

ICDR TOOLKIT

# Aging with Disability

A Toolkit for  
Interagency Collaboration



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# Introduction

In a period of ten years, the number of people age 65 and older has increased 33 percent from 37.2 million in 2006 to 49.2 million in 2016 (Administration for Community Living [ACL], 2018). As the United States population continues to age, it is essential that the growing research and resources on aging do not overlook people aging with long-term disability. Disability and aging are often intertwined, as people tend to experience higher rates of disability as they age. In addition, people with many types of disabilities are living longer than previously and are therefore experiencing aging with long-term disability. Health care and service providers, caregivers, and individuals with disabilities are often unaware of how age can impact certain types of disabilities. Collaboration in the disability and aging fields is vital to promote the healthy aging of people with disabilities. Federal interagency collaboration can help facilitate additional research and resources in the emerging field of aging with disability and promote inclusion in all aging resources.

## About the ICDR

The Interagency Committee on Disability Research (ICDR) was authorized by the amended 1973 Rehabilitation Act to coordinate federal research efforts surrounding disability, independent living, and rehabilitation research, to include assistive technology research and universal design. The ICDR's vision is to be widely recognized for facilitating and coordinating federal interagency efforts and for promoting collaborative relationships that maximize the best use of federal resources for disability, independent living, and rehabilitation research.

## Strategic Plan Goals

The three goals designated in the **ICDR's 2018–2021 Government-Wide Strategic Plan** are:

**Goal #1:** Improve interagency coordination and collaboration in four thematic research areas: transition, economics of disability, accessibility, and disparities.

**Goal #2:** Develop a government-wide inventory of disability, independent living, and rehabilitation research.

**Goal #3:** Promote ongoing stakeholder input on gaps and priorities for disability, independent living, and rehabilitation research.

To address Goal #1 (improve interagency coordination and collaboration), the ICDR initiated a focus on creating materials to promote and encourage collaboration on aging with a disability. In 2020, the ICDR released a toolkit on **Health Disparities and Disabilities in Research** which includes a section on aging and disability. This toolkit will expand upon the ideas presented in that section.

## Purpose of the Toolkit

The resources in this toolkit are designed to facilitate further research by federal agencies in the field of aging with a disability and to promote interagency collaboration. The toolkit offers a wide range of current research and resources from federal agencies and examples of best practices from across the public and private sectors. Additionally, this toolkit discusses current gaps in the research on aging with a disability and highlights areas for future research and collaboration.

# Background

The population of older adults in the United States is rapidly growing, with the U.S. Census Bureau predicting that **adults over 65 will make up 21 percent of the population by 2030** (up from 15 percent in 2017). By 2060, the U.S. Census Bureau predicts that one in four Americans will be over age 65, with the number of people over 85 tripling (Vespa, 2018). With this increase in the population of older adults, it is more important than ever to address concerns related to aging.

One in four adult Americans report some type of disability, while two in five Americans over age 65 report having at least one disability (Centers for Disease Control and Prevention [CDC], 2020). Within this percentage of older adults with disabilities there are two main groups, older adults who are aging with a long-term disability and older adults who developed a disability later in life. The section below defines these two groups in more detail.

## **Aging with Disability vs. Aging into Disability**

As disability and aging are frequently interconnected, it is important to define aging with a long-term disability versus aging into disability. When individuals experience the early onset of a disability and begin to experience aging, they are considered to be **aging with long-term disability**. When people experience the onset of disability as an older adult, they are **aging into disability**.

A majority of aging literature focuses on aging into disability and neglects to discuss the population of people aging with a long-term disability. The population of adults who are aging with a long-term disability was estimated to be between 12 to 15 million people in 2014 (LaPlante, 2014). It is important to consider this sub-population, as they often experience effects of aging earlier than people without

disabilities (Institute of Medicine [IOM], 2007). Additionally, since people with certain types of disabilities, such as developmental disabilities, are living longer lives than previously, information about how aging interacts with these disabilities is scarce. It is important for research and resources to be strengthened in this area so clinicians, researchers, and policymakers can address the needs of this subpopulation to promote healthy aging.

**“Older adults with long-term disabilities may offer an important perspective on successful aging, not because they have managed to avoid disability, but rather because they have lived it.”**

—Molton and Yorkston (2019)

While both groups experience unique aging trajectories, they also share a variety of similarities. Both groups need integrated services, such as community-based rehabilitation or assistance with activities of daily living (Molton & Yorkston, 2017). Furthermore, support with transportation, community participation, and health promotion are beneficial to both people aging into disability and aging with disability. Coordinating research and resources on these two groups of older adults with disabilities is essential to ensuring the best services and supports are available for both subpopulations.

## **“Successful Aging” and Aging with Disability**

Aging and disability networks have historically looked at the concept of “successful aging” from vastly different perspectives. One author puts it succinctly: “For the disabilities system, aging is a success; for the aging network, disability is a failure” (Ansello, 2004, as cited in Molton & Yorkston, 2017). The concept of successful aging as discussed in aging literature is often too narrow, focusing only on older

adults with good health, high cognitive functioning, and active social engagement (Tesch-Römer & Wahl, 2017). This excludes the population of people aging with a disability who may have lower cognitive functioning, chronic health problems, and limited social engagement.

To illustrate what desirable living situations look like for people aging with disabilities, the concept of “successful aging” must be modified. Berridge and Martinson (2018) discuss how the concept of successful aging is rooted in the medical model of disability. In a review of 25 years of literature on successful aging, they found reoccurring themes of: narrow criteria, missing perspectives of older adults, perpetuation of individualistic views of aging, and ageist and ableist impulses. Berridge and Martinson propose that a new model of successful aging should be developed using the social model of disability instead, which describes disability as contextual, with the focus on the social and physical environments that cause disabling interactions for individuals. Use of the social model furthers the important work of making society less disabling and challenging for many older adults and people aging with disability.

“Recognizing and valuing the experiences of disability and illness in later life does not return us to ‘decline and loss’ stereotypes, but instead reflects the diverse and ecological processes of aging.”

—Berridge & Martinson (2018)

## **The Relationship Between Aging and Disability Research and Service Networks**

The aging and disability fields have been separated traditionally, with research and services in two distinct siloes. These two fields differ in scope and focus, mainly on

the timing of onset of disability and type of disability. For able-bodied adults, disability tends to occur after retirement age, so disability at this point in the lifespan has historically been categorized as aging research. In addition, types of conditions have been “assigned” to either disability or aging research; for example, Alzheimer’s disease has traditionally been studied in the aging research network but not the disability research network (Molton & Ordway, 2019).

This chasm between the two fields creates problems for collaborative research, impeding the ability to share information and resources. Additionally, for consumers, accessing services across both domains can be difficult to navigate. Aging and disability fields often focus on different aspects of the definition of disability and use different language (Molton & Ordway, 2019). For example, “family support” is discussed frequently in aging literature, while “caregiver support” is more frequently used in disability literature. Additional barriers include differences in organization and funding mechanisms, a lack of knowledge about the other field, reluctance to share limited resources, and differing guiding principles and values (Factor et al., 2012). The disability community has historically been one of advocacy and resistance to a medical definition of disability, instead emphasizing a social definition of disability. On the other hand, many older people who experience disability at an older age are hesitant to identify as having a disability and be part of a program for people with lifelong disabilities. As a result, this lack of collaboration and cohesive language across the two fields has been a target of reform over the past several decades.

## **The History of Attempts to Bridge Aging and Disability Networks**

To address this problem, efforts began in the 1980s to bridge the gap between aging and disability research and services. People receiving developmental disability services were living longer, yet a study found that less than half of families made future residential plans for their adult family member with a disability (as cited in

Factor et al., 2012). To address this, amendments to the Developmental Disabilities Act (DD Act) in 1987 authorized a network of Training Initiative Programs focused on aging, early intervention, and direct care training for people with developmental disabilities. Additionally, a conference brought together the directors of state developmental disability agencies and state units on aging at the 1986 *Wingspread Conference on Aging and Developmental Disabilities* to collaborate on ways to improve the gap between the two service systems (Factor et al., 2012).

**People receiving developmental disability services were living longer, yet a study found that less than half of families made future residential plans for their adult family member with a disability.**

Throughout the 1990s many efforts occurred to try to bridge aging and disability service networks. Reauthorizations of the DD Act and the Older Americans Act both included provisions for collaboration. Formal interest groups were formed, and memorandums of understanding were written between government agencies. However, these efforts were not sustained due to turnover in agencies, competing policy priorities, and grants being time-limited (Factor et al., 2012).

In 2003, the Administration for Community Living (ACL) within the U.S. Department of Health and Human Services (HHS) established the Aging and Disability Resource Center (ADRC) program, with an ADRC present in every state. The goal of the ADRCs is to establish integration across the aging and disability long-term services and supports system to make it easier for people with disabilities, older adults, and their families to navigate. While progress has been made through the ADRCs, a 2016 analysis showed that they may not be addressing the needs of specific disability subpopulations, such as people with intellectual and developmental disabilities (I/DD) (Coyle et al., 2016).

