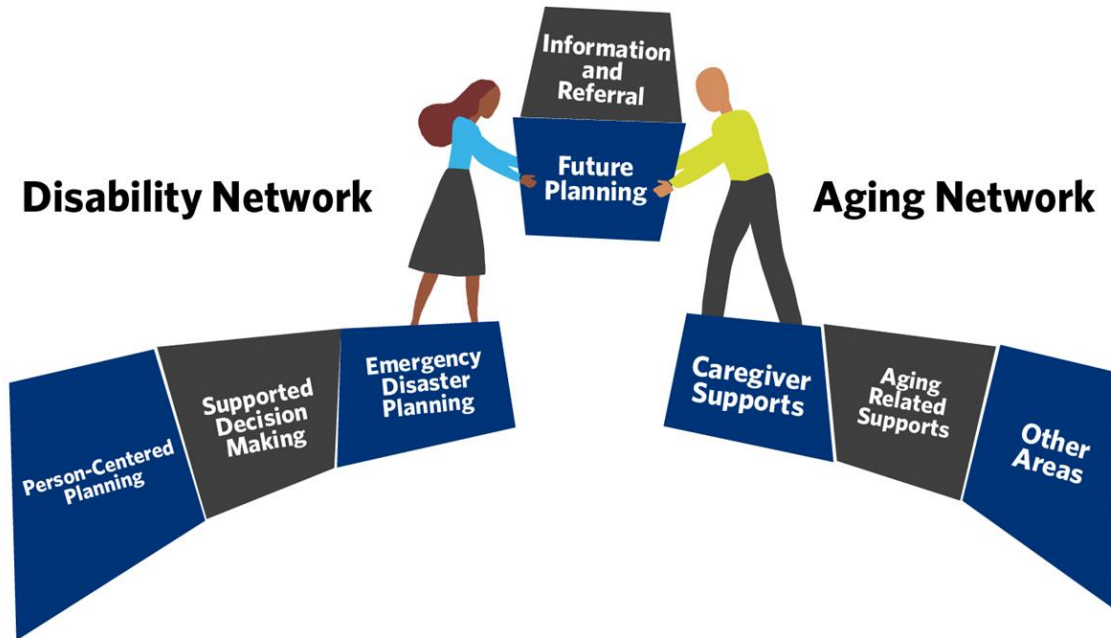


Opportunities to Bridge Aging and Disability Networks to Improve Supports for Aging Adults with IDD and Family Caregivers



Information and Referral	
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Inclusion of Disability in Connecticut Multisector Plan for Aging	Connecticut
Incentivizing Aging-Related Community Projects at Regional Centers	California
Silver Alert Program	Hawaii

INFORMATION AND REFERRAL

District of Columbia Modified Intake Form

Primary Practice:

Modification of aging system intake forms to identify aging caregivers and adults with IDD

Location:

District of Columbia

Description:

The District of Columbia modified its intake form for the Aging Systems entry by including questions that ask, “are you caring for someone else and are they an adult with disabilities?” If the answer to this question is ‘Yes,’ individuals are also automatically referred to the Developmental Disabilities System to ensure that the individuals with intellectual and developmental disabilities (IDD) also receive necessary services in addition to their caregivers. This promising practice is an example of a simple implementation that supports the bridging between aging and disabled populations. Modifying intake forms can result in more referrals across aging and disability service systems, where individuals often fall through cracks based on eligibility.

For More information:

<https://ddc.dc.gov/>

Hawaii Addition of Disability Information to ADRC Resources

Primary Practice:

Information and resources on disability services and supports

Location:

Hawaii

Description:

Aging and Disability Resource Centers (ADRCs) serve as single points of entry into the long-term services and supports (LTSS) system for older adults, people with disabilities, veterans, and family caregivers. Some states refer to ADRCs as “No Wrong Door” systems. ADRCs provide unbiased, reliable information, and counseling to individuals with all levels of income. Since 2003, support for ADRCs/No Wrong Door Systems has been provided through various opportunities funded by the Administration for Community Living (ACL), Administration on Aging (AoA), Centers for Medicare and Medicaid Services (CMS), and Veterans Health Administration (VHA). However, federal funding has not been consistent. States rely on state funding to support systems and functioning of ADRCs/No Wrong Door Systems varies from state to state. While aging and disability partnerships have improved, disability advocates in many states have expressed concerns that ADRCs do not serve the disability communities well, particularly the intellectual and developmental disabilities (IDD) population. Through the ACL funded Bridging Aging and Disabilities Community of Practice, the Hawaii DD Council developed a partnership with the Hawaii ADRC. They reviewed ADRC resources and found gaps in information and resources for individuals with IDD and their families. They worked together to develop and add a list of relevant resources such as agency providers, advocacy groups (i.e., Hawaii Disability Rights Center), and community supports. Additionally, the Hawaii ADRC worked to further expand its outreach by designing and distributing fridge magnets with a logo created by a self-advocate, which advertised “Kapuna and Disability Resources.” The fridge magnets were distributed at community events and fairs.

For More Information:

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

Kapuna Resource Fairs

Primary Practice:

Resource fairs on aging and disability services

Location:

Hawaii

Description:

Hawai'i has begun hosting "Kapuna" resource fairs across their state, bringing agency representatives from over 20 related offices directly to the local community. So far, there have been three gatherings held in the community of Lihue in Kauai, Kahului in Maui and both Kona and Hilo on Hawaii Island. Throughout each of these events, approximately 460 individuals came to speak with agency staff to obtain information relating to aging and disability services. Based on surveys across these events, 100% of participants found the information provided at the events helpful. This program is designed to be applicable to both urban and rural populations throughout the state to ensure equity in information dissemination geographically. Further, the partnerships developed with other agencies through this effort have now encouraged continued opportunities for collaboration. For example, the Hawaii State Council on Developmental Disabilities will be co-hosting another Aging and Disability event on May 6, 2026 in Kauai with Generations Magazine and the County of Kauai Agency on Elderly Affairs as well as tabling in an Aging in Place event on August 1, 2026, in Oahu with disability specific resources.

