

The National Institute on Disability and Rehabilitation Research (NIDILRR) is requesting comments on its draft long-range plan for the period 2018-2023. NIDILRR is a component of the Administration for Community Living in the Department of Health and Human Services. Its aim is to enhance the ability of people with disabilities to achieve their maximum desired participation in the community through research and development in areas of health and function, employment, and community living and participation. This long-range plan provides an overview of the state of people with disabilities in the United States, NIDILRR's current research investments, and potential future directions. We are publishing this plan to obtain public comment on the proposed research and development activities to help the agency fulfill its mission. Comments will be accepted by email at [NIDILRRfuture@acl.hhs.gov](mailto:NIDILRRfuture@acl.hhs.gov).

## **Title: NIDILRR Long-Range Plan**

### **Introduction and Background**

The Rehabilitation Act 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 NIDILRR's work in both research and development.

The Long-Range Plan of the [National Institute on Disability, Independent Living, and Rehabilitation Research](#) (NIDILRR) presents a five-year agenda that will advance the vital work being done in applied disability, independent living, and rehabilitation research and development<sup>1</sup>. NIDILRR intends for this plan to emphasize the demands of 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 proposed 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 scientific research to meet the diverse needs of people with disabilities.

The Plan extends NIDILRR's emphasis on the major outcome “domains” of health and function, employment, and community living and participation. NIDILRR measures contributions toward improved outcomes in these domains by systematically tracking the outputs of grantees and

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<sup>1</sup> The previously termed domain of independent living and community integration in the FY1999–FY2003 Long- Range Plan was renamed community living and participation for the FY2005–FY2009 plan to better capture the broad goal of increased participation, which is intrinsic to the NIDILRR mission.

the new knowledge that they have created. NIDILRR measures the new knowledge it generates in the form of citation of peer reviewed articles and in 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.

The Plan also reinforces the need for investment in three areas that support outcomes in 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-sponsored research and development – capacity building and knowledge translation – will also continue under the Plan.

This Plan will be used to guide NIDILRR's upcoming research and development agenda, aligning with 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 and development is to enhance the ability of people with disabilities to achieve their maximum desired participation in the community, with full access to all societal and life activities; and
- 2) NIDILRR has a legacy and future as a primary funder of rigorous disability, independent living, and rehabilitation research and development, recognizing that this spans the continuum from acute setting and into the home-and community-based service environment.

## 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 as diverse as it was 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 of all ages want to lead active lives in the community and access the same things their able-bodied peers want: 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 regarding local providers.
- ***Choice and control matters.*** Whether it's access to affordable and accessible housing or a ride to the doctor's office, people with disabilities want meaningful choices that respect a desire for safety, security, and their valuable time. This is consistent with the trend toward

person-centered planning, which respects 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 engagement. Reimbursement rates paid to provider agencies and the inability to provide competitive wages for their workforce was also cited. 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 true not just for medical and clinical services, but also for long term services and supports (LTSS) that are provided in the community. People reported feeling overwhelmed and confused by these changes, and frustrated that it treats 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 described frustrations with their inability to gain access to cell phones, durable medical equipment, and assistive technology. Poverty, lack of existing sources of reimbursement, and policy challenges were given as barriers to access.
- ***What works and what doesn't?*** All stakeholders were hungry for research and development 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. Specific attention was paid by respondents 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"

1. Improve the abilities of people with disabilities to participate in community activities of their choice; and
2. To expand society's capacity to provide full opportunities and accommodations for these individuals. NIDILRR is both cross-age and cross-disability in scope, serving individuals across the age continuum and including all disability subpopulations: developmental, cognitive, sensory, and mobility-related.

There is a variety of definitions of disability used in the United States. 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 and development that it sponsors, especially on the experiences and needs of individuals with the most significant disabilities, as defined in the act.

While authorized in 1978 under amendments to the act, NIDILRR’s history and legacy of rehabilitation research date to the 1950s and the vision of inclusion defined by Mary E. Switzer, then the federal director of vocational rehabilitation (VR). A strong supporter of research, Switzer understood that rehabilitation must be understood as a continuum, stretching from acute hospital interventions through post-acute and outpatient services, and ultimately into the community. Funded federal research begun during Switzer’s tenure grew, and in the 1960s led to the development of both rehabilitation engineering and regional spinal cord injury centers. These would later become the rehabilitation engineering research centers and spinal cord injury model systems programs funded by NIDILRR today.

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

People with disabilities, especially those living with severe disabilities, often face barriers that complicate the simple goal of leading a happy and 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. These interventions span multiple policy areas and governing jurisdictions, each with their own challenging eligibility requirements and procedures.

### **Access To and Maintenance of Needed Supports**

Failing to access or maintain needed supports can result in adverse health, financial, and community living outcomes for people with disabilities. Navigating this complicated “system” can require the assistance of others. Unfortunately, there is often a mismatch between the assessed needs of an individual and the localized infrastructure to meet these needs. The availability of consumer friendly information about the quality of these supports is often lacking. Further complicating matters is the current environment of fiscal austerity – at both the state and federal level – which threatens the funding for programs and services for people with disabilities.

### **Employment Is a Critical Source of Financial Independence and Community Participation**

Employment, especially a job at the minimum wage and above, is a critical source of financial independence and community participation. It is also the traditional gateway to (employer-sponsored) health insurance coverage. However, achieving employment remains elusive for

many people with disabilities. People with disabilities have dramatically lower employment rates than people without disabilities, and this difference has been relatively stable since 2009. Even among workers, those with disabilities are more likely to work part-time, to earn less, and to experience greater challenges in retention and advancement than those without disabilities. Members of some disability groups, e.g., those with psychiatric disabilities, are particularly likely to experience low levels of employment. Young adults with disabilities frequently find it difficult to enter, or remain in, the world of competitive integrated employment. Individuals who are unemployed or under-employed frequently find themselves dependent on public benefits, and living in economically straitened circumstances. The employment rate (or employment to population ratio) for people with disabilities declined by nearly 10 percent from 2008 to 2010, and this rate was more than double that for people without disabilities. Since 2010, the employment trend for people with disabilities has improved, though it has not kept pace with that of people without disabilities despite notable improvements in 2015 and 2016. The employment rates for people with and without disabilities is 26 percent and 73 percent, respectively. Consequently, people with disabilities are more likely than those without disabilities to live in poverty or economic insecurity, and are more vulnerable to its consequences, including poor health, inadequate housing, and food insecurity.

### **Safe, Accessible, Affordable and Useable Housing Environment Critical to People with Disabilities**

A safe, accessible, affordable, and useable housing environment is critical for people with disabilities, and its existence or absence has been found to be a predictor of community engagement and participation. An estimated 41 percent of working-age public housing tenants have a disability, and many participate in multiple public benefit programs. Working-age people with disabilities who live in public housing, but do not receive disability program benefits are significantly less likely to be employed than disabled non-beneficiaries who do not reside in public housing. New models of shared living and/or shared supports are being developed across the country in an effort to improve community living outcomes.

### **Health Care System: Acute To Home- and Community-Based Services Contributes to Community Living Outcomes**

The health care system -- broadly defined across the continuum of care (from acute to home and community-based services) is changing quickly and is difficult to navigate. This includes clinical and rehabilitation services, but also community supports like assistive technology, home health aides, and wellness programs that have been found to meaningfully contribute to community living outcomes. People with disabilities generally have higher health care needs than the non-disabled population and are also more likely to have unmet needs. This is especially true for those with physical disabilities and those with mental health conditions. Access to long term services and supports has improved in some states, as policymakers and Medicaid agencies have shifted funding away from institutional settings. But the variability of these state-controlled programs (that are jointly funded by the federal government) has created geographic inequities regarding access to needed services. At the same time, new

service delivery models are emerging, as are new financing models that reward positive health outcomes. More study and a greater understanding of the effects of these models on people with disabilities are needed.

### **Transportation--Gateway to Employment and Social Participation for People with Disabilities**

Transportation is often the gateway to employment and meaningful social participation for people with disabilities. Research has shown it also remains a primary barrier to accessing health care and wellness services. The link between housing and transportation is strong. Given that people with disabilities are less likely to drive than their able-bodied peers, their housing options can be narrowed based on access to public transportation. This challenge is especially acute in rural areas, where public transportation can be very limited or non-existent. The advent of driverless vehicles and related robotic and automation technologies present opportunities for people with disabilities. Disability presence and competency is needed as these transportation options mature and multiply, as is research to understand their potential and effectiveness.

Despite these multiple challenges, and the tenuous nature of multiple supports that must function in concert to support the optimal community living needs of people with disabilities, many people across the United States are thriving. Public testimony and written comments received by NIDILRR clearly indicates that tremendous progress has been made to support the integrated, community living principles first outlined in the Rehabilitation Act of 1973 and reinforced by the Americans with Disabilities Act and Olmstead Decision of 1999. Pockets of innovation and creativity in the delivery of services and supports continue to emerge, even as state and federal budgets continue to search for needed savings. 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. Erosion of progress is occurring in some communities, especially in the absence of robust research and data to articulate which policies, processes, and practices can lead to desired outcomes for people with disabilities.

### **Agency Context**

The Workforce Innovation and Opportunity Act of 2014 (WIOA) transferred NIDILRR to the U.S. Department of Health and Human Services 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 (AoA), the Office on Disability (OD), and the Administration on Intellectual and Developmental Disabilities (AIDD) 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.

WIOA made changes to the NIDILRR statute, but did not detract from or remove any responsibilities or current 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 and development initiatives that NIDILRR sponsors.

## Federal Research Planning

While NIDILRR occupies a unique space within the federal government in conducting applied research, it is one of several agencies conducting research on behalf of people with disabilities. Other agencies include the National Institutes of Health [and within it the National Center on Medical and Rehabilitation Research (NCMRR), the National Institute on Aging (NIA), the National Institute of Mental Health (NIMH)], The Substance Abuse and Mental Health Services Administration (SAMHSA), the Department of Defense (DOD), and the Department of Veterans Affairs (VA). 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. While the demand for disability and rehabilitation research and development has never been greater, current funding levels don’t match this demand. In response, NIDILRR continues to work with other research agencies to understand where funding priorities may intersect and collaborations may be formed.

NIDILRR has a proud history of formal interagency agreements, where common interests across agencies have resulted in a combined funding opportunity. 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, they are required:

“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.”

“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.”

## **Key accomplishments of NIDILRR grantees since last LRP**

Since the publication of NIDILRR's Long Range Plan for 2013-2017, there has been increased emphasis on field-initiated priorities that allow researchers to propose innovative research and development projects to promote improved outcomes among people with disabilities in the broad outcome domains of community living and participation, employment, and health and function. These actions, along with NIDILRR's sponsorship for the development of new knowledge and innovative new technological devices, prototypes, measurement tools, intervention materials, and other informational products to enhance community living has resulted in more than 1,200 products, including peer-reviewed publications, intervention protocols, software, and databases that enhance the community living opportunities of people with disabilities.

## **I. Research and Development Agenda**

### **Overview**

NIDILRR's Research and Development 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) employment, and (3) health and function. Its research and development agenda for the next five years involves building on its current investments, moving them along the stages of research and development, while also initiating new research in developing fields, with the goal of improving community participation outcomes for people with disabilities. As a component of this, translational research will be used to expand the utility of evidence-based programs and practices by adapting them for different populations of people with disabilities and the environments in which they live. Research and development activities will be aligned with the 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 and development agenda that blends three important factors: a) 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; b) taking advantage of the expertise of our colleagues in ACL to expand our research on issues of aging and disability and community living; and c) conducting research on health policy issues to inform the national agenda. Highlights of potential areas are provided below.

