# National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

# 2018-2023 Long-Range Plan



#### Introduction

The Rehabilitation Act of 1973 states that "disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society." This view of disability guides the <a href="National Institute on Disability, Independent Living, and Rehabilitation Research's">National Institute on Disability, Independent Living, and Rehabilitation Research's</a> (NIDILRR) work.

NIDILRR's 2018-2023 Long-Range Plan (the Plan) presents a five-year agenda that will advance the vital work being done in applied disability, independent living, and rehabilitation research.<sup>1</sup> NIDILRR intends for this plan to emphasize consumer relevance and scientific rigor, to present an agenda that is scientifically sound and accountable and, as a result, to contribute to the refinement of national policy affecting people with disabilities.

The Plan builds on the work of the 2013–2017 Long-Range Plan while responding to new developments in the disability, independent living, and rehabilitation research field and in government. Both plans stress the importance of NIDILRR's significant role as a research institute in the public interest, carrying out a scientific research agenda to meet the diverse needs of people with disabilities.

The Plan extends NIDILRR's emphasis on the major outcome domains of community living and participation, health and function, and employment. NIDILRR measures contributions toward improved outcomes in these domains by systematically tracking the outputs and outcomes of grantees, including the new knowledge and products that they have created. NIDILRR measures long-term outcomes by assessing the extent to which this research-based knowledge is used to create new programs, policies, or practices to improve services and supports for people with disabilities. NIDILRR grantees regularly produce the following kinds of outputs based on their research activities including, but not limited to: peer-reviewed publications, research-based fact sheets, tools, measures, intervention protocols, technology products and devices, industry standards and guidelines, and patents. The results of this research are shared through mechanisms such as knowledge translation, technology transfer, training, and technical assistance. These mechanisms are supported by our statutes, regulations, and funding opportunity announcements (FOAs).

The Plan also reinforces the need for investment in three areas that support outcomes across these domains: technology for access and function; disability statistics; and a nationwide network of technical assistance, training, and research centers to support implementation of the Americans with Disabilities Act (ADA). Activities that promote the quality and use of NIDILRR-

<sup>&</sup>lt;sup>1</sup> Throughout the plan, NIDILRR's use of the term "research" includes both research and development activities unless otherwise specified. According to NIDILRR's program regulations (45 CFR Part 1330), NIDILRR grantees carrying out development activities must create—using knowledge and understanding gained from research—models, methods, tools, systems, materials, devices, applications, or standards that are adopted by and beneficial to the target populations (45 CFR 1330.10(b)).

sponsored research—capacity building and knowledge translation—will also continue under the Plan.

This Plan will guide NIDILRR's upcoming research agenda, based on two overarching principles that guide our past, present, and prospective sponsorship of efforts to improve the community living and participation of people with disabilities:

- 1) The ultimate aim of all NIDILRR research is to enhance the ability of people with disabilities to achieve inclusion and integration into society; and
- 2) NIDILRR has a legacy and future as a primary funder of rigorous and relevant disability, independent living, and rehabilitation research, recognizing that this spans the continuum from acute settings into home- and community-based services (HCBS) and competitive-employment environments.

# **Background**

In developing the Plan, NIDILRR solicited written comments and public testimony at six in-person regional listening sessions to better understand the experiences and perspectives of people with disabilities, the providers who serve them, caregivers and other support system members (both formal and informal), policymakers, and academic researchers. Hundreds participated in the sessions. Feedback was diverse and often passionate. A number of themes emerged:

- People with disabilities have high expectations for themselves and the services and supports they receive to achieve their personal goals. In a post-ADA and post-Olmstead (Olmstead v. L.C. and E.W.) decision world, people with disabilities of all ages want to lead active lives in the community and access the same things as their able-bodied peers: a good job, friends, and a social life. They need consistent, high-quality services to accomplish these goals. There is frustration with the lack of information regarding the quality of services available from local providers.
- Choice and control matters. Whether it is access to affordable and accessible housing or a ride to the doctor's office, people with disabilities want meaningful choices that respect their desire for safety and security and the value of their time. This is consistent with the trend toward person-centered planning, which prioritizes the goals and wishes of the end user of goods and services rather than the choices offered by a provider or care planner.
- The current environment of fiscal austerity is negatively impacting people with disabilities and the providers that serve them. Many states are facing budget deficits even as the economy has rebounded. In this environment of retrenchment, hard-fought gains to improve access to needed services are perceived to be threatened. This was most acutely felt in the area of caregiver support and availability, a key facilitator of community participation and inclusion. Stakeholders also cited reimbursement rates paid to provider agencies and the inability to provide competitive wages for their workforce. Waiting lists for Medicaid-funded

services were also described.

- The health care system is rapidly changing, getting more complicated, and not always meeting defined needs. This was noted not just for medical and clinical services, but also for long-term services and supports (LTSS) that are provided in the community. People with disabilities reported feeling overwhelmed and confused by these changes and frustrated that the changes provide treatment for their episodic sickness and symptoms rather than proactively managing their wellness and stability of health. Caregiver shortages and quality issues were of particular concern.
- Access to technology would make life better. People with disabilities described frustrations with their inability to gain access to cell phones, durable medical equipment, and assistive technology. They noted that poverty, lack of existing sources of reimbursement, and policy challenges were barriers to access.
- What works and what doesn't? All stakeholders were interested in research that showed promising or best practices that could be used in their local communities. Some specifically requested information in a form that is easy to understand. This knowledge translation function is one NIDILRR has devoted increased resources toward since implementation of the previous Long-Range Plan.

Taken together, the feedback received is consistent with findings from the existing research literature. People with disabilities of all ages want to live successfully in the community, with access to the tools and supports they need to lead productive and meaningful lives. Respondents paid specific attention to the areas of employment, housing, health, and transportation and their effects on community participation.