For More Information:

<https://www.kukuigrovecenter.com/events/kauai-disability-and-kupuna-resource-fair/>

Use of Tribal Liaisons to Improve Aging and Disability Information and Outreach

Primary Practice:

Tribal liaisons to improve aging and disability information and resources

Location:

North Dakota

Description:

North Dakota's Department of Health merged with their Department of Human Services, creating a new state department of Health and Human services (HHS). With this combination of offices, several new positions were created focused on community outreach to underserved populations. Tribal liaisons were established that represent each of the five recognized tribes in North Dakota. They have assisted in the development of culturally competent training modules, such as Diversity, Equity, Inclusion, and Accessibility (DEIA), to combat bias throughout agency staff as they serve a diverse population throughout their state.

Through the Bridging Aging and Disability CoP, North Dakota included these tribal liaisons within their State Alliance Team. The tribal liaisons have supported efforts to design plain language, culturally competent public documents to improve information and outreach to the 5 nations which have been historically underserved. North Dakota is also planning to develop a toolkit guided by simple yes/no questions to improve awareness of services available to aging and disability populations. This resource will be distributed broadly across aging and disabilities service systems.

For More Information:

North Dakota State Council on Developmental Disabilities, (Executive Director, Julie Horntvedt)

jhorntvedt@nd.gov

Aging and Disability Topical Roadmaps for Service Navigation

Primary Practice:

Roadmaps for service navigation

Location:

North Dakota

Description:

In an effort to assist individuals with disabilities, caregivers, and family members navigate the aging and disability systems, North Dakota has begun developing 15 different topical road maps. These topics are selected to encompass some of the major themes these communities face, and work to create a step-by-step process for which individuals and families can refer to when navigating the aging and disability networks to locate services.. Some of these topics include Transition Planning, Rural Transportation, Housing Vouchers, Employment support, and more. Further, in partnership with state Health and Human Services (HHS) tribal liaisons, language and cultural considerations were weaved into the development of the roadmaps to ensure that they are culturally competent and tailored to each tribe across the state that may use the resource. These roadmaps are being posted on the North Dakota State Council on Developmental Disabilities website so that they are easy to access for all.

For More Information:

<https://www.nd.gov/scdd/campaigns>

<https://www.nd.gov/scdd/sites/www/files/documents/Aging/6%20ND%20Medicaid%20Waiver%20Eligibility%20Roadmap%2009.19.25.pdf>

Training of ADRC Staff on Disability Rights and Culture

Primary Practice:

Disability training for ADRC staff

Location:

Iowa

Description:

The Iowa State Alliance Team (SAT) developed a training in partnership with their Area Agencies on Aging, Protection and Advocacy Agencies, and Aging and Disability Resource Centers (ADRCs). The first pilot training was held in person on May 19th, 2025 and focused on providing information on topics such as disability rights, history of discrimination and the disability advocacy movement, disability culture, and the importance of the ADA to improve aging services. The training was provided by staff from Disability Rights Iowa and individuals with lived experience to model the importance of accessibility and inclusion. The training has since been conducted three additional times to a total of 50 participants. The SAT is now developing a community of practice to expand to other potential training topics and encompass the various needs of the disability community as they strive to educate aging networks and staff throughout the state.

For More Information:

Contact Brooke Lovelace, Executive Director, Iowa Developmental Disabilities Council,
brooke.lovelace@hhs.iowa.gov

Training to Improve Accessibility of Digital Information and Resources Across Aging and Disability Systems

Primary Practice:

Training on accessibility of digital information, including use of plain language

Location:

Iowa

Description:

Easterseals Iowa, with support from the federally-funded State Assistive Technology (AT) Program at the Center for Disabilities and Development at University of Iowa, developed a free online training program called “Digital Access for All.” The online course consists of six modules that cover a wide range of topics to ensure that digital information that is provided is accessible and understandable to everyone.

Through the Bridging Aging and Disability CoP this work was expanded to include a module on “Clear Language.” The module provides guidelines and examples of developing content that uses plain language so it is understandable to as wide an audience as possible, including individuals with intellectual and developmental disabilities. The Clear Language module provides tips such as using shorter sentences and paragraphs, giving definitions of complex terms, avoiding use of jargon and abbreviations, and providing examples to help individuals understand. Through the State Alliance Team, this training course was shared with aging and disability agencies and networks to improve accessibility of digital information and resources.

For More Information:

The Iowa Department of Health and Human Services (Executive Officer, Julie Bergeson)

julie.bergeson@hhs.iowa.gov

<https://training.iowaat.org/courses/digital-access-for-everyone/>

Massachusetts Webinar Series on Aging with IDD

Primary Practice:

Webinar series focused on aging with IDD

Location:

Massachusetts

Description:

The Massachusetts Department of Developmental Services offers webinars focused on aging with IDD that were funded by the Massachusetts State Legislature. The intended audience for these webinars includes caregivers, families, direct service workers, residential managers, and case managers. Webinar training consists of several modules with person-centered planning topics including health, adapting to age-related changes in the home, dementia and IDD, and honoring cultural practices and individual preferences. Additionally, there are also separate resources regarding more legal-related topics such as life-sustaining treatment policy, guardianship, and Five Wishes. In addition, the Massachusetts Department of Developmental Services is conducting research and interviews as part of a needs assessment for aging caregivers and has an aging and caregiver workgroup to better support caregivers. These webinar resources and information (i.e., total general aging and dementia trainings, end-of-life trainings, etc.) are available to the public on their website.