Efforts to bridge aging and disability networks have led to emerging partnerships, such as the one between Area Agencies on Aging (AAAs) and Centers for Independent Living (CILs), since both have similar missions of advocacy and information referral (Factor et al., 2012). However, progress has remained slower and more limited for partnerships between developmental disability agencies and aging agencies, often due to different funding sources or different missions and philosophies.

## **Relevant Legislation on Aging and Disability Services**

The following section provides a brief overview of legislation related to aging with a disability. These laws have helped shape the landscape for how the disability and aging service networks currently exist and interact.

### **OLDER AMERICANS ACT**

The Older Americans Act was originally passed in 1965 to address the lack of social services for older Americans. This law established the Agency on Aging, as well as state grants to provide community services, research and development, and training related to aging. The Act's broad mandate created social and nutrition services for older Americans, to include support services, home-delivered nutrition services, caregiver support, the Long-Term Care (LTC) Ombudsman program, abuse and neglect prevention services, and several others (Napili & Colello, 2013). More information on the Older Americans Act, as reauthorized in 2020, is available on ACL's [website](#).

### **AMERICANS WITH DISABILITIES ACT**

The Americans with Disabilities Act (ADA) of 1990 provides protection against discrimination for people with disabilities in various arenas, including employment, government activities (to include Congress), commercial facilities, transportation, telecommunications, and public accommodations. The ADA does not list the specific conditions or impairments covered under "disability," but it defines a disability as a "physical or mental impairment that substantially limits one or more major

life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such an impairment” (U.S. Department of Justice [DOJ], 2020).

### ***OLMSTEAD V. L.C. DECISION***

After two women with developmental disabilities and mental illness were confined in an institution for years after initial treatment was complete, they filed a lawsuit under the ADA to be released from the mental institution (DOJ, n.d.a). In 1999, the U.S. Supreme Court declared that segregating individuals with disabilities unjustly violates Title II of the ADA. The Olmstead decision also states that public entities must provide community-based services when appropriate and preferred by the individual with a disability and when these community-based services can be reasonably enacted with the public resources available.

### **DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT**

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), passed in 2000, authorized programs to ensure that people with developmental disabilities and their families have access to “community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” (ACL, 2017a). The DD Act also emphasizes the role of individuals with developmental disabilities and their families in participating in the design of their services. Programs authorized by the DD Act, referred to as the DD Network, include the following in every state and territory: State Councils on Developmental Disabilities; University Centers for Excellence in Developmental Disabilities Education, Research, and Services; and Protection and Advocacy Systems. More detailed information on the DD Act is available [here](#).

### **THE ELDER JUSTICE ACT**

The Elder Justice Act was passed in 2010 and addresses abuse, neglect, and exploitation of older adults at the federal level (ACL, 2017b). This law mandates

a coordinated federal response to elder abuse through programs and initiatives. The Elder Justice Act authorizes elder justice research and innovation, supports the Adult Protective Services systems, and provides protections for people living in LTC facilities. Additionally, this law established the Elder Justice Coordinating Committee in the DOJ, which coordinates activities related to elder abuse, neglect, and exploitation across federal agencies. More about the Elder Justice Act is available [here](#).

# Federally Funded Research and Resources

Numerous federal agencies are working to address the topics of aging and disability. This selection of federally funded research and resources will highlight projects working on important topics related to aging with a disability, with the goal of encouraging interagency collaboration to address pressing issues for this population.

## National Science Foundation

The National Science Foundation (NSF) is an independent federal agency with the mission to advance science; improve the national health, prosperity, and welfare; and secure the national defense (NSF, n.d.). NSF funds a quarter of all federally funded research at the nation's colleges and universities. NSF's **Disability and Rehabilitation Engineering** program funds and promotes engineering research to improve the quality of life for people with disabilities. This program funds devices, software, and technology that advance understanding of “the characterization, restoration, rehabilitation, and/or substitution of human functional ability or cognition, or to the interaction between persons with disabilities and their environment.” Below is a selection of projects that have application to the field of aging with a disability.

### **ADVANCING ONLINE SOCIAL SUPPORT FOR OLDER ADULTS WITH DISABILITIES (2016 – 2020)**

An NSF-funded project at Northwestern University examined the social network of older adults experiencing disability and provided an innovative solution through “hybrid social computing.” The grantee used familiar communication interfaces, integrated with online social platforms, while harnessing support networks to enable and protect users online. The main goal of this project was to develop both

a conceptual and technical framework for enabling and studying online social support for older adults with severe late-life disabilities. This project specifically focused on older adults with late-life vision impairments and late-life speech-language impairments. More about this grantee’s project can be found on the [NSF website](#).

**TRAINING FOR INDEPENDENT LIVING THROUGH OBSERVANT ROBOTS AND DESIGN (2019 – 2023)**

An NSF-funded project at the University of California San Diego aims to develop human-centered robotics technology to offer personalized neurorehabilitation for older adults with mild cognitive impairment. Using technology in this manner could assist millions of people with maintaining their functioning, quality of life, and ability to live independently. This project provides older adults with cognitive impairments and their family members an opportunity to provide input regarding the creation of this technology and to participate in the research process. More about this grantee’s project can be found on the [NSF website](#).

**AGING IN PLACE THROUGH ENHANCED MOBILITY AND SOCIAL CONNECTEDNESS: AN INTEGRATED ROBOT AND WEARABLE SENSOR APPROACH (2019 – 2022)**

This NSF-funded project at Columbia University investigates human-robot-sensor interaction and seeks to develop mobility and social connectedness of older adults through use of an assistive service robot. With the concept of “aging in place,” this advanced technology aims to reduce health costs and support older adults with living independently in their own homes. The two main goals of this technology in this project are to support exercise and to enhance social connections. While this project focuses solely on older adults, the findings to support community living could be applied to people with disabilities, particularly people aging with long-term disabilities whose needs are changing. More about this project can be found on the [NSF website](#).

### **NEXT GENERATION ROBOTIC INTELLIGENCE THAT PROVIDES PSYCHO-SOCIAL SUPPORT FOR OLDER ADULTS (2017 – 2021)**

A project at Brown University, funded by the NSF, is working to develop Affordable Robotic Intelligence for Elderly Support (ARIES) in order to meet the wide-ranging issues faced by the aging population. ARIES is designed to work in conjunction with and not replace health care professionals or family members. The goal of ARIES is to offer affordable assistance with small but challenging tasks that are part of daily living, such as finding keys, remembering to take medication, connecting with friends and family, relieving loneliness, etc. This project combines new research insights in the fields of cognitive and behavioral sciences, geriatric psychiatry, computer science, and industrial design. ARIES seeks to be easily understandable and reliable and to improve health care for older adults, enabling them to live fulfilling lives while aging in place. Further information about this project is available at the [NSF website](#).

### **SOCIAL INTERACTION BARRIERS AND MENTAL HEALTH AMONG OLDER ADULTS WITH PHYSICAL DISABILITIES (2017 – 2019)**

An NSF-funded project at the University of Nebraska – Lincoln explored perceived barriers to social interaction for older adults with physical disabilities. The project examined how these perceived barriers impact mental health. The purpose of the study was to use this knowledge to inform intervention strategies, assist families with providing a supportive environment, help health insurers develop early intervention strategies, and optimize implementation of the ADA by architects and designers. The study employed a mixed-methods approach, analyzing the National Social Life, Health, and Aging Project survey data as well as in-depth interviews with older adults with physical disabilities. More information about this study can be found at the [NSF website](#).

## **U.S. Department of Health and Human Services**

HHS is a federal executive department whose mission is to “enhance the health and well-being of Americans, by providing for effective health and human services by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services” (HHS, 2020). The Department’s scope is broad. With 11 different operating divisions, HHS is working on aging with disability from a variety of angles.

### **AGENCY FOR HEALTHCARE RESEARCH AND QUALITY**

The Agency for Healthcare Research and Quality (AHRQ) is a federal agency mandated to improve the safety and quality of health care in America. AHRQ develops knowledge, tools, and data necessary to initiate improvements in health care that benefit Americans, health care professionals, and policymakers (AHRQ, 2018). The AHRQ website offers several research-based tools and a variety of datasets. AHRQ hosts information on **quality measures** for home health agencies, nursing homes, and hospices. Additionally, AHRQ provides **patient safety resources** to help prevent avoidable complications in hospitals, emergency departments, LTC facilities, and ambulatory settings.

### ***The Role of Aging and Disability Resource Centers in Serving Adults Aging with Intellectual Disabilities and Their Families (2008 – 2018)***

A **study completed in 2016** by the Yale School of Public Health, funded by an AHRQ grant, examined ADRCs. This study looked at whether the ADRCs are meeting the needs of adults who are aging with intellectual disabilities across seven states. This study used 21 qualitative in-depth interviews and determined that ADRCs are not explicitly focusing on adults aging with I/DD. While meeting the needs of this population is a future goal for the ADRCs, current challenges exist with coordinating referral services between the aging and disability service systems.