#### Mission

NIDILRR's mission is to generate new knowledge and promote its effective use to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

NIDILRR is governed by the definitions in Title II of the Rehabilitation Act (the Act). 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 of such person's major life activities; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment."

NIDILRR is required to focus the research it sponsors on the experiences and needs of individuals with the most significant disabilities, as defined in the Act. NIDILRR focuses on individuals across the age continuum, including all disability subpopulations: developmental, cognitive, sensory, psychiatric, and physical.

#### State of People with Disabilities in the U.S.

People with disabilities, especially those living with significant disabilities, often face barriers that complicate the simple goal of leading a productive life in the community of one's choosing. While some require little or no assistance to achieve this, others require a complex array of services and supports to facilitate social inclusion and participation.

Despite multiple challenges and the often tenuous nature of multiple supports that function in concert to facilitate optimal community living needs of people with disabilities, many people across the United States are thriving. Public testimony and written comments received by NIDILRR indicate that significant progress has been made to support the principles of integration and community living first outlined in the Rehabilitation Act and reinforced by the ADA and the 1999 Olmstead decision. At the same time, not all people with disabilities have access to necessary supports and services. Successful community living can depend on geographic location and disability subpopulation. Interventions span multiple policy areas and governing jurisdictions, each with their own eligibility requirements and procedures.

Improved research-informed policies and interventions in these critical areas would help support improved outcomes for people with disabilities in NIDILRR's three inter-related domains: health and function, employment, and community living and participation.

#### **Agency Context**

The Workforce Innovation and Opportunity Act of 2014 (WIOA) transferred NIDILRR to the U.S. Department of Health and Human Services (HHS) from the U.S. Department of Education. Specifically, NIDILRR became a part of the Administration for Community Living (ACL), whose mission is to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers. Created in 2012, ACL combined the Administration on Aging, the Office on Disability, and the Administration on Intellectual and Developmental Disabilities to create a single agency charged with developing policies and improving supports for older adults and people with disabilities. NIDILRR's addition brought research capacity and competency to a strong policy, program, and services organization. NIDILRR has established collaborations within ACL on topics such as traumatic brain injury and remains committed to exploring collaborative opportunities with Federal and state partners.

WIOA made changes to the NIDILRR statute but did not detract from or remove any responsibilities or program authorities. It did add the words "independent living" to the NIDILRR name, stressing a key philosophy that has long been an organizational priority and is an integral part of the ACL mission. Ultimately, active community living and meaningful social participation for individuals with disabilities is the desired goal and outcome of the research initiatives that NIDILRR sponsors.

#### **Federal Research Planning**

While NIDILRR is one of several Federal agencies conducting research on behalf of people with disabilities, it is unique in conducting applied research. Other agencies include the National Institutes of Health (and within it, the National Institute on Aging, the Eunice Kennedy Shriver National Institute of Child Health and Human Development and its National Center on Medical Rehabilitation Research (NCMRR), and the National Institute of Mental Health), the Substance Abuse and Mental Health Services Administration (SAMHSA), the U.S. Department of Defense, the National Center for Special Education Research, and the U.S. Department of Veterans Affairs. Additionally, the Interagency Committee on Disability Research (ICDR), currently chaired by the NIDILRR director, is charged with coordinating disability research across the Federal government. The Plan acknowledges recent strategic planning processes conducted by the ICDR and NCMRR. NIDILRR has also worked with the U.S. Department of Transportation in research efforts to develop new transportation options for people with disabilities.

NIDILRR has a history of formal interagency agreements, where common interests across agencies have resulted in numerous combined funding opportunities. SAMHSA, for example, has partnered with NIDILRR for more than three decades to advance the mental health and community living outcomes of people with disabilities. Similar arrangements have existed with the VA and DOD. These arrangements are not just desirable, but are required by the Rehabilitation Act:

In order to promote cooperation among Federal departments and agencies conducting research programs, the [NIDILRR] Director shall consult with the administrators of such programs, and with the [ICDR], regarding the design of research projects conducted by such entities and the results and applications of such research.  $29~U.S.C.~\S762~(i)$ 

The [NIDILRR] Director shall take appropriate actions to provide for a comprehensive and coordinated research program under this subchapter. In providing such a program, the [NIDILRR] Director may undertake joint activities with other Federal entities engaged in research and with appropriate private entities.  $29~\mathrm{U.S.C.}~\$762~(j)$ 

#### **Key Accomplishments of NIDILRR Grantees Since Last Long-Range Plan**

Since the publication of NIDILRR's Long-Range Plan for 2013—2017, there has been a concerted effort by NIDILRR to increase the number of field-initiated research opportunities. Such opportunities allow researchers to propose innovative research projects to promote improved outcomes among people with disabilities in the broad outcome domains of community living and participation, employment, and health and function. The field-initiated grant opportunities, along with NIDILRR's sponsorship of the development and dissemination of new knowledge and innovative technological devices, prototypes, measurement tools, intervention materials, and other informational products to enhance community living, have resulted in more than 1,200 products, including peer-reviewed publications, intervention protocols, software, and databases that may be used to enhance the community living opportunities of people with disabilities.

NIDILRR has also established requirements for applicants to define progress along a series of stages. This requirement is designed to help applicants refine their rationale for proposed research or development and to help ensure that the knowledge or products generated will contribute to improved outcomes for people with disabilities. This requirement also helps NIDILRR monitor the progress of research initiatives.

#### I. Research Agenda

#### Overview

NIDILRR's research programs have long been aimed at improving outcomes of people with disabilities in the three inter-related domains of: (1) community living and participation, (2) health and function, and (3) employment. Its research agenda for the next five years involves building on current investments and moving them along the stages of research and development while also initiating new research in developing fields. As a component of this, NIDILRR will sponsor translational research to expand the utility of existing evidence-based programs and practices by adapting them for different populations of people with disabilities and the environments in which they live. Research activities will be aligned with the three outcome domains, with each supporting NIDILRR's ultimate goal of enhancing the ability of people with disabilities to achieve their maximum desired participation in the community, with full access to all societal and life activities.

