

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

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 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



Preparation of this document was funded by the Centers for Medicare & Medicaid Services, Contract # HHSM-500-2014-00033I to The Lewin Group.

References

- ¹ Larson, S., van der Selm, B., Sowers, M., Anderson, L., Pettingell, S., Neidorf, J., & Vegas, L. (2021). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2018*. Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Retrieved from <https://ici-s.umn.edu/files/yFXkkmRteg/2018-risp-full-report?preferredLocale=en-US>.
- ² Reinhard, S.C., Feinberg, L.F., Houser, A., Choula, R., & Evans, M. (2019). *Valuing the Invaluable: 2019 Update: Charting a Path Forward*. AARP Public Policy Institute. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>.
- ³ Kaye, N. & Teshale, S. (2020). *Medicaid Supports for Family Caregivers*. National Academy for State Health Policy. Retrieved from <https://www.nashp.org/wp-content/uploads/2020/10/Medicaid-Supports-for-Family-Caregivers.pdf>.
- ⁴ Cox, C. (2013). Factors Associated with the Health and Well-being of Dementia Caregivers. *Current Translational Geriatrics and Experimental Gerontology Reports*, 2(1), pp. 31–36. Retrieved from <https://doi.org/10.1007/s13670-012-0033-2>.
- ⁵ McAtee, R. E., Spradley, L., Tobey, L., Thomasson, W., Azhar, G., & Mercado, C. (2021). Caregiver Burden: Caregiving Workshops Have a Positive Impact on Those Caring for Individuals With Dementia in Arkansas. *Journal of Patient Experience*, 8. Retrieved from <https://doi.org/10.1177/23743735211018085>.
- ⁶ Dionne-Odom, J. N., Demark-Wahnefried, W., Taylor, R. A., Rocque, G. B., Azuero, A., Acemgil, A... Bakitas, M. A. (2017). The self-care practices of family caregivers of persons with poor prognosis cancer: differences by varying levels of caregiver well-being and preparedness. *Supportive Care in Cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 25(8), pp. 2437–2444. Retrieved from <https://doi.org/10.1007/s00520-017-3650-7>.
- ⁷ Smith, V.A., Lindquist, J., Miller, K.E.M., Shepherd-Banigan, M., Olsen, M., Campbell-Kotler, M... Van Houtven, C.H. (2019). Comprehensive Family Caregiver Support and Caregiver Well-Being: Preliminary Evidence From a Pre-post-survey Study With a Non-equivalent Control Group. *Frontiers in Public Health*, 7(122). Retrieved from <https://doi.org/10.3389/fpubh.2019.00122>.
- ⁸ RAISE Family Caregiving Advisory Council. (2021). Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act: Initial Report to Congress. U.S. Department of Health and Human Services. Retrieved from https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf.
- ⁹ National Academy for State Health Policy. (2021). *Map: ARPA Initial Plan Proposed Supports for Family Caregivers*. The RAISE Act Family Caregiver Resource and Dissemination Center. Retrieved from <https://nashp.org/map-arpa-initial-plan-proposed-supports-for-family-caregivers/>.
- ¹⁰ “The RAISE Family Caregivers Act called for a comprehensive inventory of federal programs that assist family caregivers. As of September 2021, over 50 program descriptions have been collected from federal agencies. The council will use the inventory to increase awareness and understanding about programs to support caregivers and transparency to avoid duplication of effort when developing the National Family Caregiving Strategy. The inventory will be updated as information becomes available. Learn more about the inventory.” To learn more, view the report here: <https://acl.gov/RAISE/report>.
- ¹¹ An ABLE account, also known as a 529 ABLE or 529A account, is a state-run savings program for eligible people with disabilities in the United States.
- ¹² Centers for Medicare & Medicaid Services. (2019). *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria*. U.S. Department of Health and Human Services. Retrieved from https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf.
- ¹³ Pluta-Ehlers, L. (2021). Washington Demonstrates Cost Savings and Improved Outcomes from Supporting Family Caregivers. *National Academy for State Health Policy*. Retrieved from <https://nashp.org/washington-demonstrates-cost-savings-and-improved-outcomes-from-supporting-family-caregivers/>.

-
- ¹⁴ Kelly, K., Wolfe, N., Gibson, M.J., & Feinberg, L. (2013). *Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waiver Programs*. AARP Public Policy Institute. Retrieved from https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/the-need-to-include-family-caregiver-assessment-medicaid-hcbs-waiver-programs-report-AARP-ppi-ltc.pdf.
- ¹⁵ National Academy for State Health Policy. (2022). Family Caregiver Services and Supports: Section 3a of the RAISE Act State Policy Roadmap for Family Caregivers. Retrieved from <https://nashp.org/family-caregiver-services-and-supports/>.
- ¹⁶ Centers for Medicare & Medicaid Services. (2020). *Planning for the Resumption of Normal State Medicaid, Children's Health Insurance Program (CHIP), and Basic Health Program (BHP) Operations Upon Conclusion of the COVID-19 Public Health Emergency (SHO# 20-004)* [State Health Official Letter]. U.S. Department of Health and Human Services. Retrieved from <https://www.medicaid.gov/federal-policy-guidance/downloads/sho20004.pdf>.
- ¹⁷ Centers for Medicare & Medicaid Services. (2014). *Fact Sheet: Summary of Key Provisions of the 1915(c) Home and Community-Based Services (HCBS) Waivers Final Rule*. U.S. Department of Health and Human Services. Retrieved from https://www.medicaid.gov/sites/default/files/2019-12/1915c-fact-sheet_0.pdf.
- ¹⁸ Centers for Medicare & Medicaid Services. (2016). *Community First Choice State Plan Option (SMD # 16-011)* [State Medicaid Director Letter]. U.S. Department of Health and Human Services. Retrieved from <https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/smd16011.pdf>.
- ¹⁹ State plan home and community-based services under section 1915(i)(1) of the Act, 42 CFR 441.710(e)(2) (2014).
- ²⁰ Centers for Medicare & Medicaid Services. (2020). *Long-Term Services and Supports Rebalancing Toolkit*. U.S. Department of Health and Human Services. Retrieved from <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf>.
- ²¹ Centers for Medicare & Medicaid Services. (2014). *Medicaid Home and Community-Based Services (HCBS) Taxonomy Category and Subcategory Definitions*. U.S. Department of Health and Human Services. Retrieved from <https://wms-mmdl.cms.gov/WMS/help/TaxonomyCategoryDefinitions.pdf>.
- ²² Wu, J.M., Tam, M.T., Buch, K., Khairati, F., Wilson, L., Bannerman, E... Robillard, J.M. (2022). The impact of respite care from the perspectives and experiences of people with amyotrophic lateral sclerosis and their care partners: a qualitative study. *BMC Palliative Care* 21(26). Retrieved from <https://doi.org/10.1186/s12904-022-00919-2>.
- ²³ ARCH National Respite Network and Resource Center. (2022). *Annotated Bibliography of Respite and Crisis Care Studies, 6th Edition, 2022*. Retrieved from <https://archrespite.org/library/arch-annotated-bibliography-of-respite-and-crisis-care-studies-6th-edition-2022/>.
- ²⁴ Avison, C., Brock, D., Campione, J., Hassell, S., Rabinovich, B., Ritter, R., Severynse, J...Zebrak, K. (2018). *Outcome Evaluation of the National Family Caregiver Support Program*. Report prepared by Westat for the Administration of Community Living. U.S. Department of Health and Human Services. Retrieved from https://acl.gov/sites/default/files/programs/2018-12/Caregiver_Outcome_Evaluation_Final_Report.pdf.