### ***Leveraging Physical Therapy to Improve Physical Activity in Older Adults with Chronic Musculoskeletal Conditions (2018 – 2023)***

An AHRQ-funded project at the University of Utah is engaging in patient-centered outcomes research designed to improve the quality and effectiveness of physical therapy for older adults with chronic musculoskeletal conditions. This project implements use of a program called Coach2Move that originated in the Netherlands and has shown promising results for increasing and improving physical activity among older adults with mobility limitations. While this project focuses on older adults who have developed musculoskeletal conditions in mid to late life, the findings of this project can offer important insight for people aging with a long-term disability as well. More about this grantee’s project is available [here](#).

### **OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION**

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) advises the Secretary of HHS regarding policy development in health, disability, human services, data, and science. They also advise and provide analysis on economic policy. ASPE “conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress” (ASPE, n.d.).

### ***Office of Behavioral Health, Disability, and Aging Policy***

The Office of Behavioral Health, Disability, and Aging Policy within ASPE provides research and analysis on programs and policies related to the independence, productivity, health and well-being, and LTC for older adults and people with disabilities, mental disorders, or substance use disorders. This office has a specific division that focuses on disability and aging policy. This division coordinate cross-cutting disability and aging collaboration across federal agencies. Specific areas of focus for this division are intellectual disabilities, autism spectrum disorder, and Alzheimer’s disease. More about this office’s work can be found [here](#).

## CENTERS FOR MEDICAID & MEDICARE SERVICES

The Centers for Medicare & Medicaid Services (CMS) is a federal agency in HHS that administers the Medicare program and partners with states to administer Medicaid, the Children’s Health Insurance Program, and health insurance standards (CMS, 2020a). CMS is also responsible for ensuring quality standards in LTC facilities, oversight of the HealthCare.gov platform, and clinical laboratory quality standards.

### *Managed Long-Term Services and Supports*

CMS provides LTC to beneficiaries through Medicaid, and many states use managed care delivery systems to do so. The term “managed long-term services and supports” (MLTSS) describes arrangements between state Medicaid agencies and contracted managed care health plans in which the state pays a fixed amount per member per month to cover enrollees’ benefits. Benefits range from primary care to behavioral health to home health. The goal of MLTSS is to increase access and quality while reducing excess costs. MLTSS also aims to increase the number of people receiving home and community-based services (HCBS) and to reduce institutionalization, which is less cost-effective.

For further information on who enrolls in Medicaid MLTSS, view [this report from CMS](#).

The Kaiser Family Foundation has a [primer on MLTSS](#) for further details. Specific to aging with disability, ASPE released a [2014 report](#) on the details of three disability-competent MLTSS plans.

### *Medicare-Medicaid Coordination Office*

The **Medicare-Medicaid Coordination Office** within CMS serves people who are dually enrolled in both Medicare and Medicaid, known as dually eligible individuals. The Medicare-Medicaid Coordination Office seeks to ensure that dually eligible individuals can seamlessly access services across the two programs, experiencing

cost-effective but high-quality health care. Additionally, this office provides coordination across the Medicaid and Medicare programs and across federal agencies, states, and stakeholders to improve effectiveness and align benefits. As a significant portion of dually eligible individuals are also aging with a disability, this office's resources can be beneficial to this population.

### *Integrated Care Resource Center*

The Integrated Care Resource Center (ICRC) is a technical assistance resource center that assists states with delivering integrated health care services to dually eligible individuals. The ICRC's technical assistance options help states that are working to develop programs that coordinate medical, behavioral, health, and long-term services and supports (LTSS) for people who are dually eligible. Some activities the ICRC engages in include one-on-one technical assistance, training opportunities, creating customized state data profiles, sharing best practices across states, and developing and curating resources to support state efforts to coordinate services for dually eligible individuals. More information about the ICRC is available [here](#).

### *Program of All-Inclusive Care for the Elderly*

The Program of All-Inclusive Care for the Elderly (PACE) coordinates medical and social services for older adults who live in the community, many of whom are also dually eligible for Medicare and Medicaid (CMS, 2020b). This model of care focuses on the idea that it is best for older adults with chronic care needs to be served in the community. To be eligible for PACE, individuals must be “age 55 and older, certified by their state to need nursing home care, able to live safely in the community at the time of enrollment, and live in a PACE service area” (CMS, 2020b). The PACE program coordinates and delivers all types of care, including medical and supportive services. It aims to help older adults who have chronic care needs remain in their home and maintain independence for as long as possible. The wide-ranging services comprised in PACE are:

- Adult day care;
- Physical, occupational, and recreational therapies;
- Medical care;
- Home health care and personal care;
- Necessary prescription drugs;
- Social services;
- Medical specialties;
- Respite care; and
- Hospital and nursing home care when necessary.

More information about this program is available on the [CMS website](#) or on the [National PACE Association website](#).

## **ADMINISTRATION FOR COMMUNITY LIVING**

ACL aims to help older adults and people of all ages with disabilities to “live where they choose, with the people they choose, and with the ability to fully participate in their communities” (ACL, 2020a). ACL funds a variety of community-level targeted programs for older adults and people with disabilities, as well as research and education efforts.

ACL funds the [Aging, Independence, and Disability Program Data Portal](#), which includes data from a variety of aging and disability programs. It is an online query system, where users can navigate the data at four different levels of aggregation and focus. Other data projects ACL is working on related to disability and aging are

described on its [website](#). ACL also has information on additional [projects working to strengthen aging and disability networks](#), as well as a comprehensive [list of resources](#) related specifically to aging with disability.

### ***National Institute on Disability, Independent Living, and Rehabilitation Research***

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is the primary disability research agency in the federal government. NIDILRR's aim is to produce new knowledge and promote its effective use to improve the abilities of people with disabilities to perform their daily activities (ACL, 2020b). In addition, NIDILRR's research hopes to expand the capacity for society to provide opportunities and accommodations for people with disabilities. NIDILRR examines a wide range of disabilities across the lifespan, including all aspects of a living with a disability. The following are a selection of recent and ongoing NIDILRR-funded grantee projects related to aging with disability.

### ***Investigating Disability Factors and Promoting Environmental Access for Healthy Living Rehabilitation Research and Training Center (IDEAL RRTC) – (2018 – 2023)***

The NIDILRR-funded **IDEAL RRTC at the University of Michigan** aims to promote the healthy aging of people aging with long-term physical disabilities. This RRTC investigates the factors at the intersection of the person and the environment that either assist or deter with positive health and function outcomes. The IDEAL RRTC develops solutions to address these factors and promote successful aging in this population. Another main goal is to further the understanding of what successful aging with a long-term disability looks like and to provide resources on this topic. The IDEAL RRTC engages in research projects, training activities, knowledge translation, technical assistance, community grants, and research briefs to support this mission. Additionally, this RRTC also hosts the **National Resource Center for Aging with Disability**, which provides a wide range of resources, policy summaries, and policy briefs related to aging with disability.

*Rehabilitation Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities (TechSAge RERC II) (2018 – 2023)*

The NIDILRR-funded **RERC on Technologies to Support Aging-in-Place for People with Long-Term Disabilities** is a collaboration between the Georgia Institute of Technology and the University of Illinois at Urbana-Champaign. This RERC provides research, development, and training projects centered on investigating the needs of people aging with long-term disabilities and developing supportive technology to address these needs. The goal of the TechSAge RERC is to empower people aging with long-term disabilities to age-in-place; have access to effective technologies; live healthy, independent lives; and participate fully in society. A recent study done by the TechSAge RERC on aging concerns, challenges, and everyday solution strategies is available [here](#).

*A Panel Discussion on Human Factors Considerations for Persons Aging-in-Place with Disability*

In 2019, the TechSAge RERC hosted a panel discussion to bring together leaders in aging and disability research to discuss research collaboration on understanding the relationship between age-related changes and disability when designing technology interventions. The panel focused on the following four themes: (1) understanding user needs; (2) innovative environmental supports; (3) translational technology interventions; and (4) closing the gap between research and practice. The panel discussion proceedings are available [here](#).

*Accommodation Expert Support System for Aging Well (ACCESS for Aging Well) – (2020 – 2025)*

The **ACCESS for Aging Well** project is developing an “online accommodation assessment system that service providers can use while conducting community living evaluations with older adults with disabilities and their families.” This project partners with state agencies to evaluate feedback from users and to use predictive analytics to create a mobile application of the ACCESS for Aging Well system. This system incorporates assistive technology, strategies, inclusively designed features of technology and environments, and community services. The goal is to ensure that older adults with disabilities can make informed choices about their accommodations and maintain independence and participation in decision-making.

*Environmental Barriers and Facilitators to Assisted Toilet Transfers by People Aging with Disability and Their Spousal Caregivers (2020 – 2021)*

The NIDILRR-funded project, **Environmental Barriers and Facilitators to Assisted Toilet Transfers by People Aging with Disability and Their Spousal Caregivers**, examines “barriers and facilitators to caregiver assisted transfers for individuals aging with disability” to inform the development of interventions for toilet transfers using assistive technology. This project evaluates the effectiveness of current assistive technology toilet transfer interventions and identifies unmet needs in this field for people with disabilities and their caregivers. Additionally, this project develops effective solutions to address these unmet needs and identifies ways to educate stakeholders on the findings of this study.