During the next five years, NIDILRR plans to carry out a research agenda that includes three important factors: (1) building on current investments through our stages of research and development, with the goal of both developing new interventions and moving existing findings into evidence-based programs, practices, and policies for people with disabilities; (2) taking advantage of the expertise of our colleagues in ACL to expand our research on issues of aging and disability and community living—viewing aging as a cross-cutting research area relevant to community living and participation, health and function, and employment; and (3) conducting research on health policy issues to inform the national agenda.

It is also NIDILRR's expectation that projects that receive NIDILRR funds will involve people with disabilities in research activities to help ensure that the perspective of the end users is taken into consideration. NIDILRR believes that this input is essential to ensure that the knowledge and products are useful in addressing real issues faced by people with disabilities.

Finally, NIDILRR is interested in research that expands the integration of person-centered planning into decisions affecting people with disabilities. While there have been many small studies of the impact of individual preference in decisions about rehabilitation and other interventions, there remains a need to expand current knowledge by supporting more evidence-generating research for effective implementation of this approach across community, medical, and vocational settings.

# **Community Living and Participation Domain**

While the three outcome domains contain equally important and rich areas of research investment, the domain of community living and participation is the ultimate outcome of all of NIDILRR's research, development, capacity building, and knowledge translation grants. NIDILRR sponsors research on health care and rehabilitation not just to improve health and functional abilities, but because improved health and function allows people with disabilities to be more active and engaged in their communities and families. It sponsors research on employment not just to generate new knowledge that can be used to close the large employment gap between those with and without disabilities, but because employment provides income and the financial means for people with disabilities to have real choices about how they engage and participate in their communities.

While the U.S. continues to create opportunities for integration and inclusion of people with disabilities through implementation of the ADA and the Supreme Court's Olmstead decision, people with disabilities of all ages continue to experience significant barriers to living in the community and participating in typical educational, employment, recreational, civic, and social activities. People with disabilities, especially those with more significant disabilities, report feeling socially isolated and lonely in their communities. They are less satisfied with their community participation than their counterparts without disabilities and participate in fewer community activities than their counterparts without disabilities. Barriers to community living and participation include, but are not limited to, insufficient home- and community-based LTSS, shortages of affordable and accessible housing, inadequate transportation services, and inaccessible built and natural environments.

NIDILRR seeks to improve community living outcomes among people with disabilities by sponsoring research to improve our knowledge of a wide variety of factors that promote or hinder community living. NIDILRR and its grantees will then apply this new knowledge toward improved policies, practices, services, and supports that promote improved community living outcomes for people with disabilities.

# Context for Research on Community Living and Participation

NIDILRR's sponsored research in the community living and participation domain is motivated by its statutory mandate to improve community living outcomes for people with disabilities. NIDILRR's research in the community living and participation domain will continue to be influenced and guided by the Act's ultimate aim of full integration for people with disabilities and by the integration mandate that is central to the ADA and the Olmstead decision.

For more than 20 years, the U.S. has been actively shifting its provision of LTSS for people with disabilities into the community and away from institutional settings such as nursing homes. In 1995, fewer than 20 percent of Medicaid LTSS dollars were spent on services and supports in home- and community-based settings. In 2013, that percentage had expanded to more than 50 percent for the first time, and the figure currently rests at approximately 53 percent. The Centers

for Medicare and Medicaid Services (CMS) project the continued growth of home- and community-based LTSS, with expenditures for such services to reach 63 percent of all Medicaid LTSS expenditures by the year 2020. As more people with significant disabilities live in and receive services and supports in the community, new research-based knowledge about individual- and system-level factors that impact community living outcomes is needed to guide and shape the provision of those services.

# Proposed New Community Living and Participation Research Agenda

NIDILRR supports the development of new knowledge and products that can be used to increase community living and participation among people with disabilities. It will build upon current and prior investments in this domain, coordinating with its partners in ACL, other HHS components, and the broader Federal government, whenever possible. Given NIDILRR's prior investments and the ongoing U.S. aim of expanding home- and community-based LTSS for people with disabilities, the areas of potential investment include:

- Community living and participation measurement. Sponsoring the development, validation, and use of measures of community living and participation among people with disabilities. NIDILRR considers these tools to be critical infrastructure for research that can be used to improve services and supports for, and outcomes of, people with disabilities. With the expansion of home- and community-based LTSS to people with a broad range of disabilities, the need for valid and reliable tools to measure the quality and the ultimate outcomes of these services is growing.
- Transportation access. Funding research activities to create knowledge and products that improve access to transportation for people with disabilities. This work may include research activities to support the development of standards for the accessibility and usability of autonomous vehicles for people with disabilities as well as enhanced standards for accessibility and usability of paratransit vehicles, taxis, and emerging ride-share services. These investments may also include research toward reducing the most common transportation barriers experienced by people with disabilities—which occur in the first and last miles of their trip—as well as ensuring that existing and emerging transportation modes, technologies, and infrastructures are accessible, useful, available, and affordable to people with disabilities.
- **Family caregivers.** Sponsoring the development and implementation of a research agenda on family caregivers of people with disabilities. Research in this area can be used to promote the community living outcomes of people with disabilities by better understanding and providing for the economic, social, and health-related well-being of their family caregivers.
- **Community access.** Supporting: (1) research on specific unmet needs for services and supports among people with disabilities who are living in the community, (2) research on promising practices for delivering such services and supports, and (3) development of an evidence base needed for existing services and supports. As opportunities to receive home-

and community-based LTSS expand to new jurisdictions and populations of people with disabilities, there will be an ongoing need to systematically track and understand communities' capacity to provide those services and supports in a way that promotes community living.

• Accessible homes. Sponsoring research on ways to promote the accessibility, usability, and visitability of homes for people with disabilities. This research work may include applications of universal design principles to living spaces as well as research toward the development of policies, practices, programs, and incentives to promote accessibility and visitability features in new home construction and home additions.

