

State Spotlights: Supporting Adults with Intellectual and Developmental Disabilities and Their Aging Caregivers

The Centers for Medicare & Medicaid Services (CMS) offers this resource for state Medicaid and partner agencies seeking to address the needs of adults with intellectual and developmental disabilities (I/DD) and their aging caregivers with the aim of improving access to high-quality home and community-based services (HCBS) for people eligible for Medicaid. This resource synthesizes information on innovative state strategies and programs designed to strengthen supports for adults with I/DD and their aging caregivers, who often provide substantial supports in addition to those provided through HCBS programs. Strategies discussed in this resource include building interagency partnerships and relationships, engagement and navigation supports, person- and family-centered systems of support, and planning for the future.¹

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Background

Nearly one million households in the United States include an adult with I/DD living with and supported by an aging caregiver.¹ Most family members providing this support are parents (87 percent).² Adults with I/DD often rely on caregivers throughout their lives for support meeting basic needs and navigating service systems. Given that many adults with I/DD continue to experience barriers to living independently in the community, caregivers play a key role in facilitating inclusion in the community and relationships with friends and family. Nationally, nearly one in five caregivers (19 percent) are 65 years or older, and two in five caregivers (40 percent) provide support to a member of their own household, which may include a child, spouse, parent, or other household member.³ Caregivers who are aging experience a range of circumstances, and some may be able to safely remain in their own homes as they age with additional supports and care systems. Other caregivers may no longer be able to provide support at home due to changes in their own health status, hospitalization, illness or ill health, transition to a nursing facility, or death.

Adults with I/DD and their aging caregivers may be known to, and receive services from, their state Medicaid agency; other families may not currently receive services but may need services in the future. Of the estimated 7.43 million people with I/DD in the United States in 2018, only 21 percent, or 1.54 million, were known to or served by state I/DD agencies.⁴ People with I/DD not currently served by state I/DD agencies may first interact with state systems when they are in crisis (e.g., after a parent's sudden death or decline in health) and, as a result of their urgent circumstances, may end up with less desirable and/or more costly services.⁵ The number of people

¹ These four areas of focus were identified through a CMS-sponsored summit, webinar, and learning collaborative on this topic held in 2021 – 2022 and refined through the input of a technical expert workgroup comprised of federal, state, and national association representatives.

with I/DD living at home with aging caregivers is expected to increase. Nationally, long-term services and supports (LTSS) are trending away from institutional services towards HCBS. Consistent with many beneficiaries' preferences in where they would like to receive their care, HCBS have become a critical component of the Medicaid program, and adults with I/DD are living longer. Additionally, associated increases are expected in the demand for publicly funded services, which include services funded by state or federal funds, primarily Medicaid state plan and HCBS waiver programs.⁶

State Medicaid and partner agencies can better support adults with I/DD who have aging caregivers by proactively planning in the present and for the future, when new supports are needed, and, when possible, before a crisis happens. (A companion brief, *Person-Centered Planning Across the Lifespan* highlights state strategies.) To provide such supports across the lifespan, state Medicaid and partner agencies can collaborate to identify and implement innovative and effective strategies. The examples described in this resource spotlight states supporting adults with I/DD and aging caregivers in ways that assist individuals during important life transitions and across their lifespans.

Key Areas of State Focus for Supporting Adults with I/DD and Their Aging Caregivers

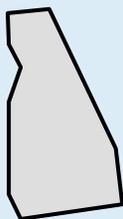


Interagency Partnerships and Relationships

Partnerships between state Medicaid agencies and key state agencies, including state I/DD, aging, and mental health agencies, ensure coordinated access to HCBS for individuals with I/DD and their families. Strong cross-agency partnerships create opportunities to better support individuals with I/DD and their families and caregivers, including the capacity to identify aging caregivers early, engage families ahead of transitions, and increase the coordination of services provided by multiple agencies for a single family. Examples of strategies states can use to develop and strengthen interagency partnerships and relationships include aligning divisions and agencies to facilitate collaboration and establishing a shared culture and understanding of goals across agencies.

Align divisions and agencies to facilitate collaboration

While states vary in their organizational strategies across divisions and agencies, many states have found opportunities to realign their systems to promote integrated efforts across agencies (e.g., shared initiatives, common goals) and facilitate delivery of streamlined, person- and family-centered services and supports.



State Spotlight: New Hampshire

New Hampshire’s approach to supporting adults with I/DD and their families includes all life stages and the entire [Department of Health and Human Services](#), including developmental services, aging services, and Medicaid.