### **Health and Function**

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 60 percent of individuals with serious mental illness die 25 or more years earlier than 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 for these individuals.

### **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 funder of disability and rehabilitation research and development. NIDILRR has 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 the Veteran's Administration, among others. For example, NIDILRR has been a partner in the development of the National Research Action Plan (NRAP) on posttraumatic stress disorder, other mental health conditions, and traumatic brain injury (TBI) 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 and development, 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, given new health care reform initiatives of a newly elected President and Congress, there may be new opportunities for examining access to services and short and long-term outcomes, including the impact on health and function outcomes of people with disabilities.

## **Accomplishments**

NIDILRR-sponsored researchers have examined foundational issues related to health service access among people with disabilities and its impact on long-term health status and ability to live in community settings. Research has also focused on development of treatments and other interventions that help promote functional independence among people with disabilities. This research contributes to the growth of evidence-based practice in rehabilitation service delivery.

### *Longitudinal Databases.*

NIDILRR funds the Spinal Cord Injury Model Systems, the Traumatic Brain Injury Model Systems, and the Burn Model Systems research programs. These programs have created longitudinal databases that allow for examination of characteristics and long-term outcome trajectories of populations of individuals with these injuries. NIDILRR has partnered with the Department of Defense, the Veteran's Administration, and the CDC to use this valuable information to inform changes in service delivery.

### *Interventions Research Leading to Evidence-Based Practice.*

An important goal of NIDILRR's research efforts is to create evidence-based practices that will improve the outcomes of people with disabilities and maximize the return on investment of innovations in health care and rehabilitation service delivery. Recent accomplishments in this area include:

- ***Development of a diabetes tool kit designed to help people with mental health disorders.*** This kit supports people with psychiatric disabilities who are at increased risk for diabetes or pre-diabetes to understand and manage their diabetes or pre-diabetic condition. Materials from the tool kit have been downloaded more than 48,000 times.
- ***The first practice-based evidence study of TBI rehabilitation.*** The study enrolled 2,205 individuals with TBI who were receiving initial inpatient rehabilitation across 10 rehabilitation centers, resulting in the richest dataset on TBI rehabilitation ever assembled. These data identified characteristics associated with patient outcomes, how clinical events mediated outcomes, and treatments used in response to various clinical problems, leading to determination of the best treatment options. The findings inform clinical guidelines and decision-making.
- ***A study of self-directed recovery and integrated Health Care.*** A NIDILRR grantee is creating, modifying, and improving self-directed models of medical care and mental health services that promote recovery, health, and employment for people with psychiatric disabilities. This

includes a new intervention designed to help people with serious mental illnesses self-manage their physical health while working toward recovery of their emotional wellness and an evaluation of costs and service utilization following discharge from hospitalizations.

- ***The promulgation of a standard for real-time text.*** The Federal Trade Commission recently amended its rules to allow phone companies to support real-time text (RTT), developed with NIDILRR funding. RTT allows characters to be sent automatically as they are created unlike older technology (TTY) which required users to hit a send button as the message was completed. This new technology will improve the communication ability of individuals with hearing impairments.

## Health Care Reform

NIDILRR has been successful in conceptualizing and sponsoring research on the effects of various health care reform efforts on the experiences and outcomes of people with disabilities. These efforts include the “Collaborative on Health Reform and Independent Living” (CHRIL), which seeks to provide disability stakeholders with accurate, current, and actionable information on how recent changes in health policy directly or indirectly impact the community living and participation of working-age adults with disabilities. These efforts also include a grant on “Innovation in Disability Empowerment and Service.” This research seeks to identify potential models of health care delivery for people with disabilities that are effective in improving health and the patient experience of care, while reducing cost. One research objective is to develop and test a health delivery system that uses a community-based organization as a mode of delivery of some health services and to determine the impact of this delivery approach on cost, health, and quality of care.

## Research and Development Agenda

NIDILRR anticipates continuing to fund of 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.** Aging with 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 and development 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 disability. Given NIDILRR’s previous investments, potential research and development includes the following:
  - Research that results in a portfolio of evidence-based practice and programs that are effective in moderating the negative consequences of aging with disability on health, function, participation, and community living.
  - Collaborations that bring together researchers, practitioners, policymakers, and individuals aging with disabilities and their advocates to generate new knowledge that

promotes and facilitates the common interests of affordable health care, long-term services and supports, 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 disabilities.
- **Continued Development of Interventions that Improve Health and Function Outcomes.** Despite the progress that has been made, treatments and other interventions are needed to help improve health and function outcomes for people with disabilities. As people with disabilities rely more on Home and Community-Based Services (HCBS) as a vehicle for maintaining health, minimizing re-hospitalizations and maximizing community living outcomes, research that investigates the relationship between these services, interventions, and health and function outcomes is also needed. 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 other programs and grant mechanisms.
- **Implementation of Existing Evidence-Based Practices.** NIDILRR will expand its efforts to 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 efforts may support translational research to develop practical strategies for ensuring more widespread use of new evidence-based findings in the area of disability and rehabilitation research and development.
- **Policy Impacts on Access to Health Care Services and Outcomes.** NIDILRR plans to continue its 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.
- **Person-Centered Planning and Services.** NIDILRR is interested in research and development that expands the integration of person-centered planning into decisions regarding health and function of people with disabilities. While there have been many small studies of the impact of individual preference in decisions about rehabilitation interventions, there remains a need to expand current knowledge by supporting more evidence generating research to provide data for systematic implementation of this approach across rehabilitation broadly including medical, vocational, and community settings. In addition, NIDILRR is supportive of personalized medical rehabilitation treatments that take into consideration the natural variation in the neurobiological characteristics of individuals.