*Building Capacity to Improve Community Participation for People Aging with Long-Term Disability Through Evidence-Based Strategies (2017 – 2022)*

The NIDILRR-funded project, **Community Engagement for Disability and Aging Research (CEDAR) Midwest**, examines the challenges with navigating both the aging and disability service networks for people aging with disability. CEDAR brings together organizations, such as the AAAs and CILs, to determine the needs of

people aging with disabilities. This grantee’s goal is to “translate, adapt and evaluate evidence-based interventions for people aging with long-term disabilities.” As part of this project, CEDAR is working to develop a community-based research network and to adapt existing evidence-based interventions to enhance community participation for people aging with long-term disabilities. CEDAR’s website provides access to **publications, fact sheets and infographics, webcasts, and information and resources** on community participation and aging with a long-term disability.

*Center for Research, Training, and Dissemination of Family Support for People with Disabilities Across the Life Course (2019 – 2024)*

The **RRTC on Family Support** at the University of Pittsburgh conducts research on caregiving for people with disabilities and disseminates original and existing research in this field. Its mission is to ground its research in addressing the practical day-to-day needs of caregivers and people with disabilities throughout the life course. The RRTC on Family Support offers health and rehabilitation providers training in the field of family caregiving. The Center disseminates findings from its projects to a variety of stakeholders including researchers, service providers, policymakers, family caregivers, employers, and people with disabilities.

One of its current projects focuses on scaling up the Community Aging in Place, Advancing Better Living for Elders (CAPABLE) intervention for older adults to expand its use to people with disabilities not on Medicaid and their caregivers. CAPABLE has been shown to be successful at reducing disability and Medicaid costs for low-income seniors, so this project attempts to expand this intervention to a new population group. More about this project is available [here](#).

*Rehabilitation Research and Training Center (RRTC) on Family Support (2014 – 2019)*

The previous NIDILRR-funded **RRTC on Family Support at the University of Illinois** supported the mission to bridge aging and disability research, practice, and policies. Additionally, the RRTC worked toward generating new knowledge in this field

to improve community living, participation, and health and function outcomes for people with disabilities from different racial and ethnic backgrounds who are supported by family members. This grantee focused on a wide range of projects, from developing a Strategic Plan of Family Support to examining family support in managed care. Important partners of this RRTC included the Lurie Institute for Disability Policy at Brandeis University, the National Resource Center for Participant-Directed Services at Boston College, the RRTC on Community Living at the University of Minnesota, and the National Council on Aging. A list of all of the publications from this RRTC is available on its [website](#).

### *Caregiving and Family Support Interventions: Crossing Networks of Aging and Developmental Disabilities*

This grantee published a paper that examines types of caregiver interventions present across 20 years of both aging and disability research. The paper discusses the similarities and differences, outcomes, and innovative approaches. The study found that across both fields, family support benefited participants' well-being and improved their service access and satisfaction. The authors emphasize that it is important for the aging and disability fields to continue to partner to improve the services and caregiving for both populations. The paper can be found [here](#).

*RRTC on Promoting Healthy Aging for Individuals with Long-Term Physical Disabilities (2013 – 2018)*

The NIDILRR-funded **RRTC on Healthy Aging and Physical Disability** at the University of Washington focused on promoting healthy aging for people with long-term physical disabilities. This grantee collaborated with rehabilitation researchers, physicians, psychologists, and public health professionals. The RRTC conducted research and training activities to learn more about the challenges people aging with muscular dystrophy, multiple sclerosis, post-polio syndrome, and spinal cord injury face. To address these challenges, the Center also adapted and tested a health promotion program with a focus on reliance and coping skills. The goal of this RRTC was to share its findings with relevant stakeholders such as advocates, health care providers, policymakers, and people living with long-term disabilities. Additionally, this Center published a paper on aging with a disability in the workplace, which is available [here](#).

***Aging with and into Disability:  
Current Status and Future Directions***

*A 2011 State of the Science Conference*

In 2011, a previous iteration of this RRTC at the University of Washington hosted a State of the Science meeting in Washington, D.C., on aging and disability research. The goal of this meeting was to review recent research findings and identify a research agenda in crosscutting areas in the aging and disability field. The findings and recommendations from this conference are available [here](#).

## **NATIONAL INSTITUTES OF HEALTH**

The National Institutes of Health (NIH) is the country’s main medical research agency. The NIH works to pursue “fundamental knowledge about the nature and behavior of living systems and the application of the knowledge to enhance health, lengthen life, and reduce illness and disability” (NIH, 2017). The NIH develops and maintains resources to help the nation prevent disease and improve health. Additionally, promoting scientific integrity, public accountability, and social responsibility are other integral parts of the NIH’s mission. Two agencies within the NIH that focus on aging and disability, the National Institute on Aging (NIA) and the National Center for Medical Rehabilitation Research (NCMRR), are described below.

### ***National Institute on Aging***

The NIA, as part of the NIH, aims to “improve the health and well-being of older adults through research” (NIA, 2020). The NIA conducts research in a wide range of areas, including genetic, biological, clinical, behavioral, social, and economic

### ***Publications Funded by the NIA on Aging and Disability***

- **Aging with Disability for Midlife and Older Adults**  
by L. M. Verbrugge, K. Latham, & P. J. Clarke (2017)
- **Aging and Disability: Implications for the Housing Industry and Housing Policy in the United States**  
by S. K. Smith, S. Rayer, & E. A. Smith (2008)
- **Research Gaps in the Demography of Aging with Disability**  
by V. A. Freedman (2014)

research on aging. Healthy aging is a main focus of the NIA, and it is the lead agency for research on Alzheimer’s disease and related dementias. The NIA also disseminates its research findings about aging to the public, health care professionals, and the scientific community.

### ***National Center for Medical Rehabilitation Research***

NCMRR seeks to build scientific knowledge to “enhance the health, productivity, independence, and quality of life of people with physical disabilities” (NCMRR, 2021). Topics of research NCMRR supports include: pathophysiology and management of chronically injured nervous and musculoskeletal systems (including stroke, traumatic brain injury, spinal cord injury, and orthopedic conditions); repair and recovery of motor and cognitive function; functional plasticity, adaptation, and windows of opportunity for rehabilitative interventions; rehabilitative strategies involving pharmaceutical, stimulation, neuroengineering approaches, exercise, motor training, and behavioral modifications; pediatric rehabilitation; secondary conditions associated with chronic disabilities; improved diagnosis, assessment, and outcome measures; and development of orthotics, prosthetics, and other assistive technologies and devices.

In 2002, NCMRR funded a grant that led to the publication **Aging with Disability and Disability with Aging** by L. M. Verbrugge and L. Yang. This journal article examines two population groups, people aging with disability and people aging into disability, and discusses major similarities and differences between the two. The authors provide recommendations on how to find interventions that address the pressing needs of both populations.

## U.S. Department of Justice

The DOJ is the federal agency charged with enforcing the law and defining U.S. interests. Its mission is to “ensure public safety against threats foreign and domestic; to provide federal leadership in preventing and controlling crime; to seek just punishment for those guilty of unlawful behavior; and to ensure fair and impartial administration of justice for all Americans” (DOJ, n.d.b).

The DOJ’s **Elder Justice Initiative** is a program that coordinates and supports the DOJ’s efforts to prevent elder abuse, neglect, and financial fraud targeting older adults. The Elder Justice Initiative hosts a **Neighborhood Map** that lists the following programs and services by state for older adults and people with disabilities: Adult Protective Services, programs for underserved communities, State Office of Rural Health, Office on Aging, transportation, ADRCs, LTC Ombudsman, counseling, crime victims compensation, local domestic violence and sexual assault programs, legal aid, food programs for older adults, and elder shelters. Additionally, the Elder Justice Initiative offers **webinars** on a wide range of elder abuse topics.

## U.S. Department of Labor

The U.S. Department of Labor (DOL) is a federal executive agency that oversees federal labor laws. This encompasses issues related to occupational health and safety, wage and pay standards, unemployment insurance, economic statistics, and protection from employment discrimination. DOL's mission is to “foster, promote, and develop the welfare of the wage earners, job seekers, and retirees of the United States; improve working conditions; advance opportunities for profitable employment; and assure work-related benefits and rights” (DOL, 2020).

### OFFICE OF DISABILITY EMPLOYMENT POLICY

The Office of Disability Employment Policy (ODEP) is an agency within DOL that promotes policies that foster increased employment opportunities and success for people with disabilities. It accomplishes this mission by coordinating with employers and various levels of the government to increase the use of practices and policies to encourage the employment and retention of people with disabilities. ODEP offers effective strategies, policy information, and technical assistance for all types of employers. ODEP recognizes that as workers age, they often develop disabilities, or long-term disabilities can become more significant. As a result, ODEP hosts a list of resources for **older workers**. The resource list includes reports on older workers, ODEP/DOL resources and programs, and information on age discrimination. An ODEP-funded paper, **Recruitment and Retention of Older Workers: Application to People with Disabilities**, discusses strategies that have benefited older workers and can be applied to people with disabilities as well. Additionally, the National Technical Assistance and Research Center to Promote Leadership for Increasing the Employment and Economic Independence of Adults with Disabilities produced a report on aging and disability, **Impact of Federal Policies on an Aging Workforce with Disabilities**.

