

# 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.<sup>1</sup>
- 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.<sup>1</sup>
- 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.<sup>1</sup>

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,<sup>2</sup> 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.<sup>3</sup>

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.<sup>4</sup>

## 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.<sup>5</sup> 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,<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup>

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.”<sup>9</sup> 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.



## 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.

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.<sup>10</sup> 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

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](#)

Preparation of this document was funded by the Centers for Medicare & Medicaid Services, Contract # HHSM-500-2014-000331 to The Lewin Group.

## References

- <sup>1</sup> 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>.
- <sup>2</sup> Residential Information Systems Project. (n.d.). Public Funding Sources Used by Adults with IDD. Retrieved from <https://publications.ici.umn.edu/risp/infographics/how-many-adults-with-idd-got-ltss-through-state-idd-agencies>.
- <sup>3</sup> Centers for Medicare & Medicaid Services. (2014). *Home and Community Based Services*. U.S. Department of Health and Human Services. Retrieved from <https://www.medicare.gov/sites/default/files/2019-12/final-rule-fact-sheet.pdf>.
- <sup>4</sup> National Center on Advancing Person-Centered Practices and Systems. (n.d.) About NCAPPS. Retrieved from <https://ncapps.acl.gov/about-ncapps.html>.
- <sup>5</sup> Reynolds, M.C., Palmerx, S. B., & Gotto, G.S. (2018). Chapter Six - Reconceptualizing Natural Supports for People with Disabilities and Their Families. *International Review of Research in Developmental Disabilities*, 54, pp. 177-209. Retrieved from <https://doi.org/10.1016/bs.irrdd.2018.07.006>.
- <sup>6</sup> Heller, T. (2010). People with Intellectual and Developmental Disabilities Growing Old: An Overview. *Impact Feature Issue on Aging and People with Intellectual and Developmental Disabilities*, 23(1). Retrieved from <https://publications.ici.umn.edu/impact/23-1/people-with-intellectual-and-developmental-disabilities-growing-old-an-overview>.
- <sup>7</sup> National Center on Advancing Person-Centered Practices and Systems. (2019). *Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Definitions and Principles*. Retrieved from [https://ncapps.acl.gov/docs/NCAPPS\\_Principles\\_NationalEnvironmentalScan%20191202.pdf](https://ncapps.acl.gov/docs/NCAPPS_Principles_NationalEnvironmentalScan%20191202.pdf).
- <sup>8</sup> National Core Indicators-IDD, National Core Indicators-Aging and Disabilities, & National Center on Advancing Person-Centered Practices and Systems. (2021). *Person-Centered Practices in the National Core Indicators Data*. Retrieved from <https://ncapps.acl.gov/docs/Resources/Person-Centered%20Practices%20in%20the%20National%20Core%20Indicators%20Data%20Accessible.pdf>.
- <sup>9</sup> Tondora, J., Croft, B., Kardell, Y., Camacho-Gonsalves, T., & Kwak, M. (2020). *Five Competency Domains for Staff Who Facilitate Person-Centered Planning*. National Center on Advancing Person-Centered Practices and Systems. Retrieved from [https://ncapps.acl.gov/docs/NCAPPS\\_StaffCompetencyDomains\\_201028\\_final.pdf](https://ncapps.acl.gov/docs/NCAPPS_StaffCompetencyDomains_201028_final.pdf).
- <sup>10</sup> Centers for Medicare & Medicaid Services. (2019). *HCBS Instructions, Technical Guide and Review Criteria*. Retrieved from [https://wms-mmdl.cms.gov/WMS/help/35/Instructions\\_TechnicalGuide\\_V3.6.pdf](https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf).