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HEALTH MANAGEMENT ASSOCIATES

*Medicaid Services for People with Intellectual or
Developmental Disabilities - Evolution of
Addressing Service Needs and Preferences*

REPORT TO

THE MEDICAID AND CHIP PAYMENT AND ACCESS COMMISSION

BY

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OCTOBER 2020

This report was prepared under contract to the Medicaid and CHIP Payment and Access Commission (MACPAC). The findings, statements, and views expressed in this report are those of the authors and do not necessarily reflect those of MACPAC.

About Health Management Associates

Health Management Associates (HMA) is a consulting and health policy research firm specializing in health system restructuring, health care program development, health economics and finance, program evaluation, and data analysis. HMA is widely regarded as a leader in providing technical and analytical services to health care purchasers, payers, providers, and foundations, with a special concentration on those who address the needs of the medically indigent and underserved. Founded in 1985, HMA has offices in Albany, New York, Atlanta, Georgia; Austin, Texas; Boston, Massachusetts; Chicago, Illinois; Columbus, Ohio; Costa Mesa, California; Denver, Colorado; Harrisburg, Pennsylvania; Indianapolis, Indiana; Lansing, Michigan; Los Angeles, California; New York, New York; Philadelphia, Pennsylvania; Phoenix, Arizona; Portland, Oregon; Raleigh, North Carolina; Sacramento, California; San Antonio, Texas; San Francisco, California; Seattle, Washington; Tallahassee, Florida; and Washington, DC.

About the Funder

The Medicaid and CHIP Payment and Access Commission (MACPAC) is a non-partisan legislative branch agency that provides policy and data analysis and makes recommendations to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states on a wide array of issues affecting Medicaid and the State Children's Health Insurance Program (CHIP). The U.S. Comptroller General appoints MACPAC's 17 commissioners, who come from diverse regions across the United States and bring broad expertise and a wide range of perspectives on Medicaid and CHIP.

The research underlying this report was completed with support from the Medicaid and CHIP Payment and Access Commission (MACPAC). The findings, statements, and views expressed are those of the authors and do not necessarily represent those of MACPAC.

Acknowledgements

The authors would like to thank the Medicaid and CHIP Payment and Access Commission (MACPAC) for funding this study, and Kristal Vardaman, PhD, MSPH, and Erin McMullen, MPP for their guidance and support throughout the project. We also express our appreciation to the many individuals and organizations representing an array of stakeholders who agreed to be interviewed (listed in Appendix A) and shared their time, expertise and valuable insights.

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I. EXECUTIVE SUMMARY

Covering 53 percent of all long-term services and supports (LTSS) spending in 2015,¹ Medicaid is the predominant LTSS payer for people with intellectual disabilities or developmental disabilities (ID/DD). In 2017 there were approximately 7.4 million people with ID/DD in the U.S. including approximately 5.3 million children and two million adults.² For the same year, total LTSS expenditures for people with ID/DD was \$46.3 billion.³

The Medicaid and CHIP Payment and Access Commission (MACPAC) contracted with Health Management Associates (HMA) to provide a resource for comprehensive information about people with ID/DD and the Medicaid program policies and services that support their needs. HMA conducted an expansive literature review, interviewed key stakeholders, and synthesized the information to demonstrate the importance of, and distinctions within, Medicaid programs as the primary payer for ID/DD services.

Summary Findings

The findings from this study demonstrate the complexity and variability of state ID/DD systems, and gaps in access to healthcare and healthcare data. Medicaid programs for people with ID/DD continue to evolve as states seek to develop service delivery systems that support people with ID/DD to live healthy lives as fully participating members of the community.

Study findings are organized into eleven categories and summarized below.

Population Characteristics and Service Needs

People with ID/DD rely on a broad range of services and supports that vary among individuals and across the lifespan, distinct from other populations needing LTSS. People with ID/DD often need services and supports from birth to end of life. People with ID/DD rely on assistance with Activities of Daily Living (ADLs), such as bathing and dressing, and Instrumental Activities of Daily Living (IADLs), such as shopping and cooking,⁴ as well as often needing other home and community-based services (HCBS), such as employment-related services, positive behavior supports, and supervision and cueing to complete tasks.⁵ The majority of people with ID/DD, 72 percent, live with their families or in a home of their own.⁶

As adults, they experience poorer health outcomes than adults without ID/DD,⁷ and shorter life expectancies than the general population.⁸ Research demonstrates that people with ID/DD experience avoidable disparities in health outcomes,⁹ beyond the health differences caused by their primary disabling conditions.¹⁰

Addressing Racial and Cultural Disparities

The literature demonstrates emerging evidence that people with ID/DD from racial, ethnic and linguistic minorities experience further disparities in access, quality, and outcomes.¹¹ However, data and research on the intersection of race, ethnicity and disability in health and human services is limited.^{12,13}

Medicaid Programs and Spending for People with ID/DD

An array of policies has expanded provision of LTSS for people with ID/DD in home and community-based settings over the past four decades as part of a growing de-institutionalization movement. See *Appendix E: Policy Milestones for People with ID/DD*.

States use a combination of federal Medicaid authorities and state-only funding to operate programs for people with ID/DD, reflecting a wide range of policy decisions related to financing, services offered and target population(s). While people with ID/DD have been included in many mandatory Medicaid

managed care programs for acute and primary care services, only seven states require people with ID/DD to enroll in mandatory Medicaid managed long-term services and supports programs (MLTSS).¹⁴

Over the past 35 years, the significant increase in HCBS enrollment has been the primary driver of overall ID/DD LTSS spending growth. Per person expenditures are higher than other populations due to intensity of need and supports delivered across the lifespan.¹⁵

Medicaid Home and Community-Based Services (HCBS) Waiver Waitlists

States use different approaches for establishing and reporting Medicaid HCBS waiver waitlists, making it impossible to determine how many eligible people on a national basis are going without HCBS while they wait for enrollment opportunities.¹⁶

Medicaid HCBS Waiver Structures

Many states are providing limited services to a larger number of people with ID/DD through HCBS waivers with a service array that excludes residential services. These states operate separate concurrent HCBS waivers that provide access to round-the-clock services for a smaller number of eligible participants with higher support needs. These approaches are intended to improve community integration, reduce waitlists, and increase equitable access to services while also managing expenditure growth.¹⁷

Case Management and Person-Centered Planning

Case management is a key component of Medicaid ID/DD services and supports. Federal Medicaid HCBS regulations require person-centered planning,¹⁸ and systems are striving to implement and operationalize person-centered thinking, planning and practice in meaningful ways.[†] Families and people with ID/DD depend upon HCBS case managers for assistance navigating multiple systems, problem-solving and advocacy.¹⁹ While all states offer case management for most HCBS participants, funding, data and program silos between state Medicaid agencies and DD agencies contribute to the lack of care integration and coordination of services for individuals with ID/DD.

Trends Toward Individualized Supports and Self-Direction

While most states' LTSS for people with ID/DD are largely rebalanced away from institutional care, ID/DD services continue to evolve and move toward full community integration and individualized supports. Employment and day services are a growing component of HCBS for people with ID/DD, yet individuals are often unable to pursue their employment goals, participating in day services instead.

The majority of stakeholders interviewed noted self-directed services are an important option for people with ID/DD and are most effective when there are robust supports to assist people in managing their plans and services. Additionally, many states are expanding access to technology solutions in HCBS to complement direct supports provided by workers and to increase independence for people with ID/DD.²⁰

[†] State definitions of person-centered thinking, planning, and practice vary but several key principles are common to most definitions, including a focus on the person, an understanding of the importance of choice and self-determination, and a commitment to full inclusion and access to the community. (Source: Jane Lawrence, *Person-Centered Thinking, Planning, and Practice: Representative Examples of State Definitions* (Cambridge, MA: National Center on Advancing Person-Centered Practices and Systems, 2020), https://ncapps.acl.gov/docs/NCAPPS_Definitions_RepresentativeExamples_200930.pdf, page 6).

Supporting Families Across the Lifespan

The majority of people with ID/DD live with their families across the lifespan.²¹ States are supporting families to develop skills as facilitators of a good quality of life for both their family member(s) and themselves. Approaches that focus on supporting all members of the household may be helpful in addressing the needs of both adults with ID/DD and their aging caregivers. Siblings often have the longest relationships during the life of a person with ID/DD, but many families do not include them in the process of planning for future caregiving arrangements.²²

Workforce Issues and Challenges

The responsibilities of direct support professionals (DSPs) working with people with ID/DD are complex and require a range of skills. Multiple stakeholders noted, while DSPs often provide personal care to people with ID/DD, they are also expected to facilitate engagement in the community, assist in skills development, and contribute to improved quality of life. Improving the quality of the DSP workforce and creating better career opportunities are critical to maintaining and sustaining a system that effectively supports people with ID/DD. Nearly every stakeholder indicated that high turnover rates, consistent vacancies and low wages limit system capacity to serve people with ID/DD and compromise the overall quality of services provided.

People with ID/DD, advocates, researchers and state DD agencies indicated that a lack of access to disability-competent and appropriate clinical care is a challenge for many people with ID/DD. In order to improve access to effective health care, clinicians including physicians, dentists, and behavioral health professionals need basic training and information about people with ID/DD. Another potential solution recommended by stakeholders is the federal designation of ID/DD as a medically underserved population to increase the number of clinicians prepared to work with people with ID/DD.

Behavior Supports and Mental Health Integration within ID/DD Services

Behavior supports and mental health treatment are critical for people with ID/DD. A significant proportion of people with ID/DD, with or without psychiatric diagnoses, require behavior support services to help them improve adaptive skills and positive functioning.²³ A smaller number, nearly half of the people receiving ID/DD services, are formally diagnosed with a co-occurring mental health condition.²⁴

Multiple interview participants, including state Medicaid and DD agency staff, noted an unmet need for behavioral supports and mental health providers who are comfortable and knowledgeable in working with people with ID/DD. Further, interviewees acknowledged the difficulties of collaborating across systems to help people with ID/DD and their families identify and access appropriate mental health services and interventions. State DD agency interviewees and researchers indicated many states have developed Medicaid HCBS waiver services such as positive behavior supports and crisis services to address the needs of the ID/DD population.

Information Technology, Data Analysis and Metrics

To better understand the prevalence of ID/DD and the health status, health determinants, and health needs of people with ID/DD, there is need for national health surveillance data and additional analysis of clinical and administrative data.²⁵ Gaps in state ID/DD system information technology (IT) infrastructure and data analysis capacities limit data-driven program policies and decision-making.

States are seeking to develop ID/DD HCBS quality outcome metrics that are comparable, valid, reliable and useful, and reflect quality of life across multiple domains. Beyond the IT infrastructure issues, challenges mentioned by state DD agencies and researchers include the limitations of administrative

datasets, subjectivity in determining and measuring quality of life, and resources necessary to collect robust consumer experience data at an effective sampling rate.

Looking Ahead

This project identified focus areas warranting further attention going forward, including the following:

- Additional health research and data would help policymakers better understand and support effective programs for the population.
- Aligning federal performance expectations to support HCBS quality could promote additional improvement at the state level.
- Consideration of support needs in the context of families, including addressing multi-generational caregiver issues.
- Supporting adults with ID/DD to exercise informed decision-making and have their preferences honored in the LTSS context.
- Further research on the effectiveness of state initiatives designed to address workforce issues could help inform policies that support the stability and quality of the workforce going forward.
- Improvements in access to disability-responsive medical care, as well as better coordination across physical health, behavioral health and HCBS, would benefit people with ID/DD.
- Several stakeholders stated that federal designation of people with ID/DD as a medically underserved population could assist in furthering access to clinical provider networks better prepared to serve people with ID/DD.
- In this year of the pandemic and social change, the need to address equity issues and health disparities for people with ID/DD, and particularly people with ID/DD of color, has been brought to the forefront and must be considered, moving forward.

Text Box 1: The Impact of the COVID-19 Pandemic

The literature review and interviews conducted for this study were nearly complete in March 2020, and therefore the perspectives conveyed throughout the report do not reflect the significant impact of the COVID-19 pandemic. [Section V. The Impact of COVID-19 Pandemic](#) was added after completion of the draft report. It highlights the pandemic and response concerns and implications for people with ID/DD and actions taken by the Centers for Medicare & Medicaid Services (CMS) and states to ensure continuity of HCBS. It underscores that actions taken during the pandemic, while intended to be temporary responses to the public health emergency, have affected the ID/DD LTSS system in ways that are likely to be long-lasting.

II. INTRODUCTION

Covering 53 percent of all long-term services and supports (LTSS) spending in 2015,²⁶ Medicaid is the predominant payer for providing LTSS to people with intellectual disabilities or developmental disabilities (ID/DD), a population with very few other sources of insurance coverage for these services. While states initially provided all funding for LTSS for this population in large-scale state-run institutions, they have been slowly rebalancing those services toward home and community-based services (HCBS) since 1981, with over 90 percent of people with ID/DD receiving HCBS as of 2017. Another trend was the

increased availability of HCBS waiver program options between 1998 to 2017, contributing to an increase in the total number of people with ID/DD receiving publicly funded LTSS. During this period, states also reduced reliance on large congregate facilities, as the number of LTSS recipients with ID/DD in state-operated settings of 16 or more people declined 76 percent.²⁷

Definitions Related to People with ID/DD

Although the terms intellectual disabilities (ID) and developmental disabilities (DD) are often used together – ID/DD – to describe people with varying conditions and functional limitations, they have different definitions.

Text Box 2: Definitions of Intellectual Disability and Developmental Disability

Developmental disability is defined by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) as a severe, chronic disability of an individual that is:

- ✓ Attributable to a mental or physical impairment or combination of mental and physical impairments
- ✓ Manifested before the age of 22
- ✓ Likely to continue indefinitely
- ✓ Results in substantial functional limitations in 3 or more or more of the following areas of major life activity:
 - Self-care
 - Receptive and expressive language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living
 - Economic self-sufficiency
- ✓ Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinatedⁱ

Intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) as:

- ✓ A disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills; and
- ✓ Condition originates before the age of 18ⁱⁱ

i. Definitions, 42 U.S.C. § 15002(8) (2002).

ii. Robert L. Schalock et al., "Definition of Intellectual Disability," in *Intellectual Disability: Definition, Classification, and Systems of Supports, 11th Edition* (American Association on Intellectual and Developmental Disabilities, 2010).

Definitions for the collective term for people with ID/DD differ across states for eligibility for ID/DD services, including Medicaid-funded programs. The Supplemental Security Income (SSI) program, an important Medicaid eligibility pathway for people with ID/DD, generally uses condition-specific definitions and does not recognize developmental disabilities.* Different ways that states define ID/DD populations include:

- Alignment with the DD Act (see Text Box 2), reliant upon three or more substantial functional limitations.
- Intellectual Disability, using an explicit IQ score combined with an assessment of adaptive deficits in the conceptual, social, and practical skills learned by people that help them function in their everyday lives.
- Alignment with the broader construct described by the American Association on Intellectual and Developmental Disabilities, including consideration of factors such as community environment typical of the individual's peers and culture, linguistic diversity, and cultural differences in the way people communicate, move, and behave.²⁸
- Inclusion of specific conditions such as autism, cerebral palsy, Down syndrome, epilepsy, and/or neurological impairment.²⁹

These variations result in differing eligibility standards for Medicaid and state funded ID/DD programs across states.

Objectives

To provide insights into Medicaid-funded LTSS for people with ID/DD across the country, MACPAC contracted with Health Management Associates (HMA) to conduct a literature review, interview key stakeholders, and synthesize the information. The objective is to produce a resource for comprehensive information about people with ID/DD and the Medicaid program policies that support their needs, to inform the Commission's deliberations on future approaches for serving people with ID/DD enrolled in Medicaid.

