

How State Agencies Can Anticipate and Meet the Needs of Adults with Intellectual and Developmental Disabilities and Their Aging Caregivers

Overview

About this Brief

This brief is part of a collection of resources based on state Medicaid and partner agencies' successful approaches for enhancing supports for adults with intellectual and developmental disabilities (I/DD) and their aging caregivers.

Trends:

- In 2018, there were an estimated 7.43 million people with I/DD in the U.S. Only 21 percent (1.54 million) of people with I/DD were known to, or received services through, state I/DD agencies, with an overwhelming majority of these individuals receiving Medicaid-funded long-term services and supports.¹

-An estimated one million households in the U.S. include an adult with I/DD living with and supported by an aging caregiver, and this number is growing.¹

-The number of people with I/DD receiving Medicaid home and community-based services and living with family increased by 143 percent between 1998 and 2018.¹

Sixty-one percent – nearly 800,000 – of all adults receiving home and community-based services (HCBS) through their state intellectual and developmental disabilities (I/DD) agency live at home with family.¹ In addition to those receiving supports from state I/DD agencies, many individuals may be on a waiting list for services or have no contact with the formal service delivery system at all. Regardless of whether individuals with I/DD receive Medicaid-funded supports, family members and others in their support system play important roles in helping them live independent, self-determined lives.

State Medicaid agencies and their partners can benefit from holistic approaches to planning that consider the current and future needs of all individuals with I/DD and their caregivers. State agencies may need additional data to fully understand how caregivers support adults with I/DD receiving Medicaid-funded HCBS, the characteristics (e.g., age, health status) of those caregivers, and the current and future needs of adults with I/DD not receiving services from or known to state agencies.

Considerations

States generally recognize the importance of providing timely access to services for individuals needing support as a means to avert crisis. It can be helpful for state systems to identify patterns and trends that enable the development of support and prevention strategies and services for those who are known to or supported by the system. The [Administration for Community Living](#) (ACL) is leading the [I/DD Counts](#) initiative to establish and maintain accurate data on the prevalence of I/DD in the U.S. and improve the collection, analysis, and interpretation of health-related data of people with I/DD. This initiative responds to variability in data collection across and within states

and a nationwide lack of demographic data for people with I/DD, which can lead to health disparities and gaps in needed services.²

State systems can develop a clearer picture of current and future service system demands by capturing data related to age, level of support needs, comorbidities, unique considerations of under-represented communities, and preferences of individuals with I/DD. These data become even more useful when triangulated with data related to individuals' support systems, including age and health status of caregivers.

High-Quality Data Enable States to:

- drive system performance and gain operational insights;
- forecast future service delivery demands and future service needs;
- identify data gaps or underserved populations;
- enable accurate resource requests to anticipate changes, customize services, and address social and health disparities;
- intercede early to avert or delay crises and improve strategies for assuring health and welfare; and
- anticipate life transitions and offer early support to minimize individual and family disruption.

State Medicaid agencies' partnerships with sister agencies for aging, mental health, and I/DD are important to effectively support individuals as well as their caregivers. In alignment with the U.S. Department of Health and Human Services' [Roadmap for Behavioral Health Integration](#), ACL supports state agencies in implementing strategies to better serve people with I/DD and co-occurring mental health disabilities, including a new center to improve supports for people with I/DD and mental health conditions. Data can provide insights into the partnerships that will be necessary at the state level to effectively prepare to support individuals in the future. For example, one estimate suggests that roughly 35 percent of people with intellectual disabilities also experience mental

health conditions, though the exact prevalence is unknown. Individuals with I/DD who have co-occurring conditions require tailored supports for both the individual and their aging caregiver.³

National Family Caregiver Strategy

In September 2022, the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren published four National Family Caregiver Strategy documents, including the [2022 National Strategy to Support Family Caregivers: Federal Actions](#), which describes over 300 actions that 15 federal agencies will take over the coming three years. As federal agencies continue their implementation of their initiatives to support family caregivers, additional opportunities for coordination and cooperation across agencies may also be identified. This document is complemented by the [2022 National Strategy to Support Family Caregivers: Actions for States, Communities, and Others](#) document, which describes more than 150 actions other entities can take. States may also reference the [First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) document, which includes workforce considerations and equity and person- and family-centered approaches. The strategy is expected to evolve based on public input and in response to the caregiving landscape.

Stakeholders, including individuals with I/DD, their caregivers, and providers of I/DD services, are critical in terms of gathering valuable insights that supplement data on demographics and service needs. Stakeholder engagement provides an opportunity for individuals, their families and caregivers, and partners in the community to contribute ongoing and meaningful input and can highlight areas of need and areas requiring improvement in the service delivery system. In particular, CMS strongly encourages states to intentionally seek input from under-represented communities as part of efforts to promote health equity.

Strategies

States use varied strategies to anticipate and meet the needs of adults with I/DD and their aging caregivers, including data analysis, waiver program management, design of sets of programs and services, partnerships with community-based organizations, and ongoing stakeholder engagement. States are also using the resources made available through section 9817 of the American Rescue Plan Act of 2021, which provides states with additional federal funding for HCBS. States must use these resources to enhance, expand, and strengthen HCBS, and many are using the funds to further invest in No Wrong Door (NWD) Systems,⁴ data systems and quality strategies to improve overall HCBS system visibility, and the direct care workforce.

These strategies can help states understand current and future service system needs.



State Spotlight

Wisconsin

Wisconsin plans to use section 9817 funding to strengthen their NWD System, including through increased outreach and marketing of [Aging and Disability Resource Centers](#) and a one-year Independent Living Support pilot offering intermittent and one-time services and supports for qualifying individuals. As part of the pilot, they will contract for the development of an evaluation to gain a better understanding of the needs of the pre-Medicaid population and those who provide care for them in the community. A separate initiative will also launch a NWD System for children with special needs. Wisconsin's plan is available [here](#).

Data Analysis, Data Forecasting, and Data Sharing

States may use forecasting data to develop service offerings or expectations within their HCBS programs. As individuals with I/DD age, some life transitions are predictable. As states design HCBS programs, these transitions can be important indicators of services or activities that may be needed. For example, a common example is the transition from school-based support to the adult service system for youth with I/DD as they transition to adulthood. A potentially lesser-known example is that many individuals with I/DD may be considered a Disabled Adult Child (DAC) under Social Security rules.¹ As a DAC, a person may begin receiving a portion of their parent's Social Security benefits if the parent is deceased or begins receiving retirement benefits. This transition also shifts individuals from being eligible for Medicaid-only to dually eligible for Medicare and Medicaid, potentially changing how the individual receives health care. This transition is important to anticipate so that planning can begin early, and transitions can be as seamless as possible. States may consider incorporating data on transitions into their forecasting of future needs.

