

Bridging Aging and Disability Networks to Support Aging Adults With Intellectual and Developmental Disabilities and Family Caregivers

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Advances in rights, technology, healthcare, and community-based supports over the past several decades have contributed to increased lifespan of adults with intellectual and developmental disabilities (IDD) within the United States and across many other industrialized countries (Heller, 2019). In addition to reaching older ages, most adults with IDD live with family caregivers who have provided lifelong support and are also aging in place. While this population of older adults and aging caregivers faces similar aging-related needs to those of the general population, they also have unique situations and needs that require tailored approaches, adaptations, and supports. Collaboration between aging and disability service systems and networks is needed to support these families.

Within the United States, there are an estimated 7.39 million individuals with IDD. The vast majority of adults with IDD live at home with family caregivers and are not known to the formal IDD service system (Larson et al., 2022). Only about 19% of these families (1.40 million) receive services from the IDD system. Among adults with IDD living at home with family in the United States, approximately 24% reside with family caregivers ages 60 years and older and another 35% reside with caregivers between the ages of 41 and 59 years (Tanis et al., 2022). A central task faced by these families is planning for the future, which involves thinking about transitions when the primary family caregiver can no longer provide support or passes away (Heller, 2019). Key aspects of future planning include financial planning and benefits; future living arrangements; employment and vocational preferences; decision-making supports; and healthy aging. Lack of adequate planning can result in poor outcomes, including abrupt changes for individuals with IDD, loss of benefits due to lapse in eligibility from sudden inheritance, burdens on siblings and other family members, and crises for IDD service systems.

Developmental Disabilities Network

Medicaid is the primary payer of long-term services and supports in the United States for both older adults and individuals

with IDD. States have used various Medicaid authorities, particularly 1915(c) Medicaid Home and Community-Based Services waiver, to build the foundation of the IDD service systems. However, the number of individuals served, benefits provided, scope of services, and settings where services are provided vary widely across states (Larson et al., 2022). For example, in 2023 over 511,000 individuals with IDD were on waiting lists for Medicaid Home and Community-Based Services (HCBS) waiver services (Burns et al., 2023). Families wait many years, sometimes decades, to access such services. Moreover, racial and ethnic disparities exist in awareness of service systems and access to culturally and linguistically appropriate supports.

In addition to the IDD service system, the Developmental Disabilities Assistance and Bill of Rights Act provides a national network of programs across the United States and in territories (*The Developmental Disabilities Assistance and Bill of Rights Act of 2000* | ACL Administration for Community Living, n.d.). While these programs typically do not provide direct services, they support infrastructure that drives IDD systems and advances the rights of people with disabilities. State Councils on Developmental conduct advocacy, systems change, and capacity building efforts. State Protection & Advocacy Systems provide advocacy and legal services to protect the rights of individuals with disabilities. University Centers for Excellence in Developmental Disabilities Education, Research & Service provide training, technical assistance, service, research, and information sharing. Projects of National Significance support special projects focused on the most pressing issues impacting people with IDD.

Aging Network

The Older Americans Act (OAA) is the foundation of what is broadly referred to as the “aging network” in the United States (Colello & Napoli, 2024; Shaughnessy et al., 2021). The OAA authorizes a wide array of health and social services

through a nationwide network of State Units on Aging, Area Agencies on Aging, tribal organizations, and thousands of local community-based providers. A wide array of services and supports is provided through various titles of the OAA such as supportive services (i.e., personal care, chore services, and transportation), congregate nutrition services, home-delivered nutrition services, family caregiver support, community service employment, the long-term care ombudsman program, and services to prevent the abuse, neglect, and exploitation of older persons. Similar to the IDD service system, states also utilize Medicaid HCBS authorities to provide community-based services to older adults. Moreover, OAA funding is often supplemented by additional local and state funding. Older adults with IDD as well as aging family caregivers are eligible for OAA services and supports and could benefit. However, historically there have been challenges in bridging aging and disability networks to fill gaps and better coordinate support for these populations.