For the report, the following topics related to people with ID/DD covered by Medicaid were researched:

- Demographics and common conditions
- Variations in eligibility, definitions, covered services, and access to services and supports
- The role and evolution of case management, person-centered planning, individualized supports and self-directed services
- Interaction between state Medicaid agencies and developmental disability (DD) agencies
- Gaps in information technology, and use of technology to enhance independence
- Living situation and preferences, and supports for families/caregivers across the lifespan

* The SSI program defines people with intellectual disability as those who: Are unable to complete an intelligence quotient (IQ) test independently; Have an IQ score below 60; Have an IQ score of 60 through 70 and another physical or mental impairment that limits the ability to work; or Have an IQ score of 60 through 70 and some combination of restricted activities of daily living (ADLs), difficulty maintaining social function, difficulty maintaining concentration, and repeated episodes of decompensation. (Source: Gina A. Livermore, Maura Bardos, and Karen Katz, Social Security Administration, "Supplemental Security Income and Social Security Disability Insurance Beneficiaries with Intellectual Disability," *Social Security Bulletin*, 2017, <https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html>).

- Workforce shortages and state strategies to address them, including paying family caregivers
- Gaps and disparities in access to clinical services, including behavior supports and mental health treatment

Methodology

HMA sought to achieve the study's objectives through a literature review and stakeholder interviews, resulting in a synthesis of findings. The literature review identified and summarized studies, overviews, and analyses of the population of people with ID/DD who are covered by Medicaid, and the services they receive. The review looked at the characteristics, needs, and service utilization of the ID/DD population enrolled in Medicaid who live in the community and in institutions; how the needs of the people with ID/DD vary across their lifespans; the extent and impact of waiting lists for Medicaid HCBS waiver programs and how individuals access services while on waiting lists; the role of state ID/DD agencies in administering Medicaid HCBS waiver programs; providers who serve the ID/DD population and implications of limited provider capacity on access to services; and the role of self-directed programs in serving people with ID/DD.

HMA conducted 18 individual and group interviews involving 37 individuals that included people with intellectual or developmental disabilities, state Medicaid officials, state Developmental Disabilities agency officials, health plans, a federal official, associations representing providers of ID/DD services, and consumer organizations. The interviews were conducted using a standardized set of twelve questions, from which five or six questions were selected for each interview.

Detailed descriptions of the literature review and the stakeholder interviews are contained in *Appendix A: Literature Review and Stakeholder Interview Methodology*.

Data Limitations

Our sources provide a wide range of perspectives on the characteristics and health of the population of people with ID/DD. However, many studies note the limitations of health data sources due to several challenges: failure to identify people with ID/DD within available data sets; sampling frames that do not take into account people in congregate living situations; exclusion of institutionalized populations;³⁰ and, as noted above, varied definitions, including distinctions between intellectual disabilities and developmental disabilities.³¹

In addition, there is no available national data to compare the acuity and intensity of support needs of populations currently in institutional settings versus home and community-based settings. Surveillance gaps and definitional discrepancies limit the national understanding of service use, unmet service and support needs, health outcomes and prevalence of particular conditions or diseases for people with ID/DD.³² There is an acknowledged need for national health surveillance data and additional analysis of clinical and administrative data to better understand the health status, health determinants, and health needs of people with ID/DD, along with more complete information to understand their life circumstances.³³

III. FINDINGS

Population Characteristics and Service Needs

The population of people with ID/DD in the United States in 2017 was estimated to be 7.4 million, including approximately 5.3 million children and two million adults.³⁴ Of this population, an estimated 1.3 million received publicly funded LTSS by state developmental disabilities (DD) agencies.³⁵

People with ID/DD rely on a broad range of long-term services and supports that vary among individuals and across the lifespan and are distinct from other populations that use LTSS. Older adults and people with physical disabilities most frequently rely on personal care services to support Activities of Daily Living (ADLs), such as bathing and dressing, and Instrumental Activities of Daily Living (IADLs), such as shopping and cooking.³⁶ People with ID/DD also rely on assistance with ADLs and IADLs, as well as often needing other HCBS, such as employment-related services, positive behavior supports, and supervision and cueing to complete tasks.³⁷ Many require intensive case management/support coordination, including navigation across healthcare, human services, education, employment, income maintenance and other community-based supports, as well as help to coordinate medical, therapeutic, and behavioral health services.³⁸ Some need support with challenging behavior, including those who are dually diagnosed with mental health disorders.* People with ID/DD often need supports and services from birth to end of life. See *Appendix B: Long-Term Supports and Services Used by People with ID/DD*.

While older adults receiving LTSS rely upon increasing levels of support as they age, many younger people with ID/DD receive services that promote the goal of completing tasks and achieving more independence that may result in decreasing levels of support. The population of people with ID/DD is quite heterogeneous with diverse characteristics,³⁹ as are their service and support needs.

The majority of people with ID/DD live with their families or in a home of their own, estimated to be 72 percent of people with ID/DD receiving services, while a smaller proportion use residential services.⁴⁰ The population of people with ID/DD living in large public institutions tends to be older and are more likely to have profound intellectual disabilities⁴¹ (meaning people with the most significant cognitive impairments) than non-institutionalized populations.

Adults with ID/DD experience worse health outcomes than adults without ID/DD.⁴² While average life expectancy for people with ID/DD has increased overall in recent decades, for people with higher impairment severity, additional comorbidities, and increased frailty, early death is not uncommon.⁴³

During their lifespan, people with ID/DD live with more complex health conditions and are more likely than the general population to:

- Have limited access to appropriate health care⁴⁴
- Have a psychiatric disability than the general population⁴⁵
- Experience mental health problems with potential overuse of psychotropic medications⁴⁶
- Be obese or overweight⁴⁷
- Experience a high rate of falls⁴⁸
- Live with undetected vision and hearing loss⁴⁹

* Medicaid also covers behavioral health services for mental health or substance use disorders.

- Face health issues associated with aging related to their disability or genetic syndrome⁵⁰

Research demonstrates that people with ID/DD experience avoidable disparities in health outcomes^{1*} beyond the health differences caused by their primary disabling conditions.⁵¹ Health disparities also contribute to excess premature mortality rates.⁵²

People with ID/DD are a heterogeneous population with diverse characteristics who rely on a wide range of publicly funded LTSS. See *Appendix C: Demographics of People with ID/DD Receiving LTSS Across Institutional and Community-Based Settings (2017-2018)* and *Appendix D. Demographics and Intensity of Needs of People with ID/DD Living in Public Residential Facilities*. Due to the complexities of different state policies and systems for people with ID/DD, variation in individual needs and choices, and the overall diversity of the population, there are no clear conclusions to be drawn about the relationship between demographic distinctions and the characteristics of people with ID/DD living in different settings.⁵³ Research and data have shown that people with ID/DD with varying characteristics and needs, including people with highly complex medical and/or behavioral support needs, are being served successfully in home and community-based settings.⁵⁴

Addressing Racial and Cultural Disparities

Data and research on the intersection of race, ethnicity and disability in publicly funded health and human services for people with ID/DD are limited.^{55,56} Comprehensive national information on the racial, ethnic and linguistic characteristics of people with ID/DD participating in Medicaid-funded LTSS does not yet exist in a single dataset.⁵⁷ From the limited data that do exist, the demographic profile of people with ID/DD receiving publicly-funded services differs from the cultural, racial and ethnic make-up of the broader population, suggesting disparities across subgroups.⁵⁸

For the 35 states participating in the National Core Indicators (NCI) project in 2017-18, there are some limited demographic data as indicated in *Appendix C: Demographics of People with ID/DD Receiving LTSS Across Institutional and Community-Based Settings (2017-2018)*. Additional demographic information from another study indicates that people with ID/DD who are Black are more likely to live in large state institutions (20 percent) and people of Hispanic origin are less likely to be residents in these facilities (7 percent), as compared to people who are White.⁵⁹

Researchers and advocates noted that Medicaid ID/DD delivery systems need to develop more culturally responsive supports and services. The literature demonstrates emerging evidence that people with ID/DD from racial, ethnic and linguistic minorities experience disparities in access, quality, and outcomes.⁶⁰ Black and Latino people with ID/DD have worse health outcomes than white people with ID/DD, even when controlling for factors such as income, education and insurance status.⁶¹

Advocates interviewed observed that some states are seeking to identify disparities and address gaps in racial, cultural and linguistic competence, but there are limited reports on strategies demonstrating measurable success. Federal funding is supporting efforts such as the [Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities](#), with ten states participating in a five-year initiative to advance and sustain cultural and linguistic competence systemically and respond effectively to the growing cultural and linguistic diversity among people with ID/DD. Additionally, with support from the Administration for Community Living, the Georgetown University National Center for Cultural

* Disparities defined as avoidable inequities in health outcomes linked to social, economic, or environmental disadvantages or discrimination. (Source: Paul Braveman, "Health Disparities and Health Equity: Concepts and Measurement," *Annual Reviews in Public Health* 27 (October 2005): 167-194, <https://www.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.27.021405.102103>).

Competence* has developed a [framework](#) that can be used by systems and organizations to consider and address disparities in availability, accessibility, acceptability, quality and utilization of supports and services for people with ID/DD across multiple domains including health, housing, employment, transportation and more.

California is an example of a state that has conducted studies to identify the racial and ethnic composition of the population of people with ID/DD receiving publicly funded services. The state has implemented efforts in recent years designed to address identified disparities in the ID/DD service delivery system.

Text Box 3: California's Efforts to Identify and Address Racial and Ethnic Disparities

California has grappled with racial and ethnic disparities in the state ID/DD system for many years. In 2012, a new state law required the state developmental disability agency, California Department of Developmental Services (DDS), and each of its Regional Centers* (case management entities) to publicly report authorization, utilization and expenditure data for all ID/DD services including Medicaid-funded supports, disaggregated by ethnic and racial groups, language, age, and general diagnosis categories.ⁱ Studies found the following:

- People enrolled with a Regional Center who were **Black, Asian/Pacific Islander, Hispanic, and other races had significantly lower rates** (9% to 29% lower) of **receiving services** than white people in 2013ⁱⁱ
- In 2015-16, **average annual expenditures were nearly 50 percent lower for non-white participants** at \$11,952 compared to \$22,140 for white Regional Center enrolleesⁱⁱⁱ
- **When residential services are excluded, disparities are even more pronounced** – service spending for white people receiving in-home services were 40% higher than for Latinos, and 49% higher for white people receiving Independent or Supported Living services compared to Latinos^{iv}
- The most recent statewide **data for 2017-18 continues to show disparities in service spending**; per capita expenditures for white adults with ID/DD is \$38,404, \$21,957 for Hispanic populations and \$31,055 for Black populations^v

California stakeholders have identified several factors contributing to disparities, affirmed by the state, including:

- An inadequate supply of culturally and linguistically appropriate and accessible information, service options, and providers
- Cultural barriers, including discomfort challenging authority figures, for some families that prevent them from requesting needed services and exercising their rights
- Mistrust of public systems by some communities of color
- Socioeconomic factors^{vi}

Actions taken by the state in response include:

- In 2016, the state added annual Regional Center contract measures to track the progress of reducing disparities and improving equity^{vii}
- In 2019, eleven standard statewide disparity measures and improvement targets were created to further track progress^{viii}

- The state legislature annually funds a grant program, the Disparity Funds Program, to support local efforts to encourage the development and expansion of culturally and linguistically appropriate services and to reduce disparities. The grant program has supported efforts such as hiring culturally responsive navigators and educators to outreach and assist minority families, peer mentorship programs, and developing targeted culturally and linguistically diverse service delivery capacity.^{ix}

*Note: DDS oversees the coordination and delivery of services for individuals with developmental disabilities through a statewide network of 21 community-based, non-profit agencies known as Regional Centers that develop, purchase and manage services for individuals and their families. <https://www.dds.ca.gov/rc/>

- i. Services for the Developmentally Disabled, CA WIC § 4519.5 (2014).
- ii. Charlene Harrington and Taewoon Kang, “Disparities in Service Use and Expenditures for People With Intellectual and Developmental Disabilities in California in 2005 and 2013,” *Intellectual and Developmental Disabilities* 54, no. 1 (Feb 2016): 1–18, <https://doi.org/10.1352/1934-9556-54.1.1>.
- iii. “Background and Process for Developing Disparity Measures,” California Department of Developmental Services, March 12, 2019, https://www.dds.ca.gov/wp-content/uploads/2019/03/Disparities_BgProcessDevelopingDisparityMeasures_20190329.pdf.
- iv. “Moving Toward Equity: Addressing Disparities in Services Provided by the Regional Center System,” Senate Human Services Committee Oversight Hearing, March 14, 2017, https://shum.senate.ca.gov/sites/shum.senate.ca.gov/files/03-14-2017_heraing_background_paper_final.pdf.
- v. “Purchase of Service Report by Ethnicity and Race, FY 2018-2019,” California Department of Developmental Services, last modified September 17, 2019, <https://www.dds.ca.gov/rc/dashboard/purchase-of-service-report/ethnicity-race/>.
- vi. “Grant Structure,” California Department of Developmental Services, last modified September 10, 2019, <https://www.dds.ca.gov/rc/disparities/disparity-funds-program/grant-structure/>.
- vii. “Disparities Data,” California Department of Developmental Services, last modified November 21, 2019, <https://www.dds.ca.gov/rc/disparities/data/>.
- viii. “FY 15-16 Statewide Disparity Measures,” California Department of Developmental Services, https://www.dds.ca.gov/wp-content/uploads/2020/07/Disparities_DisparityMeasuresHowToReadGuide_20200701.pdfLkj.
- ix. “Disparity Funds Program Awarded Projects,” California Department of Developmental Services, last modified June 15, 2020, <https://www.dds.ca.gov/rc/disparities/disparity-funds-program/awarded-projects/>.

Medicaid Programs and Spending for People with ID/DD

An array of policies has expanded provision of LTSS for people with ID/DD in home and community-based settings over the past four decades as part of a growing de-institutionalization movement.

Throughout the 1980s and 1990s, states increasingly expanded their use of Medicaid HCBS waivers and reduced reliance on institutional care. The Affordable Care Act of 2010, Public Law 111–148, promoted supporting individuals in the community rather than institutions through multiple demonstrations and incentives. *See Appendix E: Policy Milestones in Medicaid LTSS for People with ID/DD.*

States use a combination of federal Medicaid authorities and state-only funding to operate programs for people with ID/DD, reflecting a wide range of policy decisions related to financing, services offered and target population(s).

Nearly every state maintains at least one Medicaid HCBS waiver specifically for people with ID/DD. As of 2017, 47 states cover Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IID) under Medicaid, and seventeen states no longer maintain large state-operated ICF-IIDs.⁶² Eight states provide Medicaid 1915(i) state plan services. Eight states provide Medicaid 1915(k) state plan personal care and related services, known as Community First Choice services. Nine states offer ID/DD HCBS services as part of a Medicaid Section 1115 demonstration waiver and four states use 1915 managed care waivers. Forty-five states use non-Medicaid state-only funding

to provide ID/DD HCBS services⁶³ for varied purposes, including services for people not eligible for Medicaid for people on waitlists, and/or services not covered under the state-specific Medicaid HCBS waiver.

