions and practice of KT, the focus shifted from the perception of dissemination and utilization as a linear, mechanical process of information transfer—in which knowledge is packaged and moved from one place to another—to a highly complex, nonlinear, interactive process, critically dependent on the beliefs, values, circumstances, and needs of intended users. This refocusing provided a key element for successful KT activities as potential users now take an active role in acquiring and using new knowledge. This change has paralleled the progressive improvement in models used in disability research that position people with disabilities in a highly integrative role as opposed to a non-participatory role.

Most NIDRR centers and projects now fund information and dissemination activities, with these activities becoming more coordinated and integral to planning in recent years with the establishment of a national center to disseminate NIDRR grantees' research. NIDRR also has carried out specific KT activities through grants and contracts monitored by NIDRR staff.

NIDRR intends that every new research project funded under this Plan should develop and share new knowledge to improve the lives of citizens with disabilities. In the United States, NIDRR and many other research agencies have endeavored to make scientific results accessible to all citizens, particularly results of Federal government-supported research. Several science-related institutions including the National Academy of Sciences (NAS), the National Science Foundation (NSF), and the National Institutes of Health (NIH) have developed portals of information that present research results, in various formats, to a large numbers of users. Since 1994, NIDRR has funded the National Center for Dissemination of Disability Research (NCDDR) for many of its KT activities. Most of the NCDDR work is done through databases and Web pages linked to other critical sources of research information. Researchers, educators, service providers, and individuals with disabilities use these easily accessible sources.

Challenges in Knowledge Translation

The biggest challenge faced by NIDRR, and other major research agencies, is to diversify KT activities to better serve various constituencies. While research organizations generally are good at peer-to-peer dissemination, the leap required to move from research to practice can be much more difficult. This process demands filtering the information, determining the quality of the findings (source and content), and aggregating research information from a number of NIDRR research venues (no single project addresses all aspects of a problem). It also requires a clear determination of how the research was conducted and how it might fit the user's needs. KT also requires the development of expertise in a number of media areas and development of strategies that could be employed to reach end users. The tasks of translation require regular contact between the translator and the original researcher. While a researcher might not be the best person to do the final dissemination, his/her involvement is essential to KT. The research must envision the target system in the beginning of research, the creation of a dissemination plan, and the development of a plan to evaluate the outcome.

NIDRR intends to assist people with disabilities and their families, and the general public, to efficiently access information. This may require ''mediated navigation,'' that is, individuals may need an intermediary to help them in the search for answers to their questions. Some of the most common intermediary roles are librarian, information specialist, knowledge management specialist, database coordinator, or trainer. Similarly, many stakeholders may benefit from appropriate translation of information into accessible forms. The use of multiple mechanisms for dissemination will be employed including knowledge sharing practices that make the maximum use of Web servers, subscriptions systems, e-forums, feedback systems, databases, Communities of Practice (COP), virtual libraries and other solutions-related activities. COPs involve groups of people who share a concern, set of problems, mandate, or sense of purpose. COPs serve to reconnect individuals with each other in self-organizing, boundary-spanning communities. COPs complement existing information structures by promoting collaboration, information exchange, and sharing of best practices across boundaries of time, distance, and organizational hierarchies.

Accomplishments in Knowledge Translation

For more than 20 years, NIDRR has funded several research databases for individuals with disabilities. These and other vehicles of KDU have served as important resources for consumers, practitioners, policymakers and researchers. NIDRR-funded databases

have focused on applied rehabilitation research and the provision of resources to provide access to up-to-date information on assistive technology and other useful consumer information. In the last decade, NIDRR has refocused and strengthened its KDU effort through focusing on the end users of information, by capitalizing on technology and by creating a technical assistance resource and a network of KDU centers (KDUCs). By refocusing on the end users of information, the KDU program has made researchers increasingly aware of the need to look beyond parochial dissemination channels to the information needs of stakeholder audiences such as people with disabilities and their families, disability organizations, policymakers and researchers in other fields.