## Employment

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 allow 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 policy, developing interventions to improve employer practices, and developing employment-related services and supports that maximize employment outcomes.

### Context for Research and Development on Employment

The current disability employment environment has been shaped by a number of recent events, including the Great Recession and recent changes in legislation and public policy, programs, and services. Changes have included:

- **Great Recession.** The recent recession (2007-2009) 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.
- **Workforce Innovation and Opportunity Act (WIOA).** This workforce act, passed by Congress in 2014, 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 & Developmental Disability (IDD) agencies; and new definitions of customized and supported employment.
- **Legislation designed to improve employer practices.** Despite the fact that the Americans with Disabilities Act became law more than 25 years ago, 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.** People with disabilities are frequently beneficiaries of publicly funded programs (e.g., SSI, SSDI) that can serve as disincentives 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 affect employment outcomes for people with disabilities.
- **Vocational rehabilitation programs.** Vocational rehabilitation (VR) programs provide services and supports to help people with disabilities prepare for, obtain, keep, or re-gain

employment. Vocational rehabilitation services are included in the coordinated programs covered by WIOA. There is, therefore, a need for evidence-based practices for use in vocational rehabilitation. 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.** Federal agencies have been encouraged to increase efficiency and decrease duplication by 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.

## Accomplishments

NIDILRR-funded research has generated knowledge about employment relevant to the context described above. In recent years, NIDILRR has emphasized the importance of funding research and development that progresses along a series of stages (from exploration to intervention development and efficacy, to scale-up of interventions), so that the knowledge generated by research can be used to improve outcomes for people with disabilities. In the area of employment, the accomplishments of NIDILRR grantees have contributed to the knowledge base concerning employment outcomes for people with disabilities in the following ways:

- **Employment statistics.** Tracked employment statistics, comparing people with disabilities to people without disabilities, demonstrating the persistent gap in employment between the two groups, as well as how recovery from the Great Recession is occurring more slowly for people with disabilities than for those without disabilities.
- **Individuals with psychiatric disabilities.** Investigated and demonstrated how variations in supported employment (e.g., in combination with vocational peer support, in combination with cognitive remediation) can improve employment outcomes for people with psychiatric disabilities. The resulting evidence base, much of which was generated by centers receiving funds from both NIDILRR and SAMHSA, has led to a scale-up project involving the combination of supported employment with cognitive remediation.
- **Young adults with disabilities.** Studied and developed interventions that help youth and young adults with disabilities (including youth with autism spectrum disorders, with traumatic brain injury, with visual impairments, with serious mental health conditions, and with physical disabilities) transition successfully to postsecondary education and the workplace.
- **Employer practices.** Advanced the field of research on employer practices from exploratory surveys of employer opinions to intervention research to improve employment outcomes for people, including workers, with disabilities.
- **Return on investment.** Advanced knowledge of vocational rehabilitation practices, by developing a model of return on investment for use by state vocational rehabilitation agencies, and by laying the groundwork for the development and use of evidence-based vocational rehabilitation practices

- **Employment disincentives.** Examined possible employment disincentives, possible approaches to mitigating them, and possible employment incentives, by studying how SSI/SSDI programs and enrollment, the Medicare program and enrollment, and health care reform, affect employment and economic security for people with disabilities.

## Research and Development Agenda

NIDILRR’s research and development agenda for the next five years involves building on its current investments and moving them along the series of research and development 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, RSA), who can provide substantive expertise to inform research and development priorities. Given NIDILRR’s previous investments, and the current context of employment for people with disabilities, possible areas of research and development 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 will 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 increase knowledge to inform policies that improve employment outcomes for people with disabilities.
- **Young adults.** Funding research and development that identifies and develops effective services and programs to improve employment, career, and, relatedly, postsecondary education outcomes for youth and young adults. This age group is particularly critical: if young adults can succeed in competitive integrated employment, expenditures on publicly funded benefits might be reduced. In addition, this time of life is particularly important for young people with mental health conditions. The onset of serious mental illness frequently occurs in people in their late teens or early twenties – a time in which young adults are typically engaged in training or postsecondary education in preparation for their future working lives. Disruption at this stage of development may lead to a lifetime of dependence on public benefits.
- **Employer practices.** Funding research and development on improving employer practices. NIDILRR-funded researchers have just 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 vocational rehabilitation 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.

## **Community Living & Participation**

While the three outcome domains contain equally important and rich areas of research and development investment over the years, the domain of community living and participation is the ultimate outcome of all of NIDILRR's research, development, capacity building, and knowledge translation grants. We sponsor research and development 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. We sponsor 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, and 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 long-term services and supports (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 and development to improve our knowledge of a wide variety of factors that promote or hinder community living. NIDILRR and its grantees 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 and Development on Community Living & Participation**

NIDILRR's sponsored research and development in the community living and participation domain is motivated by its statutory mandate to improve community living outcomes for people with disabilities. The Rehabilitation Act 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." The Act authorizes NIDILRR to administer programs of

research and development to generate new knowledge and products that “empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society.” NIDILRR’s research and development 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 mandated in the Americans with Disabilities Act and the Supreme Court’s Olmstead decision that followed.

For more than 20 years the U.S. has been actively shifting the its provision of long term services and supports (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.