State Medicaid agencies' efforts to anticipate needs for individuals with I/DD and their caregivers may benefit from interagency communication and collaboration. For example, state partners can jointly review available data sets across state agencies to inform planning. Another best practice that has proven successful in many states is that state Medicaid agencies, state I/DD agencies, and state aging agencies collaborate to identify respective data sets that could be shared across systems. These tools can be used to inform targeted and broad-based improvement activities to improve outreach, particularly with underserved or marginalized communities.

¹ An adult who has a disability that began before age 22 may be eligible for benefits if their parent (or in some cases, stepparent, grandparent, or stepgrandparent) is deceased or starts receiving retirement or disability benefits. More information is available from the Social Security Administration here: <https://www.ssa.gov/benefits/disability/qualify.html#anchor7>.

Many states are also improving data sharing across federal and state data sets. Most state Medicaid agencies are now receiving Medicare data to improve coordination of services and quality improvement activities. Given that many adults with I/DD are also eligible for Medicare, these data are important to share with partner agencies. Strong collaboration across state Medicaid agencies, state I/DD agencies, state aging agencies, and federal partners (including the Social Security Administration) where possible, helps optimize visibility and planning.

Collaboration may include data sharing agreements to capture individual and family needs across systems. Data sharing may also help identify data gaps in demographics for adults with I/DD and

their caregivers, including the age of caregivers, race, ethnicity, and preferred language. State agencies can jointly review the information to devise cross-system solutions to improve data gaps and design system improvements. States are increasingly refining data strategies to enhance quality improvement opportunities and to measure outcomes data for individuals with I/DD and their aging caregivers. While formative, as states make data capability enhancements, some are using predictive analytics to anticipate supports and interventions and to avert crises.

Quality Improvement: HCBS Measures

In July 2022, CMS released a [State Medicaid Director Letter](#) providing information on the first official version of a nationally standardized quality measures set for Medicaid-funded HCBS. The HCBS Quality Measure Set aims to promote consistent use of nationally standardized measures in HCBS programs, create opportunities for CMS and states to compare data across programs, and drive improvement in quality of care and outcomes for people receiving HCBS, including people with I/DD living with aging caregivers. CMS encourages states to stratify their data to assess disparities across demographics, including race and ethnicity, sex, age, rural/urban, disability, and language as part of efforts to improve equity of services. The measure set aims to support states with improving the quality and outcomes of HCBS and can play an important role in states' efforts to promote equity in their HCBS programs, including for adults with I/DD with aging caregivers.⁵



State Spotlight

Pennsylvania

Pennsylvania uses the Prioritization of Urgency of Need for Services (PUNS) as its key tool for identifying individuals awaiting services. The PUNS identifies the types of services and supports an individual is currently receiving and what services are needed. The PUNS indicates the urgency of need for services through one of three categories:

- Emergency Need: The service need will occur within six months.
- Critical Need: The service need is anticipated to occur after six months but within two years.
- Planning for Need: The service need is anticipated to occur more than two years away but less than five years away.

The Commonwealth uses PUNS data in forecasting need to inform budget requests, planning strategies, and service adaptations. The data has informed statewide policy around transitions and prioritization of individuals with aging caregivers for services. Pennsylvania also includes an array of supports for families in its HCBS programs and is increasingly using data to ascertain differences in experiences among individuals and families who are receiving supports.

Waiver Program Management Strategies

States can design and manage waiver programs to effectively support individuals with I/DD with aging caregivers, including through strategies for managing waiting lists and reserving capacity.

Data and Management Strategies

States vary in the way they manage enrollment for waiver programs. Increasingly, states are gaining the capacity to aggregate waiting or interest list data to forecast future service delivery needs for the system as a whole. In addition to data on caregivers' age, some states are considering other data elements, such as data on key social determinants of health and caregiver health status. States using a priority-based approach frequently incorporate data related to living situations and age and health status of caregivers when determining priority status. Many states prioritize individuals with aging caregivers in the highest priority category or categories and deploy case management or other system partners to build relationships and begin planning early.

Reserved Capacity

A tool many states utilize, including those operating multiple waiver programs along a continuum, is reserved capacity. Reserving capacity allows a state to reserve a portion of a waiver program's capacity for specified purposes, meaning that some waiver program openings ("slots") are set aside for persons who will be admitted to the waiver program on a priority basis for the purpose(s) identified by the state. States frequently reserve capacity for individuals with aging caregivers or caregivers with increased needs. States can use data to drive decisions around the capacity needed to support individuals with aging caregivers.



State Spotlight

Tennessee

Tennessee prioritizes enrollment into their [Employment and Community First CHOICES program](#) for people with I/DD with older caregivers, pursuant to their Aging Caregiver's Law. This law provides prioritization for individuals who have an intellectual disability if their parents or other unpaid caregivers providing most of their support are age 75 or older or for individuals who have a developmental disability if their parents or other unpaid caregivers providing most of their support are age 80 or older.

Sets of Programs and Services

Some HCBS programs include supports to help understand the potential changes to health care and other benefits that may occur as individuals and their caregivers age. States can provide necessary education and information for an adult with I/DD and their caregiver(s) to anticipate such life changes and plan accordingly. States may consider strategies to help individuals prepare for major life changes, in the hopes of ensuring a strong plan for a person and their caregiver(s) as different supports and services are needed. These strategies are best developed by the state Medicaid agency and their state partners in the I/DD and aging agencies to ensure a collaborative approach to supporting families.

Person-centered counseling for individuals on waiting lists through the state NWD System can serve as a way to support individuals who are waiting for Medicaid services as well as to connect individuals to private and informal supports. State NWD Systems can also support individuals and families with transitions between care settings, such as hospital, home, and nursing facility, using

evidence-based models. Additionally, NWD Systems can capture data on unmet needs. Robust NWD Systems can also offer a way to build collaborative partnerships and ensure a comprehensive and coordinated approach to planning for the future.

Other services that states can leverage to support individuals and their aging caregivers include:

- respite, provided in an array of settings to best meet family needs;
- training and counseling for unpaid caregivers; and
- assistive technology and specialized devices (to increase or maintain independence at home).

Case managers also serve important roles in helping to identify necessary supports that may enable an individual to continue to live successfully with their caregiver(s).