The KDU program increased the outreach of grantees in many ways including by taking advantage of the growth of the World Wide Web and distance learning techniques to promote electronic dissemination. Through publication of Research Exchange issues on dissemination, reinforced by presentations at the National Association of Rehabilitation Research and Training Centers (NARRTC), SCI and RERC meetings, and technical assistance in one-on-one sessions, the number of NIDRR grantees with Web sites increased from 33 percent to more than 85 percent over a five-year period. Currently, almost all NIDRR grantees have Web sites. By continually monitoring the sites and referring grantees to tools such as the Web Accessibility Initiative (WAI), NIDRR has seen major improvements in the accessibility of the grantee Web sites to people with disabilities.

Specific KDUCs, which have focused on such topics as IL, have provided an array of ''translated'' material derived from NIDRR research. The material is presented in language that can be used readily by consumers. The materials produced by KDUCs have helped the public understand issues regarding the *Olmstead* decision, the capabilities of people with mental disabilities or illness, and the success that people with disabilities can have as parents. They also have encouraged private entities such as the Pew Foundation, to include disability as an issue of importance in reports and grants.

The NIDRR KDU program also has expanded its component projects and increased their utility to the public by establishing a public Web site with about 60,000 holdings on NIDRR disability research. Instant online searching of that information is available. A NIDRR Program Directory provides descriptions on and contact information for the wide range of NIDRR-funded activities. A searchable online database was created to provide ready access to findings and results of NIDRR grantees' research, and is updated weekly. Through the centralization of information, numerous reports and data on many NIDRR grantees are readily available, thus reducing the need to search every NIDRR grantee's Web site for research outcomes. More than 1,200 resources now are entered in the Electronic Library, and 250 entries are in the Spanish version, the Biblioteca Electronica.

In addition, NIDRR has funded the premier database of information on assistive technology, ABLEDATA, since 1980; it is a national resource for assistive and rehabilitative technology product information. Using the World Wide Web, the database is searched more than 1 million times annually, and generates telephone inquiries. The database offers more than 30,000 assistive technology products from domestic and international sources, and information on more than 6,000 manufacturers, and has been cited as a model for the development of similar systems.

To enable rehabilitation service providers to work more effectively with individuals born outside the United States, NIDRR funded a series of 11 monographs that describe the cultures and customs of foreign countries. The 11 countries chosen for the monographs were those with the highest number of emigrants to the United States. The monographs addressed issues that are crucial for service providers to understand in their work to achieve successful rehabilitation outcomes with foreign-born individuals who have disabilities.

Future Agenda

NIDRR is interested in developing improved ways to make information accessible to the research community and to disability-related agencies and organizations. NIDRR will continue to encourage and support dissemination of research information to consumers as an important aspect of its mission and legislative mandate. Building on NIDRR's solid foundation of peer-to-peer dissemination, individual centers will be encouraged to reach out to their constituent populations.

NIDRR intends to strengthen the dissemination work done by its specific content-based KT centers and regional networks of technical assistance centers. NIDRR will examine the use of its regional networks of technical assistance centers that focus on the ADA and educational technology, and look at expanding their scope to include high quality review and discussion of research results from NIDRR researchers before translation and dissemination to the public. NIDRR will advance its KT activities by emphasizing expert judgments on the value of information for further dissemination; better accountability for outputs produced by NIDRR researchers, and improved methods for making this information available beyond the research community. NIDRR will support all centers as they maintain and disseminate information of wide relevance to persons with disabilities and will encourage the effective use of electronic transmission, accessible media, and translation into multiple formats. In this effort, NIDRR will focus on ways of publishing and disseminating research to the public that will improve upon the traditional dissemination tools and methods and advance the use of technology to promote accessible video libraries and virtual libraries, among other methods.

Knowledge Translation includes the provision of information, technical assistance, and training in areas related to disability policy. The Act assigns to NIDRR the responsibility for those activities in relation to the ADA. NIDRR intends to implement those activities through a national network of regionally based centers that will provide assistance to disability organizations, individuals with disabilities, businesses, public agencies, and the general public, and that will contribute to research on topics covered under the ADA.