New Hampshire strengthens their long-standing interagency partnerships through their work as part of the Community of Practice for Supporting Families program. An example of this joint focus is the adoption of a set of core principles and standards for person-centered planning expectations using the [Charting the LifeCourse](#) framework. This common approach to person-centered planning strengthens the holistic network of support for an individual, building on services provided by Medicaid providers and aging caregivers. The Bureaus of Developmental Services, Elderly and Adult Services, and Family-Centered Services, all within the Division of Long-Term Supports and Services, are leveraging the Charting the LifeCourse framework to collaborate on supports for individuals and families across the lifespan.

Establish a shared culture and understanding of goals across agencies

State Medicaid and partner agencies are encouraged to collaborate through regular strategy or planning sessions and consider additional ways to improve collaboration. For example, state Medicaid and partner agencies can establish a memorandum of understanding (MOU) to clearly describe how they are going to engage with each other to achieve shared goals. MOUs can also clarify any key differences in terminology. State agencies and the people who receive services and supports may use different terms and definitions to describe operations, services, and the people receiving those services and supports. For example, a state Medicaid agency may refer to those enrolled as “members,” a developmental disabilities agency may use the term “people with developmental disabilities” or “consumers,” and a vocational rehabilitation agency may say “clients.” An MOU with a common set of definitions can assist in clearly identifying populations, better coordinating services, and assisting information technology (IT) experts in identifying available data sets for quality improvement, coordination, and oversight efforts.

To further coordination, state Medicaid and partner agencies may also implement data use agreements (DUA), which describe the goals of the data exchange partnership; the privacy, technical, and operational issues to be addressed; and the agencies’ responsibilities related to data use, transfer, disclosure, and storage. DUAs may facilitate joint efforts to identify target populations, predict future service needs, analyze outcomes data, and collaborate on quality improvement activities.

Resources on Interagency Partnerships and Relationships

- [Medicaid Innovation Accelerator Program \(IAP\): State Medicaid-Housing Agency Partnerships Toolkits](#), CMS (2019): This toolkit is designed to assist states in considering systems-level changes to further community integration, particularly in the intersection between health care and housing. It provides a list of common housing partners and best practices for establishing housing partnerships.
- [Data Privacy, Data Use, and Data Use Agreements](#), CMS (2017): This brief summarizes challenges commonly encountered by states taking part in the Medicaid IAP Improving Care for Medicaid Beneficiaries with Complex Care Needs and High Costs program area and provides resources these states have found useful when developing DUAs.



Engagement and Navigation Supports

Navigating the HCBS system, including the various processes for determining eligibility and person-centered service planning, can be an intimidating and complex task, especially if such navigation occurs during or directly after a crisis or other major change in family or caregiver status. Anticipating or avoiding crisis situations enables states to predict demand for and costs of services and supports and helps individuals, families, and caregivers to plan proactively for services that align with their preferences. States can ensure services meet the needs and preferences of a diverse range of Medicaid beneficiaries, in part, by engaging individuals with I/DD and their families in design, implementation, and evaluation of programs and services.⁷ Engaging families and caregivers in system design and improvements and leveraging No Wrong Door (NWD) Systems are strategies states can use to improve engagement and navigation supports.

Engage families in system design and improvements

Many states gather feedback from individuals, families, and caregivers to inform system improvements through focus groups, surveys, advisory councils, and other strategies. Gathering feedback helps to ensure services and supports are responsive to the needs and preferences, including linguistic and cultural needs and preferences, of people receiving services and supports.

State Spotlight: Hawaii



The Hawaii Department of Health, Developmental Disabilities Division operates Hawaii’s section 1915(c) HCBS waiver program for people with I/DD. The Division has endeavored to strategically transform the systems of services and supports for people with I/DD and their caregivers by incorporating Charting the LifeCourse, design thinking, self-advocate and family partnerships, and culturally responsive and competent approaches. The division has facilitated a shift in the power balance between state case managers and families to a more person- and family-centered culture. To further support this change, Hawaii has an effort underway to conduct trainings for case managers focused on perspectives and dimensions of various cultures to help case managers better understand the preferences and needs of all individuals. Additionally, the Division has set the expectation that self-advocates and families must have input into the design and evaluation of programs by including parents and self-advocates in workgroups and in policy, planning, quality management, and program development. To ensure consistency and accountability, the Division meets with work group participants throughout the year to listen and collect feedback and follow up on their concerns and priorities. Additionally, Hawaii is using funding made available through section 9817 of the American Rescue Plan Act of 2021 to evaluate its systems and to design peer-to-peer mentoring services in partnership with families and the community.