While people with ID/DD have been included in mandatory Medicaid managed care for acute and primary care services, only seven states require people with ID/DD to enroll in mandatory Medicaid managed long-term services and supports programs (MLTSS). As of 2019, three states, Iowa, Kansas and Tennessee, * require people with ID/DD to receive all Medicaid-funded services, including LTSS, through managed care plans with full-risk contracts. Several factors influence the exclusion of services for people with ID/DD from MLTSS, including:

- Managed care plans and ID/DD service providers lack experience working with each other
- Managed care plans have not historically served individuals with ID/DD and therefore lack experience with the types of services they receive
- Organized and engaged ID/DD stakeholder communities have resisted and expressed mistrust of MLTSS
- Cost savings are difficult to achieve with the ID/DD population, given that services are largely rebalanced toward HCBS, limiting potential savings from transitioning beneficiaries out of institutional settings

Elements for success in MLTSS programs serving people with ID/DD include the need for incremental program transitions, effective payment policy and support for providers, and critical stakeholder support, particularly among beneficiaries and advocates.⁶⁴

Over the past 35 years, the significant increase in HCBS enrollment has been the primary driver of overall ID/DD LTSS spending growth. (See Chart 1.) Total institutional spending has remained comparatively flat over time, with significantly higher per-person costs keeping the aggregate ICF-IID expenditure level high, despite a declining census. At the same time, total spending on HCBS for people with ID/DD has grown on a steep trajectory that aligns with the rapidly increasing number of HCBS recipients. As states have added HCBS waivers and expanded the number of available slots in existing HCBS waivers, the number of people served has grown tremendously.

* Tennessee has allowed enrollees with ID/DD who were participating in the fee-for-service HCBS waiver system prior to 2016 to remain in Medicaid fee-for-service; all new enrollees with ID/DD receive services through the state's MLTSS program.

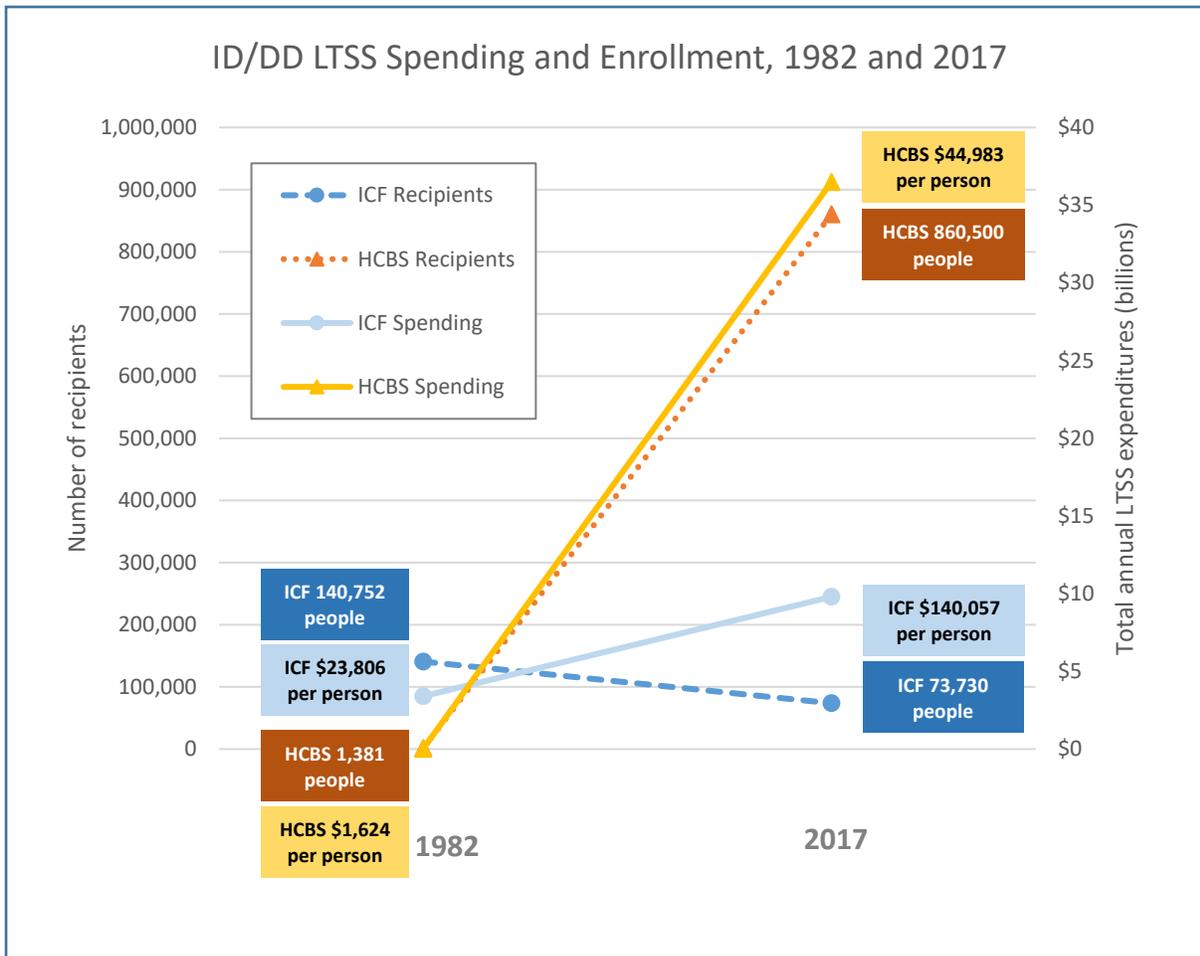


Chart Data Source: Larson, S.A., Eschenbacher, H.J., Taylor, B., Pettingell, S., Sowers, M., Bourne, M.L. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

For people with ID/DD, Medicaid spending on LTSS is more rebalanced towards HCBS than for other populations, while people with ID/DD represent the majority of high-cost Medicaid HCBS users. In 2015, HCBS spending represented 77 percent of LTSS expenditures for people with ID/DD, whereas for older adults, HCBS spending represented only 44 percent of LTSS spending.⁶⁵ HCBS for people with ID/DD has consistently cost significantly less per person relative to institutional care. In 2017, 92 percent of people with ID/DD received HCBS representing 83 percent of total LTSS spending for the population, while 8 percent of people with IDD received institutional care representing 17 percent of total LTSS spending for the population.⁶⁶

People with ID/DD represent a substantial proportion of high-cost Medicaid HCBS enrollees, defined as the top 3 percent for HCBS spending. A 2018 MACPAC-commissioned report found that in 2012, about 60 percent of high-cost Medicaid HCBS users were people with ID/DD and related conditions.^{67,68} Over 56 percent of the HCBS expenditures for high-cost enrollees were for round-the-clock services such as residential group homes.⁶⁹ HCBS waivers with capped enrollment for people with ID/DD that do not include round-the-clock services have been estimated to cost thirty percent less per person as compared

to waivers that include residential and comprehensive services.⁷⁰ In 2012, ID/DD expenditures represented 10.2 percent of all Medicaid spending; for each year 2015-2017, the proportion has been consistently 8.4 percent.⁷¹

Medicaid Home and Community Based Service (HCBS) Waiver Waitlists

States use different approaches for establishing and reporting Medicaid HCBS waiver waitlists, making it impossible to determine how many eligible people on a national basis are going without HCBS while they wait.⁷² Some states require individuals be identified as eligible while others do not, and some states provide some services while people are on waitlists, while others do not. Other state variables include whether states address duplication and how often states verify current or future needs.

Many people with ID/DD wait for HCBS waiver enrollment for years, sometimes decades,⁷³ with many eligible individuals choosing to forgo the opportunity to receive services if they are only available in institutional settings. One 2017 national study found over 182,000 people with ID/DD waiting for HCBS,^{*} with five states reporting waitlists of over 10,000 people each and 13 states reporting no ID/DD waitlists.⁷⁴ Reporting for this waitlist data was limited to eligible people who are on state DD agency caseloads, living with family, who are not receiving any Medicaid-funded HCBS (beyond case management). Among these individuals, about 35 percent were seeking HCBS in order to move out of the family home.⁷⁵

A different national survey of states accepts a broader waitlist definition for people interested in HCBS waiver services, including people who are waiting while living in institutional settings, receiving other HCBS, *or who have expressed interest in services without going through the eligibility process*. This survey estimated the total number of people with ID/DD on state waitlists to be nearly 590,000 in 2018.⁷⁶

Different approaches to Medicaid HCBS waiver waitlists across states include:

- The majority of states do screen potential participants for eligibility; however, eight states allow people to express interest and be placed on a waitlist without determining eligibility.⁷⁷
- Some states maintain separate waitlists for each waiver, some allow people to be on multiple waitlists, and others include people who are currently receiving services on one HCBS waiver and waiting to access a different waiver.
 - ✓ In Texas, each Medicaid HCBS waiver for people with ID/DD has a separate waitlist, and individuals may be on multiple waiver waitlists without having been screened for eligibility, resulting in individuals counted more than once on a list of over 320,000 people.⁷⁸
- States use different processes to manage and prioritize people on their waitlists, with some relying only on “first come, first served” while others consider additional situational factors such as crisis or loss of a caregiver.⁷⁹
 - ✓ In Pennsylvania, the state maintains a detailed Medicaid HCBS ID/DD Waiver waitlist by county, with about 13,000 people currently waiting. The waiting list prioritizes people by

* Waitlist data from the study reflects a 21 percent decline since 2013. (Source: Sheryl A. Larson et al., *In-home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2017* (Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, 2020), 58. https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017).

urgency of need for services (PUNS) in three categories (emergency, critical, planning) in each county. People on the waitlist in Pennsylvania can access supports coordination (case management) and sometimes some limited state-funded resources while the state carefully tracks the waiver services each person needs.⁸⁰

According to many interviewees, states take various approaches to assist people on waiting lists, including providing access to case management services, person-centered planning,^{*} respite, state-funded services, peer support, or Medicaid state plan HCBS. Informal and natural supports, including family and friends as well as non-disability specific community programming and activities, often support individuals who are waiting.⁸¹

Medicaid HCBS Waiver Structures

Many states are providing limited services to a larger number of people through HCBS waivers with a service array that excludes residential services. As noted by both Medicaid and state DD agency staff, states are trying to balance the increasing number of people who need individualized community supports against constrained state budgets and resources. To address this need, some states are operating concurrent HCBS waivers for people with ID/DD with different service levels, often referred to as *support waivers* and *comprehensive waivers*.

Support waivers can be sustainable and cost-effective by offering limited non-residential services under a budget cap to a larger number of people.⁸² Support waivers often offer employment or day services, supports that facilitate community integration or skills development, peer-to-peer or family support, respite and transportation. Families or other unpaid caregivers are relied upon for round-the-clock support as needed.⁸³

States can then reserve more costly service packages for fewer participants in comprehensive waivers, including residential services. Individuals prioritized for comprehensive services are often people with more complex and intensive support needs who are seeking residential services, may have more limited options for natural or family living arrangements, or are at the highest risk of institutionalization.

Text Box 4: Indiana's Use of an HCBS Supports Waiver and HCBS Comprehensive Waiver to Support Faster Access to Some HCBS Waiver Servicesⁱ

In Indiana, most newly eligible ID/DD waiver applicants are able to enroll and receive services in a timely manner through its Family Supports Waiver, a more limited HCBS waiver that does not include residential services and caps individual service budgets at \$17,300 annually. Access to the state's comprehensive HCBS waiver, the Community Integration and Habilitation Waiver, is prioritized for people meeting additional criteria reflecting intensity and urgency of need, such as: individuals experiencing extraordinary health and safety risks; death of a primary caregiver or caregiver over 80 years old; abuse or neglect in their living situation or care setting; or transitioning out of an institutional setting.

- i. "Developmental Disability Services," Indiana Family and Social Services Administration, <https://www.in.gov/fssa/ddrs/developmental-disability-services/>.

^{*} The person-centered planning process is defined in Medicaid regulations at 42 CFR § 441.301(c)(1-3) as required for Medicaid-funded HCBS. Some states provide the opportunity for individuals who are not receiving Medicaid HCBS to access person-centered plan facilitation to assist in achieving goals and outcomes without paid services.

Case Management and Person-Centered Planning

Case management is a key component of person-centered Medicaid ID/DD services and supports.

Regardless of Medicaid funding authority, most states establish the functions of HCBS case management using a variation of the four core elements described in the CMS 1915(c) Technical Guide:⁸⁴ assessment of needs; person-centered planning; referrals to resources and services; and monitoring of services.

Terminology, detailed definitions, and types of entities providing case management for ID/DD programs vary. ID/DD case management services are delivered by private agencies (55 percent of states), state agencies (46 percent of states), sub-state/regional entities (27 percent of states), counties (16 percent of states), managed care plans (11 percent of states), independent practitioners (9 percent of states) and tribes (2 percent).⁸⁵ For people with ID/DD, HCBS case management is often referred to as supports coordination or service coordination, while many Medicaid managed care or integrated care programs refer to case management as care management or care coordination.⁸⁶ This distinction in terminology reflects the philosophical orientation in ID/DD systems towards a social model, as opposed to a medical model. Further, self-directed programs* may offer case management inclusive of supports brokering or counseling to assist self-direction participants with service planning and implementation as well as the identification, hiring and management of providers.⁸⁷

Families and people with ID/DD depend upon HCBS case managers for assistance navigating multiple systems, problem-solving and advocacy across the lifespan.⁸⁸ Several interviewees, including people with ID/DD, advocates and researchers, shared that case managers often serve as trusted guides, assisting people to access supports to pursue a good life while advancing autonomy, dignity and choice. However, stakeholders also report that some case managers often have limited time and capacity necessary to meet all of the complex demands expected of them.

Interviewees noted person-centered planning and good case management are especially important during life transitions, such as adolescents transitioning into adulthood, or when aging parents or family are no longer able to continue providing support. One approach to assist during these episodes of change was mentioned several times -- the Charting the LifeCourse (CtLC) framework and tools⁸⁹ is being incorporated into several states' person-centered planning practices. CtLC creates opportunities for holistic conversations about natural supports, technology, community participation and personal strengths, considering long-term goals and needs -- not just annual paid services. States view the CtLC framework as particularly helpful in developing processes and anticipatory guidance across the stages and transitions people experience from beginning to end of life.

State DD agency officials acknowledge some states experience shortcomings in the coordination of medical care. They indicated HCBS case managers may have limited roles in coordinating and integrating medical services with other aspects of the person-centered plan, especially for individuals living with family. The federal expectation for case management is to provide assistance with accessing "medical, social, educational and other services."^{90,91} Yet, state agency officials and health plan representatives noted ID/DD case management is often based upon a social model focusing primarily on HCBS, inclusive of health and welfare overall but not medical services, especially in non-integrated delivery systems. However, advocates expressed little concern about this gap in health care coordination, instead

* CMS describes self-directed services as allowing the individual to "have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports...Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided." (Source: "Self-Directed Services," Medicaid, Long Term Services & Supports, <https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html>).

worrying more about integrated care management approaches moving ID/DD services back towards a medical model, away from a social model.

Funding, data and program silos between state Medicaid agencies and DD agencies contribute to the lack of care integration and coordination of services for individuals with ID/DD, according to several interviewees. States have a wide range of agency structures that implement health and human services programs, and in many states the single State Medicaid Agency (SMA) is not in the same department as the DD agency. State DD agencies, which are the offices or divisions responsible for implementing programs for people with ID/DD, often have delegated authority from the SMA to operate the Medicaid HCBS waivers for people with ID/DD. Stakeholders note DD Agencies offer deep knowledge and expertise specific to ID/DD, but often do not have access to certain information or may not be involved when the SME is negotiating managed care contracts. State agency staff said these barriers limit not only medical care coordination within HCBS case management, but also result in under-utilization of state plan health services.

Federal Medicaid HCBS regulations require person-centered planning,⁹² and systems are striving to implement and operationalize person-centered thinking, planning and practice in meaningful ways.* To assist states and providers with best practices, the Administration for Community Living (ACL) established a national technical assistance initiative, The [National Center on Advancing Person-Centered Practices and Systems](#), to promote the systemic development of person-centered thinking. Additionally, the National Quality Forum recently published a report with a consensus definition of person-centered planning, core competencies of facilitators, and a framework for measuring the quality of person-centered planning and practice.⁹³

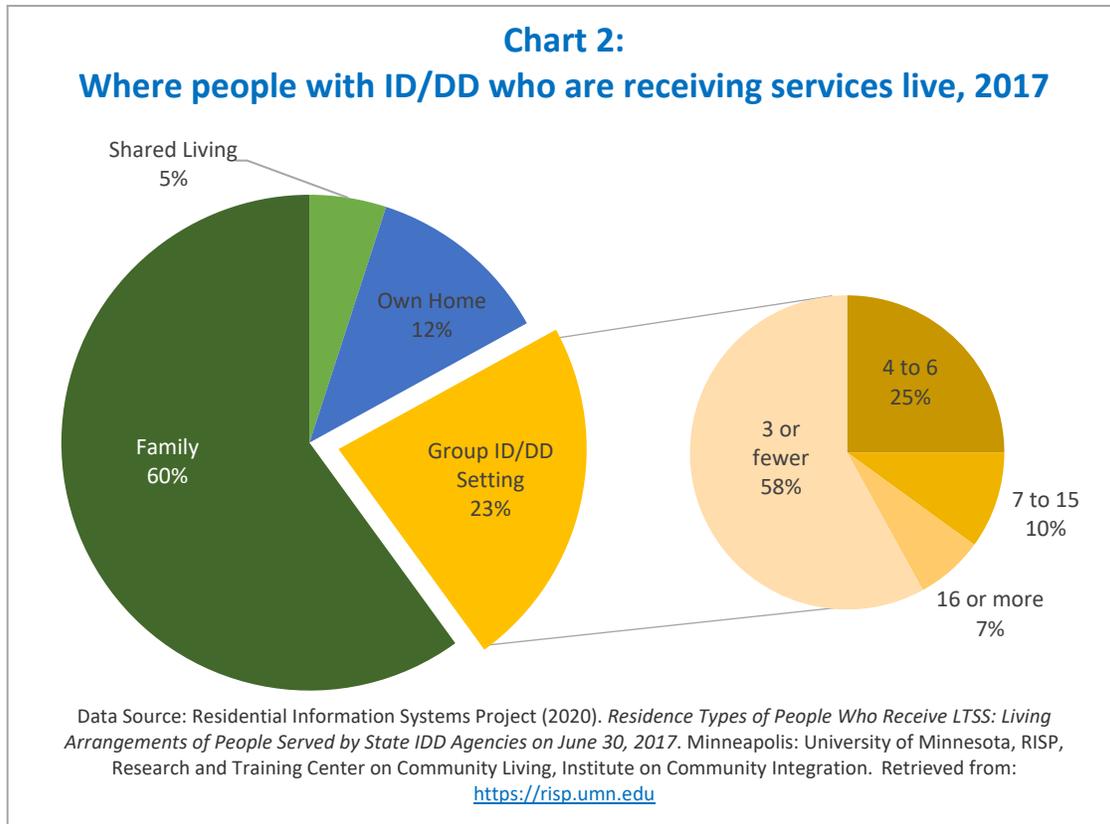
Most states require case managers to be knowledgeable and trained in person-centered planning.⁹⁴ However, researchers interviewed note that the demonstration of person-centered competencies and practice skills are not always required. This may result in gaining knowledge of the technical steps of the planning process without full understanding of the philosophical foundation of person-centered thinking.

Of note, some states have established *person-centered facilitation* as a distinct, non-duplicative Medicaid HCBS waiver service in addition to case management given the complex responsibilities and time constraints of HCBS case managers, and the importance of person-centered planning.⁹⁵

Trends Toward Individualized Supports and Self-Direction

While most states' LTSS for people with ID/DD are largely rebalanced away from institutional care, ID/DD services continue to evolve toward full community integration and individualized supports. As of 2017, three states (Alaska, Michigan, Oregon) had completely eliminated all ICF-IID facilities, 17 states had closed or down-sized their large state-operated ICF-IIDs, and six states had no public or private ICF-IIDs with 16 or more people.⁹⁶ Less than a quarter of people with ID/DD receiving LTSS live in congregate care, as shown in Chart 2. Among those who do, the majority are living in smaller settings.

* State definitions of person-centered thinking, planning, and practice vary but several key principles are common to most definitions, including a focus on the person, an understanding of the importance of choice and self-determination, and a commitment to full inclusion and access to the community. (Source: Jane Lawrence, *Person-Centered Thinking, Planning, and Practice: Representative Examples of State Definitions* (Cambridge, MA: National Center on Advancing Person-Centered Practices and Systems, 2020), 6, https://ncapps.acl.gov/docs/NCAPPS_Definitions_RepresentativeExamples_200930.pdf).



Many stakeholders interviewed noted the generation of people with ID/DD who grew up after passage of the Americans with Disabilities Act (ADA) and in more inclusive schools and communities want to be supported in different ways than the generation of people with ID/DD that moved out of institutions throughout the 1970's and 1980's. People with ID/DD want access to supports that are not tied to buildings and walls, and that enable them to live and thrive in their natural and typical environments – at home, work, school, and in the broader community. Stakeholders expressed there is a need to further develop and deliver services in typical family and individual homes, workplaces and other mainstream, non-disability-specific community environments.

Advocates and researchers interviewed stated that larger HCBS group homes, although not currently categorized as institutional settings, often have institutional characteristics. The 2014 Medicaid [HCBS Settings regulation](#) established clear differences between institutional and home and community-based settings. States and providers were given a transition period and are still working towards full compliance with the regulation. The federal rule requires that HCBS settings are integrated in and support full access to the greater community, ensure individual rights of privacy, dignity and respect, and optimize autonomy and independence in making life choices.⁹⁷ Interviewees indicated that many group homes do not yet demonstrate these qualities. While states continue to work to bring HCBS settings into compliance, it has been challenging,⁹⁸ and CMS has extended the compliance deadline multiple times.*

* The HCBS Settings rule (42 CFR § 441.301(c)) was first published as an Advanced Notice of Proposed Rulemaking in June 2009 and the final rule was effective in March 2014. Initially, the compliance deadline was March 2019, which was later revised to

Stakeholders further noted that in many states, group homes have become the default option for adults with ID/DD who want to move out of their family home, regardless of whether this is their desired living arrangement or whether they require continuous care and supervision. This is due in part to families preferring the consistency and security of a provider-controlled residence. This is also compounded by limited access to alternative housing options that are financially and physically accessible.

Some states have partnered with state housing authorities to create more independent housing options for people with ID/DD, utilizing both state and federal funding.

Text Box 5: Medicaid and Housing

Medicaid funding for institutional care (nursing facilities and ICF-IIDs) includes the cost of room and board as part of the daily rate. But under federal law, Medicaid HCBS must exclude room and board costs, including in residential settings.ⁱ

Per the Medicaid HCBS waiver 1915(c) Technical Guide:

- Room costs are categorized as shelter and property-related costs such as the rental or purchase of real estate and furnishings, maintenance, utilities, and related administrative expenses.

As noted in a previous MACPAC-commissioned report,ⁱⁱ states use several different strategies to try to make room and board more affordable. This can prove challenging when Federal Supplemental Security Income (currently \$783/month) provides the only funds available to an individual for room and board.

- i. Social Security Act, 42 U.S.C. § 1396(n), 1915(c)(1).
- ii. Medicaid and CHIP Payment Access Commission (MACPAC). *State Room and Board Affordability Policies for Residential Care Settings by State, 2016* (Washington D.C.: MACPAC, 2016). <https://www.macpac.gov/subtopic/table-5-state-room-and-board-affordability-policies-for-residential-care-settings-by-state-2016/>.
- iii. "Understanding Supplemental Security Income SSI Benefits – 2020 Edition," Social Security Administration, <https://www.ssa.gov/ssi/text-benefits-ussi.htm#:~:text=Effective%20January%201%2C%202020%20the,SSI%20benefit%20with%20additional%20payments>

While Medicaid HCBS does not cover room and board costs, HCBS waivers can fund housing-related activities and services including transition expenses (when an individual moves from a provider setting to their own residence), tenancy supports to assist an individual to be a successful tenant, and collaborative efforts across public agencies and the private sector to identify and secure housing options for HCBS participants.⁹⁹ State housing collaboration initiatives include:

- Arizona offers housing vouchers and U.S. Department of Housing and Urban Development (HUD) Section 811 housing subsidies* to help people with ID/DD achieve their housing goals without having to rely upon group homes.

March 2022. The current compliance deadline was extended to March 2023. As of June 2020, only fifteen states had final approval of their statewide transition plans to bring all settings into compliance.

* HUD provides funding through the Section 811 Supportive Housing for Persons with Disabilities program to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities. (Source: "Section 811 Supportive Housing for Persons with Disabilities Program," U.S. Department of Housing and Urban Development, https://www.hud.gov/program_offices/housing/mfh/grants/section811ptl).

- The Indiana DD agency collaborates with the Indiana Housing & Community Development Authority to create allocation plans for setting aside and providing housing units to qualified people with ID/DD.
- In partnership with the state Housing and Mortgage Finance Agency, the New Jersey DD agency offers rental subsidies and housing vouchers to people with ID/DD through the state’s Supportive Housing Connection.¹⁰⁰

State Medicaid and DD agencies, researchers and advocates all noted that access to subsidized state and federal housing and voucher programs help some individuals live in more independent settings and can help reduce reliance upon 24/7 services. However, the limited resources for these initiatives leaves a gap between need and program capacity.

States continue to seek alternatives to address housing needs and develop more individualized and sustainable residential options such as Shared Living and Supported Living arrangements. According to advocates, *Shared Living* (also called Host Homes or Adult Foster Care) are preferred by many people with ID/DD over provider-controlled group home settings. At least forty states offer some version of this service.¹⁰¹ In this model, people with ID/DD live with a person or a family who agrees to share their life and provide support, in either their home or the home of the person with ID/DD. Shared Living allows for choice, individualization, and relationship-based living, usually with only one or two people with disabilities living in a home, in a mutually agreed upon arrangement. Participants choose to live together in a relationship that is expected to endure. Multiple stakeholders further noted this model may be more fiscally sustainable than group home models.

Text Box 6: Shared Living Options for People with ID/DD - Pennsylvania

Pennsylvania has established a Lifesharing service option for people with ID/DD, with over 1,600 participating homes, and an expectation that through this service people “will acquire, maintain, or improve skills necessary to live in the community, to live more independently, and to participate meaningfully in community life.”ⁱ While traditional provider agencies experience high staff turnover, the Lifesharing approach offers a more stable relationship with the people providing supports. A review of 842 participating Pennsylvanians receiving the Lifesharing service showed that 31 percent had lived together for five years, 15 percent for ten years, and 9 percent for fifteen years or more.ⁱⁱ

“Pennsylvania Consolidated Waiver (0147.R06.00),” Medicaid, July 1, 2017, <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/83016>.

i. Pennsylvania Office of Developmental Programs, “FY 2008-09 Lifesharing Through Family Living Directory Lifesharing Agency Survey Results”, PowerPoint Presentation, p. 5.

Supported Living is another related service option offered in some states which enables a person to live in their own home and receive support from live-in staff or intermittent services. It also provides autonomy and relationship-based living, in which the person with ID/DD chooses who to live with and is not subject to losing their home if they decide to change providers.¹⁰² For example, Oregon defines the purpose of Supported Living as creating “opportunity for an individual to live in the residence of his or her choice within the community with recognition that the needs and preferences of the individual may change over time.”¹⁰³

Employment and day services (See Table 3) are a growing component of HCBS for people with ID/DD, yet individuals are often unable to pursue their employment goals, participating in day services instead. In 2017, states spent over \$9.12 billion on these services, up from \$6.62 billion in 2016.¹⁰⁴ Over 641,600 people with ID/DD participated in employment and day services in 2017, an increase of over

200,000 people per year since 1999.¹⁰⁵ However, only about 20 percent of people with ID/DD receive integrated employment services,¹⁰⁶ despite CMS policy to encourage integrated employment. * Research indicates that ID/DD HCBS resources have not shifted away from facility-based work towards integrated employment,¹⁰⁷ and participation in non-work day services continues to grow.¹⁰⁸ In 2017, less than 12 percent of HCBS day and employment funding was spent on integrated employment services,¹⁰⁹ yet research has documented that many people with ID/DD want to participate in the general workforce.¹¹⁰ Among individuals who do not have a paid job in the community, nearly half indicate they would like a job, and within this group 60 percent do not have this goal documented on their individual person-centered plan.¹¹¹

TABLE 1. DESCRIPTIONS OF DAY AND EMPLOYMENT SERVICES FUNDED BY STATE DD AGENCIES*

Type of Setting/Service	Work	Non-Work/Day Programs
Community	Integrated employment services are provided in a community setting and support or lead directly to paid employment of the participant. Specifically, integrated employment includes services that support entering or maintaining competitive employment, individual supported employment, group supported employment, and self-employment supports.	Community-based non-work includes all services that are focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. It does not include paid employment.
Facility	Facility-based work includes all employment services that occur in a setting where the majority of employees have a disability. These activities occur in settings where continuous job-related supports and supervision are provided to all workers with disabilities. This service category is typically referred to as a sheltered workshop, work activity center, or extended employment program.	Facility-based non-work includes all services that are located in a setting where the majority of participants have a disability. These services do not involve paid employment of the participant.

* In 2011 CMS issued a policy bulletin that provides guidance for the development of employment-related service definitions in Medicaid HCBS 1915(c) waivers, establishing individual integrated employment as a priority goal. This guidance has since been incorporated into the CMS 1915(c) Technical Guide, which describes integrated employment as “paid employment at or above the minimum wage in an integrated setting in the general workforce, in a job that meets personal and career goals.” (Source: *Updates to the §1915(c) Waiver Instructions and Technical Guide Regarding Employment and Employment Related Services*, U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS), Center for Medicaid, CHIP & Survey Certification (CMCS), https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf).

* Jean Winsor et al., *StateData: The National Report on Employment Services and Outcomes Through 2017* (Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion, 2019), 15, https://www.thinkwork.org/sites/default/files/files/bluebook2019_Final.pdf.

The majority of stakeholders interviewed noted self-direction is an important option for people with ID/DD, and it is most effective when there are robust supports to assist people in managing their plans and services. Self-direction allows the individual to have decision-making authority over certain services and take direct responsibility to manage their services. It promotes personal choice and control over delivery of services, including who provides the services and how services are provided.¹¹² There are a range of self-direction approaches with varying degrees of decision making and control over services and budgets, and varying levels of support provided to assist with the process.¹¹³ Most common is *employer authority*, which gives the participant decision-making authority to recruit, hire, train and supervise the individuals who furnish their services.¹¹⁴ According to researchers, fewer states are implementing full *budget authority*, whereby participants also have decision-making authority over how the Medicaid funds in their budgets are spent on goods and services.¹¹⁵ Researchers and advocates note that lack of budget authority may reduce innovation and the appeal of self-direction for some people.