In designing services offered through waiver programs and demonstrations, states may structure a set of programs and services that anticipate life transitions, allowing for changes in supports as individuals and their caregivers age. For example, Maryland, Washington, and Pennsylvania all have a continuum of section 1915(c) waiver programs to meet the needs of individuals with I/DD at the most appropriate level to support them in the context of their families. Tennessee offers an [array of services](#) through a section 1115 demonstration that includes targeted and essential supports to enable an individual to live successfully with family, including services titled Family to Family Support and Family Caregiver Stipend in lieu of Supportive Home Care. By offering flexible services to adapt to changing needs, states can support individuals with I/DD to live in their preferred settings.

Partnerships with Community-based Organizations

In addition to strengthening relationships among key state agencies, state Medicaid and operating agencies often partner with local communities and community-based organizations. These “on-the-ground” relationships can ensure a comprehensive understanding of caregiver status and cultural and linguistic considerations for outreach and prevention and can be important in building trust with individuals and their caregivers. Community partnerships can also assist states seeking to capture data related to social determinants of health and to identify potential areas of need for individuals with aging caregivers. States investigating the impacts of social determinants of health on outcomes may benefit from input, advice, and partnerships with community-based organizations to inform data strategies. CMS’ issuance of a [January 2021 State Health Official Letter](#) related to social determinants of health has spurred much state activity and creativity in this area, which can be leveraged to improve supports for individuals living with aging caregivers.



Spotlight: No Wrong Door Systems

Since 2003, CMS, ACL, and the Veterans Administration have worked together to outline a vision for NWD Systems. NWD Systems serve as coordinated access systems that serve older adults, individuals with disabilities, and their caregivers. Though each state varies in the level of progress towards the NWD vision, NWD Systems were among the top five areas with the most improvement overall in the AARP’s 2020 Long-Term Services and Supports (LTSS) Scorecard.⁶ NWD Systems bring together state Medicaid agencies, as well as state aging and disability agencies, to create systems of access to LTSS. States looking to meet current and future needs of individuals with I/DD and their aging caregivers may focus on their NWD System capacity. The [NWD Key Elements](#) document outlines the NWD System vision.



State Spotlight

Missouri

Missouri has leveraged ACL COVID-19 response funding to continue to grow their NWD System, including having the University Center for Excellence in Developmental Disabilities Education, Research, and Service host a quarterly NWD stakeholder meeting. The quarterly meeting provides an opportunity for state and local aging and disability agencies and organizations, such as Area Agencies on Aging, Centers for Independent Living, and the Missouri Department of Health and Senior Services, to discuss barriers, challenges, successes, new information, and innovations. In addition, stakeholders listen to individuals currently receiving services and provide training and technical assistance to people and systems working to enhance the community integration, inclusion, independence, and productivity of adults with disabilities.

Ongoing and Continuous Direct Engagement with Individuals with I/DD and Their Caregivers

Meaningful, continuous communication with individuals with I/DD and their caregivers is foundational to delivering effective supports and services over time. Family needs are not static, and direct ongoing communication with individuals and their caregivers can help states to anticipate future needs and demands for services consistent with the needs and preferences of individuals. Evidence-based, culturally competent caregiver assessments can inform a family-centered plan of care and ensure caregivers receive needed services to better meet the needs of the people they are supporting. States can support the adoption of caregiver assessments, integration into existing processes, and effective messaging on the purpose of assessments. Data from caregiver assessments can also be aggregated and analyzed to inform policy makers on needed programs and services and create a more effective system of supports.⁷

Additional Resources

- [2017 Profile of Older Americans](#), ACL Administration on Aging
- [Support to Caregivers](#), ACL
- [30 Years of Community Living for Individuals with Intellectual and/or Developmental Disabilities](#), ACL
- [Department of Health and Human Services Roadmap for Behavioral Health Integration](#)
- [Waiting Lists and Medicaid Home and Community Based Services](#), National Association of State Directors of Developmental Disabilities Services
- [Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2018](#)
- [Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences](#), Health Management Associates on behalf of the Medicaid and CHIP Payment and Access Commission
- [Housing and Services Resource Center](#), ACL
- [NWD Key Elements](#), ACL
- [Family Caregiver Services and Supports Roadmap](#), National Academy for State Health Policy



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- ⁷ The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren. (2022). *2022 National Strategy to Support Family Caregivers*. Retrieved from https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf.

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State Policies and Practices to Support Aging Caregivers of Adults with Intellectual and Developmental Disabilities

Overview

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Trends:

- In 2018, there were an estimated 7.43 million people with I/DD in the U.S. Only 21 percent (1.54 million) of people with I/DD were known to, or received services through, state I/DD agencies, with an overwhelming majority of these individuals receiving Medicaid-funded long-term services and supports.¹

-An estimated one million households in the U.S. include an adult with I/DD living with and supported by an aging caregiver, and this number is growing.¹

-The number of people with I/DD receiving Medicaid home and community-based services and living with family increased by 43 percent between 1998 and 2018.¹

The Centers for Medicare & Medicaid Services (CMS) recognizes the significant role family caregivers play in supporting adults with intellectual and developmental disabilities (I/DD) to remain in their homes. State Medicaid agencies and their partner agencies that support people with I/DD and their aging caregivers can lead the planning for expanding home and community-based services (HCBS), improving infrastructure, and advancing new initiatives that contribute to the quality of community life for individuals currently enrolled in home and community-based services (HCBS) and those not yet involved in support programs.

Most adults with I/DD who are known to or served by their state I/DD agencies are eligible for Medicaid and Medicare. Some portion of those individuals will also have caregivers who are or will become eligible for Medicaid and Medicare and may benefit from specific caregiver supports based on the need of the waiver program participant (e.g., respite care). As a result, states are increasingly recognizing the need to 1) conduct strategic and ongoing planning to expand and strengthen HCBS for adults with I/DD and 2) consider the HCBS needs of both adults with I/DD and their aging caregivers. Planning takes the collective

efforts of state Medicaid agencies, state I/DD agencies, state aging agencies, and other partners along with the ongoing involvement of people with I/DD and their caregivers. This paper offers state strategies to enhance supports for aging caregivers of adults with I/DD.

Considerations

Most individuals with I/DD prefer to remain at home and in their communities rather than moving into facilities. Family caregivers play an essential role in meeting these preferences² through helping to offset the cost of services and delaying the need for more costly services.³ In 2017, the estimated economic value of family caregiving was \$470 billion, based on about 41 million caregivers providing an average of 16 hours of care per week.²

The value of family caregivers extends far beyond economic value. Family caregivers often facilitate active community participation for adults with I/DD through shared cultural background and community affiliation, as well as knowledge of the individual's preferences and communication styles. Similarly, remaining in familiar communities can provide stability for aging caregivers to ease planning for life transitions. A growing body of research shows increased well-being and quality of life for caregivers and their family members when caregivers receive assistance appropriate to their needs. Assistance may include technology, mental health interventions,⁴ training,⁵ self-care and rest,⁶ and financial resources.^{7,8} Aging caregivers may benefit from support to navigate their own changing needs, as well as strategies to assist them in supporting their family member.