NIDRR will further the development of a theory of KT, the development of measures of success, and uniform definitions and requirements of NIDRR grantees and contractors. These complex endeavors will be undertaken with support from the network of all NIDRR's DRRP and KT projects. The efforts will concentrate on developing mechanisms to learn how research results are relevant to stakeholder needs and how the research results can help people with disabilities improve their conditions—for example, achieve better access to education, employment, independent living and wellness.

NIDRR will increase its KT activities by examining the needs of the end users of information. The new approach will look at the user needs in terms of: characterizing users of NIDRR's research; identifying users' goals or purposes; assuring alignment of the nature and quality of the information disseminated with the goals of the users;

providing support and assistance to different users to help them find the information that they need; and meeting the accessibility requirements of people with disabilities. This approach also will facilitate NIDRR's growth in the KT area by addressing questions on methods for KT including: a mechanism for the review and validation of project results as a stage in translation; assistance to projects in using existing clearinghouses; and a mechanism to track specific results to identify long-term accomplishments.

NIDRR will focus on high quality peer review and discussion of one major product for each research and development area each year. This type of peer discussion and consensus by researchers will be facilitated through a special database and the results will be reviewed for accuracy and completeness.

Thus, NIDRR's agenda in the area of KT is designed to:

- Increase the availability of relevant information to NIDRR's intermediate and intended beneficiaries by developing and implementing a systematic approach to vetting information.
- Increase understanding of how best to communicate new knowledge to beneficiaries.
- Increase the availability of technologies that enable independent mobility, control, and manipulation of the home, community and workplace environments and access and use of information through technology transfer.

Appendix 1—Expert Panel Members

Elena Andresen, a professor and chief of the epidemiology division in the Department of Health Services Research, Management and Policy at the University of Florida, has over 15 years of experience in the area of epidemiology. Her research interests include women's health and chronic disease epidemiology, disability, and the use of outcomes measures in clinical, epidemiologic and health services research. Andresen's grant review participation includes the Centers for Disease Control and Prevention (CDC), the National Institutes on Aging, and Department of Veterans Affairs (VA). She also has served on committees for the Institute of Medicine, the Agency for Healthcare Research and Quality (AHRQ), and the CDC. Andresen is a member of the American Public Health Association, the American College of Epidemiology, the Association of Teachers of Preventive Medicine, and the Society for Epidemiologic Research. Andresen has a doctoral degree in epidemiology from the University of Washington.

Bobbie J. Atkins, a professor in the Master's Program in Rehabilitation Counseling at San Diego State University, has over 25 years of experience in teaching, research, writing, and service in rehabilitation counseling. She has distinguished herself as a leader nationally and internationally with expertise in diversity, alcohol and drug prevention, AIDS education, and supervision. In 1999, the National Association for Multicultural Rehabilitation Concerns named its research award the Bobbie J. Atkins Rehabilitation Research Award. Atkins has received numerous awards including the Mary E. Switzer Fellow from the National Rehabilitation Association and has served on the President's Committee on Employment of Persons with Disabilities. She is the 2003 recipient of the National Rehabilitation Association (NRA) Presidents' Award for outstanding contributions to the field of rehabilitation. As the current project director of Project Success, a Rehabilitation Services Administration (RSA) funded capacity-building project, she is directly impacting people of color through training and technical assistance on grant writing and submission. Atkins' doctoral degree in rehabilitation counseling psychology is from the University of Wisconsin-Madison.

Henry B. Betts, chairman of the Rehabilitation Institute of Chicago (RIC) Foundation, is a pioneer in the field of rehabilitation medicine. He has served the RIC as president, chief executive officer and medical director. He was chairman of the Department of Physical Medicine and Rehabilitation at Northwestern University's Feinberg School of Medicine until October 1994 and also the first Paul B. Magnuson Professor in that department. Betts has spent his life changing attitudes and improving conditions for people with disabilities. At RIC, he created what is now one of the Nation's largest residency programs in physical medicine and rehabilitation. He has advocated for many issues including the Americans with Disabilities Act of 1990, improved accessibility in public buildings and walkways, and seat belt and drunk driving laws. He works vigorously on issues of employment of people with disabilities. Betts serves as a board member on many professional and community organizations. The Prince Charitable Trusts honored his efforts in 1990 by establishing the Henry B. Betts Award, conferred annually upon an individual whose work has benefited the disability community. Betts has a medical degree from the University of Virginia.

Frank G. Bowe, the Dr. Mervin Livingston Schloss Distinguished Professor at Hofstra University, teaches courses in special education, technology and rehabilitation in the department of counseling, research and special education. His first job was working with the late Mary E. Switzer, America's foremost leader and trailblazer for innovative programs at the national, State and local levels for people with disabilities in vocational rehabilitation. As the founding chief executive officer of the American Coalition of Citizens with Disabilities (ACCD) in the late 1970s, Bowe was instrumental in the implementation of historic civil rights for people with disabilities, including sections 501–504 of the Rehabilitation Act, housing, transportation and special education. He has held several congressional and presidential appointments. For over 25 years, Bowe has advised the U.S. Senate, the U.S. House of Representatives and executive branch agencies on Federal disability policy. He has received numerous awards including the Distinguished Service Award of the President of the United States and the Americans with Disabilities Act Award for his role in the enactment of the legislation. Bowe has a doctoral degree in educational psychology from New York University.

Judi Chamberlin, a psychiatric survivor, author and activist is a co-founder of the Ruby Rogers Advocacy and Drop-In Center, a self-help center run by and for people who have received psychiatric services. She is the author of On Our Own: Patient Controlled Alternatives to the Mental Health System. Chamberlin is the Director of Education and Training at the National Empowerment Center and is a senior consultant at the Boston University Center for Psychiatric Rehabilitation where she directed a research project on user-run self-help services. She has spoken at conferences and meetings throughout the U.S. and abroad and has appeared on many radio and television programs discussing the topics of self-help and patients' rights. Chamberlin has received numerous awards for efforts including the Distinguished Service Award of the President of the United States by the President's Committee on Employment of People with Disabilities, the David J. Vail National Advocacy Award, and the 1995 Pike Prize, which honors those who have given outstanding service to people with disabilities.

Dudley S. Childress is a professor of biomedical engineering in the Department of Physical Medicine and Rehabilitation at Northwestern University and a research health scientist in the VA's Chicago Health Care System-Lakeside Division where he directs the Prosthetics Research Laboratory. At Northwestern, he directs NIDRR's RERC in Prosthetics and Orthotics and is the executive director for the Prosthetics and Orthotics Education Program. His present research and development activities are concentrated in the areas of biomechanics, human walking, artificial limbs, ambulation aids and rehabilitation engineering. He engages in the development of engineering systems that assist people with ambulation problems and that provide control for artificial hand/arm replacements. Childress, a recipient of numerous honors and awards including the Missouri Honor Award for Distinguished Service in Engineering, is also a member of the Institute of Medicine of the National Academy of Sciences. Childress has a doctoral degree in electrical engineering from Northwestern University.

Patrick E. Crago is a professor and chairman of the Department of Biomedical Engineering at Case Western Reserve University. With over 25 years of engineering experience, Crago's research interests include restoration of movement by functional neuromuscular stimulation and in normal and pathological movement control and regulation. His current research projects include biomechanical, neural and neuroprosthetic control of the wrist, forearm and elbow, and the clinical implementation

and evaluation of neuroprostheses for hand grasp and proximal arm control. Crago has served on many committee and advisory boards for numerous organizations and Federal agencies. Crago has a doctoral degree in biomedical engineering from Case Western Reserve University.