## **U.S. Department of Veterans Affairs**

The U.S. Department of Veterans Affairs (VA) is a federal executive agency responsible for administering benefits and services earned by veterans of the U.S. military. The VA operates in four main areas: (1) veteran health care, (2) veteran benefits administration, (3) national cemeteries, and (4) preparation for war, emergencies, and disasters (VA, 2020). As the VA serves veterans, many of whom experience injury leading to disability, it has several projects related to aging and disability.

### **IMPROVING OUTCOMES FOR OLDER VETERANS WITH CHRONIC BACK PAIN AND DEPRESSION (2016 – 2021)**

A project at the VA North Texas Health Care System is working to develop a health coach behavioral intervention via telephone designed to improve the outcomes for older veterans who have chronic low back pain and depression. The project will: (1) develop a behavioral intervention through expert input; (2) test and refine the intervention through a sample of 10 older veterans; and (3) conduct a randomized control trial to examine the study procedures and outcome measurement. The team for this project consists of experts in outcomes research, geriatrics, behavioral intervention development, and evaluation and implementation. This grantee seeks to develop non-pharmacological methods of intervention to improve the quality of life for older veterans with chronic back pain and depression. More about this project can be found [here](#).

### **PEER SUPPORT FOR EXERCISE IN OLDER VETERANS WITH PSYCHOTIC DISORDERS (2017 – 2022)**

A grant-funded project at the Baltimore VA Medical Center is developing and testing a group-based peer coaching intervention for older veterans with psychotic disorders. The intervention, Peer Education on Exercise for Recovery, offers intensive coaching with a VA peer specialist. The specialist will promote engagement in a supervised fitness training program for older veterans. A multidisciplinary team

of experts will assist with providing feedback on the draft curriculum materials for the intervention. This project will include a small trial sample as well as a small randomized control trial. Further information about this project is available [here](#).

**MULTIMODAL EXERCISE AND WEIGHT LOSS IN OLDER VETERANS  
WITH DYSMOBILITY (2016 – 2022)**

A project at the Baltimore VA Medical Center is studying exercise and weight loss interventions for older veterans with mobility limitations. The goal is to improve these older adults' mobility, reduce their fall risk, and reduce injury-related hospitalization and death. The intervention will involve nutrition classes by a dietician and the grantee's novel progressive group multimodal balance intervention, which will be compared to outcomes with just the nutrition program alone. The nutrition program and balance intervention can easily be implemented at other VAs as routine parts of care if the intervention proves successful. More about this project can be found [here](#).

## **Social Security Administration**

The Social Security Administration (SSA) is a federal agency that provides financial protection for Americans through social insurance, including retirement, disability, and survivor benefits. The SSA provides benefits to around 64 million Americans at a variety of stages of life (SSA, n.d.a). SSA's Social Security Disability Insurance program provides benefits to workers who can no longer work due to disability. Its website hosts **stories** of people who have benefited from the program.

### **RETIREMENT AND DISABILITY RESEARCH CONSORTIUM**

The SSA funds an extramural research program called the Retirement and Disability Research Consortium (RDRC). The RDRC includes the following Centers: Boston College, National Bureau of Economic Research, University of Michigan, and University of Wisconsin. Together, the RDRC aims to: (1) research and evaluate wide-ranging topics related to SSA's old age, survivors, and disability insurance and supplemental income programs; (2) disseminate research on these topics to stakeholders, including policymakers, researchers, related organizations, and the general public; and (3) host training and education for scholars and practitioners in areas related to these topics (SSA, n.d.b). More about the RDRC can be found on its **website**.

## Interagency Collaboration

### **NO WRONG DOOR**

**No Wrong Door** is a partnership between ACL, CMS, and the Veterans Health Administration designed to coordinate access to LTSS for consumers. Various recent programs have also supported No Wrong Door efforts, such as the ADRCs, Real Choice System Change grants, the Balancing Incentive Program, Money Follows the Person, and the Veteran-Directed Care program. The No Wrong Door System has four main functions: (1) state governance and administration; (2) public outreach and coordination with key referral sources; (3) person-centered counseling; and (4) streamlined eligibility for public programs. Additional details about the elements of No Wrong Door are available [here](#).

### **VETERAN-DIRECTED CARE PROGRAM**

The **Veteran-Directed Care program** is a partnership between ACL and the Veterans Health Administration that began in 2008 to address the needs of veterans of all ages at risk of nursing home placement. The program is designed to ensure that veterans who want to continue living independently at home rather than in a nursing facility can do so. Additionally, the Veteran-Directed Care program ensures that veterans have opportunities to self-direct their LTSS services. A list of current programs by state is available on the [ACL website](#).

### **NATIONAL AGING AND DISABILITY TRANSPORTATION CENTER**

The National Aging and Disability Transportation Center (NADTC) is a partnership between the Federal Transit Administration and the National Association of Area Agencies on Aging, with guidance from ACL. NADTC aims to ensure transportation options are accessible and available to older adults, people with disabilities, and caregivers. The [NADTC website](#) hosts a wealth of transportation resources for consumers, trainings and webinars, information on transportation grants, and guides for transportation programs looking to promote public participation and involvement.

# Best Practices

There is currently a lack of evidence-based programs tailored to the needs of people aging with disability. The reasons for this gap are wide ranging, including stereotypes about disability being synonymous with poor health and shorter lifespan and a lack of government funding for basic intervention development for adults aging with long-term disabilities (Campbell & Putnam, 2017).

However, a **2017 study** examined two programs in California and Minnesota funded through the Center for Medicare & Medicaid Innovation's Health Care Innovation Award program, which aim to address the needs of people aging with disability. This study examined the effect of these programs on individuals aging with lifelong disability and found that all programs examined resulted in improved quality of care, with some programs showing reduced utilization. These programs included the following elements: (1) self-management education; (2) motivational interviewing; (3) enhanced access; (4) supportive care; and (5) avoidance of acute exacerbations of chronic conditions (Ruiz et al., 2017). To develop programs designed for people aging with disability, current evidence-based programs for older adults should be tailored with these considerations. More studies are needed to determine what types of programs best meet the needs of this population.

## **Bridging Aging and Disability Service Networks**

The key to providing tailored supports and services to people aging with disability is to bridge the divide between aging and disability service networks. These two fields have many shared interests, and the more collaboration and partnerships that occur, the more aging and disability supports and services will be easily accessible for those aging with disabilities. Factor, Heller, and Janicki (2012) recommend the following ways to bridge aging and disability networks:

1. “Raise the visibility of developmental disabilities concerns in policy reforms,
2. Improve program implementation of health and long-term support initiatives to better address needs of persons with developmental disabilities,
3. Develop a workforce with knowledge and skills to address disability and aging issues, and
4. Better understand the age-related needs and best practices in meeting those needs through research and evaluation” (Factor et al., 2012).

With many types of stakeholders in the aging and disability networks, it is important to consider how changes can be made at a system level and at a program level to advance collaboration and coordination. A review conducted in 2017 recommends that aging, disability, and public health agencies within the government engage in the following practices to close the gap between aging and disability networks and encourage development of evidence-based practices: (1) advance understanding of patterns and trajectories of chronic conditions over time by including both younger and older individuals aging with lifelong disabilities in the data systems; (2) include measures of age of disability diagnosis and age of disability onset in the expanded datasets; (3) work with private funders, foundations, and organizations to bring together researchers, policy experts, and program administrators to develop a coordinated research agenda for people aging with lifelong disabilities; (4) invest in joint funding initiatives that support the development of evidence-based interventions for the traditional aging population and people aging with disability; and (5) invest in researchers with knowledge and capacity in bringing the aging and disability fields together to work across these two populations (Campbell & Putnam, 2017). For those at the practice level, such as researchers, educators, service providers, and advocates, the following actions are recommended: (1) develop partnerships and collaborations that cross the traditional aging and disability service networks; (2) draw from both aging and disability

bodies of research to select best practices and develop interventions; (3) educate other researchers, educators, service providers, and advocates on aging and disability policy, funding streams, and delivery systems; and (4) advocate for the rights of people aging with disabilities and people aging into disability to receive evidence-based interventions in community settings (Campbell & Putnam, 2017). To successfully integrate disability and aging networks at all levels, determining key goals for people aging with disability is essential.

### **Key Goals for Successful Aging for People Aging with Disability**

As discussed previously, the standard definition of successful aging across the aging network must be broadened to include people aging with disability. People with long-term disabilities are often at higher risk for many aging-related chronic diseases compared to people aging without long-term disability. Rates of smoking, obesity, and inactivity are almost twice as high in people with disabilities than for people without disabilities, so it is vital to promote services that address these risk factors and help adults with long-term disabilities age successfully within a broadened and inclusive view of successful aging (LaPlante, 2014).