ACL Family Caregiving Initiatives

The Administration for Community Living (ACL) offers several key federal initiatives and programs to support family caregivers. States may reference the ACL initiatives below and associated resources to enhance their knowledge of the resources available, learn from other state strategies, and strengthen their practices across state Medicaid agencies and their partners.

- The 2018 Recognize, Assist, Include, Support, and Engage (RAISE) Caregiver Act: The RAISE Caregiver Act set the federal government, in partnership with stakeholder including family caregivers, on a path to creating a national family caregiving strategy. Concurrently, the 2018 Supporting Grandparents Raising Grandchildren Act addresses the need for better support, information, and services to assist kinship families and grandfamilies. ACL supports the implementation of both Acts and facilitates advisory councils established by each Act. Jointly, the advisory councils engaged in significant expert deliberation, surveys, and public input, including contributions from federal agencies such as CMS, and submitted reports to Congress in the fall of 2021. Recommendations include, but are not limited to, an assessment of Medicaid and family caregiving. The groups then collaborated to draft the [national strategy](#).
- [The National Family Caregiver Support Program \(NFCSP\)](#): NFCSP grantees provide information to caregivers about available services, assistance to access services, individual counseling, organization of support groups, caregiver training, respite care, and supplemental services on a limited basis.
- [Lifespan Respite Care Program](#): Lifespan Respite Care programs work to improve the delivery and quality of available respite services, expand and enhance state respite services, improve coordination and dissemination, streamline access, fill in gaps, and improve quality of respite services.
- [Bridging the Aging and Disabilities Networks](#): Bridging the Aging and Disabilities Networks, a Project of National Significance, is developing a community of practice (CoP) designed to build capacity across and within states' aging and disability networks. The CoP will focus on creating culturally competent systems to support individuals with I/DD and their families to improve planning to address their individual needs, goals, and preferences across the lifespan.

Many states are using the resources made available through section [9817](#) of the American Rescue Plan Act of 2021, which provides states with increased funding for HCBS, to support caregivers. States must use the resources provided through section 9817 to enhance, expand, or strengthen

HCBS, and thirty states included efforts to support caregivers within their section 9817 spending plans.⁹ Many of these states are utilizing funds to offer additional supports to individuals and their caregivers, including new service offerings or, in some instances, payment for their supports. Several states have incorporated strategies to gather information on caregiver needs through the development and testing of caregiver assessment strategies.

Strategies

States use a range of strategies to support aging caregivers of adults with I/DD, from outreach, early identification, and assessment, to navigation support, resources, and services.



State Spotlight

Delaware

The Delaware Division of Developmental Services (DDDS) uses new strategies to strengthen their advanced care planning and better address the preferences and needs of adults with I/DD, even if the needs or capacity of their caregiver(s) change. For example, DDDS began capturing the birth date of caregivers during the intake process to better track and plan for aging caregiver supports before a crisis. DDDS also undertook an effort to identify individuals receiving services and supports through DDDS and being cared for by an aging caregiver. This process required multiple steps:

- DDDS used predictive modeling to identify individuals in the targeted population. Their analysis included the following data: 1) the age of the individual receiving services; 2) enrollment status in the DDDS' Lifespan Waiver, one of Delaware's section 1915(c) waiver programs; and 3) an individual's residential needs.
- DDDS then surveyed individuals identified through predictive modeling. Delaware partnered with their Community Navigators, who provide targeted case management for the individuals with I/DD and their families throughout Delaware, to conduct the survey. The survey consisted of a standard set of questions, capturing information on who lives with the individual with I/DD, such as their age and relationship, and if any advance care planning involving next-of-kin decisions were made. Individuals also responded to questions on their future residential needs and if any legal documents (e.g., Durable Power of Attorney, Health Care Power of Attorney, legal guardianship, supported decision making documents¹) vital to future planning had been completed. The Community Navigators and DDDS obtained a 94 percent response rate for the surveys.
- The survey provided DDDS with important data and information for future resource utilization. For example, DDDS is convening focus groups to learn what supports will be most critical for families that do not plan to access available residential supports. DDDS plans to continue to use the survey data to inform their approaches to better support individuals with I/DD and their caregivers directly and for system level planning.

Assessment, Early Identification, and Planning

Engaging caregivers early in care planning can provide a more in-depth and holistic picture when planning with an individual with I/DD who lives with an aging caregiver. Incorporating

¹ Supported decision making 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. A number of states have adopted legislation to advance supported decision making after ACL launched the [National Resource Center for Supported Decision Making](#) in 2014. Supported decision making 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.

discussions with caregivers into the person-centered planning process assists in ongoing planning. Examples of topics for early planning conversations related to life stages and transitions include:

- what might be needed when an aging caregiver retires;
- when a family caregiver can no longer drive and provide transportation to appointments and activities; and
- ways to stay connected to friends and relatives.

Incorporating discussion guides with optional questions into planning processes and tools has proven successful for many states. In addition, identifying health and well-being concerns of caregivers is an important part of their comprehensive assessment process.

The ability to capture demographic data about family caregivers (e.g., age, living situation, primary language) can be invaluable both for individual planning and for long-term state strategic planning for supporting adults with I/DD and aging caregivers. State Medicaid agencies may consider the data available currently through service planning as well as additional information that could be collected by partnering with other state agencies and community stakeholders. For example, state Medicaid agencies can better anticipate future service needs using data on non-Medicaid-funded caregiver services such as those offered through the NFCSP or data from local school districts on the number of students with disabilities who are graduating. As states improve their cross-system interoperability of data, they may be able to discern patterns enabling earlier outreach (e.g., communications between adult protective services and Medicaid). Data that help states identify aging caregivers and their potential future needs may be particularly useful.