Leverage NWD Systems

[NWD Systems](#) promote a coordinated system of access to make it easier for individuals and families to learn about and access LTSS. NWD Systems create more person-driven, efficient, and cost-effective LTSS systems across all populations and all payers. States seeking to improve supports for adults with I/DD and their caregivers can leverage lessons learned from NWD Systems.⁸ In a recent assessment of state NWD Systems, states with strong collaboration among their state aging, disability, and Medicaid agencies received higher performance scores than peers who lacked such collaboration. Specific actions for states to consider include leveraging Medicaid administrative claiming to support NWD System functions and [Preadmission Screening and Resident Review](#) activities. States may also explore strategies to streamline access for individuals seeking LTSS, such as developing protocols to ensure consistent access regardless of where they enter the LTSS system and designating NWD Systems to conduct initial screenings for Medicaid eligibility.⁹



State Spotlight: Wisconsin

Wisconsin's Department of Health Services, the state Medicaid agency, works directly with their Aging and Disability Resource Centers (ADRC) to provide unbiased information to help adults with I/DD and their aging caregivers connect with services. ADRCs connect adults with I/DD and their caregivers to appropriate services and supports, including the [Disability Benefit Specialist Program](#), the [Elder Benefit Specialists Program](#), and the [National Family Caregiver Support Program](#). The Disability Benefit Program is offered to individuals with disabilities ages 18 to 59 and the Elder Benefits Specialists Program is offered to adults 60 years and older in every county in Wisconsin. Disability and elder benefit specialists help answer questions and solve problems related to Social Security, Medicare, health insurance, and other public and private benefits for people with disabilities. Additionally, ADRCs provide long-term care options counseling, which includes helping individuals prepare Medicaid applications, facilitating one-on-one consultations to help individuals think through their service options, and providing tools to help choose the right managed care plan based on needs and preferences.

Resources on Engagement and Navigation Supports

- [Engaging People Who Receive Services: A Best Practice Guide](#), **National Center on Advancing Person-Centered Practices and Systems (NCAPPS) (2020)**: This guide is designed to inform state, tribal, and territory systems on best practices for including people who receive services in system planning and improvement efforts.
- [Key Elements of a NWD System of Access to LTSS for All Populations and Payers](#), **Administration for Community Living (ACL) (2017)**: The elements compiled in this report provide states with a framework for developing a robust NWD System. These elements emphasize state leadership in developing and implementing a NWD System accessible to all populations and payers.
- [NWD System and Medicaid Administrative Claiming Reimbursement Guidance](#), **CMS (2017)**: This document provides guidance to states on methods for claiming federal matching funds for Medicaid administrative activities performed through NWD Systems.



Person- and Family-Centered Systems of Support

Access to services and supports that are person- and family-centered are particularly important during periods of transition for adults with I/DD and their caregivers that occur across the lifespan. Person-centered planning is foundational to identifying the appropriate mix of paid and unpaid services to meet an individual's goals and states have found it helpful to embed person- and family-centered practices into various processes including assessments, planning, service authorization, and budgeting. Examples of strategies states are using to develop person- and family-centered systems of support include establishing processes for engaging families and caregivers early and supporting individuals, families, and caregivers within their communities.

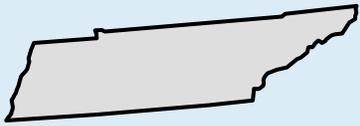
Establish processes for engaging with families and caregivers early

Some state Medicaid and partner agencies have found that early engagement with individuals, families, and caregivers, including those not yet receiving services, enhances the state's ability to assist in meeting current and future needs for the individual, family, and in systems planning. By beginning engagement earlier, states can better understand who may need services in the future and connect individuals, families, and caregivers to services and supports as their needs evolve over time. Early engagement may also help extend the time an aging caregiver can remain safely in their home, which can in turn support continuity and stability for an adult with I/DD living with their aging caregiver. For individuals receiving services, engagement may take place in the context of the person-centered planning process, which is directed by the individual receiving services and based on their choices and preferences. To conduct outreach to individuals not yet receiving services, states may consider partnerships with local community organizations with which families and caregivers may already have existing relationships.

Support individuals, families, and caregivers within their communities

The person-centered planning process often results in individual goals that are beyond the scope of program-specific services and supports available under Medicaid. The planning process should promote innovative and non-traditional methods of meeting goals,¹⁰ including engagement with family members and other natural supports. States may leverage Medicaid HCBS waiver program services and supports, such as employment supports, peer-to-peer supports, and community engagement services (e.g., services that foster the development of social networks to complement formal supports) to achieve individual goals. States may also choose to help facilitate services and supports outside of the Medicaid service delivery system. For example, states can utilize programs authorized by the [Developmental Disabilities Assistance and Bill of Rights Act of 2000 \(Public Law 106-402\)](#) to engage with families and caregivers, conduct outreach, and increase awareness of supports available to remain in the community. These programs include:

- Developmental Disabilities Councils;
- State Protection and Advocacy Systems;
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD); and
- Projects of National Significance.