For More information:

https://shriver.umassmed.edu/programs/cdder/aging_idd_education/general-aging/

<https://www.mass.gov/orgs/department-of-developmental-services>

New Jersey Aging and IDD Information and Resources

Primary Practice:

Information and resources related to aging with IDD

Location:

New Jersey

Description:

The Boggs Center is New Jersey's federally designated University Center for Excellence in Developmental Disabilities (UCEDD) and part of Rutgers' Robert Wood Johnson Medical School, Department of Pediatrics. The Center has emphasized a community-based, lifespan approach to meeting the needs of individuals with developmental disabilities and their families. Under the Training and Consultation tab, there are several resources regarding education, employment, and more, including the Aging Project in collaboration with the Division of Developmental Disabilities. This project focuses on both the experiences of aging people with (IDD) and those of their caregivers. The project seeks to provide professionals and families with information and resources to effectively support healthy aging, person-and family-centered health care decision-making, and considerations for end-of-life planning through in-person and virtual training.

For More information:

<https://boggscenter.rwjms.rutgers.edu/training-and-consultation/aging>

<https://boggscenterregistration.rwjms.rutgers.edu/index.php/event/training>

Pennsylvania's Prioritization of Urgency of Needs for Services (PUNS)

Primary Practice:

Prioritizing individuals with IDD living at home with aging caregivers for IDD services

Location:

Pennsylvania

Description:

The Pennsylvania Prioritization of Urgency of Needs for Services (PUNS) was developed to identify individuals and their particular service needs as they are waiting for access to services and supports from the state Intellectual and Developmental Disabilities Service System. The PUNS system organizes the need for services into three areas: 1) Emergency Need: the service need will occur within six months. 2) Critical Need: the service need is anticipated to occur after six months but within two years. 3) Planning for Need: the service need is anticipated to occur more than two years away but less than five years away. Data is collected on individuals residing at home with aging family caregivers (60 and over). The data from this system is then used in predicting the need of what supports are most needed and how to fund such requests, planning strategies, and service adaptations. The data from PUNS has been used to approach policy throughout Pennsylvania to center and meet the needs of individuals with aging caregivers' access to services and supports.

For More information:

<https://www.pa.gov/agencies/dhs/resources/intellectual-disabilities-autism/intellectual-disabilities-services/puns>

https://www.medicaid.gov/sites/default/files/2023-05/3.1_State_Agencies-508%5B22%5D.pdf

FUTURE PLANNING

The Future Is Now

Primary Practice:

Peer support, person-centered future planning intervention/training for individuals with IDD and aging family caregivers

Location:

National, International, multiple States

Description:

The Future is Now was developed by the University of Illinois at Chicago. The program is designed to assist aging family caregivers and adults with intellectual and developmental disabilities (IDD) to plan for the future when aging caregivers pass away or are no longer able to provide care. Workshops include family members as well as their relatives with IDD. These workshops consist of five 2.5-hour sessions, including breakout sessions for family members and individuals with IDD. Groups are co-facilitated by a professional and a peer mentors (family members who have done future planning and self-advocates with IDD). Sessions include: 1) Dreams for the future; 2) Expanding support networks; 3) Future living arrangements; 4) Work, education, and retirement; and 5) Safeguards to ensure their future plan will be implemented. Families also receive training in legal and financial aspects of planning. Families set individual planning goals and work towards achieving them. The *Future Is Now* was tested using a randomized pre-test and one-year post-test design. It contributed to outcomes of families taking concrete steps in planning, decreased caregiver burden, and increased involvement and choice-making of adults with IDD in future planning. It has been implemented in many states across the US and in other countries. The virtual version, The *Virtual Future Is Now (V-FIN)* is currently being adapted and pilot tested. The virtual version will allow more families who are unable to attend in-person groups or prefer virtual sessions to participate.

For More information:

<https://fsrtc.ahs.uic.edu/fsrtc-research/>

The Arc Center for Future Planning

Primary Practice:

Online resources and tools to support future planning

Location:

National

Description:

The Arc of the United States established the Center for Future Planning in 2014 to support and encourage adults with IDD and their families to plan for the future, particularly aging caregivers of adults with IDD. The Center provides reliable information and practical assistance to individuals with IDD, their family members and friends, professionals who support them, and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning. The Arc's Center for Future Planning hosts an interactive and user-friendly tool (*Build Your Plan*®) designed to assist families with building a plan for the future. The tool includes the following areas: 1) Expressing wishes for the future in writing; 2) Deciding where to live and how much support is needed; 3) Paying for basic and other needs; 4) Getting a job and other daily activities; 5) Making daily and major life decisions; and 6) Making friends and having good relationships. The plan is a living document that can be updated and shared with other family members. Alongside the *Build Your Plan* tool, there is a resource directory to find additional resources across various states. This directory includes an extensive video gallery providing overviews and example summaries from self-advocates with IDD of how they have approached their own future planning.

For More Information:

<https://futureplanning.thearc.org/>

Future Planning with Senior Centers

Primary Practice:

Future planning with outreach through senior centers

Location:

District of Columbia

Description:

As part of the Bridging Aging and Disability Community of Practice, the District of Columbia (DC) collaborated on a series of future planning trainings and events to reach diverse racial and ethnic communities. The DC Bridging Aging and Disability State Alliance Team is co-led by the DC Developmental Disabilities Council and the Department of Disability Services in collaboration with the Department of Aging Community Living. They have partnered with local senior centers in DC area to enhance training of senior center directors to improve their ability to adequately serve individuals aging with disabilities and their families. Building on this work, they organized a series of future planning events hosted at senior centers, offered in multiple languages, including English, Spanish, Mandarin, and ASL. They also culturally adapted the Arc's Future Planning Navigator curriculum to be specific to issues and diverse populations throughout the DC area. Navigators with multicultural and multilingual backgrounds are trained to support, guide, and reach diverse communities.