#### **Health and Function Domain**

NIDILRR's focus on health and function stems from its founding as a rehabilitation research agency aimed at developing an evidence base for interventions that maximize independence of people with disabilities. People with disabilities are significantly more likely than individuals without disabilities to be in fair or poor health and to experience a wide variety of diseases and chronic conditions. Health risks vary by condition or type of impairment. For example, individuals with significant vision loss or with an intellectual disability have a greater prevalence of obesity, hypertension, and heart disease than people without disabilities. Such risks often have major adverse health outcomes, including reduced longevity. It is estimated that people with serious mental illness die 10 years earlier than people in the general population due to preventable or treatable chronic diseases. Despite their substantial health needs and elevated risk of adverse health outcomes, people with disabilities experience significant health disparities attributable to poor access to needed health care services.

In addition to having a greater likelihood of being in poor health, people with disabilities experience a wide range of functional limitations that jeopardize their access to employment and other forms of community participation. According to the U.S. Census Bureau, five million adults need assistance from another person to perform one or more activities of daily living, such as getting around inside the home, getting into or out of bed, bathing, dressing, eating, and toileting. Approximately 15 million people have difficulty with one or more instrumental activities of daily living, such as going outside the home, managing money, preparing meals, doing housework, taking prescription medication, and using the phone.

Many individuals with disabilities who possess significant health conditions and functional limitations lack adequate access to health care, personal assistance services, and rehabilitation services. Maximizing the health and function of people with disabilities is critical to their general well-being and their fulfillment of personal aspirations in areas such as employment and community participation. As the number of people with disabilities in the U.S. continues to grow, it is necessary to improve the nation's capacity to meet their needs and access their talents. This will require the development of new and improved rehabilitation strategies and refinement of policies, programs, practices, and technologies that reduce functional limitations and improve health outcomes.

#### Context for Research on Health and Function

The context for NIDILRR's work in the area of health and function includes its historic role as the principal Federal funder of disability and rehabilitation research. During the period of the last Long-Range Plan, NIDILRR leveraged this position to collaborate with centers within the National Institutes of Health, the Center for Mental Health Services, the Centers for Disease Control and Prevention (CDC), and the VA, among others. For example, most recently, NIDILRR has been a partner in the development of the National Research Action Plan on post-traumatic stress disorder, other mental health conditions, and traumatic brain injury (TBI). This plan is part of a White House initiative designed, among other goals, to "improve the coordination of agency research on these conditions."

NIDILRR's move to ACL has created opportunities for new or expanded research, particularly in the area of aging with long-term disability. ACL provides improved access to service delivery programs that can serve as sites for testing new research-based interventions. Pending changes in how health care, rehabilitation, and social services are implemented, there may be new opportunities for examining access to services and the impact on health and function outcomes of people with disabilities.

# Proposed New Health and Function Research Agenda

NIDILRR anticipates continuing to fund research related to rehabilitation interventions and access to rehabilitation and other health care services by people with disabilities. Areas of potential investment include:

- Aging with and into disability. Refers to individuals who experience the onset of a disability in early to mid-life as well as individuals for whom aging results in disabilities. NIDILRR's research agenda will emphasize the development of a continuum of promising and evidence-based practices to promote health, support participation, and improve services for the growing population of people who are aging with and into disability. Examples include:
  - Research that results in a portfolio of evidence-based practice and programs that are effective in moderating the negative consequences of aging with and into disability on health, function, participation, and community living.
  - Collaborations that bring together researchers, practitioners, policymakers, and individuals aging with and into disability and their advocates to generate new knowledge that promotes and facilitates the common interests of affordable health care, LTSS, and assistive technologies.
  - Development of analytic models and techniques to examine the differential effects of chronological age, age of onset, and duration of disability on the health and well-being of adults with long-term disability and aging with disability.

- Development of interventions that improve health and function outcomes. Develop treatments and other interventions that help improve health and function outcomes for people with disabilities. As people with disabilities rely more on HCBS as a vehicle for maintaining health, minimizing re-hospitalizations, and maximizing community living outcomes, research that investigates the relationship among these services, interventions, and health and function outcomes is also needed. Intervention studies focused on mental health, substance abuse, suicide, and obesity are examples of areas of concern for people with disabilities. These investments toward evidence-based interventions to promote health and function outcomes will take place in NIDILRR's long-standing Model Systems programs as well as other programs and grant mechanisms.
- Implementation of existing evidence-based practices. Move proven practices into broader settings that can directly benefit people with disabilities. To do this, NIDILRR proposes to support competitions that build on prior investments that resulted in evidence of efficacy and effectiveness. These competitions will provide funding for further development and testing of practices and interventions in additional settings or among new populations of people with disabilities. These translational research efforts may help develop practical strategies for ensuring more widespread use of new evidence-based findings in the area of disability and rehabilitation research.
- Policy impacts on access to health care services and outcomes. Continue research on the impact of health care policy on access to and outcomes of needed health care, rehabilitation, and long-term community supports among people with disabilities. NIDILRR will build on existing research initiatives to determine how policy changes impact the ability of people with disabilities to obtain needed rehabilitation and other health care services and what changes to morbidity, mortality, and independent living are associated with these changes.

#### **Employment Domain**

For many people with disabilities, employment is a significant component of community living and participation. It provides income and the opportunity to engage in meaningful, productive activity. In addition, it may enable people with disabilities to reduce their dependence on public benefits.

Employment research funded by NIDILRR is motivated by the need to improve employment outcomes, broadly defined, for people with disabilities. Areas of focus have included improving our understanding of the effects of public policy on the employment and financial well-being of people with disabilities, informing the development of improved policies that support employment for people with disabilities, developing interventions to improve employer practices, and developing employment-related services and supports that maximize employment outcomes.