A way to promote successful aging for people aging with long-term disabilities is to increase provider awareness about successful aging for people aging with disability (LaPlante, 2014). With more awareness, providers will be able to collaborate across aging and disability networks to increase access to services. Addressing issues with access to LTSS is also crucial to ensure people aging with long-term disabilities have the support they need to age in place. However, LTSS are expensive, so improving the ability of people aging with disabilities to accumulate assets is another important step to work toward regarding successful aging for people with lifelong disabilities (LaPlante, 2014). Additionally, future planning resources for adults aging with disabilities are lacking. Factor, Heller, and Janicki (2012) recommend that the following resources be developed to assist people aging with disabilities:

*A study in 2017 argues for a more nuanced vision of “successful aging.” The study interviewed people aging with a disability and found the following themes for successful aging with a disability:*

**1. Resilience and adaptability:** The participants described having a positive outlook and adapting to changes in their lives as being important for successful aging. One participant said, “Life is what you make it, and it can be a very beautiful thing if you just look for the beauty that is in your life, present every day, as opposed to looking for the problems.”

**2. Autonomy and choice:** The participants felt it was important to have control over life decisions, such as choosing where to live and what adaptive equipment to use.

**3. Social connectedness:** The participants described having strong relationships with others, such as spouses and friends. They also found it helpful to meet others with the same disability through support groups or community programs to share experiences and advice.

**4. Physical health and access to healthcare:** The participants described the importance of maintaining their physical wellness so they could keep participating in valued life activities, like working or pursuing hobbies. They felt it was important to minimize bothersome symptoms, such as pain, fatigue, and sleep problems. Along with this, the participants valued access to doctors, rehabilitation therapists, and community wellness programs. The participants stated the importance of having access to reliable health care, including doctors and specialists who know about their disability or are willing to learn, and medical offices that are wheelchair-accessible (Molton & Yorkston, 2017).

- Financial planning to maintain eligibility for government benefits and services,
- Legal and advocacy planning when appropriate, such as guardianship or decision-making support if needed,
- Residential planning concerning where the individual will move when older caregivers move, pass away, or can no longer provide supports,
- Vocational preferences, supports, and planning, and
- The individual's preferences for community participation.

### **Promoting Interagency Collaboration on Aging with Disability**

Fostering interagency collaboration and developing a unified research agenda is vital to fully addressing the needs of people aging with long-term disability. As aging with disability crosses both the aging and disability research networks, it is not realistic for it to remain under the purview of one single federal agency. With the ICDR's charge to coordinate federal disability research and its increased funding since its inception, the ICDR aims to improve interagency collaboration in the field of aging with disability. The following are identified barriers to and methods of fostering interagency collaboration in this sphere.

In 2007, the IOM identified the following barriers to interagency collaboration on the topic of aging with disability: (1) different agency missions and organizational cultures; (2) competitive budget processes that do not provide incentives for coordination and collaboration; (3) development of long-range strategic plans being conducted separately across agencies; and (4) procedures differ across agencies regarding research funding mechanisms, application deadlines, review processes, etc. Additionally, IOM identified that a lack of coordination between agencies that fund disability research and those that provide supports and services to people with disabilities is an additional impediment to collaboration (IOM, 2007).

To promote collaboration, NIDILRR's Healthy Aging RRTC identified that increasing communication and cross-citation will help bridge current gaps (Goetz et al., 2011). Additionally, producing a standard definition of "secondary health conditions" across all fields and agencies will assist with streamlining research across disability and aging networks (Goetz et al., 2011). Identifying which secondary conditions impact an individual's community participation and quality of life will assist with determining and advancing the collaborative research agenda. Another consideration for advancing collaboration on aging with disability is building and developing research capacity in this area. The IOM recommends that the following elements be considered when determining research capacity:

- Number of researchers and experience and skills to conduct socially valued and ethically sound research,
- Education programs to produce these researchers,
- Research and analytical methods and standards that match the problems being investigated,
- Institutional settings with the resources to manage research and leadership to stimulate good science and attract and retain investigators,
- Mechanisms of accountability for research conduct, and
- Public and private funding and policies to support the research (IOM, 2007).

Improving collaboration across federal agencies with these techniques will help to narrow in on a specific research agenda and utilize resources in the most efficient manner.

# Areas for Future Research

As the field of aging with disability is still in its infancy, there are a variety of issues that remain unaddressed by the current aging and disability networks. In the last decade there have been efforts to develop a research plan related to aging with disability to streamline and integrate the disability and aging research networks. Two major conferences were held on this topic, as well as recommendations from the IOM in its 2007 report. The resulting recommendations for future research in the field of aging with disability are outlined below.

The IOM 2007 report provides several recommendations for areas that need further investigation in the field of aging with disability. These include: (1) further study and classification of secondary and aging conditions related to primary health conditions; (2) classification of secondary health conditions associated with aging with a disability that are common across primary health conditions; (3) clarification on the extent to which different levels of functioning and performance earlier in life are linked with the development of secondary and aging conditions; (4) evaluation of prevention strategies and interventions; (5) assessment of the effects of aging with a disability on caregivers and family members; and (6) systemic reviews of the literature, with the consolidation, development, and dissemination of practice guidelines (IOM, 2007, pp. 155–156).

In 2011, the University of Washington’s RRTC hosted a State of the Science Conference to review research and set a research agenda in the areas of aging and disability. The chart on the next page shows five overarching research topics they developed, along with key research goals for each:

<b>Bridge the Gap</b>	<ul style="list-style-type: none"> <li>• Improve communication and cross-citation among aging and disability research and clinical practice networks.</li> </ul>
<b>Secondary Health Conditions and Self-Management Strategies</b>	<ul style="list-style-type: none"> <li>• Further develop standard terminology of “secondary health conditions.”</li> <li>• Identify which conditions most negatively impact community participation and quality of life and how these conditions causally interrelate.</li> <li>• Collect longitudinal data on secondary health conditions.</li> <li>• Develop multi-target interventions with synergistic effects (e.g., pain and sleep) to lessen the impact and incidence of secondary health conditions.</li> <li>• Make interventions more widely available within collaborative or stepped care models (e.g., via internet and bibliotherapy, group interventions, and brief primary care interventions).</li> </ul>
<b>Community Participation</b>	<ul style="list-style-type: none"> <li>• Develop and examine customized programs to prevent falls based on evident falls risk factors.</li> <li>• Identify ways to overcome specific barriers to employment.</li> <li>• Refine measurement of communicative participation and the development and testing of participation-based interventions.</li> </ul>
<b>Outcomes Measurement in Disability Research</b>	<ul style="list-style-type: none"> <li>• Further examine how well instruments can measure a population or individuals with a particular disability.</li> <li>• Further development of cut-offs/categories that can be translated into clinical actions and significance, and decide on appropriate comparison groups and develop corresponding norms.</li> </ul>
<b>Research and Public Policy</b>	<ul style="list-style-type: none"> <li>• Link research findings with key issues facing individuals with disabilities.</li> <li>• Advocate for research funding with proposal grounded in state of the science.</li> <li>• Give research findings a voice through popular media outlets to reach and benefit target populations.</li> <li>• Form partnerships with stakeholders.</li> </ul> <p style="text-align: right;">(Goetz et al., 2011)</p>

In May 2012, ACL, NIA, and NIDILRR hosted a conference on aging with a disability. The participants of this event developed six main categories that need further research: (1) resources to support independent living, (2) improving quality of life and participation; (3) performing activities of daily living and instrumental activities of daily living; (4) role of families; (5) medical care; and (6) concerns bridging aging and disability networks (Iezzoni, 2014). The conference participants also developed pressing questions to investigate under each of these categories, which can be viewed in the [summary paper](#). A [companion paper](#) on additional research gaps goes into further detail on a few key areas.

# Toolkit Resources to Promote Future Research on Aging with Disability

The following are both federal and non-federal resources related to aging with disability to encourage collaboration among federal agency staff, researchers, advocacy organizations, and people aging with disability and their caregivers. The resources are organized by type and include: (1) datasets and research tools; (2) fact sheets, guidelines, and plain language summaries; (3) organizations; (4) reports/journal articles; (5) resource centers; (6) resources for people aging with disability; and (7) webinars.

## Datasets and Research Tools

- **ACL's Aging, Independence, and Disability Program Data Portal**

This Data Portal hosted by ACL is a query system that includes information from ACL and the Census Bureau on aging and disability to make comparisons. The site has various levels of focus and aggregation, from Data-at-a-Glance to full access to databases. Resources and data source descriptions are also available in this portal.  
<https://agid.acl.gov/>

- **CMS Data on Dual Beneficiaries of Medicare and Medicaid**

The CMS Medicare-Medicaid Coordination Office offers many resources related to the health, health care needs, and health care experiences of dual eligible individuals. Its site has reports, data, and other information to assist researchers and states with research on this population.

<https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/DataStatisticalResources/Data-and-Statistical-Resources>

- **CDC's Disability and Health Data System**

The CDC's Disability and Health Data System hosts national and state-level information about the health needs of people with disabilities. This data tool allows stakeholders like policymakers or researchers to view 30 different health categories for people with disabilities and sort by health topic. This tool also allows for sorting by location and can help create charts, maps, and tables to view the information.

<https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-health-data.html>

- **CDC List of Public Population Surveys that Include Standard Disability Questions**

The CDC website lists datasets across several government agencies (HHS, DOL, DOJ, U.S. Department of Education, and the Census Bureau) that include a standard set of six disability questions. To access the public datasets for each, the CDC provides the link to each survey's main website.