Multiple evaluations of self-direction programs have found high levels of satisfaction among participants, with health and safety concerns equivalent or lower than for people using agency-managed supports.¹¹⁶ Employment and community participation increase among users of self-direction, as compared to people with ID/DD who did not use a self-directed service delivery option.¹¹⁷ Self-directed services are largely cost-effective.¹¹⁸ Many state DD agency administrators credit people with ID/DD and their families for their careful management of self-directed resources as one aspect of cost savings.¹¹⁹

Advocates and people with ID/DD feel that self-direction requirements and processes are too complex in many states, which disincentivizes participation and makes it less likely that the person with ID/DD is the person directing services and making the decisions. Self-direction requires invested and well-trained case managers and/or support brokers to assist participants in meeting program requirements.¹²⁰ For example, [Wisconsin's Include, Respect, I Self-Direct \(IRIS\) program](#), one of the country's largest and longest operating full-budget and full-employer authority models with over 20,000 participants, requires participants to work with support brokers called IRIS Consultants. IRIS Consultants assist individuals with person-centered service plan development, identification of providers and resources, budget management, and meeting program requirements. About one-third of Wisconsin's HCBS participants with ID/DD choose the IRIS program.¹²¹

Stakeholders emphasized the importance of ensuring the rights and preferences of the person with ID/DD are asserted and protected in the planning and delivery of services and supports. Several stakeholders shared that for many people with ID/DD, exercising choice and self-determination* requires that they get assistance in understanding complex information and developing needed skills to advocate for their own preferences and decisions.

Legal decision-making support options for people with ID/DD are evolving, with new and expanded alternatives to guardianship available, including supported decision-making. [The National Resource](#)

* As defined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000, self-determination activities “result in individuals with developmental disabilities, with appropriate assistance, having: the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individual receives; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and contribute to their communities; and support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.” (Source: The Public Health and Welfare, 42 U.S.C. § 15002(8) (2002)).

[Center for Supported Decision-Making](#) describes supported decision-making as supports that “help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to help understand the issues and choices; ask questions; receive explanations in language he or she understands; and communicate his or her own decisions to others.”¹²²

Supported decision-making as an alternative to guardianship enables people with ID/DD to better engage in important decisions about HCBS and to self-direct. At least fifteen states have passed or are actively considering laws related to supported decision-making.¹²³ Stakeholders noted establishing supported decision-making agreements and processes can help effectuate the CMS requirements that an individual receiving HCBS will lead the development of their person-centered plan and the plan will reflect the preferences of the individual.¹²⁴

There is increasing interest in the impact of decision-making authority and guardianship on HCBS outcomes for people with ID/DD. Recent NCI data reflect that a significant proportion of respondents, 68 percent, are under guardianship.¹²⁵ People with ID/DD who have guardians are:

- More likely to live in group residential facilities (32 percent versus 28 percent),
- More likely to take medications for behavior challenges (49.9 percent vs. 42.1 percent)
- Less likely to work in a paid community job (13.8 percent vs. 17.7 percent)¹²⁶

Many states are expanding access to technology solutions in HCBS to complement direct supports provided by workers and to increase independence for people with ID/DD.¹²⁷ In a recent survey of state DD agencies, more than half of responding states require consideration of technology options as part of HCBS service planning.¹²⁸ From 2015 to 2017, both the number of people with ID/DD using HCBS technologies and state investments in these options more than doubled.* Technology covered by many states includes environmental adaptations and home modifications, assistive technology and vehicle modifications. A smaller number of states cover technology training, smart home technology or technology-based companion care.¹²⁹

The literature indicates technology assists people with ID/DD in a multitude of ways,^{130, 131} including communication, social engagement and inclusion,¹³² navigation and wayfinding,¹³³ cueing and reminders,¹³⁴ health supports,¹³⁵ assistance with skill development and employment tasks.¹³⁶ One researcher interviewee noted technology can be best utilized not to replace human support, but to assist with independence and make relationships more efficient and effective.

Remote supports, when in-person support is reduced through the use of technology and off-site personnel, offer increased independence as well as a sense of security for an increasing number of people with ID/DD, with at least twenty-one states funding these services as HCBS program benefits.¹³⁷ Different models are emerging and evolving. Many allow for ongoing monitoring, synchronous communication and real-time response and problem-solving provided by direct support professionals at another location, with the ability to dispatch on-site assistance to the home as warranted.¹³⁸ Providers and state DD agencies note that remote supports can supplement the workforce, helping with worker shortages.

* The number of people with I/DD using personal support technologies, remote supports and smart home technologies grew from 2754 to 6110, while expenditures increased from \$6.87 million to \$16.63 million annually, 2015-17. (Source: Shea Tanis and Barbara Brent, “State of the States in Technology,” (Conference Presentation, September 2018).

Notably, several states (including Ohio, Missouri, Tennessee, and others) have formed a Technology First consortium to develop strategies for incorporating technology as a critical element of Medicaid HCBS to improve outcomes and maximize independence for people with ID/DD.¹³⁹

Supporting Families Across the Lifespan

The majority of people with ID/DD live with their families across the lifespan. It is estimated that of the 7.4 million Americans with ID/DD in 2017, 72 percent lived with a family caregiver, 18 percent lived alone or with a roommate or spouse, and 10 percent lived in a supervised residential setting.¹⁴⁰

The literature describes a range of experiences among families supporting a family member with ID/DD, including differences related to race, gender and age.

- Families who feel empowered and confident in assisting their family member with ID/DD are more resilient and able to adapt to the needs of their loved one and evolving life circumstances.¹⁴¹
- Families who are more involved in coordinating services, and those receiving self-directed services, experience less caregiver stress.¹⁴²
- Caregiving families co-residing with an adult with ID/DD report lower marital stability, reduced leisure time, higher limitations in parental ability to do address their own activities of daily living (ADLs), and lower health-related quality of life.¹⁴³
- Existing health disparities among people of color are more pronounced among caregiving families of color, who experience poorer health outcomes than their white counterparts and poorer health outcomes than non-caregiving families.¹⁴⁴
- Parents, especially mothers, experience fewer opportunities for employment and less expansive social networks.¹⁴⁵
- Aging-related health or functional declines among parents is significantly related to having fewer informal supports helping the person with ID/DD.¹⁴⁶

Families have a long history of problem-solving without reliance on paid residential services for their family member with ID/DD. Researchers and advocates both note families have created their own innovative approaches that contribute to community integration and great outcomes for their loved ones. States also recognize this and are seeking to learn from families and people with ID/DD, and from one another. For example, nineteen states are participating in the [National Community of Practice for Supporting Families Across the Lifespan](#). They are using the [Charting the LifeCourse framework](#), developed in partnership with families, to consider the preferences and needs of the person with a disability within the context of family.*

States are supporting families to develop skills as facilitators of a good quality of life for both their family member(s) and themselves. As noted by state DD agencies, state support for families is extending beyond providing respite and other forms of direct care, to innovative HCBS such as family education and training, family-to-family peer networks, and access to supported decision-making.

* The Charting the LifeCourse framework helps individuals and families address goals and support needs across the lifespan in six domains (Daily Life & Employment, Community Living, Safety & Security, Healthy Living, Social & Spirituality, Citizenship & Advocacy), creating opportunities for conversations about natural supports, technology, community participation and personal strengths as well as paid services. (Source: George S. Gotto, "Supporting Families Through the Charting the LifeCourse Framework," *Intellectual and Developmental Disabilities* 57 no. 1, (Feb 2019): 56-65, <https://doi.org/10.1352/1934-9556-57.1.56>).

Through these initiatives, they are helping families understand the importance of maintaining high expectations for people with ID/DD to contribute and participate in decisions, develop self-advocacy skills, and establish strong community relationships in order to achieve positive quality of life outcomes.

States are increasingly including paid family caregivers to address workforce shortages. Research has shown that paid family caregivers are more reliable and flexible, more sensitive to the person's needs, provide quality care that produces better health and satisfaction outcomes, and may be more cost effective than agency-based service providers.¹⁴⁷ Advocates, researchers and people with ID/DD share that paying family caregivers requires oversight to ensure that the choices of the person receiving supports remain paramount, and the economic and employment needs of the paid family member do not dictate decisions about services and supports for the person with ID/DD. States such as Maryland include provisions in their HCBS waivers to ensure people with ID/DD drive decisions about their services and supports, particularly when paid caregivers are legally responsible guardians or relatives.

Text Box 7: Maryland HCBS Waiver Program Requirements for Paid Legal Guardians and Relatives

Maryland requires that the following are met and documented in the person-centered plan when a legal guardian or a relative is paid to provide services to a person with ID/DD:

- Choice of the legal guardian or relative as the provider truly **reflects the participant's wishes and desires**
- The provision of services by the legal guardian or relative is **in the best interests of the participant** and his or her family
- The provision of services by the legal guardian or relative is **appropriate and based on the participant's identified support needs**
- The services provided by the legal guardian or relative **will increase the participant's independence and community integration**
- There are **documented steps** in the PCP that will be taken **to expand the participant's circle of support** so that he or she is able to maintain and improve his or her health, safety, independence, and level of community integration on an ongoing basis should the legal guardian or relative acting in the capacity of employee no longer be available
- A **Supportive Decision Making (SDM) agreement** is established that identifies the people (beyond family members) who will support the participant in making her or his own decisions
- The **legal guardian or relative must sign a service agreement** to provide assurances that he or she will implement the PCP and provide the services in accordance with applicable federal and state laws and regulations governing the program.ⁱ

i. "Application for a §1915(c) Home and Community-Based Services Waiver," Maryland Community Pathways Waiver Renewal, July 2018, <https://dda.health.maryland.gov/Documents/Community%20Pathways%20Waiver%20Renewal%20Approved%20Waiver%20effective%20July%201,%202018%20.pdf>

Approaches that focus on supporting all members of the household may be helpful in addressing the needs of both adults with ID/DD and their aging caregivers. Approximately one-quarter of individuals living with family members (both those receiving publicly-funded supports and those who are not) are living with family caregivers over the age of 60.¹⁴⁸ States are interested in multi-generational, integrated

systems of support extending to aging parents of adults with ID/DD as the parents begin to develop their own LTSS needs. These structures do not currently exist. NASDDDS indicated that states are interested in developing waivers to address this need, but little progress has been made. Additionally, state DD agencies and researchers note that many public programs targeted at older adults have not considered the needs of older people with ID/DD.

Siblings often have the longest relationships during the life of a person with ID/DD, but many families do not include them in the process of planning for future caregiving arrangements.¹⁴⁹ Siblings often take over caregiving and support responsibilities from aging parents.¹⁵⁰ Even though many people with ID/DD are now outliving their parents, parents often do not have future caregiving plans in place and are reluctant to consider changes of residence for the family members they are supporting.¹⁵¹ When parents provide good care for their family member with a disability, siblings are more likely to also provide a high level of support – however, when parents have struggled, siblings are less likely to assume that caregiving role.¹⁵² Additionally, there are generational differences in family perspectives about supporting people with ID/DD. As advocates and people with ID/DD shared, siblings often have different expectations for their brothers and sisters than their parents do, seeking community inclusion and independence as much as worrying about health and safety.

Workforce Issues and Challenges

The responsibilities of direct support professionals (DSPs) working with people with ID/DD are complex and require a range of skills. The role of many DSPs reaches far beyond addressing basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs). While DSPs often provide personal care to people with ID/DD, they are also expected to facilitate engagement in the community, assist in skills development, and contribute to improved quality of life. They are expected to provide habilitative supports and services, those that help individuals keep, learn and improve skills and functioning for daily living.¹⁵³ The role encompasses efforts that support increased independence, pursuit of individual goals, prevention and navigation of crises, relationship and friendship building in the community, and participation in broader society.

Providers and advocates interviewed pointed out that DSPs providing habilitative supports, as well as their direct supervisors, often require a different level of skills and knowledge than personal care attendants offering primarily physical personal care. The distinction between these roles is important when states consider ID/DD service definitions, including staff qualifications and wages. Further, providers interviewed noted that the Bureau of Labor Statistics does not include an appropriate Standard Occupational Code for DSPs, making it difficult to define their role in a consistent way and for states to develop sufficient provider reimbursement rates as required by federal law.*

Nearly every stakeholder indicated that high turnover rates, consistent vacancies, and low wages limit provider capacity to serve people with ID/DD and compromise the overall quality of services provided. There is a significant and growing shortage of DSPs in all service categories of LTSS for people with ID/DD. In 2017, the average DSP turnover rate was 43.8 percent among ID/DD provider agencies. The full-time vacancy rate was 8.1 percent and the average part-time vacancy rate was 17.3 percent.¹⁵⁴ Nationally, the average wage for DSPs in 2017 was \$10.72,¹⁵⁵ well below the typical living wage (\$16.07 in 2017¹⁵⁶), making it harder to recruit workers.

* Social Security Act §1902(a)(30)(A) requires that states assure that Medicaid “payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers”

DSP staff shortages create multiple challenges that affect the quality of services provided to people with ID/DD which include:

- Workers tired from long hours or multiple jobs make mistakes and have lower tolerance for stressful situations.
- Substantial investment in overtime payout is required to overcome staff shortages¹⁵⁷
- Workers who take over vacancies and do not know the person they are supporting may not recognize signs and symptoms of illness and may not understand individualized support needs such as positive behavior supports.
- Lack of DSPs to support people with ID/DD causes family frustration, stress, health issues and burnout, posing an additional societal cost.¹⁵⁸

Improving the quality of the DSP workforce and creating better career opportunities are critical to maintaining and sustaining a system that effectively supports people with ID/DD. All stakeholders interviewed expressed that increases in DSP wages and benefits are needed to address DSP shortages and to improve quality. Researchers noted that credentialing and competency requirements could also help increase wages, expand retention, and improve quality.

Some states offer small wage increases to DSPs if they achieve certain training or competencies.

- Ohio increases wages by one dollar per hour for workers who complete 60 hours of eligible competency training and work for at least two years directly with people with ID/DD.¹⁵⁹
- TennCare, Tennessee's Medicaid program, developed a value-based purchasing initiative to promote quality in LTSS, [Quality Improvement in Long Term Services and Supports \(QuILTSS\)](#), that incorporates a comprehensive career ladder and education system for DSPs and other LTSS staff. QuILTSS is linked to the higher education and workforce development systems, which allow direct support workers to participate in multiple levels of workforce training courses, some even connected to advanced degrees, and earn credentials that may result in higher wages.¹⁶⁰

Advocates with ID/DD emphasized in interviews that people with disabilities want the right to define the training expectations and competencies expected of their own workers at the individual level, in order to assure that each DSP is able to meet the needs and preferences of each person they support. This includes cultural and linguistic considerations, and the opportunity for people receiving services to define additional qualifications beyond state requirements.*

People with ID/DD, advocates, researchers and state DD agencies indicated that a lack of access to disability-competent and appropriate clinical care is a challenge for many people with ID/DD. The literature has documented that people with ID/DD often face difficulty when moving from pediatric to adult care, causing many young adults with disabilities to continue to see pediatric clinicians into adulthood.^{161,162} Adults with ID/DD face challenges finding primary care physicians who will listen to them and take the necessary time with them. Very few physicians are reimbursed for that extra time. Advocates expressed a desire to find physicians with the time and interest to seek holistic understanding

* For example, under the Medicaid Community First Choice option, individuals have the right to train providers in the specific areas of assistance needed by the individual, and to have assistance provided in a manner that comports with the individual's personal, cultural, and/or religious preferences, as well as the right to establish additional staff qualifications based on the individual's needs and preferences and access training to meet those qualifications, per 42 CFR 441.565(a)

about the person, including their communication and support needs to participate in their own health care. They also prefer doctors who value and encourage their health and wellness regardless of their disabilities.