In addition to the partnership with senior centers, they also included a session on future planning at the 5th Latinx Conference on Disabilities, which is held entirely in Spanish. They offered a family planning session that discussed aspects of future planning to initiate family conversations and drafting of a letter of intent. With this community engagement practice in mind, they are looking to expand this work to offer similar sessions in multiple languages to reach other diverse populations of individuals with disabilities and their families in the DC area.

For More Information:

District of Columbia Developmental Disabilities Council (Alison Whyte, Executive Director),
alison.whyte@dc.gov

Person-Centered Approaches for Healthcare Decision Making

Primary Practice:

Training course on advance care planning and future planning

Location:

National, multiple states

Description:

The Person-Centered Approaches for Healthcare Decision Making is an 18-hour virtual course that teaches skills needed to facilitate advance care planning and future planning with people with IDD and other disabilities. Participants leave the training more informed on how to complete advanced care directives and support others with such future plans. This is a new training led by Leigh Ann Kingsbury, a consultant and gerontologist who has supported people with complex healthcare and disabilities for more than thirty years. She is the author of the American Association on Intellectual and Developmental Disabilities (AAIDD)'s *People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes*. The course is relatively new and has been run twice with participants from several states (California, Indiana, Minnesota, New Jersey, Virginia, Ohio, Maryland, Oklahoma, and South Carolina).

For More information:

<https://tlcpcp.com/md-profile/leigh-ann-kingsbury/>

Planning Forward

Primary Practice:

Information and resources related to aging and future planning with IDD

Location:

Missouri

Description:

Planning Forward is a project offered by the St. Louis, Missouri Arc focused on educating aging individuals and their families on future planning. In addition, Planning Forward is testing an enhanced training plan for improving the quality of care for aging individuals with IDD from their direct support caregivers. Planning Forward is an eight-week series designed to develop and provide peer group learning opportunities about future planning and provides consultation to interested families who have completed the group sessions. This project utilized resources such as Future Planning training through The Arc of the United States, LifeCourse Ambassador Training through the University of Missouri – Kansas City, and financial resource training through the National Disability Institute (NDI).

For More information:

<https://www.slarc.org/programs/family-support/support-groups/>

PERSON-CENTERED PLANNING

Extension of Charting the LifeCourse within Connecticut Aging System

Primary Practice:

Person-centered planning framework, training, and tools

Location:

National and multiple states, including Connecticut

Description:

Charting the LifeCourse is a framework that was developed by families to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. The University of Missouri at Kansas City hosts the LifeCourse Nexus training and technical assistance center. They offer many resources, tools, technical assistance and certified training based on the framework.

Charting the LifeCourse tools were primarily developed for use with individuals with intellectual a developmental disabilities (IDD) across the lifespan. Providers and states have used these tools to enhance person-centered planning and practices. Through the Bridging Aging and Disability community of practice, Connecticut expanded the use of Charting the LifeCourse tools more broadly for use in the aging network. Federal regulations require person-centered planning in all federally funded home and community-based (HCBS) programs. Connecticut already had widely embedded Charting the LifeCourse tools and certified training within its IDD service system. The aging system in Connecticut became more aware of this practice through the Bridging Aging and Disability Community of Practice. They were able to build on this existing infrastructure to enhance person-centered planning and practices. Individuals from the aging service system became trained Charting the LifeCourse Ambassadors and embedded tools and practices within the aging service system.

For More Information:

<https://www.lifecoursetools.com/>

Connecticut Developmental Disabilities Council (Walter Glomb, Executive Director),

Walter.Glomb@ct.gov

Addition of Aging and Future Planning Questions to Statewide Person-Centered Planning Guide

Primary Practice:

Addition of aging and future planning questions and prompts to statewide person-centered planning guide for service coordinators.

Location:

California

Description:

Person-centered planning is process through which the individual receiving services and supports develops a service plan that reflects and advances their personal goals, needs, preferences, and values. Rooted in the principles of empowerment, choice, and dignity, person-centered planning prioritizes the unique needs and preferences of each individual, ensuring their active participation in decision-making processes related to their care and support. Federal regulations require person-centered planning for individuals receiving Home and Community-Based Services.

The California Department of Developmental Services serves more than 400,000 individuals. California developed a new statewide, standardized Individual Program Plan (IPP) template and accompanying Service Coordinator guide. The IPP is a detailed document tailored to an individual's needs and preferences. It is designed to ensure that supports and services are aligned with what is most important to and most important for the person and their goals.

An IPP should:

- Showcase a person's strengths and preferences
- Be self-directed
- Include people the individual wants involved in the process
- Use easy to understand language and writing styles
- Keep culture and communication preferences in mind
- Respect an individual's comfort level with sharing details of their life

Starting in January 2025 all Service Coordinators from the 21 Regional Centers across California are required to use this person-centered template and guide. During development of the new statewide guide, the Bridging Aging and Disability Community of Practice state team worked together to add aging-related and future planning questions and prompts to the guide.

Examples include:

- The “Vision for the Future” section, includes the following prompt: “for those individuals whose caregivers are aging, what are the long-term plans to support those who may benefit from assistance in areas of daily living, community or lifestyle.”
- The “Decision-Making” section, includes several prompts to discuss a wide range of informed, supported, and substituted decision-making options as individuals move into and through adulthood.
- The “Life Choices: Home Life/Housing” section includes several prompts to discuss desired future living situations and supports, particularly for individuals living with aging caregivers.

For More Information:

[California's IPP Guide for Service Coordinators](#)

[California's Individual Program Planning](#)

Embedding Future Planning in Person-Centered Planning Process and Development of Individual Plans

Primary Practice:

Inclusion of key aspects of future planning in person-centered planning process and development of individual plans

Location:

Oklahoma

Description:

Person-centered planning is process through which the individual receiving services and supports develops a plan that reflects and advances their personal goals, needs, preferences, and values. Federal regulations require person-centered planning for individuals receiving Home and Community-Based Services. Oklahoma's Division of Developmental Services (DDS) is in the process of updating guidance for case managers developing Individual Plans, often referred to as an Individual Support Plan (ISP).

Through the Bridging Aging and Disability CoP, the Oklahoma State Alliance Team reviewed the proposed guide and developed suggested revisions to incorporate key areas of future planning for aging adults with IDD and their families during the person-centered planning process and development of the Individual Plan. They embedded key areas of future planning including residential living, financial literacy, and supported decision-making. The additions to this guide will ensure that conversations surrounding future planning are a pivotal theme throughout the process of designing services and supports for persons with disabilities, supported by state case managers. The updates to Oklahoma's Individual Plan have been submitted for review and aim to be applied in the next year.

For More Information:

Oklahoma Division of Developmental Disabilities Services (DDS) (Business Analyst II, Miranda Hutchinson)

Miranda.Hutchison@okdhs.org

SUPPORTED DECISION MAKING

My Life, My Decision: New Mexico

Primary Practice:

Supported decision-making

Location:

New Mexico

Description:

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. At these full day workshops, information is provided on topics such as Supported Decision Making, Power of Attorney, Future Planning, and navigating services, where once participants engage in materials they find relevant to their lives, they are then able to easily access relevant legal services to execute such strategies. These legal clinic resources include assistance with tools such as powers of attorney, advanced directives, and supported decision-making agreements. Spanish and ASL interpreters are provided at all events to enhance language access. Through the Bridging Aging and Disability Community of Practice, deeper relationships have formed with the aging network which also sees a shared need for these resources and assistance. The Aging and Long Term Services Department hosts an annual aging conference where the *My Life, My Decision* campaign was presented, fostering more collaboration. New Mexico also recently passed a bill to have all Medicaid services under one agency (Health Care Authority), coordinated at state leadership level, which will likely foster additional opportunities for bridging.

For More Information:

New Mexico Developmental Disabilities Council (Alice Liu McCoy, Executive Director),

aliceliu.mccoy@ddc.nm.gov

District of Columbia Disability Services Reform Act of 2018

Primary Practice:

Legislation protecting the decision-making rights of individuals with IDD

Location:

District of Columbia

Description:

The District of Columbia established legislation for Supported Decision Making (SDM) as an alternative to guardianship. When guardians or parents, who sometimes serve as legal guardians to adult children over age 18, are no longer able to provide care, adults with IDD are at risk of having a court-appointed guardian with no personal relationship or knowledge of the individual's needs or preferences. With the passage of the *District of Columbia Disability Services Reform Act*, individuals with disabilities identify supporters for key areas in their lives (e.g., health care decisions, purchases, moves), and include them in the decision-making process. Supporters help the individual gather information and assist them through the decision-making process.

For More information:

[https://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/DSRAA%20IDCRR
A%201-10-2018%20Plain%20Language%20Fact%20Sheet.pdf](https://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/DSRAA%20IDCRR%20Plain%20Language%20Fact%20Sheet.pdf)

<https://dds.dc.gov/page/dds-decision-making-rights-people-disabilities>

EMERGENCY AND DISASTER PLANNING

Bridging Aging and Disability in Hawaii Disaster Response

Primary Practice:

Aging and disability collaboration in disaster response

Location:

Hawaii

Description:

Through participation in the ACL Bridging Aging and Disability Community of Practice, Hawaii established a Hawaii State Alliance Team (SAT) comprised of eight different agencies to improve collaboration across aging and disability networks. This established a forum for regular communications that previously did not exist within the state. In August 2023, wildfires in Maui caused widespread damage and destruction. Often, when disasters strike, people with disabilities and older adults are more impacted and less accommodated in states' approaches to disaster relief. Hawaii was able to quickly leverage the SAT forum to coordinate disaster response across aging and disability systems. Within 48 hours of the Maui fires beginning, the Hawaii SAT had worked to identify the locations of every impacted individual with IDD supported by its agencies, and representatives traveled to the respective shelters to ensure that the needs and resources of the disability population were being met. Those with IDD who were not receiving supports were also identified and outreach was conducted.

For More Information:

<https://www.mauinuistrong.info/resource-categories/agingdisabilities>

CAREGIVER SUPPORTS

WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies)

Primary Practice:

Intervention/training for people with IDD to support aging family caregivers

Location:

Missouri

Description:

The Missouri Developmental Disabilities Council (MODDC) has a project with the Association on Aging with Developmental Disabilities (AADD) called WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies). As caregivers age, their needs also change. This can result in the family member with IDD taking on additional tasks to support their caregiver. These supports and tasks performed by family members with IDD often occur with little to no formal training or guidance. WE CARE is a project developed to support aging caregivers and their family members with IDD by teaching people with IDD the skills necessary to recognize and respond to their loved one's basic care and home safety needs. The long-term goal of this project is to increase the ability of both family members to support each other and prolong the mutual caregivers' abilities to age-in-place in the family home. The project is based on Bromley Mencap's Mutual Caring Project, which was implemented in the early-to-mid 2000's in the United Kingdom. This project is just in its second quarter and will end in April 2024.

For More Information:

Contact the Missouri DD Council: <https://moddcouncil.org/>

Michigan Older Caregivers of Emerging Adults with Autism and Other Neurodevelopmental Disabilities (MI-OCEAN) Family Support Project

Primary Practice:

Peer navigators to support aging caregivers

Location:

Michigan

Description:

Michigan Older Caregivers of Emerging Adults with Autism and Other Neurodevelopmental Disabilities (MI-OCEAN) Family Support Project is a statewide initiative piloted with aging family caregivers (55+ years) of 'emerging' adults (age 22 and older) with autism spectrum disorder and other neurodevelopmental disabilities across Michigan. MI-OCEAN uses a peer support model to match aging caregivers with Family Support Navigators (FSN) to improve health outcomes and quality of life. Thirteen peer family support navigators (FSN) were recruited from across Michigan and participated in a 2-day online training. One hundred and three aging caregivers from across the state were enrolled and paired with an FSN in their geographic area. 32 caregivers have completed the program and 81 additional people also participated in the program. Pre- and post-survey data was collected related to caregiver health and quality of life. The project was funded with a two-year grant from the Michigan Health Endowment Fund, and extended for an additional six months due to the Covid-19 pandemic. While successful, the MI-OCEAN project was unable to be continued as grant money ended and the program was not sustained through other funding streams. Lessons learned from the study have informed a new project with different funding sources that similarly will focus on aging caregivers, health disparities, and the intersectionality of race starting in January of 2024.