State Spotlight: Tennessee

Tennessee is transitioning to a single, seamless, person-centered system of service delivery for people with I/DD. The person-centered system will support individuals with I/DD to pursue their goals, increase their independence and ability to fully participate in their communities, and achieve their competitive, integrated employment goals. The initial steps of their system transformation work include aligning administrative functions, such as claims and billing through managed care, aligning critical incident management systems, building a culture that promotes dignity of choice, and implementing a value-based reimbursement approach.

In addition, Tennessee's [Employment and Community First CHOICES](#) program, part of their section 1115 demonstration, includes a decision-making supports service that provides adults with I/DD and their families assistance in understanding the options to protect their rights and freedom, while providing the support they need to make decisions. The program helps families and self-advocates build knowledge, skills, and connections within the community through family-to-family support, peer-to-peer support, navigation for person-centered planning, providing alternatives to conservatorship, and family counseling.

Resources on Person- and Family-Centered Systems of Support

- [NCAPPS](#): NCAPPS is a joint initiative of ACL and CMS to assist states, tribal nations, and territories in implementing person-centered thinking, planning, and practice that aligns with U.S. Department of Health and Human Services policy. NCAPPS provides technical assistance, learning collaboratives, webinars, and other resources to states, tribal nations, and territories.
- [National Center for Cultural Competence](#): This Center provides training, technical assistance, consultation, research, tools, and resources to support health and mental health care providers and systems with the goal of promoting and sustaining cultural and linguistic competency.
- [ACL Diversity and Cultural Competency Resources](#): This webpage from ACL provides useful resources on cultural competency with the aim of reducing health disparities and improving access to health care that is responsive to individuals' unique needs.
- [Sibling Support Project](#): This national program assists siblings of people who require special health, developmental, and mental health supports. The project provides books and publications, online communities, workshops and trainings, and peer support groups.
- [Sibling Leadership Network](#): The Sibling Leadership Network aims to provide siblings of individuals with disabilities with the information, support, and tools necessary to advocate for their siblings. The Sibling Leadership Network also collaborates with the Sibling Support Project to host [SibNet](#), an online community for adult siblings of individuals with disabilities.



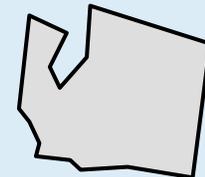
Planning for the Future

While not all transitions can be planned for in advance, anticipating major life and financial changes, such as retirement and changes in eligibility for Medicare or Social Security Disability Insurance, may help inform future planning with families. States that support individuals and families in planning for the future can better align services and supports over time with individual preferences and needs, help individuals to remain in the community even as needs change, and better predict state service utilization and budgets. Strategies states can use to improve planning for future supports include designing flexible service options to meet changing needs and, as an alternative to guardianship, incorporating a focus on choice and supported decision making (SDM) into planning for individuals, families, and caregivers.

Design flexible service options to meet changing needs

States have flexibility to choose which HCBS to offer and to set policies that increase the impact of HCBS to support people with I/DD. Many states have leveraged this flexibility to design multiple waiver programs with a range of services. With a range of options, states can offer services and supports that best meet the needs of each person, rather than adhering to a “one size fits all” approach. States can also support individuals as their needs change over time with the services that match their needs.

State Spotlight: Washington



The Washington State Developmental Disabilities Administration and the Washington State Health Care Authority, the state Medicaid agency, work together to support individuals with I/DD and their families across the lifespan. Flexible services through five different section 1915(c) HCBS waiver programs, a section 1915(k) Community First Choice state plan option, and a robust state plan allow the state to engage individuals across the lifespan and be responsive to evolving support needs. Across section 1915(c) waiver program services, the most frequently used are respite and supported employment, and the newest services offered in the state include specialized habilitation and complementary therapies. Washington State’s Department of Social and Health Services also collaborates with the Washington State Developmental Disabilities Council to reach and support families through [Informing Families](#), a resource that offers trusted news and information to individuals and families that empowers them to be active participants in planning and building a network of support. Additionally, Washington acknowledges the importance of consulting with advocacy networks and engaging community partners before making policy changes. Washington’s commitment to continuously working closely with community advocacy organizations like [Self-Advocates of Leadership](#), [People First of Washington](#), [The Arc](#), and the [Washington State Developmental Disabilities Council](#) to hear directly from those with lived experience has proven to be invaluable in designing a person-centered service system that meets participants’ needs.