In order to improve access to effective health care, clinicians including physicians, dentists, and behavioral health professionals need basic training and information about people with ID/DD.

Multiple stakeholders including state Medicaid and DD agency officials as well as advocates identified that among health care professionals, a low level of awareness about people with ID/DD and a lack of understanding creates barriers to quality clinical care, and sometimes discriminatory treatment. Some healthcare providers focus on the patient's disability as their defining characteristic instead of hearing the specific concerns of the person or family, and some assume that the quality of life of a patient with a disability is 'poor' which can result in less aggressive treatment of an acute problem.¹⁶³

Clinicians report feeling they have not been inadequately prepared to engage in the care for adults with ID/DD, even among those focused on the care of patients with ID/DD.¹⁶⁴ In one study, physicians demonstrated negative misconceptions about adults with ID/DD, identified themes of "operating without a map" and lack of knowledge. They expressed discomfort with patients with ID/DD including anxiety about challenging behaviors exhibited by some patients, and articulated a need for more exposure and experience with people with ID/DD.¹⁶⁵ Physicians also felt they could not identify appropriate resources to assist them in caring for people with ID/DD.¹⁶⁶ Consistent with the views of advocates, providers note complexities with navigating regulations and payment policy and experiencing financial disincentives to spend more time with people requiring more complicated care.¹⁶⁷

There are examples of training for clinical professionals noted by stakeholders, including:

- [Operation House Call \(OHC\)](#), a program operated by The Arc of Massachusetts, in which families and individuals with ID/DD educate young medical professionals about essential skills needed to work with people with ID/DD. Experiential learning takes place during home visits to people with ID/DD. OHC is a requirement for all third-year medical students in their pediatric rotation at Boston University and is available at Tufts Medical School, Simmons School of Health Sciences and Yale School of Nursing. The Arc reports that families and people with ID/DD volunteer to train about 600 medical professionals annually.
- Federally funded Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs operate through university systems across the country. LEND programs work to advance workforce capacity by preparing students from multidisciplinary clinical professions to develop competence to work with the ID/DD population.¹⁶⁸ The LEND program also involves experiential learning provided by families and people with disabilities.

Both researchers and advocates noted that defining ID/DD as a Medically Underserved Population (MUP) would help begin to improve healthcare disparities and clinical provider access issues by making additional resources available to focus on the needs of people with ID/DD. The federal designation as a MUP is determined by the U.S. Health Resources and Services Administration (HRSA) to help prioritize access to primary care services and to address workforce shortage areas.^{169,170} MUP designation would allow states to consider people with ID/DD when assessing whether there are shortages of physicians to serve certain population subsets (e.g. Medicaid-eligible, low income, homeless, migrant farmworkers, or Native American/Alaska Native). It would provide access to federal programs such as the National Health Service Corps, Nurse Corps, and physician loan repayment programs, to address the physician shortage.¹⁷¹

Behavior Supports and Mental Health Integration within ID/DD Services

Behavior supports and mental health treatment are critical for people with ID/DD. Many people with ID/DD, with or without psychiatric diagnoses, require behavior support services to help them improve adaptive skills and positive functioning.¹⁷² Additionally, nearly half of the people receiving ID/DD services are formally diagnosed with a co-occurring mental health condition.¹⁷³ For all of these individuals, gaps in access to a full continuum of appropriate and coordinated behavior supports and mental health services can create health and safety issues,¹⁷⁴ including the following:

- Individuals may experience victimization, misunderstandings resulting in criminalization of behavior, or traumatic transitions in care or living arrangements.
- Medications may be inappropriately used to control behavior, or challenging behavior may escalate into crises.¹⁷⁵
- Impairment of developing coping and executive functioning skills,¹⁷⁶ resulting in fewer social relationships and contributing to adverse mental health.¹⁷⁷

People with dual diagnosis of ID/DD and psychiatric conditions are at risk of poor outcomes, including higher rates of institutionalization and adverse health results. More than half of the people remaining in large public ICF-IIDs have behavior disorders,¹⁷⁸ and people with ID/DD are over-represented in state forensic settings for people with psychiatric diagnoses.¹⁷⁹ In 2017, 17% of admissions to large public ICF-IIDs came from correctional facilities.¹⁸⁰ People with ID/DD who experience severe behavioral challenges or psychiatric conditions are at higher risk of incarceration, and they often lose access to rehabilitative services and behavior supports when they enter criminal justice systems.¹⁸¹ Compared to other individuals with ID/DD, people with dual diagnosis of ID/DD and mental health conditions are also less likely to live at home with family and more likely to live in a group residential setting. They experience poorer health outcomes, with higher rates of obesity, high blood pressure and diabetes.¹⁸²

Multiple interview participants, including state Medicaid and DD agency staff, noted an unmet need for behavioral health providers who are comfortable and knowledgeable in working with people with ID/DD. Clinicians without experience interacting with people with ID/DD often struggle to diagnose and treat their psychological symptoms, especially in people with limited communication abilities.¹⁸³ Some behaviors in people with ID/DD typically ascribed by clinicians to mental health conditions may actually relate to the etiology of the person's disability, may be an expression of pain or a physical health problem, may be driven by psychosocial or environmental stressors, or may indicate unmet behavioral support needs.¹⁸⁴ Conversely, psychiatric conditions sometimes go undiagnosed, complicated by many factors including medications, differences in presentation and lack of expertise on the part of the clinician.¹⁸⁵ These clinical challenges have been well documented in the literature, including one study that indicated that over 90 percent of psychiatrists felt they did not have the training or skills to work with people with intellectual disabilities.¹⁸⁶ The scarcity of mental health providers competent to treat people with ID/DD often causes people to go to the hospital for crisis intervention, resulting in higher emergency department visits and inpatient admissions.¹⁸⁷

Interviewees acknowledged the difficulties of collaborating across systems to help people identify and access appropriate mental health services and interventions. The silos between mental health and ID/DD systems are also documented in the literature.¹⁸⁸ As noted by both advocates and state DD agency staff interviewed, mental health delivery systems, often already overwhelmed and under-resourced, struggle to serve people with ID/DD. Few systems have built formal coordination structures across mental health and ID/DD services.

Text Box 8: Arkansas - Seeking to Bridge the Gap Between ID/DD and BH services

In Arkansas' Provider-Led Arkansas Shared Savings Entity (PASSE) model, launched in 2019, people with ID/DD participate in a fully integrated managed care model including HCBS. PASSE was developed to serve both people with ID/DD and people with BH needs, but the state and the health plans found that most providers have remained focused on one or the other population. In response, the state is developing a "combined" provider type with qualifications to work with both populations, including people with dual diagnosis of ID/DD and mental health conditions. It has also developed a higher capitated reimbursement rate for services provided to people with dual diagnoses, to develop an array of coordinated services that is more effective for these individuals.

State DD agency interviewees and researchers indicated many states have developed Medicaid HCBS waiver services such as positive behavior supports and crisis services to address the needs of the ID/DD population. Positive behavior supports assist in the development of adaptive skills to minimize challenging behaviors. This may include psychological and functional behavioral assessments, behavior support plan development, counseling, therapy, and positive behavior training for support staff and family members.¹⁸⁹ States also include crisis services with the goal of assisting a person with ID/DD to remain in a home or community setting by addressing acute and urgent mental health needs.¹⁹⁰ As indicated by state DD agency staff, these services are often critical in diverting people from institutional admissions. According to NASDDDS and researchers interviewed, one behavior supports initiative, among others, that a few states have found to be successful is the Systemic, Therapeutic, Assessment, Resources, and Treatment (START) model, which takes a holistic and integrated approach to addressing behavioral health, physical health and psychiatric needs of people with ID/DD.

Text Box 9: Systematic, Therapeutic, Assessment, Resources, and Treatment (START)^{i, ii}

The START model was developed at the University of New Hampshire to provide community-based crisis intervention for individuals with ID/DD and mental health needs. It is a person-centered, solutions-focused approach that utilizes positive psychology and other evidence-based practices, as well as including families and DSPs in the program as collaborators and supporters for the person with ID/DD. The tertiary-care model focuses on continuous quality improvement, outcome monitoring and peer-to-peer learning. Peer-reviewed research shows a significant decrease in psychiatric hospitalizations and emergency department visits among START participants. Once cited by the U.S. Surgeon General's Report as a model program, START is now implemented in 10 states: California, Colorado, Connecticut, Iowa, Maryland, New York, New Hampshire, North Carolina, Rhode Island, and Texas.

- i. "The START Model," Center for START Services, Institute on Disability/UCED, University of New Hampshire, <https://www.centerforstartservices.org/>
- ii. Luther G. Kalb, et al., "Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with the START Program," *American Journal on Intellectual and Developmental Disabilities* 124, no. 1 (Jan 2019): 25-34, <https://doi.org/10.1352/1944-7558-124.1.25>.

Information Technology, Data Analysis and Quality Metrics

To better understand the prevalence of ID/DD and the health status, health determinants, and health needs of people with ID/DD, there is need for national health surveillance data and additional analysis of clinical and administrative data.¹⁹¹ Historically, a significant number of people with ID/DD have not been included in health surveillance data, affecting our understanding of prevalence and the

characteristics that contribute to their health.¹⁹² Institutionalized persons are not counted in U.S. health surveillance surveys. Further, it is estimated that this data only identifies about 60 percent of adults with ID/DD who are living in the community.¹⁹³ The most recent national ID/DD prevalence data comes from the National Health Interview Survey—Disability (NHIS-D) conducted in 1994-1995, which has since been updated on a very limited basis.¹⁹⁴

People with ID/DD are not readily identifiable in many health and human service data sets. People who are not participating in Medicaid LTSS requiring ID/DD eligibility may not be identified as individuals with ID/DD in the Medicaid data, including Medicaid administrative claim and encounter data which likely undercount the population of people with ID/DD.¹⁹⁵ Further, researchers interviewed noted that accuracy of claims data depends on coding and decisions made at the point of service. For example, an emergency room clinician treating a person with a broken leg may not code ID/DD in the encounter, because ID/DD is not relevant to the delivery of care in that circumstance. These factors contribute to the limited publicly available national research and data on the health care utilization patterns specific to Medicaid beneficiaries with ID/DD.

Gaps in state ID/DD system information technology (IT) infrastructure and data analysis capacities limit data-driven program policies and decision-making. Stakeholders identified a number of factors at the state and federal levels contributing to information technology infrastructure and data analysis challenges which include:

- Lack of federal and state investment in information technology infrastructure to collect and manage data on HCBS at the provider, case management and state system levels
- Limited coordination between state Medicaid agencies and state ID/DD operational agencies to understand and access the enhanced federal matching funds available for Medicaid Management Information Systems (MMIS) and Medicaid Eligibility and Enrollment Systems
- Medicaid state plan and HCBS waiver program siloes that prevent or limit opportunities for state Medicaid and DD agency staff to share, leverage and analyze data important to ID/DD policy and program decisions

Waiver expenditure data do not provide the full picture needed to assess ID/DD services and whether the holistic needs of people with ID/DD are being met. State DD agencies operating Medicaid HCBS waivers noted they need the opportunity and capacity to review and analyze a broad range of data such as Medicaid claims and encounter data, critical incident reporting, program monitoring, case management data and other important information as they prioritize policy and resource choices. However, many state ID/DD agencies do not have access to all of the Medicaid data about the people with ID/DD they serve.

Ohio provides an example of an ID/DD operational agency's ability to improve the health of people with ID/DD when provided access to Medicaid data. The Ohio Department of Developmental Disabilities reviewed data on hospitalizations of people with ID/DD compared to the general Medicaid population, identifying an extraordinarily high admission rate for septicemia/severe sepsis.¹⁹⁶ The department implemented interventions to reduce infection rates by engaging with county boards and ID/DD providers to provide additional technical assistance and training, as well as educational outreach to case managers, providers and family caregivers.

There are varying levels of confidence and trust in the functional assessments, associated algorithms and statistical methodologies used for the allocation of resources and services for people with ID/DD.¹⁹⁷ Under federal HCBS regulations, states are required to assess the needs of each person served as part of person-centered planning.¹⁹⁸ States are increasingly using standardized functional assessment

tools to determine the level of HCBS resources available to people with ID/DD, relying on algorithms incorporated in assessment tools or used by the state to categorize assessment results, aligning assessment scoring to individual budgets or service grouping tiers.^{199,*} As relayed by providers, advocates and researchers, using these instruments to identify individual needs and to determine an equitable allocation of resources has proven challenging for some states, even as they become more sophisticated in their statistical analysis. As noted by legal advocates, decisions limiting allocation of resources based solely on assessment data can become the basis for litigation against the state or health plans when individuals are unable to receive adequate services and supports to remain healthy and safe in the community.

States are seeking to develop ID/DD HCBS quality outcome metrics that are comparable, valid, reliable and useful, and reflect quality of life across multiple domains. Beyond the IT infrastructure issues, challenges mentioned by state DD agencies and researchers include the limitations of administrative datasets, subjectivity in determining and measuring quality of life, and resources necessary to collect robust consumer experience data at an effective sampling rate. States rely on the [National Core Indicators](#) (NCI) to monitor state-level systems performance across multiple domains, and to compare across states. Researchers noted NCI has limited applicability for disaggregated purposes such as identifying local trends, assessing provider quality, or understanding individual outcomes.

The lack of valid and reliable measures that can appropriately attribute specific outcomes to Medicaid-funded ID/DD services limits states' ability to move toward payment structures that incentivize quality in ID/DD services. As noted by one interviewee, federal Medicaid HCBS waiver quality assurance and performance reporting requirements focus on process and compliance, limiting state Medicaid and ID/DD agency capacity to prioritize development of quality measurement based on individual outcomes to complement the process measures. Relatedly, in September 2020, CMS released a "Request for Information on a Recommended Measure Set for Medicaid-Funded Home and Community-Based Services," seeking public input on the potential benefits and challenges of a national voluntary set of recommended measures to assess quality and outcomes for HCBS.²⁰⁰

Health plans stated it is challenging to engage states and stakeholders in testing value-based approaches and innovations in service delivery for people with ID/DD. A few states and health plans are testing alternative payments on a limited basis, starting with incentives and outcome payments for employment services that result in a person with ID/DD getting or maintaining competitive integrated employment.[†]

* In 2016, MACPAC published a report and 50-state inventory on State Functional Assessment Tools for LTSS Eligibility Determination and Care Planning, noting that information about the relationship between assessment tools and resource allocation was limited because the documentation for most tools did not address payment. (Source: Medicaid and CHIP Payment Access Commission (MACPAC). *Report to Congress on Medicaid and CHIP: Functional Assessments for Long-Term Services and Supports* (Washington D.C: MACPAC, 2016), <https://www.macpac.gov/wp-content/uploads/2016/06/Functional-Assessments-for-Long-Term-Services-and-Supports.pdf>).

[†] [Section 7\(5\) the Rehabilitation Act](#), as amended by the Workforce Innovation and Opportunity Act of 2015, defines competitive integrated employment as full or part-time work at minimum wage or higher, with wages and benefits similar to those without disabilities performing the same work, in workplaces and settings fully integrated with coworkers without disabilities. (Source: "Rehabilitation Act of 1973," U.S. Congress, <https://www2.ed.gov/policy/speced/leg/rehab/rehabilitation-act-of-1973-amended-by-wioa.pdf>).