# Context for Research on Employment

The current disability employment environment has been shaped by a number of recent events,

including the Great Recession (2007–2009) and recent changes in legislation and public policy, programs, and services. The research context includes:

- **Great Recession.** Decreased employment rates for U.S. workers with and without disabilities. Since 2010, employment rates for people with disabilities have recovered more slowly than those for people without disabilities.
- WIOA. Includes a number of points relevant to people with disabilities including: competitive integrated employment as a preferred employment outcome; transition to employment for students and young adults; use of evidence-based practices in employment and training programs; limitations on sub-minimum wage employment for people with disabilities; required coordination between state vocational rehabilitation, Medicaid, and Intellectual and Developmental Disability agencies; supports and services to facilitate the transition of people from nursing homes and other institutions to home- and community-based residences; and new definitions of customized and supported employment.
- Legislation designed to improve employer practices. The employment gap between people with and without disabilities is due, at least in part, to employer practices. The gap remains despite more recent actions (e.g., sections 501, 503, 504, and 508 of the Rehabilitation Act, Executive Orders 11478, 13160) to eliminate disability-related discrimination in the workplace.
- **Disincentives to employment.** Being a beneficiary of publicly funded programs (e.g., Supplemental Security Income, Social Security Disability Insurance) can serve as a disincentive to employment. Workers who no longer receive such benefits may have insufficient earnings to avoid economic insecurity or poverty. Health care reform, as well as reforms in Social Security programs, could also affect employment outcomes for people with disabilities.
- Vocational Rehabilitation programs. Services and supports to help people with disabilities prepare for, obtain, keep, or regain employment. VR services are included in the coordinated programs covered by WIOA. There is, therefore, a need for evidence-based practices for use in VR. In addition, given the current economic situation, many states require that their VR agencies demonstrate adequate returns on investment in their programs, creating a need for valid models of return on investment that are usable by state VR agencies.
- Collaboration among Federal agencies. Increasing inter-agency coordination and collaboration. A number of agencies address employment of people with disabilities and have historically worked with NIDILRR to identify critical research questions. NIDILRR is committed to working closely with other agencies to improve employment outcomes for people with disabilities.

# Proposed New Employment Research Agenda

NIDILRR's research agenda for the next five years involves building on its current investments and moving them along the series of research stages with the goal of impacting employment

outcomes for people with disabilities. This work will include collaboration with other relevant Federal agencies (e.g., SAMHSA, Rehabilitation Services Administration) that can provide substantive expertise to inform research priorities. Given NIDILRR's previous investments and the current context of employment for people with disabilities, possible areas of research for the next five years include the following:

- **Disability statistics.** Supporting work in employment disability statistics to track the employment status of people with disabilities nationwide.
- People with psychiatric disabilities. Advancing research to help people with psychiatric disabilities, who are among the most disadvantaged in terms of employment, prepare for and succeed in employment. NIDILRR has collaborated with SAMHSA for more than 20 years to develop interventions to help people with psychiatric disabilities. The two agencies plan to continue to work together to encourage research-related activities that improve employment outcomes for youth and adults with psychiatric disabilities.
- **Employment disincentives**. Developing research that moves beyond the identification of disincentives to employment with a strategic focus on the relationships among poverty, income assistance, and employment that would inform policies that improve employment outcomes for people with disabilities.
- Young adults. Funding research that identifies and develops effective services and programs to improve employment, career, and, relatedly, postsecondary education outcomes for youth and young adults. Disseminating and promoting research findings related to successful transition to adulthood for youth and young adults with disabilities. Of particular interest is research to find methods of meeting the needs of young adults experiencing the onset of serious mental illness.
- Employer practices. Funding research on improving employer practices. NIDILRR-funded researchers have begun to develop interventions for employers to improve employment outcomes for people with disabilities. This work will continue for employers across a variety of settings (e.g., small v. large business, private v. public sector) and will include developing and testing a variety of interventions.
- **Return on investment**. Funding research in VR to improve efficiency and effectiveness of services. This includes the identification and development of evidence-based practices and the continuation of development of return-on-investment models that can be used by VR agencies to optimize the services they provide.

# II. Cross-Cutting Research Activities

# **Technology for Access and Function**

NIDILRR supports research, development, and adoption of technology products to promote positive near- and long-term outcomes of people with disabilities in the domains of health and function, community living and participation, and employment. While many Americans are born with, acquire, or age into disability, most will likely experience transient disability at some point in life due to life circumstances or environmental factors. Consequently, NIDILRR's investments in technology products have broadly and positively impacted people with disabilities and American society as a whole.

Technology is the application of knowledge through scientific means to solve practical problems. NIDILRR expects that technology development will employ systematic methods to produce models, methods, tools, standards, applications, devices, and systems that promote and facilitate positive outcomes for diverse populations of people with disabilities. NIDILRR also expects that technology research will result in products that can be made available to people with disabilities and their families and service providers. Technology products are generally transferred through partner organizations including, but not limited to, manufacturers and distributors.

NIDILRR recognizes four key technology research topics that include rehabilitation, assistive, service, and system technologies. Rehabilitation technologies restore, maintain, or slow the decline of function among people with disabilities. Assistive technologies address activity and participation difficulties encountered by people with disabilities by augmenting, compensating for the loss of, or restoring function to improve performance. Service technologies facilitate the provision of rehabilitation, assistive technology, training, and other interventions to people with disabilities. Systems technologies provide improved access to and use of critical infrastructures used by people with disabilities and others in the general population. These include but are not necessarily limited to information and communication technology, the built environment, public transportation, and health care infrastructures.

Members of many engineering and non-engineering disciplines contribute to technology research. However, NIDILRR has long recognized the importance of the field of rehabilitation engineering to people with disabilities. Rehabilitation engineering is concerned with research of technologies to evaluate, diagnose, restore, maintain, or slow the decline of a person's physical, sensory, communicative, or mental functions so as to maximize performance in community living and participation education and employment settings. This includes both rehabilitation and assistive technologies.