<https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html>

- **National Core Indicators – Aging and Disabilities (NCI-AD)**

NCI-AD is a partnership between ADvancing States and the Human Services Research Institute to provide a way for states to assess the performance of their programs and service delivery systems for older adults and people with disabilities. NCI-AD has developed indicators and outcomes to evaluate quality of life, community integration, and person-centered services. Additionally, NCI-AD has measures that assess LTSS for older adults and people with disabilities.

<https://nci-ad.org/>

- **National Health and Aging Trends Study**

The National Health and Aging Trends Study hosts a website that provides access to study data, publications, and tutorials for researchers. The website also offers information for participants in the study.

<https://www.nhats.org/>

- **National Social Life, Health, and Aging Project (NSHAP)**

NSHAP is a longitudinal, population-based study that examines health and social factors of older adults living in the community. Some of the categories examined include physical health and illness, medication use, cognitive function, social connectedness, health behaviors, etc. Information about accessing the data is available on the NSHAP website, in addition to a comprehensive list of publications using NSHAP data.

<https://www.norc.org/Research/Projects/Pages/national-social-life-health-and-aging-project.aspx>

- **The University of Michigan Health and Retirement Study (HRS)**

The HRS is funded by both the NIA and SSA and surveys 20,000 people in America. The HRS website hosts information for researchers related to data documentation, available data products with their corresponding policies, reports and graphs, and submissions of publications using HRS data.

<https://hrs.isr.umich.edu/about>

### **Fact Sheets, Guidelines, and Plain Language Summaries**

- **CEDAR Midwest – Fact Sheets and Infographics on Aging with Long-Term Physical Disabilities**

CEDAR Midwest has a collection of fact sheets and infographics related to people aging with long-term disability. The fact sheets cover topics such as sociodemographic information, participation in activities, and developing a community-based research network.

<https://cedarmidwest.org/fact-sheets/>

- **Healthy Aging RRTC – Evidence-Based Factsheets**

The Healthy Aging RRTC has developed a variety of informational fact sheets on wide-ranging topics such as fall prevention, hearing and vision loss, and staying

physically active for people aging with a disability. These fact sheets are both evidence-based and easy to read. In addition, this Center has fact sheets for clinicians and providers on health care accessibility and aging with disability.

<http://agerrtc.washington.edu/info/factsheets>

- **Healthy Aging RRTC – Plain Language Summaries of Research Articles on Disability and Healthy Aging**

The Healthy Aging RRTC has plain language summaries on its website of all of its research projects from 2013 to 2017. These documents provide easy-to-read information on what the research was about, what the researchers did, and what the researchers found during the study. The summaries conclude with how the research can be used and things the reader should know.

<http://agerrtc.washington.edu/info/summaries>

- **National League for Nursing – Teaching Resource for Nurses Providing Care to People Aging with Disabilities**

The National League for Nursing hosts a teaching resource on aging with a disability as part of its Advancing Care Excellence for Persons with Disabilities program. This resource sheet outlines specific aging changes that nurses should be aware of by disability type.

<http://www.nln.org/professional-development-programs/teaching-resources/ace-d/additional-resources/aging-with-a-disability>

- **Today's Geriatric Medicine – Guidelines, Tips, and a Case Study for Physicians Treating Older Adults with Intellectual Disabilities**

This article offers an overview for providers of the unique needs of people aging with disabilities. It includes questions to consider when treating an adult aging with disability. The end of the article includes a case study for physicians to review, along with related resources.

<https://www.todaysgeriatricmedicine.com/archive/050613p22.shtml>

## Organizations

- **ADvancing States**

ADvancing States is an organization that represents all state and territorial agencies in aging and disabilities and long-term services. It seeks to foster innovation in the design of these systems and advance policy that supports LTSS. ADvancing States hosts the **HCBS Clearinghouse** on its website, which consists of resources and tools for research, policymaking, and program development related to HCBS.

<http://www.advancingstates.org/>

- **American Society on Aging**

The American Society on Aging is an advocacy organization that works to defend Social Security benefits, fights for elder justice, backs beneficial provisions in the Affordable Care Act, and champions reauthorization of the Older Americans Act. Its website hosts advocacy and educational resources such as webinars, a podcast, toolkits, seminars, and forums.

<https://www.asaging.org/>

- **Association on Aging with Developmental Disabilities (AADD)**

The AADD aims to bridge the aging and developmental disability fields to develop best practices for people aging with developmental disabilities. It serves three county areas but provides consultation and resources outside of this geographic region. The AADD website hosts a wide array of resources, including videos, web links, webinars, and a quarterly newsletter. Annually, the AADD hosts the Conference on Aging with Developmental Disabilities.

<https://www.agingwithdd.org/>

- **Disability and Aging Collaborative (DAC)**

The DAC is a coalition of around 40 national agencies that collaborate to advance long-term services and support federal policy. The DAC began in 2009, at the outset of coordinated efforts to bridge disability and aging networks. It meets twice a month to discuss policy, strategy, and advocacy surrounding bridging aging and disability organizations. The DAC has a series of policy-focused webinars on its website.

<https://heller.brandeis.edu/community-living-policy/dac/index.html>

- **National Council on Aging**

The National Council on Aging is an advocacy organization and voice for older adults. The Council offers resources on its website for older adults, caregivers, professionals, and advocates. It provides best practices, tools, and advocacy to ensure that people can age with health and financial security.

<https://www.ncoa.org/>

- **The Arc**

The Arc is a national organization that promotes and protects the human rights of people with I/DD. Its website hosts resources by topic area on advocacy and policy issues. The Arc supports full inclusion and participation in the community throughout the lives of people with I/DD.

<https://thearc.org/position-statements/aging/>

## Reports/Journal Articles

- ***Aging with a Disability: A Systematic Review of Cardiovascular Disease and Osteoporosis Among Women Aging with a Physical Disability* by Rosso, Wisdom, Horner-Johnson, McGee, & Michael (2011)**

This paper discusses the increased risks of morbidity that women aging with disabilities face due to barriers in accessing medical care. Specifically, the paper discusses the risk of cardiovascular disease and osteoporosis for women aging with disability. It discusses future directions for evaluating the health of women aging with disabilities.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4877625/>

- **CEDAR Midwest – Publications**

CEDAR Midwest provides its recent publications on aging with disability and summaries of these publications on its website. CEDAR Midwest’s website provides access to its infographics and presentations as well.

<https://cedarmidwest.org/publications/>

- **Forum on Aging, Disability, and Independence – Reports and Resources**

The Forum on Aging, Disability, and Independence has a collection of reports and resources, many related to aging with disability. The reports cover topics such as hearing loss and healthy aging, financing LTSS, and community living and participation.

<https://www.nap.edu/initiative/forum-on-aging-disability-and-independence>

- **IOM – The Future of Disability in America Report (2009)**

This report from the IOM presents a comprehensive view of disability services and research across the United States. *Chapter 5: Secondary Conditions and Aging with Disability* provides a history of the field of aging with disability as well as a variety of recommendations for future research on this topic.

[https://www.ncbi.nlm.nih.gov/books/NBK11434/pdf/Bookshelf\\_NBK11434.pdf](https://www.ncbi.nlm.nih.gov/books/NBK11434/pdf/Bookshelf_NBK11434.pdf)

- ***Journal of Aging and Health – Special Issue: Aging with Long-Term Disability***  
In 2019, the *Journal of Aging and Health* released a special issue on the topic of aging with long-term disability. This special issue provides information of the state of the science in this field, highlighting areas where aging and disability networks are collaborating. Valuable information on future directions for the aging with disability field is also discussed.  
[https://journals.sagepub.com/toc/jaha/31/10\\_suppl](https://journals.sagepub.com/toc/jaha/31/10_suppl)
- ***Stakeholders' Perceptions of Planning Needs to Support Retirement Choices by Persons with Developmental Disabilities* by Hodges & Luken (2006)**  
This publication discusses the transition to retirement for adults aging with developmental disabilities from the perspective of service providers, family members, and a potential retiree. Findings included three themes about retirement choices for people with developmental disabilities: (1) lack of retirement culture; (2) apprehensions about retirement; and (3) structural barriers to retirement.  
[https://bctra.org/wp-content/uploads/tr\\_journals/960-3760-1-PB.pdf](https://bctra.org/wp-content/uploads/tr_journals/960-3760-1-PB.pdf)
- ***Testimony from Dr. Tamar Heller to the U.S. Senate Committee on Aging – Service and Support Needs of Adults Aging with Intellectual/Developmental Disabilities* (2017)**  
This informative testimony from Dr. Tamar Heller provides background on the service and support needs for adults aging with I/DD. She explains models of services and supports for this population in the past and provides recommendations for moving forward.  
[https://www.aucd.org/docs/annual\\_mtg\\_2017/2017\\_aging\\_4\\_testimony\\_senate\\_cmte\\_on\\_aging.pdf](https://www.aucd.org/docs/annual_mtg_2017/2017_aging_4_testimony_senate_cmte_on_aging.pdf)

- **University of Michigan Population Studies Center – *Aging with Disability for Midlife and Older Adults* by Verbrugge, Latham, & Clarke (2017)**

This paper provides analysis on adults aging with disability over age 65 through HRS data. The authors discuss the social and health disadvantages that people aging with disabilities face when compared to people aging without long-term disabilities. The goal of this study was to provide empirical data to make the case that aging with disability should be considered throughout the life course and not just for a specific age group.