For More information:

<https://ddi.wayne.edu/fsnresources>

Sib2Sib Mentoring Program

Primary Practice:

Peer mentoring for siblings

Location:

National, across multiple states

Description:

The Sibling Leadership Network (SLN) serves as a network to support the siblings of individuals with IDD by providing tools and connections to social and structural supports across the lifespan, which enables them to be effective advocates with their brothers and sisters. The Sib2Sib Mentor Program is specifically for adult siblings of people with disabilities where adult siblings (18 and older) are matched with each other to share their experiences. This is important because siblings often have the longest relationships with their brother or sister with disabilities, yet they are often overlooked in receiving supports or training for this role. Sib2Sib mentors connect virtually through phone, email, and zoom for a 3-month period to provide peer support and connections. The SLN spent two years creating a Sib2Sib mentor matching model through collaboration with Parent2Parent USA and three of their state chapters. Recently, a small Sib2Sib mentoring program was piloted where 24 siblings were matched to create 12 Sib2Sib Mentor matches. A post-program survey was also distributed that was completed by 22 of the 24 mentors. The self-report of the mentors illustrated that adult siblings were most likely to discuss the topics of future planning, navigating family dynamics, and how to navigate the disability service system.

For More Information:

<https://siblingleadership.org/2021/12/23/sib2sib-adult-sibling-mentoring-program/>

Lifespan Respite Care Program

Primary Practice:

Respite systems that serve individuals across the lifespan

Location:

National, multiple States

Description:

The Lifespan Respite Care Program was authorized by Congress in 2006 and is implemented by the Administration for Community Living (ACL). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with disabilities and/or chronic conditions. They bridge aging and disability networks to remove silos and gaps in access to respite based on eligibility criteria often tied to funding streams. Such programs reduces inefficiencies and assist in the development of respite care infrastructures at the state and local levels. Lifespan Respite Care programs work to improve the delivery and quality of respite services available through the following objectives: 1) Expand and enhance respite services in the states; 2) Improve coordination and dissemination of respite services; 3) Streamline access to programs; 4) Fill gaps in service where necessary; and 5) Improve the overall quality of the respite services currently available. Since the program was first funded in 2009, thirty-nine states and the District of Columbia have received grants to establish or enhance Statewide Lifespan Respite systems. The ARCH National Network and Resource Center serves as the national Technical Assistance (TA) Center for the Lifespan Respite Program. The ARCH website provides details about current and previous grantees and state Lifespan Respite programs as well as many other resources related to respite and exemplary respite programs.

For More information:

<https://archrespite.org/ta-center-for-respite/>

AGING RELATED SUPPORTS

Training on Aging with Intellectual and Developmental Disabilities for the Aging Network

Primary Practice:

Training on aging with intellectual and developmental disabilities

Location:

Michigan

Description:

The Michigan State Alliance Team developed an online training module on aging with intellectual and developmental disabilities (IDD) for aging services professionals. The Michigan University Center for Excellence in Developmental Disabilities (UCEDD), Wayne State University, led development of the module. It is designed to equip professionals providing aging services and supports with knowledge and skills to better serve individuals with IDD. Participants learn about unique challenges and effective strategies and approaches to enhance supports for aging individuals with IDD. The training is organized into seven, hour-long topical sections, ranging from covering basic information of what IDD is to more complex issues such as building community partnerships. Upon working through the modules, participants are awarded either a certificate of completion or Continuing Education Credits towards maintaining their licensures, further incentivizing participation while contributing important knowledge of the bridging between aging and disability populations. The program has been implemented with over 100 participants thus far, and aims to reach and train 300+ staff throughout Michigan's Area Agencies on Aging and the larger service network across Michigan.

For More Information:

<https://ddi.wayne.edu/aging-with-idd>

Awareness to Action: Advancing Hospice and Palliative Care for Individuals with IDD

Primary Practice:

Information and training on hospice and palliative care for individuals with IDD

Location:

Kansas

Description:

In 2023, Kansas launched a statewide Intellectual & Developmental Disabilities (I/DD) Health Equity & Outcomes Coalition. The coalition convened self-advocates, families, and caregivers, as well as Kansas state agencies and departments, healthcare professionals, researchers and providers from across Kansas. The coalition selected hospice and palliative for people with IDD as a topic of focus because of stories from families and self-advocates, particularly a compelling story of Eddie and Kaye. After creating an advisory committee, they surveyed the community and hospice and palliative care providers. This highlighted that there was a lack of information for providers on how to support the unique needs of this community *and* for people with IDD themselves on how to utilize such services. The coalition explored various available trainings and selected a training by Dr. Jane Chargot (University of Michigan). This led to a webinar training that was attend by 344 individuals and was archived to share. In addition, they developed plain language materials for self-advocates and families. These help explain the differences between hospice and palliate care and how to find providers.