## Accomplishments

NIDILRR-sponsored research and development has generated new knowledge on the barriers to and facilitators of community living and has been used to shape policies and practices to promote the community living and participation for the diverse population of people with disabilities. In the area of community living and participation NIDILRR grantees have contributed to the knowledge base to improve outcomes for people with disabilities in the following ways:

- **Quality measures.** Provided leadership on the National Quality Forum’s multi-stakeholder committee on measuring quality of home and community-based services (HCBS). This committee developed a framework for measuring the quality of HCBS across multiple domains that are important to people with disabilities and other stakeholders, identified current measures of HCBS quality, and made recommendations to guide future development and application of HCBS quality measures. This committee’s reports are being used to shape HCBS quality measurement efforts and to measure and track the quality of HCBS being provided to people with disabilities.
- **HCBS programmatic findings.** Generated new knowledge about the impact of specific HCBS programs on the outcomes of people with disabilities. One NIDILRR grantee recently demonstrated that participation in HCBS waiver programs tailored for children with autism spectrum disorders (ASD) is associated with improved independent living skills and improved quality of life for children with ASD and their families. This research also identified specific services and supports that were closely associated with positive community living outcomes for this population.

- **Housing barriers.** Analyzed national data to create new knowledge about the multiple, specific ways that inaccessible housing can serve as a barrier to community living and participation for people with disabilities. Based on this new knowledge, NIDILRR grantees created web-based resources and networks for people with disabilities and their local Centers for Independent Living to address specific housing barriers.
- **Transportation access.** Generated new knowledge about the experience of people with disabilities as they use a wide variety of transportation options in the community, including air travel, public transit, and private vehicles.
- **Public transportation.** Provided data and research-based input to help shape federal legislation and rules related to ramps and lifts used on public transit vehicles.
- **Transportation technology.** Created new products that promote accessible and safe use of a wide variety of transportation options, including (1) a mobile application that uses crowd-sourced information to create publicly-available real-time information about the accessibility of specific buses, (2) a folding wheelchair that can be safely and effectively used by people with mobility impairments on airplanes, and (3) a virtual reality driving system for assessing the driving ability of individuals who have experienced a brain injury.
- **Environmental access.** Developed tools and research methods to allow researchers, clinicians, and service providers to measure environmental factors that shape the experiences and outcomes of people with disabilities. These tools include measures of (1) the built and natural environment in which people with disabilities live, (2) the systems, services, and policies that people with disabilities interact with, and (3) levels of access to information and technology among people with disabilities. These tools allow for systematic measurement of environmental factors and the extent to which those factors serve as barriers to or facilitators of community living and participation among people with disabilities. The knowledge generated by use of these tools can shape and guide the efforts of people with disabilities, service providers, and advocates to remove environmental barriers to community living and participation among people with disabilities.

## Research and Development Agenda

NIDILRR supports the development of new knowledge and products that can be used to increase community living and participation among people with disabilities. We will build upon our current and prior investments in this domain, coordinating with our partners in ACL, the Department of Health and Human Services, and the broader federal government wherever possible. Given NIDILRR's prior investments and the ongoing U.S. aim of expanding home and community-based long-term services and supports for people with disabilities, the research and development agenda for the next five years includes the following:

- **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 outcome of those services is increasingly important.

- **Transportation access.** Funding research and development activities to create knowledge and products that improve access to transportation for people with disabilities. Ongoing work in this area will involve coordination and collaboration with the U.S. Department of Transportation. This work may include research and development activities to support the development of standards for the accessibility and useability of autonomous vehicles for people with disabilities, as well as enhanced standards for accessibility and useability of paratransit vehicles, taxis, and emerging ride-share services. These investments may also include research and development toward reducing the most common transportation barriers experienced by people with disabilities – which occur in the first and last miles of their trip.
- **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 research on specific unmet needs for services and supports among people with disabilities who are living in the community, as well as promising practices for delivering such 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 and development on ways to promote the accessibility, useability, and visitability of homes for people with disabilities. This research and development work may include applications of universal design principles to living spaces, as well as research towards the development of policies, practices, programs and incentives to promote accessibility and visitability features in new home construction and home additions.

## II. Cross-Cutting Research and Development 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; all Americans will experience transient disability 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 recognizes that research and development are interdependent and inseparable. For practical purposes, NIDILRR expects that research will employ systematic methods to answer research questions and fill gaps in knowledge, and that research findings will be embodied as peer-reviewed publications and proceedings and disseminated. NIDILRR expects that development will employ systematic methods to produce models, methods, tools, standards, applications, devices, and systems that address problems of and difficulties encountered by diverse populations of people with disabilities.

NIDILRR recognizes four technology domains 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 useability of critical infrastructures used by people with disabilities and others in the general population. These include 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 and development. However, NIDILRR has long-recognized the critical importance of the field of rehabilitation engineering to people with disabilities. Rehabilitation engineering is concerned with research and development 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 their performance in community living and participation, and education and employment. This includes both rehabilitation technologies and those assistive technologies having medical outcomes. Rehabilitation engineering normally involves collaboration between members of biomedical, mechanical, computer, electrical, and other engineering disciplines with members of non-engineering disciplines such as occupational therapists, speech language pathologists, physical therapists, special educators, psychologists, and assistive technologists. It is notable that biomedical engineering involves interdisciplinary activities that integrate engineering sciences with biomedical sciences and clinical practice.

## Context

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, and pervasive information, computing, and communication technologies may all be adapted or built upon to address problems of or 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 access and use the new technology.

## Accomplishments

NIDILRR grantees have researched and developed significant rehabilitation, assistive, service, and systems technologies. For example, rehabilitation technologies include a portable, high performance, personal dialysis device and rehabilitation robotic tools. Assistive technologies include exoskeletons for personal mobility, augmentative and alternative communication devices with advanced user interfaces and language acquisition and generation capabilities; and ‘universally accessible’ exercise equipment. Service technologies include tools to optimize the auditory perception of individuals using hearing aids or cochlear implants, tools supporting remote service delivery, virtual reality tools for executive functioning training, and cell phone based route planning tools for public transportation. System technologies include accessible exercise facilities to provide health and recreational benefits and ‘universally accessible’ wireless emergency notification systems.