As an alternative to guardianship, incorporate a focus on choice SDM into planning for individuals and families

SDM is an alternative to guardianship, which allows individuals with disabilities to make their own decisions with support from a team of trusted people of their choosing. In recognition of SDM as a growing and important construct, ACL launched the National Resource Center for Supported Decision Making in 2014,¹¹ and a number of states have since adopted legislation to advance SDM.¹² Strong person- and family-centered planning processes can leverage and increase community support in a person's life outside of the formal service system. Planning for the future at different life stages can be complex, and there are now some states that have adopted legislation for implementing SDM as an alternative to guardianship. SDM can be a valuable process for adults with I/DD to expand their circles of support beyond aging caregivers to include siblings, friends, and other supporters.



Spotlight: District of Columbia

The District of Columbia passed the [Disability Services Reform Amendment Act of 2018 \(DSRAA\)](#), which established legislation for 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 I/DD are at risk of having a court-appointed guardian with no personal relationship or knowledge of the individual's needs or preferences. With DSRAA, 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.

Resources on Planning for the Future

- [National Resource Center for Supported Decision Making](#): This resource center provides resources, contact information, and technical assistance regarding SDM, particularly for older adults and people with disabilities.
- [Supported Decision-Making, Charting the LifeCourse Nexus](#): Charting the LifeCourse has compiled materials to help a person, family, or professional to better understand decision-making supports, plan for SDM, and find necessary supports.
- [Project of National Significance for Bridging the Aging and Disabilities Networks, ACL \(2021\)](#): Bridging the Aging and Disabilities Networks aims to build capacity across and within state aging and disability networks. Through a community of practice, the program focuses on creating culturally competent systems to support individuals with I/DD and their families to address their individual needs, goals, and preferences across the lifespan.
- [Decision-Making Supports, The Arc \(2020\)](#): This resource provides an overview of supports that people with I/DD may use to make decisions about their daily life and life trajectory.
- [Focus on Aging, Charting the LifeCourse Nexus \(2018\)](#): This resource aims to help individuals and families think about the common experiences, concerns, and questions they may have as they age, defined as 65 years old through end of life. The resource includes planning for current situations as well as for the future.
- [Future Care Planning: A Roadmap for Family Caregivers \(Workbook\), Sonoran UCEDD \(2010\)](#): This resource is designed to provide guidance to family caregivers regarding care planning and is a resource for other family members and service providers to use to provide support throughout the planning process.

Additional Resources

Data Resources

- [**In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2018**](#), University of Minnesota, Research, and Training Center on Community Living, Institute on Community Integration (2021): This report analyzes trends from two annual surveys conducted on state I/DD agencies and state-operated I/DD facilities serving more than 16 individuals. Topics touched on in the report include service settings, LTSS expenditures, and general trends in LTSS.
- [**National Core Indicators \(NCI\) Data Brief: What Do NCI Data Tell Us About the Characteristics and Outcomes of Older Adults with I/DD?**](#), Human Services Research Institute & National Association of State Directors of Developmental Disabilities (NASDDDS) (2020): This brief examines the trends and demographics of older adults with I/DD and the outcomes of their transition into their later years. The brief also makes suggestions for public managers, providers, and stakeholders on how best to use the information compiled to plan for and support older adults with I/DD as they transition into older adulthood.
- [**Family and Individual Needs for Disability Supports \(FINDS\) Community Report 2017**](#), The Arc (2017): This report summarizes the findings from the FINDS survey conducted by The Arc in 2010 and updated in 2017. The purpose of the survey was to understand the experiences of families who provide supports to a family member with I/DD.

General Resources, Strategies, and Best Practices

- [**RAISE Family Caregiving Advisory Council**](#): The RAISE Family Caregiving Advisory Council was established to provide recommendations on family caregiving and support to family caregivers and is charged with improving coordination across federal government programs. Led by ACL, the council includes members from across federal agencies, including CMS.
- [**National Community of Practice for Supporting Families Resources**](#), NASDDDS & University of Missouri-Kansas City Institute for Human Development: The National Community of Practice for Supporting Families Across the Life-Span aims to enhance and drive policy, practice, and system transformation to support people with I/DD within the context of their families and communities. This webpage shares tools, templates, information, and resources on how to better support families across the lifespan.
- [**Medicaid Supports for Family Caregivers**](#), The National Academy for State Health Policy (2020): This report examines strategies that state Medicaid agencies use to provide training, services, or payments to family caregivers and four interrelated actions the federal government can take to promote these innovative strategies.

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