Bridging Aging and Disability

Calls for bridging aging and disability research, policy, and practice have been made for decades. The Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability provided the following conceptual definition:

Bridging encompasses a range of concepts, tasks, technologies and practices aimed at improving knowledge sharing and collaboration across stakeholders, organizations and fields of care and support for persons with disabilities, their families, and the aging population (Bickenbach et al., 2012)

Bridging allows aging and disability networks, organizations, and communities to come together, share strengths and expertise, build trust, navigate similarities and differences, and find common ground on issues. Bridging can improve support for aging adults with IDD and family caregivers as well as improve coordinated systems of long-term services and supports (LTSS). The aging and disability systems can help supplement services and support where there is an overlap in needs and prevent individuals from falling through the cracks. For example, the aging network can help support the disability network in understanding and addressing age-related needs of adults with IDD and aging caregivers. The disability community can also help adapt services and supports provided by the aging network, so they are more inclusive of aging adults with IDD.

However, historically many factors have posed significant barriers to bridging aging and disability. While there has been progress, many barriers noted by scholars decades ago still persist today (Factor et al., 2012; Janicki & Ansello, 2000). Three of the most common barriers include:

- **Organizational Silos**—While the OAA and Developmental Disabilities Assistance and Bill of Rights Act originated near the same time in the mid-1960s, the networks have historically been administered within separate organizational structures and agencies at the federal and state levels. These structural silos and divides have been challenging to cross. Most individuals working within one system still have very limited knowledge and understand-

ing about how the other system is structured and what services and supports are provided.

- **Cultural and Philosophical Differences**—Aging and disability networks (i.e., advocates, researchers, and providers) have their own deep-rooted cultures, philosophical underpinnings, and terminology. Popular models of “successful aging” have been viewed as aging without disability and not incorporated individuals aging with disabilities. Traditionally, the aging system has been more medically oriented and professionally driven. Disability systems adhere more to a rights-based approach that includes tenets such as choice and control, self-determination, independent living, and peer support (Factor et al., 2012; Janicki & Ansello, 2000).
- **Limited Resources**—Both networks and systems have historically been severely underfunded to meet the existing needs of the populations they are charged with serving. Often, this leads to reluctance to engage in collaborative efforts for fear of draining resources. “Responsibility” for serving aging adults with IDD and family caregivers is often shifted back and forth between systems (Factor et al., 2012).

Progress in Bridging Aging and Disability

Early Bridging Efforts

Over the years, many initiatives have been undertaken to promote bridging aging and disability (Factor et al., 2012). Beginning in the 1980s, when community-based organizations first started witnessing an increase in older adults with IDD, incremental steps were taken to incentivize collaboration across networks. Several notable research and professional conferences were held, such as the 1986 Wingspread Conference on Aging and Developmental Disabilities (Ansello & Rose, 1989). A memorandum of agreement was signed between the Administration on Aging (AoA) and Administration on Developmental Disabilities (ADD) to collaborate on efforts to support aging adults with IDD. Similar memorandums of understanding were also signed at state levels between aging and disability agencies. Small-scale training and demonstration grants were awarded in dozens of states with funding from both AoA and ADD (Factor et al., 2012). What is now the National Institute on Disability, Independent Living, and Rehabilitation Research awarded a research center devoted to aging with IDD. During several reauthorizations of the OAA, language was revised to support aging adults with IDD and family caregivers, including language to ensure older caregivers of adults with disabilities are eligible for the National Family Caregiver Support Program. A great deal was learned from these early initiatives. However, most initiatives were short lived and ended with changes in leadership and staff (Ansello, 2004; Factor et al., 2012).

Structural and Organizational Progress

The Patient Protection and Affordable Care Act (ACA) triggered two structural and organizational changes at the federal level that have accelerated the bridging of aging and disability: 1) formation of the Disability and Aging Collaborative; and 2) establishment of the Administration for Community Living.