## Future Research and Development

NIDILRR will build on current research and development findings and invest in emerging opportunities during the next five years. For instance, NIDILRR plans to develop and support use of models and standards for ‘useability’ that can be generally applied to the design and development of rehabilitation, assistive, service, and systems technologies. Useability is defined as the extent to which a specified person can use a technology to complete specified tasks with effectiveness, efficiency and satisfaction. NIDILRR will continue its support of universal design through further research and development of advanced universal design concepts and their consideration and 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* individual with the widest possible range of functional capacities.

NIDILRR will continue to support research and development of assistive technology applications and devices 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-prosthesis, 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 hopes to continue research and development of information and communication technology, built environment, public transportation, and health care systems that maximize the independent perception, comprehension, and use by people with disabilities.

Other potential areas of investment include research and development 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’ would greatly improve the medical and functional outcomes of individuals receiving such services.

NIDILRR supports national and international collaboration on technology research and development 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, ANSII, and other technology development standards and guidelines.

## Disability Statistics Research

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

Valid and reliable demographic data serves as a foundation to the broader mission of NIDILRR and helps provide a platform for all agencies in the disability field. High-quality demographic data contribute to NIDILRR’s mission and support research and development in its outcome domains in the following ways:

- **Policy decisions.** Inform policies, practices, and programs for people with disabilities;
- **Demographics.** Identify potential changes in the characteristics and needs of the people with disabilities
- **Prevalence and context.** Understand changes over time in disability prevalence and environmental context
- **Service delivery.** Inform service delivery
- **Current and emerging needs.** Plan research to address current and emerging needs

## Context

Several national surveys have adopted the 6-question sequence of disability identifiers first included in the American Community Survey (ACS). Based on the International Classification of Functioning, Disability and Health (ICF) conceptual framework, these questions assess difficulty with hearing, vision, cognition, ambulation, self-help, or 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 and data can be pooled for analyzing 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. Although the six-question sequence has limitations, the move to collect disability data throughout federally-funded surveys represents substantial progress toward measuring the characteristics, experiences, and outcomes of people with disabilities by agencies and policies that have not typically acknowledged them.

Additionally, the National Health Interview Survey (NHIS) recently began a redesign of its methodology and questionnaires. 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. We will continue to track the final changes so that we can help plan an appropriate response in the event that components critical to what we can learn about people with disabilities are eliminated or altered.

### **Accomplishments in Disability Demographics Research**

Examples of NIDILRR-funded work in disability demographics exemplify how disability statistics and demographics support its research domains.

- **Common data elements.** As part of a Federal Interagency Team NIDILRR cosponsored and participated in the scientific development of common data elements (CDEs) for use in research regarding traumatic brain injury (TBI) and psychological health (PH). These measures allow for cross-study comparison of findings, in eight topic areas within this field. Additionally, as a result of this work, NIDILRR staff was invited to participate in the development of the National Research Action Plan, a mandate established by President Obama by Executive Order to address TBI, post-traumatic stress disorder (PTSD), and suicide prevention. An important component of the plan was establishing common data elements for PTSD and suicide prevention with the intention of integrating these with the newly-created TBI research CDEs.
- **Understanding the demographics of disability.** NIDILRR has provided both financial and intellectual support for increased understanding of the population of people with disabilities and how it 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.
- **National Center on Disability Statistics.** NIDILRR continues to fund a center on disability statistics as a resource for researchers, policymakers, service providers, consumers, and others. That investment has yielded an online user-friendly data tool, and an Annual Disability Statistics Compendium Meeting in which researchers, policy makers, service providers and federal interagency partners convene to discuss important findings from the statistics, and to consider how to address gaps. In addition, this center's staff has worked on improving disability measurement in various ways. For example, one of the center's projects used data from the National Household Travel Survey (NHTS) to publish a study about 'trips

to medical care for people with disabilities.’ As a result, the Center was invited to join conversations with the Department of Transportation about the design of the new NHTS (2016) questions to include more detail about disability and health.

## Research and Development Agenda

The goal of NIDILRR’s disability statistics and demographics effort is to increase the capacity within the field to generate new information for use by stakeholders who are working to identify and eliminate disparities experienced by people with disabilities in employment, community participation, and health and function. Data concerns thread 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 and development agenda for disability statistics and demographics for the next five years includes:

- **Uniform disability identifiers.** Continuing to support work that enhances the understanding of the number and characteristics of people with disabilities through targeted studies of existing data. Adoption of the ACS six-question sequence of disability identifiers across a growing number of surveys provides 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 related to 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 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 Americans with Disabilities Act (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 greater understanding of stakeholders' need for and use of ADA National Network services. Since these changes, the 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 about the ADA gained from their research. 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.

In addition to these NIDILRR-initiated changes, there have also been key changes in legislation and regulations that have impacted the work that the ADA National Network has conducted. For example, in 2008 the ADA Amendments Act (Pub. L. 110–325) was signed into law. The ADA Amendments Act clarifies and expanded the definition of disability through several new provisions. In 2010, the U.S. Department of Justice published new regulations implementing titles II and III of the ADA (28 CFR part 35 and 28 CFR part 36). The U.S. Equal Employment Opportunity Commission later published new regulations implementing title I of the ADA (29 CFR part 1630). In addition, a number of ADA compliance issues have gained more attention in recent years, such as access to information technologies and to emergency management services. These legislative and regulatory changes, coupled with examples of emerging issues, highlight the range of topics impacted by the ADA and addressed by the ADA regional centers. It also is indicative of the ongoing need for NIDILRR to continue its support of activities to raise awareness of, and promote compliance with, the ADA.