Navigation Support and Resources

Navigating available services and supports can be complex for aging family caregivers, particularly when families are in crisis or need services quickly. Information may be plentiful but difficult to sort through for specific interests and needs. States can connect aging caregivers to resources, link peers together to learn from each other, provide tailored information, and assist with navigation to specific entities, including through the following strategies:

- **Strengthening No Wrong Door (NWD) Systems:** NWD System entities can strengthen partnerships across aging and disability networks, assist families with navigation, and increase outreach efforts. NWD Systems are powerful networks of state agencies and aging and disability community-based organizations that work together to create seamless access to HCBS and ensure families have access to complete and accurate information, including federal (e.g., Older Americans Act¹⁰), state, and private sources of support.
- **Leveraging community organizations for financial planning support:** Most states have community advocacy or resource partners that provide financial planning essentials, such as information about special needs trusts and Achieving a Better Life Experience (ABLE) accounts.¹¹ Providers, family groups, independent living centers, and other community groups are often willing to put together workshops and collaborate with state agencies to develop plain language resources on these topics.
- **Facilitating peer-to-peer and family-to-family supports:** State agencies, in collaboration with community partners, can assist aging caregivers with finding family-to-family peer connections. Such peer-to-peer supports may increase families' networks and provide help understanding and navigating service options. States may elect to offer peer-to-peer

services through Medicaid authorities. States must demonstrate that any Medicaid service is for the benefit of the individuals served. Many states have also found that greater caregiver skills and knowledge enhance caregivers' ability to support individuals effectively in their homes and communities.

- **Disseminating resource materials:** States can collaborate with community groups to distribute outreach materials at community centers, senior centers, spiritual communities, and recreation centers. Targeted materials for different ages and stages, in multiple languages, and that are topic-specific (e.g., transportation, respite) may be useful.



State Spotlight

Missouri

The Missouri Division of Developmental Disabilities (DDD) is focusing on aging caregivers through an existing stakeholder group focused on supporting families across the lifespan. DDD plans to use learnings from different state resources such as the [Missouri Association on Aging with Developmental Disabilities](#), which hosts an annual conference, to gather information and inform the state's implementation plan for strategies to support aging caregivers. The recent conference serves as a springboard for the state's Aging and Developmental Disabilities Convening, which will bring together representatives from Medicaid, aging, and developmental disability services, as well as family groups, self-advocates, NWD, social services, and providers. The Convening is designed to strengthen relationships, identify gaps, and determine opportunities to implement best practices to improve the lives of individuals with developmental disabilities and their aging caregivers.

Caregiver Outreach and Training

Some states have found it beneficial to conduct early outreach to and identification of caregivers for planning and support, including for family caregivers of specific populations. Many existing support groups for caregivers of family members with autism, Down syndrome, medical support needs, and other specific groups meet regularly, in person or online. Support groups appreciate receiving information about lifespan planning, such as health care planning, supported decision making, paid or community services, and specialized topics such as retirement. Outreach to support groups may also help state Medicaid, I/DD, and other agencies to build relationships with caregivers, and support groups may be able to provide useful input to states on their needs and preferences regarding resources and communication.

States can provide caregiver training or counseling support under Medicaid HCBS waiver programs or state plan authority targeted toward unpaid family caregivers of older adults and people with functional limitations.

CMS Service Definitions

CMS offers the following core service definitions for reference in designing waiver programs:

- **Training and Counseling for Unpaid Caregivers:** Training and counseling services for individuals who provide unpaid support, training, companionship, or supervision to participants. For purposes of this service, individual is defined as any person, family member, neighbor, friend, companion, or co-worker who provides uncompensated care, training, guidance, companionship, or support to a person served on the waiver. This service may not be provided in order to train paid caregivers. Training includes instruction about treatment regimens and other services included in the service plan, use of equipment specified in the service plan, and includes updates as necessary to safely maintain the participant at home. Counseling must be aimed at assisting the unpaid caregiver in

meeting the needs of the participant. All training for individuals who provide unpaid support to the participant must be included in the participant's service plan.

- **Consultative Clinical and Therapeutic Services:** Clinical and therapeutic services that assist unpaid caregivers and/or paid support staff in carrying out individual treatment/support plans, and that are not covered by the Medicaid state plan and are necessary to improve the individual's independence and inclusion in their community. Consultation activities are provided by professionals in psychology, nutrition, counseling, and behavior management. The service may include assessment, the development of a home treatment/support plan, training and technical assistance to carry out the plan, and monitoring of the individual and the provider in the implementation of the plan. This service may be delivered in the individual's home or in the community as described in the service plan.¹²

Medicaid State Plan Services and Waiver Program Design

Providing support to caregivers yields direct benefits for both the caregiver and care recipient. In addition, states have shown that designing Medicaid HCBS waiver programs and offering Medicaid services that enable caregivers to better meet the needs of individuals they support yield positive results including:

- lower overall state spending on long-term services and supports;¹³
- potential reductions in hospital and nursing home services to aid in rebalancing strategies;¹⁴ and
- helping to alleviate the direct care workforce crisis.¹⁵

States have the flexibility to design HCBS waiver programs with options to best meet the needs of individuals with I/DD within the context of their family. For example, some states reserve capacity in their waiver programs for individuals with an aging caregiver. Recently, states have also begun reserving capacity in a manner that allows individuals to enter, leave, and return to the waiver program as their needs dictate. States build these tools as a means to gain trust with individuals and families so that supports are provided when needed and there is not an incentive to remain in the waiver program only to hold on to a "spot." During the COVID-19 pandemic, many states received authority to allow spouses, parents, and other family members to deliver paid services under Appendix K authority. Based on this experience, some states are taking steps to make these changes permanent.¹⁶



State Spotlight

Hawaii

The Hawaii Department of Health, Developmental Disabilities Division partners across sectors on a series of initiatives to better support individuals with I/DD and their aging caregivers. The initiatives focus on authentic engagement with individuals and their families, responsiveness to their cultures and languages, and building supports based on strengths. Hawaii's efforts include outreach, collaboration across agencies, partnerships with family and self-advocacy groups, training in aging, lifespan, and life stages for case managers, and planning across the life course. The division is currently collaborating with the Developmental Disabilities Council and [Catholic Charities Hawai'i](#) (CCH) to increase dementia awareness and provide trainings for caregivers of persons with dementia, including people with I/DD and co-occurring dementia. CCH was awarded a grant from ACL's Alzheimer's Disease Program Initiative to help individuals living with and those at high risk for developing Alzheimer's Disease & Related Dementias and their caregivers.

The division also continues efforts to ensure programs and services are person- and family-centered. For example, changes in the division's approach to case management have improved engagement with

and responsiveness to families. Along with a new case management information technology platform, case managers are now available to families via email, which provides easier access and closer communication. The division set an expectation to include self-advocates and families in the design and evaluation of programs, policy, planning, and quality management. To ensure consistency and accountability, the division meets with workgroups comprised of families and self-advocates throughout the year to listen and collect feedback and follow up on their concerns and priorities. Hawaii is currently partnering with families to design a new family-to-family peer mentoring service to ensure that families and family caregivers receive the support, training, and companionship they need to support their family members with I/DD. The division holds monthly [one-hour training workshops](#) for family caregivers, providers, direct care workers, and other stakeholders that focus on person-centered planning and health and welfare information.