Eric Dishman, a senior social scientist and principal engineer at Intel Corporation, is director of the Intel Proactive Health Lab. His team's current fieldwork and technology trials focus on helping mild cognitive impairment patients to maintain independence, function, and quality of life from their own homes through the use of wireless sensor networks and other computing technologies. In partnership with the American Association of Homes and Services for the Aging, Dishman serves as the chair of the Center for Aging Services Technologies, and he also recently co-founded the Everyday Technologies for Alzheimer's Care consortium with the Alzheimer's Association. Dishman is a nationally known speaker on the topics of aging and home healthcare technologies, and he serves as an advisor to numerous companies, universities, and Congressional members on assistive technologies, telemedicine, and home healthcare. Dishman has a master's degree in Speech Communication from Southern Illinois University at Carbondale.

Pamela W. Duncan, a physical therapist and epidemiologist, is recognized nationally and internationally as a leader in rehabilitation outcomes research and practice. Duncan recently joined the faculty at the University of Florida and is the director of the University's Brooks Center for Rehabilitation Studies and the Rehabilitation Outcomes Research Center of Excellence at the North Florida/South Georgia Veterans Health System. Her research provides leadership in evaluating the effectiveness of medical rehabilitation, the development of health status measures for the chronically disabled, and the design of clinical trials to evaluate exercise interventions for frail elders and stroke survivors. Duncan has served as co-chair of the Agency for Health Care Policy and Research (AHCPR) Post-Acute Stroke Guidelines and has served on the advisory committees for Health Care Financing Administration (HCFA), Canadian Stroke Network and the National Institute of Neurological Disorders and Strokes (NINDS). As a member of the American Heart Association (AHA) public policy committee, she advocates for national funding for rehabilitation services and research and development of quality indicators for stroke care. She is on the editorial board of numerous journals and her work has been published in a variety of journals including Stroke, the Journal of the American Geriatric Society, the Journal of Gerontology Medical Science, and the Archives of Physical Medicine and Rehabilitation. Duncan has a doctoral degree in epidemiology from the University of North Carolina-Chapel Hill.

Glenn T. Fujiura is an Associate Professor of Human Development and Director of Graduate Studies in the College of Applied Health Sciences at the University of Illinois at Chicago (UIC). Dr. Fujiura's research has focused on the fiscal structure and demography of the disability service system, on family policy, evaluation of long-term care services, poverty and disability, ethnic and racial issues in disability, and on the statistical surveillance of disability. In addition, he has a long-standing interest in research methodology, statistical analysis, and philosophy of science. He teaches research methods, advanced research concepts, and statistics for the graduate program in Disability Studies at the UIC. His current major projects include a NIDRR-supported epidemiological study of disablement in the third world using data from the World Bank and State level program evaluations. He has worked extensively in both the creation of large national data sets in mental retardation and developmental disabilities, and in the secondary analysis of national statistical surveillance systems. Dr. Fujiura was a recipient of the National Rehabilitation Association's Switzer Scholar award, served as a member of the President's Committee on Mental Retardation, and was Chair of the U.S. Administration on Developmental Disabilities Commissioner's Multicultural Advisory Committee. Fujiura has a doctoral degree in special education from the University of Illinois at Urbana-Champaign.

Allen C. Harris, the director of the Iowa Department for the Blind, has served as a chief in the Bureau of Field Operation and Implementation for the New York State Commission for the Blind and Visually Handicapped. Harris has been the recipient of numerous awards including the Lifetime Achievement Award from the National Federation of the Blind of Michigan and the Distinguished Blind Educator of the Year from the National Association of Blind Educators. He serves on several boards including the Lions Club of Iowa, the National Organization of Rehabilitation Partners and the National Council of State Agencies for the Blind. Harris has a master's degree in education from Wayne State University.

David Mank, the director of the Indiana Institute on Disability and Community, is a professor in the School of Education at Indiana University. A writer and researcher, Mank has an extensive background in the education and employment of persons with disabilities. He has extensive responsibility for Federal and State grant management of more than 20 projects as principal investigator, director or co-director. His interests include transition from school to adult life and community living. He is also past president of the Association of University Centers on Disabilities and a member of the Governing Council of the International Association for the Scientific Study of Intellectual Disabilities. In 2001, he received the Franklin Smith Award for National Distinguished Service by The Arc of the United States. Mank has a doctoral degree in special education and rehabilitation from University of Oregon.