## Accomplishments

The ADA National Network is the only federally-sponsored national network of technical assistance centers dedicated to providing information, training, and technical assistance on the ADA. Since the program's inception, the Network's impact has grown, directly training 30,000 individuals each year and serving 235,000 annually, with improved data about the direct impact of such activities being collected. Regional centers responded to nearly 19,000 direct requests for technical assistance during the past year, and addressed general to complex inquiries in such areas as reasonable accommodations, accessible communication, and facility access. The training, information, and technical assistance provided by the regional centers spans a range of topic areas and contribute to an enhanced understanding by ADA stakeholders of their rights and responsibilities under the ADA. The Network has been effective at establishing unique training initiatives with various industries and across specialized topic areas. Research and development activities pursued by the Network reflect a range of efforts that ultimately enhance ADA implementation, including conducting a systematic review and translation of

existing ADA research findings and generating new knowledge that facilitates ADA implementation.

## **Research and Development 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. In future years NIDILRR intends to continue its support of the technical assistance, training, research and data collection activities conducted by the ADA National Network, and will explore ways to expand the impact of the Network to new audiences by creating greater linkages with other ACL, HHS, and federal programs and constituencies.

## **Stages of Research and Development**

NIDILRR continues to promote the stages of research and the stages of development as we make grants in the health and function, employment, and community living and participation domains. NIDILRR advances these stages to emphasize our role as an applied research and development agency. Through the implementation of this stages framework we emphasize that all of the research we sponsor in the "exploration and discovery," "intervention development," "intervention efficacy," and "scale-up evaluations" 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 funding opportunity announcements (FOA) in 2012 and 2013. Since then we have included the stages in all of our relevant research FOAs, and asked applicants to describe and justify the stage or stages of research they propose. We formalized the stages of research in our Long Range Plan published in FY 2013 (78 FR 20299-20311), and in our final program regulations published in FY 2016 (81 FR 29156-29165). NIDILRR first published its stages of development in the draft NIDILRR program regulations in FY 2012 (80 FR 79283). We formalized these stages in the final version of the NIDILRR program regulations in 2016 (81 FR 29156-29165). In NIDILRR's final program regulations we also published 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.

We have delineated the stages of research and development to help guide applicants and grantees as they propose and implement their research and development protocols. NIDILRR's FOAs require applicants to describe and justify the stage or stages of their proposed research and development, based on the knowledge and information that is available on their chosen topic. NIDILRR's announcements also include the criteria that allow reviewers to evaluate the extent to which applicants have described and justified the stage or stages of their proposed research and development within the context of available knowledge and products.

NIDILRR values and funds research and development at each of these stages because disability, independent living, and rehabilitation research and development is a relatively young field. While our ultimate aim is to sponsor research and development toward interventions and products to improve the lives of people with disabilities, we do 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 and development that must take place to create the foundation of knowledge for new interventions and products. Nothing in our stages or our application of the stages in our FOAs and peer review process is intended to promote later stages of research and development over earlier stages, or vice versa. Instead, we seek to ensure that the work that we sponsor 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 us ensure, for example that we sponsor 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 us ensure that we sponsor the transfer and promotion of technologies only if they have been properly conceptualized, tested for utility and feasibility among users, and refined. The stages also help us ensure that we do not repetitively sponsor research that re-creates knowledge and information that is well established in the research literature, or development activities that lead to overly-duplicative or unneeded products.

NIDILRR will continue to provide training and information to our applicants, grantees, and reviewers to help ensure the proper use of our 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 and development resources and programs.

### **III. Activities that promote the quality and use of NIDILRR-sponsored Research and Development**

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 that can be used to conduct high quality research and development activities that result in new knowledge and products. As previously described, Title II of The Rehabilitation Act of 1973, as amended, authorizes NIDILRR's research and development programs, as well as its efforts to build capacity for conducting high quality disability, independent living, and rehabilitation research. This statute authorizes NIDILRR to provide for advanced training in disability and rehabilitation research, including increased opportunities for underserved populations, including people with disabilities. NIDILRR meets these statutory mandates for training and capacity building through a variety of programs and grant mechanisms.

The Research Fellowship Program (Switzer) 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. A Merit Fellowship is often the recipient's first independent grant, and consequently provides valuable experience in grant writing, management, and implementation, which helps prepare Fellows for a successful career. 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. Switzer Fellows typically go on to distinguished careers in disability, independent living, and rehabilitation research.

NIDILRR also funds institutions of higher learning to conduct post-doctoral training under its Advanced Rehabilitation Research Training (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 1percent 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 developing a cadre of researchers who represent underserved populations, including people with disabilities.

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 and development careers.

## Accomplishments

Each year NIDILRR grants consistently support approximately 200 research fellows. In 2014, grantees reported 95 peer-reviewed publications authored by fellows who were supported through their NIDILRR grants. This level of productivity among fellows has been consistent over the years, demonstrating the successes of various research training programs sponsored by NIDILRR.

NIDILRR's RERC and RRTC grants have also been active in preparing future researchers by providing research experience and mentorship to graduate students. Grantees in these and other NIDILRR programs routinely involve graduate students in the conduct of their research and development activities, and in disseminating the new knowledge and products that they generate. In 2014, grantees reported 41 peer-reviewed publications authored by graduate students.

NIDILRR has been successful in expanding its Section 21 Program to provide additional opportunities and exposure for minority researchers and minority-serving institutions across NIDILRR's funding mechanisms. NIDILRR has sponsored a number of ARRT grant competitions in recent years to give minority serving institutions (MSIs) opportunities and resources to train future disability and rehabilitation researchers. NIDILRR has also sponsored grant competitions for field initiated projects (FIP) that allow MSIs to apply for and conduct disability, independent living, and rehabilitation research projects. NIDILRR awarded a new RRTC to a historically black university to conduct targeted outreach and capacity building efforts directed at stakeholders from minority-serving institutions and underserved populations, and to encourage minority participation in the NIDILRR research portfolio. This RRTC is also conducting research toward development of an emerging research capacity building and infrastructure model that is being pilot tested across six minority-serving institutions. NIDILRR continues ongoing efforts to sponsor Section 21 Program grantee meetings to promote networking, collaboration, and mentoring opportunities with other NIDILRR grantees, as well as external researchers and stakeholders.