#### Context for Technology for Access and Function

Advances in scientific knowledge and technologies are rapid and accelerating. High-power and energy density batteries, the Internet of Things, cloud computing, machine learning, big data and analytics, rapid design and fabrication, advanced materials, micro electro-mechanical systems,

personal and environmental sensor technologies, pervasive information, computing, and communication technologies may all be adapted or built upon to address problems encountered by people with disabilities. Automation and robotics techniques have the potential to change many aspects of transportation for people with disabilities. The rapid changes happening in technology have the potential to change the lives of people with disabilities in amazing ways; however, like all change, NIDILRR is aware that accessibility must be built into each innovation to ensure that people with disabilities can use the new technology.

# Proposed New Technology for Access and Function Research Agenda

NIDILRR will build on current research findings and products as well as invest in emerging opportunities during the next five years. NIDILRR will continue its support of universal design through further research of advanced universal design concepts and their application to all rehabilitation, assistive, service, and systems technologies. Universal design means a concept or philosophy for designing and delivering products and services that are *usable by* individuals with the widest possible range of functional capacities.

NIDILRR will continue to support research of assistive technology devices and software applications that facilitate positive outcomes for people with mobility, cognitive, sensory, and communication disabilities. Such technology products may include, for example, advanced human computer interfaces, personalized exo-prostheses, exo-skeletons that augment muscle function or compensate for the loss of structure and/or function, advanced wheelchair and seating and positioning, rehabilitative and assistive robotics, or advanced sensory technologies. NIDILRR also anticipates continuing research of information and communications technology, built environment, and public transportation systems that maximize the independence of people with disabilities.

Other potential areas of investment include research of standardized evidence-based, interdisciplinary methods and guidelines (and associated outcomes measures) for face-to-face and remote provision of rehabilitation, habilitation, and assistive technology services. Such methods and guidelines would strengthen professional education and interdisciplinary practice; structure the gathering, analysis, and interpretation of service outcomes; and improve access to and efficacy of services provided to individuals living in rural and resource-limited environments. For example, guidelines for mobility assistive technology services could greatly improve the medical and functional outcomes of individuals receiving such services.

NIDILRR supports national and international collaboration on technology research to leverage the knowledge, expertise, and resources of colleagues and institutions. NIDILRR also supports the participation of grant investigators and colleagues on committees to advise the development of Federal, industry, and other technology development standards and guidelines.

# **Disability Statistics and Demographic Research**

Disability statistics research supports outcomes in each of NIDILRR's research domains.

Synthesizing and promoting the use of the vast amount of data collected each year by the Federal government and others allows for a greater understanding of the experiences and outcomes of people with disabilities. The ultimate goal of NIDILRR's disability statistics and demographics effort is to generate new information that can be used by people with disabilities, service providers, policymakers, and others working to identify and eliminate disparities in community living and participation, health and function, and employment.

Valid and reliable demographic data serve as a foundation to the broader mission of NIDILRR and help provide a platform for all agencies in the disability field. High-quality demographic data contribute to NIDILRR's mission and support research in the following ways:

- **Policy decisions.** Informing policies, practices, and programs for people with disabilities.
- **Demographics**. Identifying potential changes in the characteristics and needs of the people with disabilities.
- **Prevalence and context.** Understanding changes in disability prevalence and environmental context.
- **Service delivery.** Informing service delivery.
- Current and emerging needs. Planning research to address current and emerging needs.

# Context for Disability Statistics and Demographic Research

Several national surveys have adopted the six-question sequence of disability identifiers first included in the American Community Survey (ACS). Based on the International Classification of Functioning, Disability and Health conceptual framework, these questions assess difficulty with hearing, vision, cognition, ambulation, self-help, and independent living. Respondents who report having one or more of the six types of disabilities included in the questions are considered to have a disability. Data can be pooled to analyze outcomes for subgroups. Having these standardized measures included in national surveys, year after year, and across multiple questionnaires with different purposes has greatly expanded the opportunities to create new knowledge about the characteristics, needs, experiences, and outcomes of people with disabilities at the population level. The move to collect disability data throughout federally funded surveys represents substantial progress toward measuring the characteristics, experiences, and outcomes of people with disabilities and will inform the redesign of the National Health Interview Survey (NHIS). NIDILRR staff and grantees have provided input regarding the capacity of the NHIS to produce good knowledge about the health and function of people with disabilities and will continue to track the development of final changes.

Proposed New Disability Statistics and Demographics Research Agenda

The goal of NIDILRR's disability statistics and demographics effort is to increase capacity to generate new information for use by stakeholders who are working to identify and eliminate

disparities experienced by people with disabilities in community living and participation, health and function, and employment. Disability statistics and demographic data are interwoven through virtually all components of the study of disability as quantitative analyses play a key role in understanding population-level needs, impacts, and outcomes. NIDILRR's research agenda for disability statistics and demographics for the next five years includes:

- Uniform disability identifiers. Continuing to support work that creates and implements uniform concepts, language, and methods for identifying the number and characteristics of people with disabilities.
- Adoption of the ACS six-question sequence of disability identifiers. Including the ACS sixquestion sequence in a number of surveys to provide additional opportunities for generating new knowledge about the characteristics, experiences, and outcomes of people with disabilities.
- **Data mining.** Sponsoring research that mines existing data to examine the current state of affairs and trends for forecasting future needs of people with disabilities.
- **Policy research.** Supporting research that develops and uses standard measures such as the ACS six-question sequence to assess the effectiveness of policies designed to improve participation among people with disabilities.
- Methodological quality. Supporting research that improves the quality of disability data
  by improving methodological standards in sampling and data collection. This includes, but
  is not limited to, improvements in sampling methods to better include and identify
  individuals with intellectual and developmental disabilities in surveys.
- Usage of measures. Developing research that creates topical survey modules (e.g., unmet needs, community living, transportation, housing, employment, caregiving) with reliable and valid measures. This work should yield instruments for use in various modes of data collection so that information is available about disability subgroups or the interaction of demographic and social factors.