For More Information:

https://mosds.org/wp-content/uploads/2025/06/awareness_to_action_advancing_hospice_palliativ.pdf
<https://kcdd.squarespace.com/hospice-and-palliative-care-webinar>

Training Video for Senior Center Staff on Inclusion of Individuals with IDD

Primary Practice:

Training video for senior center staff

Location:

New York

Description:

The New York State Alliance team developed a training video for senior center staff, instructors, and volunteers to learn about how to best support people with IDD when they visit their centers and utilize their services and programs. The state team chose this topic based on stories from self-advocates about negative experiences they had experienced in the past when accessing senior centers. The training video is approximately 10-12 minutes. It includes basic information about IDD and features segments of interviews with self-advocates and their families sharing their lived experiences interspersed throughout. It provides concrete recommendations to ensure that centers are welcoming and inclusive of individuals with IDD. The video training is now being piloted with senior centers in New York and the University of Illinois at Chicago is assisting with evaluating the impact of the training.

For More Information:

<https://youtu.be/-FD4EI7Im-s?si=Mcp7Pr5aohn80Z2Y>

Dementia Friends for Intellectual and Developmental Disabilities

Primary Practice:

Resources and training on Dementia

Location:

Ohio and national

Description:

Originating from the United Kingdom's Alzheimer's Society, Dementia Friends USA Initiative is an American organization striving to educate people about dementia. People can view a series of online videos or attend live sessions to learn about the experiences of people with dementia. They can also turn this understanding into action by becoming a Dementia Friend. Dementia Friends for Intellectual and Developmental Disabilities (IDD) was adapted from Dementia Friends, with support from three Ohio-based grants from the Administration for Community Living (ACL) and the US Department of Health and Human Services. The goal of this program is to improve the quality of life for people with IDD who are living with dementia and their caregivers. Dementia Friends for Intellectual and Developmental Disabilities provides educational materials on dementia risk factors, signs, and symptoms, as well as engagement tips and community resources. Dementia Friends for Individuals with Intellectual and Developmental Disabilities strives recognize and support both aging caregivers and people with IDD living with dementia. These efforts have been shared beyond Ohio, with other states looking to expand programs.

For More Information:

<https://dementiafriendsusa.org/>

National Task Group on Intellectual Disabilities and Dementia Practices

Primary Practice:

National resource and training on intellectual disabilities and dementia

Location:

National with training provided at local and state levels

Description:

The National Task Group on Intellectual Disabilities and Dementia (NTG) was organized in late 2010 when several national organizations and university centers came together to improve policies and practices for individuals with intellectual disabilities and dementia. In 2011, the National Alzheimer's Project Act (NAPA) directed the federal government to develop the first national strategy on addressing Alzheimer's disease and related dementias in the United States. The NTG's early efforts were focused on ensuring the needs of individuals with intellectual disabilities and their families were included in the national strategy. Since that time, the NTG has expanded its scope, while also becoming a non-profit organization. The mission was expanded to become the "go-to" resource for information on dementia and intellectual disabilities. The NTG has developed numerous reports and technical resources, including a dementia screening instrument for individuals with intellectual disabilities. They have also helped bridge partnerships between IDD providers and aging and dementia organizations. The NTG developed an evidence-based training called "Dementia Capable Care of Adults with Intellectual Disabilities and Dementia." This training is offered via a two-day "foundations" workshop as well as a one-day "Introduction to Dementia and Intellectual Disabilities" workshop for agencies that need staff certification as dementia-capable. This training has been implemented at various local provider and state levels across the country. Through the Bridging Aging and Disability Community of Practice, Hawaii offered this training. 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.

For More Information:

<https://www.the-ntg.org>

Skills2Care -Intellectual Disabilities (ID)

Primary Practice:

Intervention to support family members and caregivers of individuals with dementia and intellectual disabilities

Location:

Multiple States

Description:

Skills2Care is an evidence-based intervention designed to support family members and caregivers of individuals with dementia to equip themselves with skills and information that enable them to modify living spaces and provide the best care and support they can. This intervention involves five 90-minute home visits by an occupational therapist who observes the living space and caregivers. These professionals provide education and strategies on how to provide the best care and cope with challenges in providing such care to their loved ones with dementia. Early analyses of the original Skills2Care program data revealed that family caregivers of people with ID and dementia had different needs that the program did not capture. As a result, the adapted Skills2Care ID program was developed to directly address the needs of caregivers of adults with both intellectual disability *and* dementia. Skills2Care ID program was launched in 2018, and has trained seven occupational therapy students and one clinician, in addition to developing a training for occupational therapists certified in Skills2Care to expand their services to the ID population. This program has been delivered in three states (PA, NY, and CT) in shared living and day program settings.

For More Information:

<https://www.jefferson.edu/academics/colleges-schools-institutes/rehabilitation-sciences/jefferson-elder-care/professional-training.html>

OTHER AREAS

Hawaii Direct Support Professional Internship Program

Primary Practice:

Internship program for high school students to become direct support professionals

Location:

Hawaii

Description:

The Hawaii State Council on Developmental Disabilities (DD Council) developed an internship program for high school and college students to gain experience being a direct support professional. The project is in response to the critical shortage of direct support professionals and need to improve recruitment and retention of workers. Initially, the pilot project targeted high schools students. In partnership with The Arc of Maui, Ka Lima O Maui, and Easterseals Waimea on Kaua'i, students have been provided opportunities to work with people with IDD in adult day health centers. Students undergo training in preparation for 20-60 hours of work, where they will receive additional hands-on experience, training, and a stipend. The project has now been expanded to college students in partnership with Center on Disability Studies at UH Mānoa and Lanakila Pacific. Through the Bridging Aging and Disability Community of Practice, Hawaii is also expanded training sites to include adult day and senior centers within the aging network.

For More information:

<https://www.hiddcouncil.org/internshipopportunities>

Forum for Bridging Aging and Disability in Connecticut

Primary Practice:

Forum for bridging aging and disability

Location:

Connecticut

Description:

As part of the Bridging Aging and Disability Community of Practice, Connecticut established a regular forum for aging and disability organizations to come together, share information, learn from each other, and identify organic opportunities for bridging and collaboration. The Connecticut Developmental Disabilities Council organized a kickoff event in 2022 that was widely attended by over 50 leaders and stakeholders from aging and disability networks across the state. While specific priorities were difficult to identify from this meeting, the experience highlighted the significant “siloeing” of information that was present across these various agencies and organizations.

