

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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