<https://www.psc.isr.umich.edu/pubs/rr17-876cf54.pdf?i=985025341678049877638121421&f=rr17-876.pdf>

### Resource Centers

- **ADRCs**

ADRCs are part of the No Wrong Door System and provide information to older adults, people with disabilities, and caregivers regarding LTSS. The Centers' role is to raise awareness about the full range of options; provide advice, counseling, and assistance; empower people to make informed choices about LTSS; and to assist people with accessing both public and private programs.

<https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers>

- **ADA National Network**

The ADA National Network provides information, guidance, and training on ADA implementation. The aim of this Network is to ensure that people with disabilities have access to equal opportunities, full participation, independent living, and economic self-sufficiency.

<https://acl.gov/programs/aging-and-disability-networks/americans-disabilities-act-national-network>

- **CILs**

CILs are designed and run by people with all types of disabilities and provide information on independent living programs and services. CILs promote community living and independence and provide tools, resources, and supports for ensuring people with disabilities can fully participate in their communities. For further information, the ICDR released a **Research Plan for Examining CILs Outcomes** that details past and current research as well as future directions for research.

<https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

- **National Association of Area Agencies on Aging**

The National Association of Area Agencies on Aging represents the 622 AAAs and 256 Title VI Native American aging programs. It aims to create a world where older adults and people with disabilities have choice over their homes and their communities. Its website hosts a collection of **best practices** across the AAAs, organized by category.

<https://www.n4a.org/>

- **National Clearinghouse for Long-Term Care Information**

The National Clearinghouse for Long-Term Care Information is a website hosted by ACL that provides information and resources to assist individuals and their families in planning for future LTC needs.

<https://acl.gov/ltc>

- **National Long-Term Care Ombudsman Resource Center**

The National Long-Term Care Ombudsman Resource Center provides information for consumers regarding nursing homes, HCBS, and assisted living/board and care facilities. The Center has an online library with government reports, research, federal legislation, and advocacy resources for LTC Ombudsman programs in each state as well as for consumers.

<https://ltcombudsman.org/>

- **National Resource Center for Aging with Disability**

The National Resource Center for Aging with Disability at the University of Michigan hosts an archive of programs and resources. The resources can be searched by keywords, state, and by the following topic areas: assistive technology, employment, health management and nutrition, housing, independent living and support services, legal/financial and advocacy, policy and policymakers, recreation/leisure and physical activity, senior programs, and transportation.

<https://disabilityhealthresources.org/>

- **NADTC**

NADTC aims to increase access and availability of transportation options for older adults, people with disabilities, and caregivers. The NADTC website provides training and webinars, resources and publications, and case studies on collaboration and coordination of transportation programs and services.

<https://www.nadtc.org/>

- **State Protection & Advocacy Systems (P&As)**

P&As work to empower and advocate for people with disabilities at the state level. There are 57 P&As in the United States and its territories. P&As offer legal support to underserved populations through dedication to the fight for personal and civil rights of people with disabilities.

<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>

- **State Units on Aging**

State Units on Aging are designated state-level agencies that are responsible for developing and administering multiyear state plans that advocate for and provide assistance to older residents, their families, and, in many states, adults with physical disabilities. There are 56 State Units on Aging located in each of the 50 states as well as in the District of Columbia and U.S. territories. “State

Unit on Aging” is a general term, so the specific title varies by state.

<https://acl.gov/programs/aging-and-disability-networks/state-units-aging>

## Resources for People Aging with Disability and Caregivers

- **A Guidebook on Aging and Down Syndrome**

This resource from the National Down Syndrome Society provides resources on health and well-being during aging for people with Down syndrome. It outlines common medical conditions, provides well-being resources, describes signs of Alzheimer’s disease, and discusses future planning resources.

<https://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>

- **Benefits Checkup**

Benefits Checkup, a resource of the National Council on Aging, is a search tool where older adults can see what benefits they may qualify for based on geographic area. This tool lists all of the following categories of benefits: medications, health care, income assistance, food and nutrition, housing and utilities, tax relief, veteran, and employment.

<https://www.benefitscheckup.org/>

- **Eldercare Locator**

Eldercare Locator, a service of the U.S. Administration on Aging, provides information on services for older adults. The listed services include health, transportation, support services, elder rights, insurance and benefits, and housing by geographic area. Eldercare Locator also offers the option to speak with an information specialist regarding any questions, and it hosts a “Caregiver Corner” with frequently asked questions and additional information.

<https://eldercare.acl.gov/Public/Index.aspx/>

- **Evidence-Based Programs for Older Adults and People with Disabilities**

ACL hosts a list of evidence-based programs for older adults and people with disabilities. In 2015, these programs were assessed and rated for Quality of Research and Readiness for Dissemination. ACL provides summaries and key information on these evidence-based interventions.

<https://acl.gov/programs/strengthening-aging-and-disability-networks/aging-and-disability-evidence-based-programs>
- **Family Care Navigator**

The Family Care Navigator, hosted by the Family Caregiver Alliance, helps caregivers find public, nonprofit, and private programs and services by state. Its resources include government health and disability programs, legal resources, disease-specific organizations, caregiver compensation programs, and more.

<https://www.caregiver.org/family-care-navigator>
- **Health in Aging**

This site was created by the American Geriatrics Society's Health in Aging Foundation to provide expert and up-to-date information on health and aging for older adults and caregivers. The tools it offers have been reviewed by geriatrics health professions and members of the American Geriatrics Society. HealthinAging.org includes information about health and aging by topic area, as well as in-depth information about wellness and prevention, age-friendly health care, medications, and driving safety.

<https://www.healthinaging.org/>
- **LTSS State Scorecard**

The LTSS State Scorecard is a partnership between the AARP and its AARP Foundation, the Commonwealth Fund, and the Scan Foundation that provides a state scorecard on LTSS for older adults, people with disabilities, and family caregivers. The scorecards are released annually and include information on performance and ranking on a variety of outcomes. The site allows the user to

compare rankings between states, and it also offers resources and information on best practices for LTSS.

<https://www.longtermscorecard.org/>

- **National Adult Protective Services Organization**

The National Adult Protective Services Organization provides state Adult Protective Services programs with a means to problem-solve, share information, and improve the quality of services for victims of elder and vulnerable adult mistreatment. This organization works to increase the capacity of Adult Protective Services at the local, state, and national levels to improve recognition of and response to abuse, neglect, or exploitation of older adults and adults with disabilities. Additionally, it hosts a [map with information on how to contact Adult Protective Services](#) in each state.

<https://www.napsa-now.org/>

- **National Resource Directory**

The National Resource Directory is a searchable database of verified resources for service members, veterans, family members, and caregivers. Resources are provided at the local, state, and national levels and cover topics such as benefits and compensation, employment, health, family and caregiver support, and more.

<https://nrd.gov/>

- **Needy Meds**

Needy Meds is a national nonprofit that provides prescription assistance information for people who cannot afford medications and health care costs. Needy Meds' website allows users to sort program information by diagnosis, medication name, and a variety of other categories. It also offers information on medical transportation, webinars, government programs, and coupons and rebates. Additionally, Needy Meds has a helpline that users can call for additional information and questions about affording their medications.

<https://www.needymeds.org/>

- **Respite Locator**

The Respite Locator is a service of the ARCH National Respite Network that helps caregivers and professionals locate respite services by geographic location. For each state, information on respite providers and programs is available, in addition to respite funding and eligibility requirements.

<https://archrespite.org/respitelocator>

## Webinars

- **CEDAR Midwest – Webinars on Aging with Long-Term Disability**

CEDAR Midwest’s website has a collection of webinars on topics related to promoting independence and community participation for people aging with disability. Example topics include “Depression, Aging and Disability” and “Technology for Addressing Toileting for People Aging with Disabilities.”

<https://cedarmidwest.org/information/webcasts/>

- **Resources for Integrated Care (RIC) – Aging in Individuals With I/DD**

RIC works with health plans, providers, and experts to build capacity to address the needs of people dually eligible for Medicare and Medicaid. RIC’s website has a collection of webinars with subject matters experts related to dually eligible individuals. One of RIC’s webinar series is on “Aging in Individuals with Intellectual and Developmental Disabilities” and includes topics such as aging with Down syndrome, health care disparities, medication, and dementia.

<https://www.resourcesforintegratedcare.com/webinar/series/individuals-with-idd>

- **The Arc – Webinars on Future Planning for People with Intellectual Disabilities**

The Arc, an advocacy organization for people with I/DD, hosts webinars on a wide range of topics. They have a series related to future planning for people with disabilities. Examples of the topics include “Aging with Cerebral Palsy: Health Outcomes and Management” and “Aging and I/DD: Planning for Growing Older.”

[https://futureplanning.thearc.org/pages/learn/where-to-start/webinars/archived-webinars?\\_ga=2.145688628.1840131516.1614204646-1356902825.1612890835](https://futureplanning.thearc.org/pages/learn/where-to-start/webinars/archived-webinars?_ga=2.145688628.1840131516.1614204646-1356902825.1612890835)

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