In order to remedy this, Connecticut established a regular forum with bi-weekly meetings (this formed the basis of their State Alliance Team for the Community of Practice). Originally, there were 7 organizations attending the meetings, but over 2 years, this number has grown to where there are currently 40+ participants from about 24 groups that regularly attend meetings.

Participants include representatives from the Governor's Office of Policy and Management, State Unit on Aging, Department of Developmental Services, Arc Connecticut, AARP

Connecticut, State Independent Living Council, Commission on Women Children Seniors, Area Agencies on Aging (AgingCT), Keeping the Promise (Mental Health Coalition), and many more.

Meeting agendas are organized around discussion topics and intended to create a safe space to share information, ask questions, and learn from each other. Examples of topics have included briefings on initiatives within state departments and agencies, person-centered planning and future planning, aging and disability events within the state, municipal assets (e.g. senior centers), and diversity, equity and inclusion. Participants have expressed that this forum provides invaluable learning about what others are doing has improved their ability to better

serve older adults and individuals with disabilities who are aging. The forum has also led to identification of natural opportunities for collaboration and bridging.

For More Information:

Connecticut Developmental Disabilities Council (Walter Glomb, Executive Director),

Walter.Glomb@ct.gov

Inclusion of Disability in Connecticut Multisector Plan for Aging

Primary Practice:

Multisector plan for aging

Location:

Multiple states, including Connecticut

Description:

Across the country many states are developing what are known as “Multisector Plans for Aging.” A Multisector Plan for Aging is a multi-year planning process that convenes stakeholders across different sectors to develop a plan to meet the needs of older adults and a rapidly growing aging population. Stakeholders include local and state governments, providers, advocacy organizations, philanthropy, business sector, and other private entities. Plans are typically long-range and are designed to promote such goals as health aging, independent living, and social engagement, while also addressing issues related to healthcare, housing, transportation, and other social determinants of health.

At least 22 states have developed or are in the process of developing Multisector Plans on Aging. States use a variety of names for these plans (e.g., master plans, strategic plans, and aging-well plans) but all have the same broad goals. Some initiatives have developed as a result of legislation within states. As states consider Multisector Plans on Aging, it is important that they include the disability community to ensure policies and initiatives are not siloed and also address the needs of individuals aging with disabilities.

Connecticut is in the process of developing a Multisector Plan on Aging. Through the Bridging Aging and Disability Community of Practice, the Connecticut Developmental Disabilities Council and State Alliance Team came together 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. The Connecticut DD Council is a funder and partner in the Connecticut Age Well Collaborative which is leading this multisector plan initiative.

For More Information:

<https://multisectorplanforaging.org>

<https://ctagewellcollaborative.org/multisector-planning/>

Incentivizing Aging-Related Community Projects at Regional Centers

Primary Practice:

Incentivizing age-related community projects.

Location:

California

Description:

The California Department of Developmental Services (DDS) serves more than 400,000 individuals with intellectual and developmental disabilities. Services are coordinated and delivered through a network of 21 Regional Centers across the state. To help ensure individuals with intellectual and developmental disabilities live in the least restrictive setting, appropriate to their needs, DDS designed the Community Placement Plan (CPP) and Community Resource Development Plan (CRDP) for regional centers to enhance the capacity of the community service delivery system and to reduce the reliance on the use of developmental center and other restrictive living environments.

The CPP and CRDP provide funding to the regional centers for the development of a variety of resources, including, but not limited, to residential development, transportation, day services, and mental health and crisis services, within individuals' communities.

DDS sets priorities for the CPP and CRPD projects to incentivize Regional Centers to focus on areas of need. Through the Bridging Aging and Disability Community of Practice, the California state team worked with DDS to set priorities for Fiscal Year 2024-25 that include a focus on meeting individual and community needs of aging individuals with intellectual and developmental disabilities.

For More Information:

[California's Community Placement and Resource Developmental Plan](#)

Aging and Disability Collaboration on Silver Alert Program

Primary Practice:

Silver Alert system

Location:

Hawaii

Description:

Hawaii Governor Josh Green signed into law SB 2305 to establish a new Silver Alert program in July 2024. Much like the AMBER Alert system used to locate abducted children, Silver Alert systems are already used in half of the states in America to help locate older adults (referred to as kapuna in Hawaii) who may wander off and go missing due to cognitive decline related to Alzheimer's Disease and other dementias. These alerts have proven themselves to be extremely effective when activated.

In addition to protecting kupuna, the passage of SB 2305 marks a significant step in supporting individuals with intellectual and developmental disabilities (I/DD), who are also at risk of wandering or becoming disoriented. The Hawaii State Council on Developmental Disabilities advocated for inclusion of individuals with I/DD in the protections of the Silver Alert system. Much like the kupuna, individuals with I/DD face challenges that may lead to wandering and require prompt community action and law enforcement intervention. The inclusion of I/DD in Silver Alert legislation ensures that all vulnerable populations in Hawaii are afforded the protection they need when they go missing.

The Hawaii Developmental Disabilities Council via the Bridging Aging and Disability Community of Practice worked in partnership with the Alzheimer's Association Aloha Chapter and other partners and supporting legislators to achieve this success. This emerging practice in Hawaii underscores the critical role that advocacy, collaboration with key stakeholders, and legislative action play in shaping policies that protect the most vulnerable members of society.

For More Information:

Hawaii State Developmental Disabilities Council (Executive Administrator, Daintry Bartoldus,

Daintry.Bartoldus@doh.hawaii.gov)

<https://www.papaolokahi.org/blog/silver-alert-protects-kupuna>