Text Box 10: Inclusa Employment Initiativeⁱ

One Wisconsin Family Care health plan, Inclusive, developed an alternative payment model to incentivize successful outcomes in Medicaid-funded HCBS employment services. Providers are eligible for two forms of payment:

1. Pay based on hours the person with disabilities works in competitive integrated employment (instead of the hours worked by the provider), with two variables:
 - ✓ Tiered rates to account for level of individual disability
 - ✓ Phased rates per hour worked to account for length of time on job (higher rates early in employment)
2. Permanent, minimum, ongoing payment as the person maintains employment
 - ✓ Paying for the desired outcome (a value-based payment)
 - ✓ Paying for the outcome to be sustained over time (similar to sub-capitation)

Results

In the initial pilot area that has been operating since 2012, the number of people employed in competitive integrated employment grew by 70.6 percent over six years. At the same time, the average payment per hour (based upon the hours worked by the person with disabilities) to providers fell from \$9.93 in 2013 to \$9.75 in 2018. One of the largest employment/day service providers in the area adopted the outcome-based model in 2012 and increased the number people served in competitive integrated employment by 300 percent by 2018. Inclusive has now expanded the alternative payment option to their entire provider network.

- i. "Value-Based Purchasing Supported Employment," Inclusive, Inc., 2017.
<http://www.advancingstates.org/sites/nasuaad/files/Alternative%20pay.pdf>

IV. LOOKING AHEAD

While extensive published analyses of Medicaid-funded LTSS for people with ID/DD are available, additional health research and data would help policymakers better understand and support effective programs for this population. Medicaid data analysis on healthcare utilization that disaggregates people with ID/DD from other populations, including race and ethnicity demographics, is extremely limited. Consistent definitions and identifiers of people with ID/DD within administrative data sets would allow for better understanding, as would a consistent federal definition of what constitutes a waitlist.

Revising the CMS technical guidance and aligning federal performance expectations to support quality across HCBS authorities could promote additional improvement at the state level. State accountability in HCBS waiver programs is focused mainly on processes and compliance with federal requirements, rather than on individual outcomes and quality of life indicators. Multiple stakeholders, including state agency staff and advocates, noted the importance of moving performance and quality measurement of HCBS for people with ID/DD toward meaningful individual outcome metrics.*

*On September 18, 2020 CMS published a Request for Information on Recommended Measure Set(s) for Medicaid-Funded Home and Community-Based Services, seeking feedback on "the potential benefits of and challenges that could result from a nationally available set of recommended quality measures for voluntary use."

Additional national research on various Medicaid HCBS allocation processes that rely on functional assessment is needed. States are maintaining multiple HCBS waivers offering different levels of services, as well as individual budgeting processes tied to intensity of need. Advocates and providers expressed support for expanding access through limited support waivers as well as enthusiasm for individual budgets. However, they also voiced concerns about functional assessments increasingly used for multiple purposes including resource allocation, and the appropriateness, validity and reliability of the allocation process. As researchers shared, the variation in the services and support levels of publicly funded HCBS available to people with ID/DD in different states based upon similar functional assessment data creates questions of equity that may be best answered through multi-state evaluation.

Consideration of support needs in the context of families, including addressing multi-generational caregiver issues, warrants further attention. Because the vast majority of people with ID/DD are living with family members, states have been increasingly seeking to balance support for families while maintaining the right to self-determination and independence for adults with ID/DD. Federal Medicaid HCBS policy and payment traditionally focuses on the individual, but exploration of a shift to more holistically consider the services and supports in the context of families may be informative.

Many adults with ID/DD need assistance to exercise informed decision-making and have their preferences honored, including in the planning and receipt of services and supports. Incorporating supported decision-making options into person-centered planning requirements and ensuring stronger conflict-of-interest protections (beyond current federal requirements for conflict-free case management) could help. Requiring conflict-free supports brokering assistance for self-directed services was also mentioned by stakeholders.

Further research on the effectiveness of state initiatives designed to address workforce issues could help inform policies that support the stability and quality of the workforce going forward. Some states have started to create payment incentives and enhanced qualifications for providers, seeking to improve retention and the skills, competencies and abilities of the workforce. Independent evaluation of these initiatives to determine whether quality and outcome improvements are achieved would be informative.

Improvements in access to disability-responsive medical care, as well as better coordination across physical health, behavioral health and HCBS would benefit people with ID/DD. Several stakeholders stated that federal designation of people with ID/DD as a medically underserved population could assist in furthering access to clinical provider networks better prepared to serve people with ID/DD.

In this year of the pandemic and social change, the need to address equity issues and health disparities has been brought to the forefront. States, providers and other stakeholders could start with better data collection and analysis and engagement with underserved communities. An intentional and thoughtful assessment of disparities and inequities, including gaps in access and participation among people of color, is needed. Deeper understanding may then inform further development of culturally responsive services and supports for people with ID/DD.

V. THE IMPACT OF THE COVID-19 PANDEMIC

The literature review and interviews conducted for this study were nearly complete in March 2020, and therefore the perspectives conveyed throughout the report do not reflect the significant impact of the COVID-19 pandemic.

The pandemic and the response raise multiple concerns and implications for people with ID/DD, including:

- **Higher level of risk:** Preliminary research has indicated a higher risk of COVID-19 infection for people with ID/DD (especially for individuals living in congregate settings), with a likelihood of more severe negative outcomes in part due to comorbidities.²⁰¹ Data shows significantly higher rates of fatalities among both children and non-elderly adults with ID/DD who contract the virus.²⁰²
- **Compounded disparities for people of color with ID/DD:** COVID-19 has also disproportionately affected people from racial and ethnic minority groups.²⁰³ Recent national data indicate that socio-demographically disadvantaged* people with disabilities are significantly overrepresented in counties with higher COVID-19 incidence, suggesting that the convergence of disability, race and poverty creates compounded adverse impact.²⁰⁴
- **Lack of transparency in reporting:** While there has been tremendous focus on the infection rates and deaths among residents and staff from nursing facilities,^{205,206} data on people with ID/DD in congregate care or receiving HCBS has not been collected and reported on a national basis, and very few states are making this information readily available.
- **Crisis standards of care and triage guidelines:** The HHS Office of Civil Rights (OCR) has received multiple complaints regarding state policies that discriminate against people with disabilities, including denial of access to care for people with ID/DD when resources are limited.²⁰⁷ To date, OCR resolution has been reached with four states.^{208,209,210,211}
- **Visitor policies:** People with ID/DD often rely upon in-person supports for communication, decisions and equal access to medical treatment (among other needs), yet many hospital, intermediate care and residential facilities have not established exceptions for personal supports (including family members) to accompany or safely visit individuals with disabilities. Guidance from OCR addresses hospital visitor policies,²¹² and CMS has recently updated guidance on visitors in nursing facilities,²¹³ but no federal guidance specific to ID/DD congregate facilities has been issued.
- **Social distancing:** People with ID/DD are more vulnerable to the impact of disrupted routines, isolation and loneliness.²¹⁴ Providers and states have attempted to address the needs of people with ID/DD during periods of limited community access through the use of technology to facilitate social connections, additional person-centered planning tools, and additional case management check-ins.²¹⁵
- **Workforce safety:** Like other essential health workers, direct support professionals and other homecare providers have struggled to access personal protective equipment (PPE).²¹⁶ Some people have chosen to suspend in-home services, and some workers have declined to enter individual homes, out of health and safety concerns. Providers of residential services have experienced significant overtime costs, while also experiencing challenges with securing PPE.²¹⁷

CMS and states took multiple actions to ensure continuity of HCBS which include the development and approval of 1135 waivers, 1115 public health emergency demonstrations, and Appendix K flexibilities,

* Characteristics that were disaggregated and analyzed based on American Community Survey categories: race, ethnicity, poverty status, age, and biological sex

which continue to evolve and be updated. Particular state actions of importance to people with ID/DD include:*

- **Workforce flexibilities:** Forty-nine states have temporarily modified provider qualifications, often waiving or delaying training requirements or allowing providers meeting provisional qualifications to work while they await full approval. Thirty-eight states add allowances for family members to serve as paid providers, with some states including legally responsible relatives such as spouses or parents of minors. Nineteen states are permitting case managers to deliver direct services.
- **Retainer payments:** CMS has historically allowed retainer payments for 1915(c) personal care services, as articulated in a [July 2000 State Medicaid Director's letter](#) (part of the Medicaid *Olmstead* letters issued in response to the ruling). This guidance restricted payments to “the lesser of 30 consecutive days or the number of days for which the state authorizes a payment for ‘bed-hold’ in nursing facilities.” In response to the pandemic and the need to maintain provider capacity despite reduced utilization, CMS provided updated guidance²¹⁸ allowing states to authorize retainer payments under additional HCBS authorities[†] for up to three periods of 30 consecutive days during the public health emergency (consistent with state nursing facility bed-hold policy), and explicitly added habilitation services. This has provided some financial stability, especially for day and employment services, many of which have not been able to operate, or only operate at a significantly reduced capacity, during the pandemic.²¹⁹ Thirty-nine states have pursued this flexibility.
- **Telehealth and remote delivery of services:** As in-person engagement declined due to infection risk, states quickly changed case management to delivery via phone and videoconference. This was aided by OCR guidance²²⁰ temporarily waiving Health Insurance Portability and Accountability Act (HIPAA)²²¹ enforcement and allowing the use of commonly available technologies such as Skype, Zoom and FaceTime. The majority of states also implemented flexibility to allow remote delivery via technology of some direct services.
- **Technology:** Several states are providing additional access to technology through their temporary authorities, including lifting spending caps and adding assistive technology.

These changes, while originally intended to be temporary responses to the public health emergency, have affected the ID/DD LTSS system in ways that are likely to be long-lasting. Encouraged by CMS,²²² many states are considering which flexibilities, such as technology-based remote delivery of services or paying family caregivers, should remain permanent through amendments to existing waivers or state plans.

* Based on data as of September 23, 2020.

† CMS added the ability to authorize retainer payments under 1915(i), 1915(k) and 1115(a) authorities.

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VII. APPENDICES

Appendix A: Literature Review and Stakeholder Interviews Methodology

Literature Review

HMA conducted a literature review to identify and synthesize overviews and analysis of the population of people with intellectual or developmental disabilities (ID/DD) who are covered by Medicaid. The review looked at the characteristics, needs, and service utilization of the ID/DD population enrolled in Medicaid who live in the community and in institutions; how the needs of the people with ID/DD vary across their lifespans; the extent and impact of waiting lists for Medicaid HCBS waiver programs and how individuals access services while on waiting lists; the role of state ID/DD agencies in administering Medicaid HCBS waiver programs; providers who serve the ID/DD population and implications of limited provider capacity on access to services; and the role of self-directed programs in serving people with ID/DD.

Data sources reviewed included longitudinal federally-funded studies including State of the States in Intellectual and Developmental Disabilities Project, administered by the University of Colorado; the National Residential Information Systems Project (RISP) at the University of Minnesota, Institute on Community Integration; Access to Integrated Employment, a national data-collection project on day and employment outcomes at the University of Massachusetts (Boston), Institute for Community Inclusion (ICI); as well as National Core Indicators (NCI) and other sources of ID/DD and SSI data. These sources were supplemented by reports and journal articles found using search phrases across resources such as PubMed, Google Scholar, and EBSCO going back at least five years.

HMA reviewed a number of sources, including existing grey literature and studies. HMA searched the literature for at least the last five years using multiple search engines including searching PubMed and Google Scholar, and examined references in pulled studies.

Stakeholder Interviews

Stakeholder interviews obtained input from 37 stakeholders that included people with ID/DD, state Medicaid officials, state Developmental Disabilities agency officials, health plans, a federal official, associations representing providers of ID/DD services, and consumer organizations. The 18 individual and group interviews were conducted using a standardized set of twelve questions, from which five or six questions were selected for each interview. Interview questions covered themes related to ID/DD services such as quality improvement, care integration, health disparities, workforce, caregiver support, self-direction, and rebalancing.

Stakeholder Interviewees

ID/DD Data Researchers and Quality Project Directors

Name, Title	Organization	Interview Date
Sheryl Larson, <i>Director, National Residential Information Systems Project</i> larso072@umn.edu Amy Hewitt, <i>Director, Institute on Community Integration</i> hewit005@umn.edu	Institute on Community Integration, University of Minnesota	2/26/20
E. Shea Tanis, <i>Coleman Institute Co-Director</i> shea.tanis@cu.edu Amie Lulinski, <i>Project Manager</i> amie.lulinski@cu.edu	Coleman Institute for Cognitive Disabilities at the University of Colorado	2/3/20
Alexandra Bonardi, <i>Co-Director of National Core Indicators Project</i> abonardi@hsri.org Val Bradley, <i>Founder and President Emerita</i> vbradley@hsri.org	Human Services Research Institute (HSRI)	2/6/20
MaryLou Bourne, <i>Co-Director of National Core Indicators Project</i> mlbourne@nasddds.org Laura Vegas, <i>Director of National Core Indicators</i>	National Association of State Directors on Developmental Disabilities Services (NASDDDS)	2/6/20

ID/DD Consumer Advocacy Organizations and Legal Advocacy Organizations

Name, Title	Organization	Interview Date
Nicole Jorwic, JD, <i>Senior Director of Public Policy</i> jorwic@thearc.org	The Arc of the United States	2/12/20
Alison Barkoff, JD, <i>Director of Advocacy</i> abarkoff@cpr-us.org	Center for Public Representation (CPR)	2/27/20
Elizabeth Priaux, JD, <i>Senior Disability Legal Specialist</i> elizabeth.priaux@ndrn.org	National Disability Rights Network	2/26/20
Liz Weintraub, <i>Senior Advocacy Specialist</i> lweintraub@aucd.org	Association of University Centers on Disabilities (AUCD)	4/22/20
Julia Bascom, <i>Executive Director</i> jbascom@autisticadvocacy.org	Autistic Self-Advocacy Network (ASAN)	4/27/20

State Directors of Developmental Disabilities Services

Name, Title	Organization	Interview Date
Kylee Hope, <i>Director, Disability & Rehabilitative Services</i> Kylee.Hope@fssa.IN.gov Cathy Robinson, <i>Director of Bureau of Developmental Disabilities Services</i> Cathy.Robinson@fssa.in.gov	State of Indiana Family & Social Services Administration	2/26/20
Melissa Stone, <i>Director, Division of Developmental Disabilities Services</i> Melissa.Stone@dhs.arkansas.gov Paula Stone, <i>Deputy Director of Medicaid and lead on PASSE</i> Paula.Stone@dhs.arkansas.gov	State of Arkansas Department of Human Services	3/4/20

State Medicaid Directors or Senior Staff

Name, Title	Organization	Interview Date
<p>Jami Snyder, Director, Arizona Health Care Cost Containment System jami.snyder@azahcccs.gov</p> <p>Dara Johnson, Program Development Officer Dara.Johnson@azahcccs.gov</p> <p>Jakenna Lesbock, Assistant Director of Division of Health Care Management Jakenna.Lesbock@azahcccs.gov</p> <p>Shelli Silver, Deputy Director of Plan Operations Shelli.Silver@azahcccs.gov</p>	State of Arizona Health Care Cost Containment System (AHCCCS)	2/11/20
<p>Kelly Cunningham, Interim Medicaid Director, Division of Medical Programs, Department of Healthcare and Family Kelly.Cunningham@Illinois.gov</p> <p>Allison Stark, Director, Division of Developmental Disabilities Allison.Stark@Illinois.gov</p>	State of Illinois, Division of Medical Programs, Department of Healthcare and Family	2/27/20