Kathleen Martinez, deputy director of the World Institute on Disability (WID), is an internationally recognized disability rights leader with particular focus on employment, minority and gender issues. At WID, Martinez is responsible for the development and supervision of all of WID's international, technical assistance, employment and training projects. She currently supervises Proyecto Visión, a National Technical Assistance Center for Latinos with Disabilities and the five-year International Disability Exchanges and Studies for the New Millennium Project. Through these projects, Martinez oversees the production of the bilingual international webzine, Disability World, and a Web site designed to connect U.S. based disabled Latinos to the world of employment. In July 2002, she was appointed by President George W. Bush as a member of the National Council on Disability. On the Council, she chairs the International Watch Committee and is a leader in the Council's employment and diversity initiatives. Martinez has a bachelor's degree in speech and communications studies from San Francisco State University.

John L. Melvin, the Jessie B. Michie Professor and chairman of the Department of Rehabilitation Medicine at the Jefferson College of Medicine of the Thomas Jefferson University, served as medical director of the Curative Rehabilitation Center of Milwaukee, vice president for medical affairs of Moss Rehab and chairman of Physical Medicine and Rehabilitation at the Albert Einstein Medical Center of Philadelphia. Melvin has been the president or chairman of 11 major national and international organizations and has served on 41 national and international expert advisory committees including the Institute of Medicine and the National Research Council of the National Academy of Sciences. He is currently chair of the advisory board for the Boston University RRTC for Measuring Rehabilitation Outcomes sponsored by NIDRR. Melvin has a medical degree from Ohio State University.

Erica Nash, is president and executive director of Help-Your-Self, an organization that is dedicated to helping any person with disabilities improve and maintain his or her lifestyle by providing tools and services to enable community integration, independence, and increased self-sufficiency and productivity, in accordance with individual goals. Nash is a member of the Mayor's Committee on Persons with Disabilities and on other committees including the D.C. Medical Assistance Administration and the Office of Disabilities and Aging. Nash has a bachelor's degree in international communications and public relations for arts management from American University, and will complete her master's degree in technology and management for non-profit and arts organizations from American University in June of 2005.

Margaret G. Stineman is an associate professor of rehabilitation medicine in the Department of Rehabilitation Medicine, a senior fellow of the Institute on Aging, a senior fellow with the Leonard Davis Institute of Health Economics, and an associate scholar in the Clinical Epidemiology Unit of the Center for Clinical Epidemiology and Biostatistics at the University of Pennsylvania. She was the principal architect of the patient classification approach used by the Centers for Medicare and Medicaid Services in its

prospective payment system for inpatient rehabilitation facilities. She has consulted with the World Health Organization in Geneva, Switzerland, on community-based rehabilitation. Her current work focuses on addressing social and environmental barriers to the participation of people with disabilities in activities that are meaningful to them. Stineman has a medical degree from Hahnemann University.

Carl Suter, originally from the state of Illinois, is the executive director of the Council of State Administrators of Vocational Rehabilitation (CSAVR). Prior to joining the CSAVR, Mr. Suter was the director of the Illinois Office of Rehabilitation Services for five years. He oversaw a budget of nearly $500 million that included programs such as vocational rehabilitation, a $300 million in-home care program for persons with disabilities, three schools for children with disabilities, and disability adjudicative services for determining eligibility for benefits for the Social Security Disability Insurance Program and Supplemental Security Income in Illinois. During his tenure as State director, he led sweeping reforms of the Illinois Vocational Rehabilitation Services Program to provide world-class customer service to the nearly 70,000 individuals with disabilities served through its programs. Suter has also served as the executive director of the Illinois Council on Developmental Disabilities and as the associate director of the Illinois Association of Rehabilitation Facilities. Suter has a bachelor's degree in speech communication from the University of Illinois at Urbana-Champaign.