States have the option to tailor services to meet the needs of a particular target group or groups using different HCBS authorities. Often, the systems that support older adults and individuals with I/DD have different services, providers, and case management approaches. Use of such HCBS authorities could help states to enable a seamlessly coordinated system of supports for both adults with I/DD and their aging caregivers, which deploys services and resources based on the totality of their circumstances. For example, the 2014 final rule made an important adjustment to the regulations at 42 CFR 441.301(b)(6). Prior to that change, a single section 1915(c) HCBS waiver program could only serve one of the following three target groups: “older adults, individuals with disabilities, or both; individuals with intellectual disabilities, developmental disabilities, or both; or individuals with mental illness.”¹⁷ The final rule permits but does not require states to combine target groups within one HCBS waiver program.

As another example, the section 1915(k) Community First Choice state plan option allows states to provide services across populations for people who meet an institutional level of care, in accordance with need and regardless of the type, nature, or severity of disability. Use of this option allows states to reduce administrative complexity, improve coordination of services, and standardize eligibility and assessment processes.¹⁸ Section 1915(i) state plan amendments also allow states to target services to one or more specific populations. Providing section 1915(i) services to an individual before they reach an institutional level of care could delay or prevent institutionalization.^{19,20} Combining target groups is an option that allows state Medicaid agencies to more effectively serve individuals with I/DD and aging caregivers when both qualify for HCBS.

States can choose to provide additional services under Medicaid HCBS waiver programs and state plan authority that support caregivers to meet the needs of Medicaid participants. For example:

- **Respite services** are short-term services provided under Medicaid HCBS waiver programs “because a support person is absent or needs relief” and can be provided in or out of the home.²¹ The benefits of respite for the caregiver, the person receiving support, and the relationship between caregiver and care receiver are well documented in the literature.^{22,23,24}
- **Home health services** are mandatory state plan services including, but not limited to, nursing services, home health aide services, and medical equipment and supplies but in addition to these mandatory services, states have the option to include therapies (i.e., physical therapy, occupational therapy, speech pathology, and audiology) in home health services. Home health services can support states in reducing unnecessary institutional stays and costly medical interventions. States may opt to provide therapies, which can improve recovery at home after hospitalization. Access to home health services, such as medical equipment or therapies, can enable individuals to remain in their own homes and communities with support from unpaid caregivers.²⁰

- **Case management services** include comprehensive assessment and periodic reassessment of an eligible individual's needs; development and periodic revision of a person-centered care plan; referral to services and related activities to help the eligible individual obtain needed services; and monitoring activities. The benefit is referred to as targeted case management when states choose to provide the service without regard to statewide implementation and comparability requirements. States can target the benefit to specific populations. Case management can link individuals with non-Medicaid services to support community integration and avoid or delay institutionalization,²⁰ which can relieve caregiver burden. Among states that identify caregiver needs as part of their Medicaid HCBS waiver program assessment processes, case management services can ensure caregiver needs are considered as part of the person-centered planning process.³

About this Collection of Resources:

The *Supporting Adults with I/DD and Their Aging Caregivers* resources aim to assist state Medicaid and partner agencies in their efforts to address the needs of adults with I/DD with aging caregivers. The collection includes *How State Agencies Can Anticipate and Meet the Needs of Adults with I/DD and Their Aging Caregivers*, which discusses state strategies to anticipate future needs and avoid crises as caregivers of adults with I/DD age. *State Policies and Practices to Support Person-Centered Planning Across the Lifespan for Individuals with I/DD and Their Aging Caregivers* discusses how states can implement person-centered planning processes consistent with Centers for Medicare & Medicaid Services (CMS) requirements. *State Policies and Practices to Support Aging Caregivers of Adults with I/DD* describes strategies states can use to support caregivers. *State Spotlights: Supporting Adults with I/DD and Their Aging Caregivers* highlights innovative state strategies and programs designed to assist adults with I/DD and their aging caregivers across the lifespan.

Additional Resources

- [National Center on Advancing Person-Centered Practices and Systems](#), ACL & CMS
- [ACL Support to Caregivers](#), ACL
- [HCBS Section 1915\(c\) Waiver Program Technical Guidance](#), CMS
- [Long-Term Services and Supports Rebalancing Toolkit](#), CMS
- [National Core Indicators 2019-2020 Adult Family Survey Final Report](#), National Association of State Directors of Developmental Disabilities Services
- [Medicaid Supports for Family Caregivers](#), National Academy for State Health Policy
- [State Approaches to Family Caregiver Education, Training, and Counseling](#), National Academy for State Health Policy
- [CMS Caregiver Workgroup](#), CMS
- [RAISE Family Caregiving Advisory Council and Resources](#), ACL
- [Advisory Council to Support Grandparents Raising Grandchildren and Resources](#), ACL
- [Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends Through 2014](#), University of Minnesota
- [Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2018](#), University of Minnesota



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State Policies and Practices to Support Person-Centered Planning Across the Lifespan for Individuals with Intellectual and Developmental Disabilities and Their Aging Caregivers

Overview

About this Brief

This brief is part of a collection of resources based on state Medicaid and partner agencies' successful approaches for enhancing supports for adults with intellectual and developmental disabilities (I/DD) and their aging caregivers.

Trends:

- In 2018, there were an estimated 7.43 million people with I/DD in the U.S. Only 21 percent (1.54 million) of people with I/DD were known to, or received services through, state I/DD agencies, with an overwhelming majority of these individuals receiving Medicaid-funded long-term services and supports.¹
- An estimated one million households in the U.S. include an adult with I/DD living with and supported by an aging caregiver, and this number is growing.¹
- The number of people with I/DD receiving Medicaid home and community-based services and living with family increased by 143 percent between 1998 and 2018.¹

The Centers for Medicare & Medicaid Services (CMS) is committed to supporting states in delivering quality, person-centered services that address the changing needs of adults with intellectual and developmental disabilities (I/DD) and their aging caregivers across the lifespan. The growing number of both individuals with I/DD and their aging caregivers create an increase in demand for state- and federally-funded services, primarily Medicaid state plan and home and community-based services (HCBS) waiver programs. Most adults receiving supports from I/DD agencies are Medicaid-eligible,² and some portion of those individuals will also have caregivers who are Medicaid-eligible or dually eligible for Medicare and Medicaid. States are increasingly recognizing the need to consider the HCBS needs of both adults with I/DD and their caregivers.