#### Americans with Disabilities Act—Technical Assistance, Training, and Research

Since 1991, NIDILRR has supported a network of 10 regional centers to provide technical assistance, training, and information dissemination about the ADA for the benefit of individuals and entities with rights and responsibilities under this law. The ADA regional centers also collaborate with other relevant grants funded across NIDILRR's outcome domains by sharing data and resources relevant to their training and technical assistance efforts. These 10 regional centers, along with the ADA Knowledge Translation Center and the ADA Collaborative Research Project, comprise what NIDILRR calls the ADA National Network.

A number of developments have shaped the context for how the ADA National Network program

has been implemented. In 2006, NIDILRR incorporated a research component into the scope of activities for the ADA National Network in order to develop new knowledge about barriers to ADA compliance, strategies for its effective implementation, and a greater understanding of stakeholders needs for and use of ADA National Network services. Since these changes, ADA National Network grantees have published numerous journal articles, held a series of research conferences, and conducted other knowledge translation activities to share new knowledge. Examples of key research topics include access to postsecondary education among students with disabilities, access to health care services among people with disabilities, and reasonable accommodations in the workplace.

# Proposed New ADA National Network Research Agenda

While the work of the ADA National Network leads to improved community participation opportunities and outcomes for people with disabilities, there is still much more progress to be made in improving stakeholder knowledge of their rights and responsibilities under the ADA. There is ongoing need for provision of training and technical assistance for those with rights and responsibilities under the ADA as well as data about the impact of such efforts. In addition, there is continued value derived from supporting research efforts that generate new knowledge that further enhances implementation of the ADA. This new knowledge not only contributes to NIDILRR's mission of improving community participation of people with disabilities, but also has implications for technical assistance, training, and implementation efforts of Federal enforcement agencies. NIDILRR intends to continue its support of the technical assistance, training, research, and data collection activities conducted by the ADA National Network. It will explore ways to expand the impact of the Network to new audiences by fostering innovation in practices that aim to improve community participation and by creating greater linkages with other ACL, HHS, and Federal programs and constituencies.

#### **Stages of Research and Development**

NIDILRR continues to promote concepts of stages of research and development as it funds grants in the community living and participation, health and function, and employment domains. NIDILRR uses these stages to emphasize its role as an applied research agency. Through the implementation of this stages framework, NIDILRR emphasized that all of the research it sponsors in the exploration and discovery, intervention development, intervention efficacy, and scale-up evaluation stages leads to new knowledge that can be used to create and implement interventions that improve the lives of people with disabilities. Similarly, the development work that NIDILRR sponsors at the proof of concept, proof of product, and proof of adoption stages leads to products that are used to improve the lives of people with disabilities.

NIDILRR first published and sought public comments on the stages of research as part of its FOAs in 2012 and 2013. Since then, NIDILRR has included the stages in all of its relevant research FOAs and asked applicants to describe and justify the stage or stages of research they propose. NIDILRR formalized the stages of research in its Long-Range Plan published in FY 2013 and in its final program regulations published in FY 2016. NIDILRR first published its stages of development in

the draft NIDILRR program regulations in FY 2012. NIDILRR formalized these stages in the final version of the NIDILRR program regulations in 2016. These final regulations included new review criteria that allow peer reviewers to evaluate the extent to which applicants describe and justify the stage or stages of their proposed research and development projects.

NIDILRR values and funds research at each of these stages because it is essential to derive interventions and develop products systematically and methodically based on scientifically sound foundations and concepts. While NIDILRR's ultimate aim is to sponsor research toward interventions and products to improve the lives of people with disabilities, it does not favor research in the intervention efficacy or scale-up evaluation stages over earlier stages of exploration and intervention development. NIDILRR recognizes that there is a great deal of early-stage exploratory research that must take place to create the foundation of knowledge for new interventions and products. NIDILRR seeks to ensure that the work that it sponsors is appropriate to the levels of knowledge available in specific topic areas.

Requiring applicants and peer reviewers to pay close attention to stages of research and development helps NIDILRR ensure, for example, that it sponsors research that tests the efficacy of an intervention only if there is already research-based knowledge about its relevance and feasibility and if there are measures to properly reflect the intended effects of the intervention. Similarly, use of the development stages helps NIDILRR ensure the transfer and promotion of sponsored technologies only if they have been properly conceptualized, tested for utility and feasibility among users, and refined.

NIDILRR intends to continue to provide training and information to our applicants, grantees, and reviewers to help ensure the proper use of its stages of research and development. Continued implementation and use of these stages in the field will help NIDILRR maximize the efficiency and productivity of its research resources and programs.

# III. Activities That Promote the Quality and Use of NIDILRR-Sponsored Research

# **Capacity Building**

NIDILRR sponsors capacity-building grants and activities to help ensure that the field of disability, independent living, and rehabilitation research has well-trained research personnel as well as tools and methods to support high-quality research activities that result in new knowledge and products. Title II of the Rehabilitation Act, as amended, authorizes NIDILRR to build capacity for conducting high-quality disability, independent living, and rehabilitation research by providing for advanced training in disability and rehabilitation research, including people with disabilities and underserved populations. NIDILRR meets these statutory mandates for training and capacity building primarily through its Research Fellowship Program (Switzer) and its Advanced Rehabilitation Research Training Program (ARRT). Grantees in NIDILRR's Rehabilitation Research and Training Centers (RRTCs) and Rehabilitation Engineering Research Centers (RERCs) programs are also required to provide research training to investigators in the early stages of their research careers.