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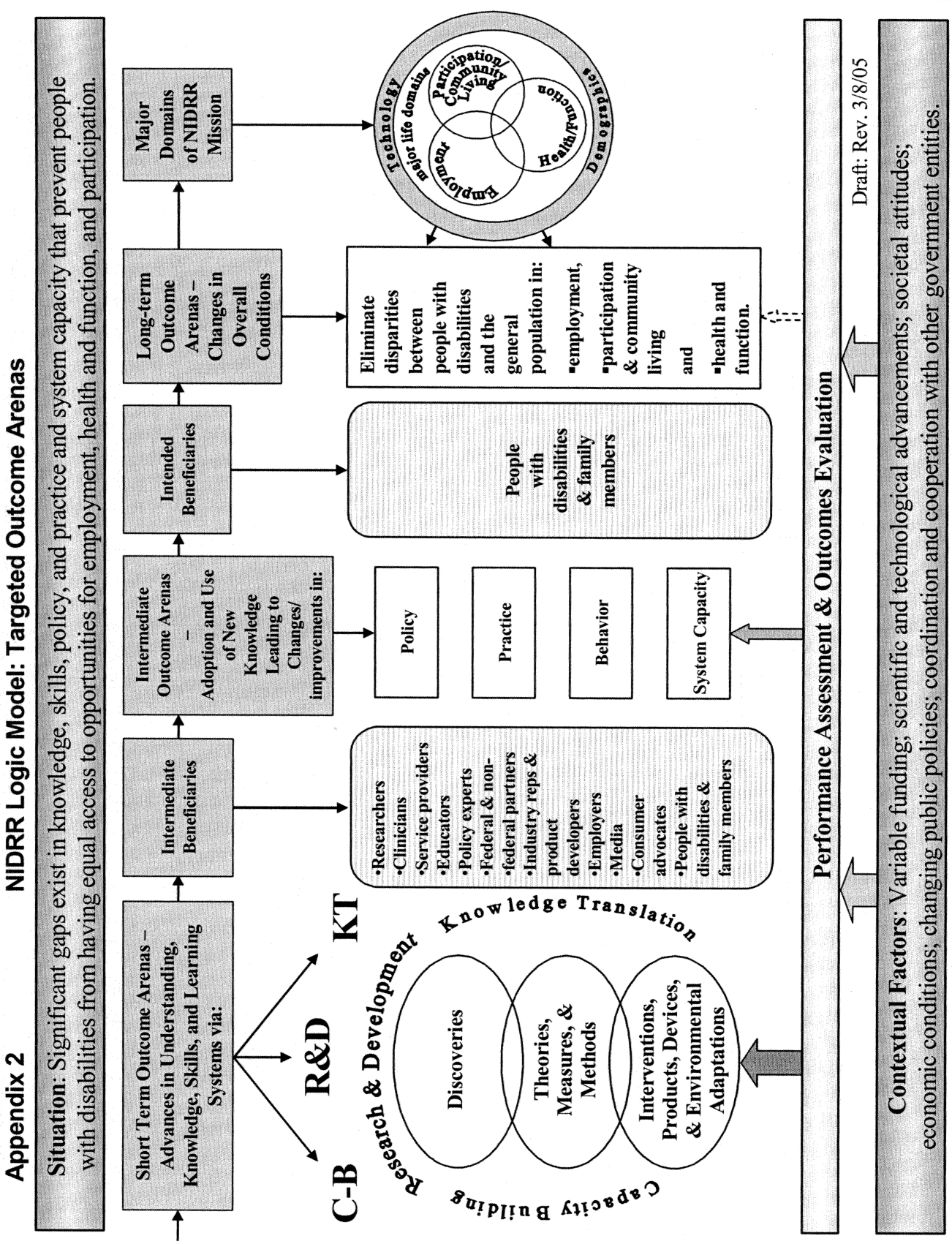

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