By leveraging strong person-centered planning and practices, states can devise approaches to better support individuals with I/DD and their aging caregivers in a culturally and linguistically competent manner that is informed by and more relevant to the context of their family and community. Applying person-centered principles across the lifespan becomes increasingly important as the number of

people with I/DD living with aging caregivers grows. Person-centered principles can help align people's choices, family context, and community resources in ways that foster state agency innovation.

Person-Centered Planning and Practice

To enhance the quality of HCBS and provide additional protections to individuals receiving these services, CMS issued [final regulations](#) in 2014 for HCBS provided under Medicaid's section 1915(c), 1915(k), and 1915(i) authorities. These regulations specify that Medicaid HCBS programs under sections 1915(c) and 1915(i) must use a person-centered planning process for service planning that addresses health and LTSS needs in a manner that reflects individual preferences and goals. The process is directed by the individual and may include a representative or others freely chosen by the individual.³

The Administration for Community Living and CMS jointly share an initiative, the [National Center for the Advancement of Person-Centered Practices and Systems](#) (NCAPPS), which can support states in complying with these provisions of the HCBS final rule. NCAPPS helps states, tribes, and territories in their implementation of person-centered thinking, planning, and practice including the following principles:

- **Person-centered thinking** focuses language, values, and actions toward respecting the views of the person and those involved in their lives. It emphasizes quality of life, well-being, and informed choice.
- **Person-centered planning** is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it.
- **Person-centered practices** are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals.⁴

Considerations

Integration in families and communities is an important part of life for all people. Whether or not a person receives formal, structured services and supports funded by federal or state agencies, individuals interact with, and receive support from, family and other members of their communities throughout their lives.⁵ For individuals with I/DD, often parents, siblings, and other community members or close friends play important roles in medical, behavioral, financial, and other daily supports. These daily supports begin early, continue through multiple life transitions, and continue throughout each person's life.



State Spotlight Washington

The Washington State Department of Social and Health Services, Developmental Disabilities Administration, is collaborating with the Washington State Developmental Disabilities Council through [Informing Families](#) to provide an online resource for individuals and families to be active participants in planning their future. It features self-paced planning tools and videos on navigating across the lifespan and offers trusted news and information to individuals and families to be active participants in planning and building a network of support and opportunities. Informing Families features [Supporting Real Lives Across the Life Course](#), which includes information, planning tools, and videos to navigate and plan from infancy through aging.

As caregivers age, they may be less able to provide care for their family members with I/DD and/or may need assistance themselves. In addition, the support needs of some families will change overall, with both the aging adult with I/DD and the aging caregiver(s) experiencing increased support needs over time. As the average life expectancy for people with I/DD increases,⁶ a growing number of adults with I/DD may outlive their family caregivers, increasing the importance of early conversations, planning, and shared discussions.

Person-centered planning approaches and practices that maintain a focus on the individual served while considering and

balancing the needs of family caregivers who support them are essential for all individuals who need HCBS. These and family-centered planning approaches and practices across the lifespan and life domains, such as work, community inclusion and relationships, and healthy living, can assist state Medicaid agencies and their partners to alleviate crises, plan for life transitions, and increase self-determination and decision-making for individuals with I/DD and their caregivers.

State systems are furthering efforts to develop practices that are person- and family-centered, flexible to accommodate diverse perspectives and cultures, and responsive to individual and caregiver choices. A review of criteria and definitions of person-centered thinking, planning, and practice identified four main principles.⁷ States are encouraged to consider the following principles proven useful in defining person-centered practices and measuring the efficacy of their efforts.

- **Focus on the person:** There is a holistic approach to the planning process in which the person is the central focus. The person's desires are heard, respected, valued, and reflected in the services received.
- **Choice and self-determination:** People make decisions about services and supports as well as their own health, well-being, and life goals.
- **Community inclusion:** People have support to participate in, be members of, and be treated as equal members in their communities.
- **Availability of services and supports:** People have access to an array of individualized services that meet their needs.⁸

As states employ person-centered and family-focused efforts to support individuals with I/DD and their aging caregivers, ensuring an approach to continuous learning and quality improvement can enable states to continually evolve practices to meet the emerging and changing needs of adults with I/DD, their caregivers, and their families as a whole.



State Spotlight

Massachusetts

The Massachusetts Department of Developmental Services offers a series of [webinars](#) focused on aging with I/DD. The intended audience for these webinars is caregivers, families, direct care workers, residential managers, and case managers. The webinars feature person-centered planning topics including health, adapting to age-related changes in the home, day, and other community settings, dementia and I/DD, and honoring cultural practices and individual preferences.

Massachusetts has an aging and caregiver workgroup to assist with state priorities, including planning and the development of supports for caregivers. The state is part of the National Community of Practice for Supporting Families and is linking its awareness and planning efforts with lifespan and cultural and linguistic competency work. For example, [Five Wishes](#) provides a framework for individuals and families to talk about and plan for the end of life and includes a video of an individual discussing his wishes with a friend.

In addition, the Department of Developmental Services is conducting research and interviews as part of a needs assessment for aging caregivers.

Strategies

States employ a range of strategies to implement person-centered planning across the lifespan, including early and ongoing planning, planning through the lens of family systems and diversity, making information available and accessible, promoting peer supports, and by engaging the community and listening to feedback.

Early and Ongoing Planning Approaches

Person-centered planning meetings offer the opportunity to engage with the person with I/DD living with their aging caregiver(s) about the future and to discover what is *important to the individual* as well as what is *important for the individual*; planning helps avoid a crisis and assists with thoughtful choice-making over time. For example, conversations about what the day will look like for the entire family when a person with I/DD retires from work or no longer attends a day program will help determine if different services, accommodations, or community supports may be needed by the person with I/DD or their aging caregiver(s). Planning for medical appointments and community activities and related transportation needs if the caregiver(s) can no longer do so without support can alleviate concerns and provide an ongoing “roadmap” for the family and case manager. States can choose from a variety of methods and [approaches to person-centered planning](#).

Planning Through the Lens of Family Systems and Diversity

Many states have also expressed the value of person-centered and family-centered outreach and planning approaches that recognize the diversity of families (e.g., values, familial expectations, family structures) and the importance of cultural competence. In addition to parents, other family members may be highly involved, including siblings. Effective strategies for state Medicaid agencies include seeking opportunities to support siblings or other family members to be partners in planning to determine if and how they would like to be involved in the future. In many communities and cultures, extended family is key to everyday life, and involvement is expected and appreciated.