- *Disability and Aging Collaborative*—Formed in 2009, the Disability and Aging Collaborative was the first successful coalition to bring together national aging and disability organizations to advance long-term services and support (LTSS) policy. Organizations came to the table because they saw the need to have a stronger voice for inclusion of LTSS reforms in the ACA. Since its formation, this has been a driving force behind advances in LTSS policy at the federal level, including passage of the Community Living Assistance Services and Supports Act, Balancing Incentive Payments Program, Community First Choice Option, extension of Money Follows the Person and HCBS Spousal Impoverishment Protections, and historic dedicated funding for HCBS within the American Rescue Plan.
- *Administration for Community Living*—Implementation of LTSS reforms within the ACA and rapidly occurring reforms at the state level toward managed LTSS and duals integration contributed to federal officials seeing the need to improve coordination. Aging and disability leaders appointed under the Obama administration were instrumental in forming the Administration for Community Living (ACL) in 2012. ACL brought together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities. Programs under the Rehabilitation Act, including the Centers for Independent Living and National Institute on Disability, Independent Living, and Rehabilitation Research were also transferred from the Department of Education to the Department of Health and Human Services. Leadership at ACL has sought every opportunity to bring together the networks and find common ground through convenings, guidance, regulations, and funding opportunities.

Structural and organizational progress has also occurred at state and local levels. Successful state-level disability and aging coalitions have also formed around LTSS initiatives (Putnam, 2014). Similar to the formation of ACL, many states have also restructured their health and social service systems to bring aging and disability agencies under one umbrella. Some states have also combined Medicaid HCBS waivers and/or moved toward integrated health and LTSS programs serving multiple populations.

Bridging Aging and Disability Community of Practice

Recognizing the need to promote renewed efforts to bridge aging and disability networks to improve services and support for aging adults with IDD and family caregivers, ACL launched a five-year Community of Practice (CoP) in 2021. The National Association of Councils on Developmental Disabilities is leading this CoP in partnership with the University of Illinois at Chicago, Brandeis University, The Arc of the United States, and USAging.

The Bridging Aging and Disability CoP consists of 17 states. It originated with five states in 2022 (CT, DC, FL, HI, and NJ). Two states were added in 2023 (CA and NM), and 10 additional states joined in 2024 (AL, AZ, IL, IA, KS, MI, NY, ND, OK, and TX). States were required by ACL to form state alliance teams, led by state councils on developmental disabilities, state developmental disability agencies, and/or state aging

agencies. States were required to have representation from aging and disability agencies and organizations, self-advocates with IDD and family members, and organizations representing racial/ethnic and other underserved communities. State teams worked together to develop work plans to bridge aging and disability. Technical assistance and small amounts of funding were provided to state teams to support them through this process. However, it was a bottom-up process, where states had a broad range to identify areas of focus, goals, and workplans that were submitted to National Association of Councils on Developmental Disabilities and ACL.

Emerging and Promising Practices

States in Bridging Aging and Disability CoP have developed and implemented their work plans. As partners and subject matter experts, we assisted in identifying emerging and promising practices. We also conducted an environmental scan to identify other current practices nationally and in states outside the CoP (Caldwell & Gladstone, 2023). While not exhaustive, the following practices highlight some common areas where bridging is occurring. They provide examples that might generate ideas, interest, and replication in other states (see Figure 1).

Future planning

Supporting aging adults and family caregivers in future planning is one of the most common areas where bridging is occurring.

- At the national level, *The Arc's Center for Future Planning* hosts online resources and tools for future planning, including an interactive and user-friendly Build Your Plan tool, a resource directory, and video gallery providing overviews and stories from self-advocates with IDD. Several states within the CoP utilized these tools to provide resources and training for families.
- The District of Columbia partnered with local senior centers to host a series of future planning events that were offered in multiple languages, including English, Spanish, Mandarin, and American Sign Language. They culturally adapted resources and training materials from *The Arc's Center for Future Planning* to train navigators with multicultural and multilingual backgrounds to support, guide, and reach diverse communities.
- The University of Illinois at Chicago developed *The Future Is Now*, an evidenced-based, person-centered future planning intervention for individuals with IDD and aging family caregivers (Factor et al., 2011; Heller and Caldwell, 2006). The intervention is based on a model of peer-support, where small groups of families participate together in workshops co-facilitated by professionals and peer mentors (i.e., families who have done planning and self-advocates). Sessions cover a range of future planning topics, including dreams for the future, future living arrangements, support networks, work and retirement, and safeguards for the future. Families develop and document a “plan for the future” and set actions to take. A virtual version is currently being adapted and pilot tested. Several states in the CoP are delivering this training.