National and State ID/DD Provider Associations

Name, Title	Organization	Interview Date
<p>Donna Martin, Director of State Partnerships dmartin@ancor.org</p> <p>Shannon McCracken, Vice President, Government Relations SMcCracken@ancor.org</p>	American Network of Community Options and Resources (ANCOR)	3/13/20
<p>Lydia Dawson, Executive Director executivedirector@iacp-idaho.com</p>	Idaho Association of Community Providers	3/13/20
<p>Sarah Pfau, JD, MPH, Senior Policy and Regulatory Affairs Specialist sarah.pfau@ncproviderscouncil.org</p>	North Carolina Providers Council	3/13/20
<p>Mark Davis, President and CEO Mark@par.net</p>	Pennsylvania Advocacy and Resources	3/13/20

National ID/DD Directors Association

Name, Title	Organization	Interview Date
<p>Mary Sowers, Executive Director msowers@nasddds.org</p>	National Association of State Directors of Developmental Disabilities Services (NASDDDS)	2/18/20

Health Plans Serving ID/DD Populations

Name, Title	Organization	Interview Date
Michael Monson, <i>Senior Vice President of Medicaid & Complex Care</i> Michael.Monson@centene.com Laura Chaise, <i>VP of LTSS and Medicare-Medicaid Plans</i> Laura.E.Chaise@centene.com Stephanie Rasmussen, <i>VP at Sunflower Health Plan (KS)</i> SRASMUSSEN@sunflowerhealthplan.com	Centene Corporation	2/10/20
Kris Kubnick, <i>Chief Member Experience Officer</i> Kris.Kubnick@inclusa.org Tracy Hetzel, <i>Regional Senior Manager</i> Tracy.Hetzel@inclusa.org Dawn Trzebiatowski, <i>Member Authorization Manager</i> Dawn.Trzebiatowski@inclusa.org	Inclusa	2/6/20
Jason Miller, <i>Plan President</i> Jason.miller@summitcommunitycare.com	Summit Community Care, Arkansas	2/24/20

Federal Official

Name, Title	Organization	Interview Date
Ralph Lollar, <i>Director, Division of Long Term Services and Supports</i> Ralph.Lollar@cms.hhs.gov	Centers for Medicare & Medicaid Services (CMS)	2/11/20

Appendix B: Long-Term Supports and Services Used by People with ID/DD

Service	Brief Description	Examples
Behavior Supports	Supports to prevent or reduce behavior-related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions	Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment
Employment and Day Services	Services provided to support participation in community-based employment, activities, and education	Job development, supported employment (individual, group, competitive), prevocational services, day habilitation
Environmental Modifications and Technology	Adaptive equipment, home modifications, modification or repair to a vehicle, adaptive equipment, augmentative communication devices,	Personal emergency response systems, ramps, grab bars, bathroom modifications, home and vehicle modifications, adaptive equipment
Family Caregiver Support	Services to help the caregiver or family provide supports to the individual	Home delivered meals, homemaker/chore services, caregiver counseling, caregiver training
Habilitation	Support for skill development for activities of daily living such as dressing and eating, instrumental activities of daily living such as cooking, cleaning, shopping, and money management, and developing and maintaining relationships	Home-based habilitation, recreation and leisure
Housing Supports	Services to assist the person to obtain and maintain housing	Housing coordination, Community Transition Services
Medical and Health Supports	Supports to improve or maintain health, and to gain or maintain physical functioning. Includes clinical services, such as occupational therapy (OT), physical therapy (PT), and speech therapies as well as in home nursing services	Home health aide, OT, PT, speech and language therapies, skilled and private nursing, clinic services
Participant Directed Supports	Assistance to individuals/families who self-direct services. Includes the development of a person-centered plan, managing individual budgets, recruiting workers and accessing services and supports	Financial management services, participant training, goods and services, interpreter, other
Personal Care Supports	Hands-on assistance, or direct supervision for activities of daily living such as dressing, eating, changing positions (getting in and out of bed/ chair), using the toilet, and bathing.	Companion services, personal care/ assistance
Residential Services	Housing and habilitation supports provided in a place other than the home of a family member or a home owned or leased by the person	Group home, Shared Living, Board and Care
Respite	Temporary relief from caregiving duties for the family caregiver	Respite (in home, out of home), individual support (day or night)
Transportation	Supports to transport an individual from their residence to community settings including day services, employment settings, and community-based activities	Community transportation services, non- medical transportation

This adaptation of the Medicaid HCBS taxonomy originally appeared in Lynda L. Lahti Anderson et al., *Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014*, (Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, 2016). <https://ici.umn.edu/products/912>.

Appendix C: Demographics of People with ID/DD Receiving LTSS Across Institutional and Community-Based Settings (2017-2018)

In the thirty-five states reporting to the National Core Indicators (NCI) project in 2017-2018, the demographic portrait of people with ID/DD receiving LTSS showed:

- 59 percent are male; Average age is 42; 94 percent are single and have never been married
- Race, ethnicity, culture composition
 - ✓ 67 percent White
 - ✓ 16 percent Black or African American
 - ✓ 10 percent Hispanic or Latino
 - ✓ 6 percent Other, including Asian, American Indian or Alaska Native, and Pacific Islander
- 6 percent reported primary language other than English
- 90 percent have an intellectual disability
 - ✓ 41 percent Mild
 - ✓ 29 percent Moderate
 - ✓ 13 percent Severe
 - ✓ 8 percent Profound
 - ✓ 8 percent Unknown or Unspecified
- Non-exclusive disability categories:
 - ✓ 26 percent Seizure Disorder
 - ✓ 20 percent Autism Spectrum Disorder
 - ✓ 15 percent Cerebral Palsy
 - ✓ 10 percent Limited or no vision
 - ✓ 9 percent Down Syndrome
 - ✓ 6 percent Severe or profound hearing loss
 - ✓ 5 percent Brain Injury
 - ✓ 2 percent Chemical Dependency
 - ✓ 17 percent Other disabilities, not listed
 - ✓ 8 percent No co-occurring disabilities
- 28 percent reported to have behavioral challenges
- 30 percent reported a mood disorder
- 27 percent report an anxiety disorder

Source: "National Core Indicators, 2017-18 In-Person Survey Final Report," NCI, <https://www.nationalcoreindicators.org/survey-reports/2019/>.

Appendix D: Demographics and Intensity of Needs of People with ID/DD Living in Public Residential Facilities

In 2017, the 18,239 people with ID/DD who reside in public residential facilities had the following characteristics: *

- 24 percent age 63 years or older
- 52 percent between 40-62 years of age
- 20 percent between 22-39 years of age
- 4 percent under the age of 22
- 20 percent African American
- 7 percent Hispanic
- 5 percent involved with the criminal justice system

And experienced the following conditions:

- 55 percent profound intellectual disability
- 16 percent severe intellectual disability
- 14 percent moderate intellectual disability
- 39 percent epilepsy
- 19 percent autism
- 17 percent cerebral palsy
- 56 percent behavior disorders

Another 2016 study noted that people with ID/DD who are defined as “frail,” based upon the Frailty Index, experience with double the rates of institutional admissions as those who are not frail, regardless of age.[†]

* Sheryl A. Larson et al., *In-home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2017* (Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, 2020). https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017.

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Appendix E: Policy Milestones in Medicaid LTSS for People with ID/DD*

- 1967: Over 228,500 Americans with ID/DD lived in state-operated institutions, the peak of U.S. institutional census.[†]
- 1967: Intermediate Care Facilities (ICF) first authorized under Title XI of the Social Security Act as demonstration projects (PL 90-248).
- 1971: Federal Financial Participation (FFP) for Intermediate Care Facilities established under Title XIX of the Social Security Act (PL-92-223).
- 1973: The Rehabilitation Act of 1973 (PL 93-112) prohibited discrimination based on disability in federally funded programs.
- 1975: The Education of all Handicapped Children Act (PL 94-142), now the Individuals with Disabilities Education Act (PL 108-446) provided opportunity for children with ID/DD to attend public school, instead of families relying upon placement in a facility or having little to no assistance with educational needs.[‡]
- 1981: Congress created section 1915(c) of the Social Security Act (PL 97-35), which allowed states to apply for a waiver to provide HCBS to individuals who would otherwise require care in an institution, consistent with a growing de-institutionalization movement for people with ID/DD already occurring in the states.^{**}
- 1982: The Tax Equity and Fiscal Responsibility (TEFRA) Act of 1982 (PL 97-248) created the Katie Beckett option, which enabled states to provide Medicaid to certain children with disabilities living at home who need extensive care but who would otherwise not qualify because their parents' income or resource levels are above the financial eligibility cutoff.^{††}
- 1990: The Americans with Disabilities Act (PL 101-336) stated an intent to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities,^{*} addressing discrimination in employment, state and local government services, public accommodations and commercial facilities.

* Medicaid and CHIP Payment Access Commission (MACPAC). *Federal Legislative Milestones in Medicaid and CHIP*, (Washington D.C: MACPAC, 2016), <https://www.macpac.gov/federal-legislative-milestones-in-medicaid-and-chip/>.

† Sheryl A. Larson et al., *In-home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2017* (Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, 2020). https://ici-s.umn.edu/files/aCHyYaFiMi/risp_2017.

‡ Douglas P. Biklen, Dianna L. Ferguson, and Alison Ford, *Schooling and Disability* (National Society for the Study of Education) (Chicago: University of Chicago Press, 1989).

** "Home & Community Based Services Authorities," Medicaid, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html#:~:text=Home%20and%20Community%20Based%20Services,Medicaid%20rules%20governing%20institutional%20care.&text=Several%20States%20include%20HCBS%20services%20in%20their%20Medicaid%20State%20plans>.

†† Janet O'Keeffe et al., *Understanding Medicaid Home and Community Services: A Primer* (Washington, DC: U.S. Department of Health and Human Services, 2010), <https://aspe.hhs.gov/system/files/pdf/76201/primer10.pdf>.

* Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(a)(7) (1990).

- 1995: More than half of all Medicaid-funded LTSS participants with ID/DD received services in HCBS settings.[†]
- 1999: The US Supreme Court ruling in the case of *Olmstead v. L.C.* established a right to “placement in the most integrated setting,” prohibiting states from requiring a person be institutionalized when community-based services could meet their needs.[‡]
- 2005: The Deficit Reduction Act (PL 109-171) included several important Medicaid HCBS provisions:
 - ✓ Created the 1915(i) Medicaid state plan option provided state Medicaid programs the flexibility to cover HCBS without the need to seek a federal waiver and allowed people who do not meet institutional care to access HCBS.^{**}
 - ✓ Created the Money Follows the Person (MFP) Demonstration designed to assist states with: (1) supporting Medicaid beneficiaries who want to transition from institutional facilities back to community-based settings; and (2) developing infrastructure to promote and enhance access to HCBS.^{††}
 - ✓ Established the Family Opportunity Act, providing states the option to allow families of children with disabilities under age 19 to buy in to Medicaid when family income or assets exceed SSI thresholds.^{‡‡}
- 2010: The Patient Protection and Affordable Care Act of 2010 (ACA) promoted supporting individuals in the community rather than institutions through multiple demonstrations and incentives:^{*}

[†] Sheryl A. Larson et al., *In-home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2017* (Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, 2020). https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017.

[‡] “On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.” (Source: “Olmstead: Community Integration for Everyone,” Information and Technical Assistance on the Americans with Disabilities Act, https://www.ada.gov/olmstead/olmstead_about.htm)

^{**} “The Use of 1915(i) Medicaid Plan Option For Individuals With Mental Health and Substance Use Disorders,” Office of the Assistant Secretary for Planning and Evaluation, November 30, 2016, <https://aspe.hhs.gov/basic-report/use-1915i-medicaid-plan-option-individuals-mental-health-and-substance-use-disorders#:~:text=EXECUTIVE%20SUMMARY-.Created%20by%20the%20Deficit%20Reduction%20Act%20of%202005%20and%20amended,to%20seek%20a%20federal%20waiver.>

^{††} “Money Follows the Person,” Center for Public Representation, March 27, 2020, [https://medicaid.publicrep.org/feature/money-follows-the-person/#:~:text=The%20Money%20Follows%20the%20Person%20\(MFP\)%20Demonstration%20%E2%80%93%20first%20authorized,facilities%20back%20to%20community%2Dbased.](https://medicaid.publicrep.org/feature/money-follows-the-person/#:~:text=The%20Money%20Follows%20the%20Person%20(MFP)%20Demonstration%20%E2%80%93%20first%20authorized,facilities%20back%20to%20community%2Dbased.)

^{‡‡} Anne Rossier Markus and Sara Rosenbaum, “The Deficit Reduction Act of 2005: An Overview of Key Medicaid Provisions and Their Implications for Early Childhood Development Services,” The Commonwealth Fund, October 2006, <https://www.commonwealthfund.org/publications/fund-reports/2006/oct/deficit-reduction-act-2005-overview-key-medicaid-provisions-and>

^{*} Sarah Barth, Brianna Ensslin, and Nancy Archibald, “State Trends and Innovations in Medicaid Long-Term Services and Supports,” Center for Health Care Strategies, Inc., December 2012, https://www.chcs.org/media/State_Trends_and_Innovations_in_Medicaid_LTSS_12_17_12_FINAL.pdf.

- ✓ Created the Medicaid State Plan option 1915(k), Community First Choice Option, to provide community-based attendant services and related supports.
- ✓ Created the Balancing Incentive Program to rebalance LTSS expenditures toward HCBS provision by provided a targeted FMAP increase to states that achieve specified HCBS expenditure targets and undertake three specific structural reforms designed to increase nursing home diversions and access to HCBS: (1) a single point of entry system for individuals to access LTSS statewide (NWD/SEP); (2) conflict-free case management; and (3) a core standardized assessment instrument for determining eligibility for services.
- ✓ Revised the 1915(i) Medicaid state plan option to allow states to target services based on population, as well as design one or multiple service packages for eligible individuals, and eliminate waiting lists after eligibility is determined (i.e. states may not set a cap on individuals enrolled or create waiting lists).
- 2014: CMS promulgated the Medicaid Home and Community-based Services (HCBS) Settings Rule requiring HCBS settings to have certain characteristics distinct from institutional settings, provide support for community integration, ensure individual choice and control, and protect rights of privacy, dignity, respect, autonomy and independence.

Appendix F: About the Authors

Sarah Barth, JD, is a principal with HMA's New York office. She has over 25 years of experience in publicly funded health care policy, research, and management. Sarah has more than 18 years of experience in Medicaid administration, working for both New Mexico and Massachusetts to develop managed long-term service and supports programs and health care reform initiatives. Throughout her career, she has worked closely with state and federal governments, health care foundations and non-profits, health plans, consumers and providers to improve the quality and cost-effectiveness of publicly financed health care. Areas of specialty include dual integration strategies to align Medicare and Medicaid benefits for dually eligible beneficiaries, Medicaid managed long-term services and supports programs, home and community-based service programs and health care reform.

Sharon Lewis, a principal in HMA's Portland office, is a national expert in disability policy spanning home and community-based services (HCBS), health, education, employment, and independent living. She has over 20 years of experience in disability policy and program management at the federal, state and local level. Sharon served in presidentially appointed leadership roles at the U.S. Department of Health and Human Services (HHS) for six years, where she was a co-founder of the Administration for Community Living, supported significant reforms in Medicaid HCBS policy and regulations to ensure community integration, and managed federal programs for people with disabilities and older adults. Prior to her service at HHS, Sharon served as senior Congressional committee staff, working on major legislation such as the Americans with Disabilities Act and the Affordable Care Act.

Taylor Simmons, MPH, is a research assistant in HMA's Denver, Colorado office. She has experience in writing in-depth literature reviews, conducting focus groups and key informant interviews, putting together models of care, performing policy analyses, and analyzing large qualitative data sets. Taylor specializes in public health initiatives and structured project management support.