A key competency of staff who facilitate person-centered planning is the recognition of “cultural and linguistic factors such as individualism and collectivism, language and communication, values and beliefs, customs and rituals, relationships to authority figures, avoidance of uncertainty, relationships to time, and other cross-cultural differences that need to be understood and respected in the person-centered planning process and its goal of community inclusion.”⁹ As state Medicaid agencies and their partners establish expectations for the application of person-centered practices in the context of families within their systems, this lens is crucial and beneficial when supporting individuals with I/DD and their aging caregivers, along with others who are important in their lives.



Resource Spotlight

NCAPPS Shorts: Culture and Person-Centered Practices

This [NCAPPS Shorts](#) series explores the role of culture in person-centered practices from the perspectives of people with a range of experiences and cultural identities. The videos provide insight into how racial, cultural, and sexual orientation and gender identities shape individuals' expectations and views of state systems of support.

State Spotlight

Washington



The Washington State Developmental Disabilities Services 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) waiver programs allow the state to support individuals with I/DD and their families as both their needs change over time.

Washington has implemented an online, self-directed lifespan planning tool, which helps to track needs and interests over time for both the individual with I/DD and their caregiver(s). Recognizing that many people with I/DD currently receive no paid services and often live with their families, Washington offers information to all families, regardless of whether someone is formally served by the state system.

The [Person-Centered Planning Guide](#) is a self-directed plan of care for all life stages. Any interested person with I/DD or family member does not need to be receiving paid services to use the tool. Individuals and families may choose to share their plan with their case manager at the Developmental Disabilities Administration.

Information Access and Supports for Peers

States may consider various ways to tailor approaches for providing information to meet the varied needs and preferences of individuals with I/DD and their caregivers. For example, states may host or connect families to caregiver support groups, partner with community agencies to hold peer

groups in different languages, and offer both web-based and physical materials. Asking and honoring a family's preference for how they access information and resources may open up choices and flexibilities.

An increasing number of states include services such as training and counseling services for unpaid caregivers in their section 1915(c) waiver programs and section 1115 demonstrations to ensure that families and unpaid caregivers receive information and support necessary to be successful in providing needed supports.¹⁰ Other states have worked with partner agencies to provide self-paced planning and navigation guides, with targeted topics on caregiving and aging.

Community Listening and Feedback

Some state agencies are conducting ongoing listening forums and opportunities for self-advocates and family caregivers to provide input and recommendations about specific strategies to address the person- and family-centered systems approaches needed to support adults with I/DD and their aging caregivers. CMS encourages states to take specific



State Spotlight

Maryland

Maryland's [Family Supports Waiver](#), [Community Supports Waiver](#), and [Community](#)

[Pathways Waiver](#) programs all include a service titled Family and Peer Mentoring Supports. Family and peer mentors have shared experiences with the participant, family, or both participant and family, and provide support and guidance to the participant and their family members. Family and peer mentors explain community services, programs, and strategies they have used to help individuals receiving waiver program services achieve their goals. Mentors foster connections and relationships, which help participants and their families build resilience.

Family and Peer Mentoring Supports encourage participants and their family members to share their successful strategies and experiences in navigating a broad range of community resources beyond those offered through the waiver program with other participants and their families. This service enables a person- and family-centered matching of individual and family needs to others with similar experiences.

measures to reach and engage culturally and geographically diverse communities to ensure representation from underserved and under-represented groups and that input is reflective of all communities served. Through such engagement, state agencies can respond to the evolving needs of families and advance equitable systems that serve all families.

State Spotlight

District of Columbia (D.C.)



D.C. has developed relationships with their local communities to improve the delivery of person- and family-centered services through increasing outreach, obtaining feedback and policy advice, and implementing a continuous feedback loop. D.C. has also implemented a cultural and linguistic competency initiative to boost access to services and align person-centered practices and planning for people from diverse backgrounds. Ongoing engagement with families and self-advocates assists in systems design and implementation.

In addition to these measures, D.C. has integrated their Community of Practice for Supporting Families Across the Lifespan with their Community of Practice for Cultural and Linguistic Competency to increase access for families from diverse populations using a lifespan approach, including aging caregivers. D.C. includes a Department of Aging and Community Living representative as a mandated appointee of the I/DD Family Advisory Council as part of its focus on lifespan supports.

Additional Resources



- [Person-Centered Practices Self-Assessment: For Governmental Agencies That Oversee Human Resources](#), NCAPPS
- [Long-Term Services and Supports Rebalancing Toolkit](#), CMS
- [Medicaid Supports for Family Caregivers](#), The National Academy for State Health Policy
- [Engaging People Who Receive Services: A Best Practice Guide](#), NCAPPS
- [NCI Data Brief: What Do NCI Data Tell Us About the Characteristics and Outcomes of Older Adults with I/DD?](#), National Association of State Directors of Developmental Disabilities Services
- [Steps to Creating a Statewide Person-centered Service Planning System](#), CMS
- [Supports for Community Participation](#), CMS
- [Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Definitions and Principles](#), Human Services Research Institute
- [National Center on Advancing Person-Centered Practices and Systems](#), ACL & CMS
- [Family & Individual Needs for Disability Supports 2017](#)

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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

Disclaimer

Resources and links to external documents and resources are provided for informational purposes only and do not constitute CMS endorsement. Recommendations contained herein do not establish requirements or supersede existing laws or official guidance. Furthermore, CMS is not responsible for the accuracy of the information included in external documents and resources.

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

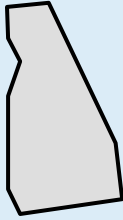


Interagency Partnerships and Relationships

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.

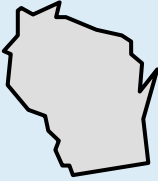
State Spotlight: Hawaii



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.

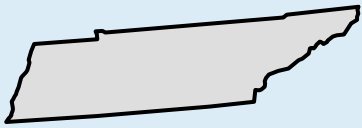
Establish processes for engaging with families and caregivers early

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

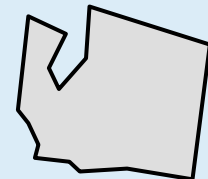
While not all transitions can be planned for in advance, anticipating major life and financial changes, such as retirement and changes in eligibility for Medicare or Social Security Disability Insurance, may help inform future planning with families. States that support individuals and families in planning 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.

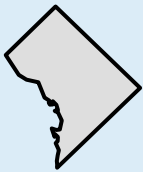
State Spotlight: Washington

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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