Person-centered planning

Within the United States, federal regulations require person-centered planning in all HCBS programs. Person-centered planning is a process through which the individual

Opportunities to Bridge Aging and Disability Networks to Improve Supports for Aging Adults with IDD and Family Caregivers

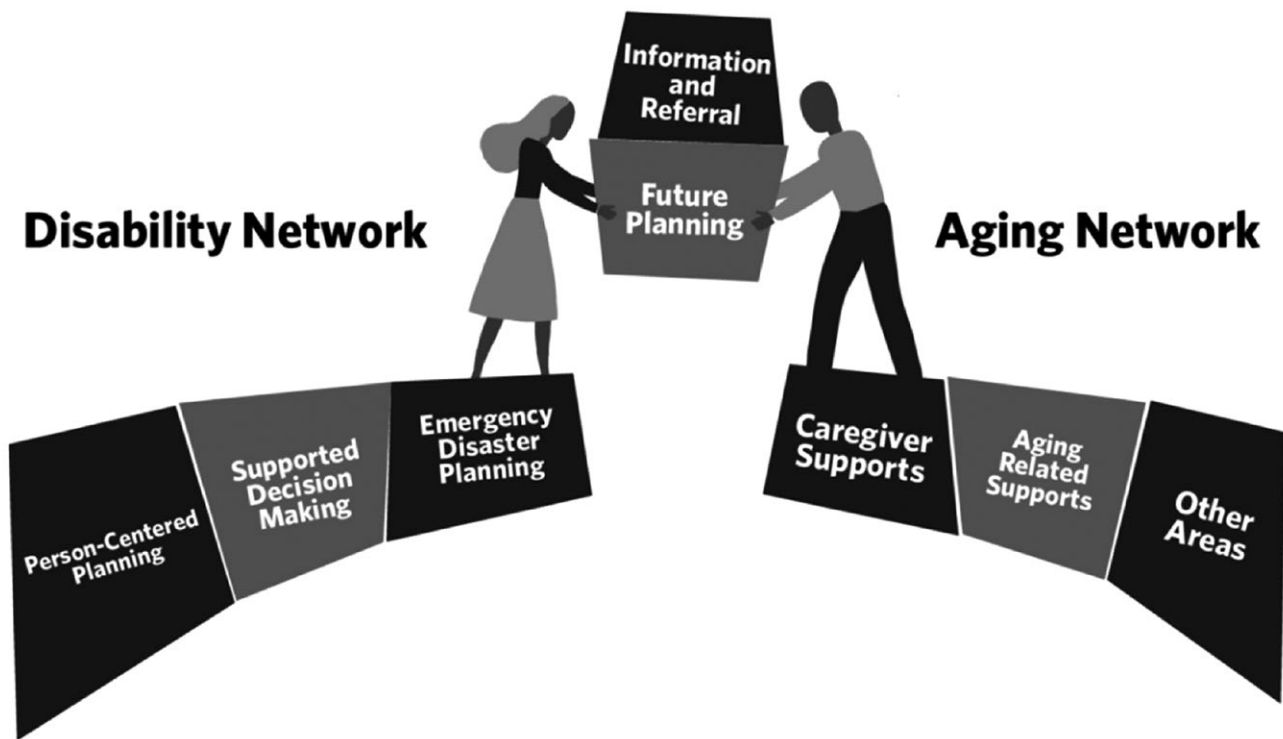


Figure 1. Opportunities to bridge aging and disability networks.

receiving services and support develops a service plan that reflects and advances their personal goals, needs, preferences, and values.

- Two states in the CoP (CA and OK) are adding questions to their guides for service coordinators/case managers that facilitate person-centered planning to prompt discussion about aging-related issues and future planning (e.g., future living arrangements, supported decision-making, aging-related needs for services and supports).
- Connecticut adopted Charting the LifeCourse tools and training to facilitate person-centered planning in their aging service system. These tools were originally developed to facilitate person-centered planning and thinking in the IDD system.

Information and Referral

Aging and Disability Resource Centers (ADRCs) serve as single points of entry into the LTSS system. Since 2003, support for ADRCs/No Wrong Door Systems has been provided through various opportunities funded by the ACL, Centers for Medicare and Medicaid Services, and Veterans Health Administration. While aging and disability partnerships have improved, disability advocates in many states have expressed long-standing concerns that ADRCs do not serve the disability community well, particularly the IDD population (Coyle et al., 2016; Factor et al., 2012).