## Capacity Building Agenda

There is an ongoing need for well-trained researchers in the disability and rehabilitation research and development field, 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 will 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 will also continue to build the Section 21 Program by creating research and development 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 continue to help ensure that the new knowledge that our grantees generate reflect the needs, experiences, and outcomes of the broad sociodemographic diversity of people with disabilities in the U.S.

## 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 and development 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, and therefore includes specific considerations for technology transfer when the knowledge or products are technological in nature. 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.

There are several components within the KT process. The needs for knowledge and products must be identified. The knowledge has to be generated or the product has to be developed. Researchers may have to go through repeated investigations and synthesis of findings from similar studies to establish reliable knowledge, or repeated testing to develop a reliable and feasible product. The knowledge or product may need to be further packaged into appropriate forms such as consumer factsheets, practice guidelines, intervention manuals, policy briefs, accessibility standards, commercial assistive devices, freeware, and other forms that would best support its intended use. It is then disseminated or distributed through appropriate channels to the users who, in some cases, may need additional training or technical assistance to be able to use such knowledge or products effectively.

To maximize the relevance, feasibility, useability, 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, policy-makers, employers, Center for Independent Living staff members, disability advocates, educators, assistive device manufacturers, insurance companies, and others as appropriate.

## Accomplishments

NIDILRR has systematically integrated the KT framework into its grant making operations. KT structures have been developed and supporting functions implemented to enable NIDILRR and its grantees to collaborate effectively in promoting the use of NIDILRR-generated knowledge and products to improve the lives of people with disabilities. NIDILRR's ongoing KT strategies include the following:

- **Incorporating KT requirements into the grant competition process.** NIDILRR requires that applicants involve people with disabilities and other relevant stakeholders in their proposed grant activities as well as present a plan indicating how their knowledge or products will be promoted to intended users in appropriate forms. These requirements are included in the Funding Opportunity Announcements (FOAs) and reflected in the criteria that reviewers use to evaluate applications for NIDILRR awards.
- **Providing KT support to grantees.** NIDILRR currently funds five KT centers: the Americans with Disabilities Act Knowledge Translation (ADAKT) Center, the Center on Knowledge Translation for Disability and Rehabilitation Research (KTDRR), the Model System Knowledge Translation Center (MSKTC), the Center on Knowledge Translation for Employment Research (KTER), and the Center on Knowledge Translation for Technology Transfer (KT4TT). These centers provide a range of support to NIDILRR grantees such as training on KT strategies to build grantees' KT capacity; technical assistance in developing, refining, and implementing grantees' KT activities, including technology transfer; and working directly with grantees and other stakeholders to package knowledge or products for dissemination or distribution. For example, the MSKTC has packaged the research findings of NIDILRR's Model Systems research grants, in combination with other relevant research findings, into factsheets for use by people with spinal cord injury, traumatic brain injury, and burn injury. These research-based factsheets address topics that are directly relevant to the lives of people with these traumatic injuries and are written in language that all stakeholders can read and understand. In a span of one year, the factsheets in all three injury areas were downloaded more than 600,000 times, and the MSKTC website received more than 1,000,000 visitors. In addition, the KT centers as well as a number of other smaller KT projects conduct research, development, and their own KT activities to help to advance the field's understanding and application of KT in the disability context.
- **Promoting awareness and use of NIDILRR-funded and other disability-related resources.** NIDILRR funds two contracts to assist with its KT initiatives: the National Rehabilitation Information Center (NARIC) and AbleData. NARIC provides free information and a library service to the public, disseminating disability-related publications and information products within the appropriate boundary of copyright laws. NARIC publishes weekly email newsletters and maintains a far-reaching social media presence to alert its subscribers to new knowledge, products, and resources available from NIDILRR grantees. Through these

communication channels, NARIC reaches more than 10,000 subscribers that include people with disabilities, researchers, policymakers, and other stakeholders. NARIC also publishes lay-language narratives of new scientific publications from NIDILRR grantees to keep the disability community informed of new findings as they become available. AbleData provides a free information service to help users locate assistive technology that meets their functional needs, and produces user-friendly information materials to aid users as they consider AT. AbleData's web-based resources are used by more than 40,000 people with disabilities and other stakeholders each month.

- **Collecting information on KT progress and accomplishments of NIDILRR grantees.** NIDILRR includes reporting of KT progress as an element in its annual performance report form, including items that track use or adoption of NIDILRR-funded knowledge or products if applicable.
- **Identifying opportunities to promote the use of knowledge and products generated from NIDILRR-funded work.** NIDILRR staff and grantees have been collaborating with colleagues within ACL to explore potential uses of NIDILRR-generated knowledge and products to improve services and policies, both within and outside ACL. These collaborations include potential use of NIDILRR-funded products and services to enhance a CMS initiative addressing the physical accessibility of health care facilities.
- **Developing and implementing public access requirements for peer-reviewed publications and data resulting from NIDILRR-funded work.** The public access requirements for peer-reviewed publications that result from NIDILRR-funded work have been published as part of the ACL Public Access Plan, effective October 1, 2016. The public access plan for scientific data is being prepared and will be effective October 1, 2017. This initiative will increase the public availability and use of NIDILRR-generated knowledge and products, as well as the data that was used to generate them.

### Knowledge Translation Agenda

For the next five years, NIDILRR will do the following 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, the Department of

Health and Human Services, other Federal agencies, and the broader community in which people with disabilities live.

- **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, with the understanding that research and development 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 and development across the domains of health and function, employment, and community living and participation, 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.