NIDILRR's Switzer Fellowship Program is designed to build capacity by funding individual researchers to conduct research activities in rehabilitation. These Fellowships provide one year of financial support with which recipients carry out independent research projects that further NIDILRR's mission. Fellowships are awarded competitively through peer review, selected primarily on the basis of the applicant's qualifications and experience and on the strength of the proposed research project. Prospective fellows apply at the "Merit" or "Distinguished" levels. Merit Fellowships are available to individuals who are at the start of their careers in disability, independent living, and rehabilitation research. Distinguished Fellowships are available to individuals with more independent research experience and are funded at a somewhat higher budget level than Merit Fellowships. Over the years, NIDILRR has awarded more than 300 Switzer Fellowships.

NIDILRR also funds institutions of higher education to conduct postdoctoral training under its ARRT program. The primary purpose of the ARRT program is to provide advanced training in disability and rehabilitation research to individuals with doctoral or similar advanced degrees who have clinical or other relevant experience. ARRT grants provide multidisciplinary research training that teaches and enhances research methodology skills. They provide researchers with experience in grant writing, conduct of research, and presentation and dissemination of research findings. The intent of this training is to support NIDILRR's mission by preparing individuals to conduct independent, high-quality research on questions related to disability, independent living, and rehabilitation.

Under Section 21 of the Rehabilitation Act, NIDILRR is mandated to allocate one percent of its annual budget to carrying out activities related to traditionally underserved populations. Under this authority, NIDILRR focuses on building the capacity of minority-serving institutions and their personnel to conduct disability and rehabilitation research and on developing a cadre of researchers who represent underserved populations, including people with disabilities.

# Proposed New Capacity-Building Agenda

There is an ongoing need for well-trained researchers in the disability and rehabilitation research fields given the rapidly changing demographics and the growing recognition of the importance of having an evidence base for disability, independent living, and rehabilitation interventions and practice. NIDILRR intends to continue its capacity-building efforts through the Research Fellowship Program and the ARRT program as well as training and mentoring opportunities in the RRTC and RERC programs. NIDILRR will build its capacity to collect and analyze data to capture the long-term impact of these capacity-building efforts.

NIDILRR also intends to highlight and promote the Section 21 program by creating research opportunities for minority-serving institutions and by enhancing data collection and evaluation practices to assess capacity building targeted at minority-serving institutions and minority researchers, including those with disabilities. NIDILRR will continue to implement strategies that result in increased minority representation across NIDILRR's grant mechanisms. Through these

efforts, NIDILRR will help ensure that the new knowledge that our grantees generate reflect the needs, experiences, and outcomes of the diverse population of people with disabilities in the United States.

# **Knowledge Translation**

For NIDILRR, Knowledge Translation (KT) is the multidimensional, active process of ensuring that new knowledge and products gained through the course of research ultimately improves the lives of people with disabilities and furthers their participation in society. KT is applicable to both technological and non-technological knowledge and products. NIDILRR uses KT to promote the effective use of NIDILRR-funded knowledge and products, which is a critical component of our mission.

For KT to be successful, NIDILRR believes that the new knowledge or product must: (1) address real issues faced by people with disabilities, (2) offer helpful information or solutions related to those issues, (3) be presented in ways that make it accessible to and feasible for the intended users, and (4) be disseminated or distributed effectively. When users are aware of the availability of new knowledge or products, they can make an informed decision or take action to change behavior, practice, policy, or systems as appropriate to improve the lives of people with disabilities and further their participation in society.

To maximize the relevance, feasibility, usability, and reach of the new knowledge or products, it is crucial that researchers involve people with disabilities and other stakeholders in all KT components starting from the initial identification of needs for knowledge and products. Stakeholders include not only direct users of the knowledge or product, but also individuals or entities with a stake in the issues because of their role and function within the context in which the knowledge or product will be used. The input, or lack of input of a variety of stakeholders, can influence the likelihood that new knowledge or products will be used in the future. Different kinds of knowledge or products have different stakeholders, determined by the type of knowledge or product, its anticipated use, and the context in which it will be used. Stakeholders may include people with disabilities, their family members, practitioners, policymakers, employers, Centers for Independent Living staff members, disability advocates, educators, assistive device manufacturers, insurance companies, and others as appropriate.

#### Proposed New Knowledge Translation Agenda

For the next five years, NIDILRR intends to continue its efforts to help ensure that knowledge and products generated by NIDILRR grantees are used to improve the lives of people with disabilities:

- **Expansion**. Fund KT grants in different content areas to provide KT support for NIDILRR grantees and advance understanding and applications of KT in the disability context.
- Strategic initiative support. Fund KT contracts to provide support for NIDILRR's KT

strategies and initiatives.

- **Business processes**. Integrate the KT framework into NIDILRR operations such as funding priority requirements, peer review criteria, performance reporting, and other business processes as appropriate.
- **Partnerships.** Strengthen existing connections with, and establish new connections to, disability, independent living, and rehabilitation stakeholders within and outside the Federal government.
- Awareness and promotion. Identify and pursue opportunities to raise awareness and promote the use of NIDILRR-funded knowledge and products within ACL, HHS, other Federal agencies, and the broader community in which people with disabilities live. Work closely with ACL and Federal colleagues to disseminate and promote NIDILRR's research findings to state and local agencies and programs that provide services and supports to people with disabilities.
- **Public access.** Fully implement the public access requirements for both peer-reviewed publications and scientific data to ensure that knowledge, products, and data from NIDILRR-funded work can be accessed and used by the public at no cost.

#### **Summary**

This Plan acknowledges the current environmental context in which people with disabilities across the lifespan are striving to forge meaningful and active lives in support of their personal goals. It recognizes NIDILRR's place within ACL and the importance of partnership and collaboration with other Federal agencies as well as other stakeholders, with the understanding that research outcomes are increasingly needed to help refine national policy in support of those individual aspirations. By investing in a relevant and robust program of applied research across the domains of community living and participation, health and function, and employment, supported by additional cross-cutting activities and initiatives to promote its quality and use, NIDILRR believes the Plan will significantly improve the social participation and community living outcomes of people with disabilities.