- Several states in the CoP are working to improve disability resources and information provided by ADRCs. Hawaii added disability resources to its ADRC resource directory. Iowa is developing training for its newly established ADRC network on disability awareness, disability rights, and culture. Michigan is developing a curriculum to educate and make resources available to staff from OAA-funded Title VI Native American programs and Area Agencies on Aging to better support older adults with developmental disabilities.
- The District of Columbia added questions to their aging intake form to identify potential family caregivers of individuals with IDD and make referrals to the IDD system.

Family caregiver support

Some states have developed innovative approaches to bridge gaps in family support services and support.

- The Missouri Developmental Disabilities Council and the Association on Aging with Developmental Disabilities developed a training program for individuals with IDD on being caregivers for their aging parents. WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies) teaches people with IDD the skills necessary to recognize and respond to their loved one's basic care and home safety needs.

- The Michigan Older Caregivers of Emerging Adults with Autism and Other Neurodevelopmental Disabilities (MI-OCEAN) family support project was a statewide initiative piloted by Wayne State University with aging family caregivers (55+ years) of adults with autism spectrum disorder and other neurodevelopmental disabilities (Wayne State University, 2022). MI-OCEAN used a peer support model to match aging caregivers with family support navigators to connect to services and supports and improve health outcomes and quality of life.
- New Mexico is in the process of developing a caregiver navigator pilot program. As part of this process, they are working to gain feedback and input from tribal communities.

Support decision-making

Several states in the CoP focused on bridging aging and disability to improve decision-making supports for individuals with IDD and older adults.

- New Mexico developed a campaign called, *My Life, My Decisions*, funded by the state legislature, to provide resources on alternatives to guardianship. The campaign aims to present information and resources on alternatives to guardianship as well as onsite legal services by partnering with public disability rights lawyers.

Aging-related supports

Another area of focus for some states is improving aging-related supports for individuals with IDD, including supports for individuals with IDD who develop Alzheimer's and related dementia.

- The National Task Group on Intellectual Disabilities and Dementia developed a training, Dementia Capable Care of Adults with Intellectual Disabilities and Dementia. This training has been implemented at various local provider and state levels across the country. Hawaii offered this training as part of the CoP. They also included an individual with IDD in the training, which was the first time that an individual with IDD underwent the training and became certified. Hawaii also partnered with Alzheimer's Association Aloha Chapter to establish a Silver Alert program that includes both aging and IDD populations at risk of wandering or getting lost.

Emergency and disaster planning

Several states in the CoP are bridging aging and disability in statewide emergency and disaster planning for people with disabilities and older adults.

- Through the relationships bridged between aging and disability agencies in the CoP, Hawaii was able to quickly mount a coordinated response to the 2023 wildfires in Maui.
- Alabama is strengthening disaster and emergency planning for older adults and individuals with disabilities. They are providing training and outreach to strengthen the engagement and partnership with OAA partners, including ADRCs, senior centers, and Meals on Wheels programs.

- Texas is exploring the development of a volunteer emergency respite program for family caregivers during emergencies.

Other areas

States have bridged in other initiatives within states, including strengthening the direct care workforce and development of Multisector Plans on Aging (West Health. n.d).

- Through the CoP, Connecticut bridged partnerships to ensure the voices and needs of individuals with IDD and other disabilities were included in the process of developing the framework for their Multisector Plan on Aging.

Conclusion

There is a long history of efforts to bridge aging and disability networks. While significant progress has been made within the United States, many of the challenges observed decades ago still remain. Many states participating in the Bridging Aging and Disability Community of Practice have expressed that perhaps the most promising practice has been establishing a regular forum for aging and disability agencies and organizations to come together, learn about what each other does, sharing best practices and approaches, and organically find shared interest and common ground. Federal initiatives like the Bridging Aging and Disability CoP or other initiatives that require collaboration across networks can incentivize these conversations, but discovering shared interests and mutual benefit is what will sustain them.

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Conflict of Interest

None.

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