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Recommendations for Strengthening Iowa's Community-Based Services System

Final Evaluation Report

January 31, 2023

Evaluation team from Mathematica and The Harkin Institute

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Acronyms and definitions

Acronym	Definition	Notes
AAA	Area Agency on Aging	Agencies designated by the state to address the needs and concerns of older adults, adults with disabilities, and family caregivers at a regional level. Iowa has six throughout the state.
ADL	Activity of daily living	Routine activity that are generally expected to be completed daily (eating, bathing, dressing, grooming toileting, transferring).
ADRC	Aging and Disability Resource Center	A resource that helps older Iowans, adults with disabilities, veterans, and caregivers learn more about long-term living services and supports available throughout the state. Access is available through the Area Agencies on Aging.
B3	1915(b)(3) services	Under the authority of 1915(b)(3) of the Social Security Act, B3 services are additional cost-saving supports that are offered to members with behavioral health conditions. In Iowa, these include intensive psychiatric rehabilitation, community support, peer support, residential substance abuse treatment, integrated services and supports, respite, and clinically managed residential treatment facilities for substance abuse.
BHIS	Behavioral health intervention service	Supportive, directive, and teaching interventions provided in a community-based or residential group care environment that are designed to improve an individual’s level of functioning (child and adult) as it relates to a mental illness. The primary goal is to assist the individual and caregivers to learn age-appropriate skills to manage behavior and regain or retain self-control.
BI	Brain Injury waiver	One of seven Medicaid 1915(c) waivers in Iowa.
CBCM	Community-based case manager	Employees of a managed care organization who work with members to identify their health needs and appropriate services to address those needs.
CBS	Community-based services	The broad set of services that support people who are aging, have disabilities, or have behavioral health needs either in their homes or in the community, as opposed to those in a facility or institutional setting. This includes home and community-based services (HCBS) funded by Medicaid as well as services funded through Iowa’s Mental Health and Disability Services (MHDS) system, the Department of Aging, and other programs in the state.
CCO	Consumer Choices Option	A self-directed service option that gives members control of a targeted amount of Medicaid dollars, allowing them to hire caregivers or purchase goods to meet their health needs.
CDAC	Consumer Directed Attendant Care	A self-directed service option that allows members to directly manage the people who provide personal care assistance.
CIL	Centers for Independent Living	Community organizations designed and operated by individuals with disabilities to support community living and independence among people with disabilities.
CMH	Children’s Mental Health waiver	One of seven Medicaid 1915(c) waivers in Iowa.
CMS	Centers for Medicare & Medicaid Services	Federal agency that oversees Medicare and Medicaid.

Acronym	Definition	Notes
CNRS	Community-based neurobehavioral rehabilitation services	Specialized category of neuro-rehabilitation services provided by a multidisciplinary team that addresses cognitive, medical, behavioral, and psychosocial challenges, as well as the physical manifestations of acquired brain injury. These services are available for individuals residing in a three- to five-bed residential care facility who meet certain requirements.
ED	Emergency department	Area of a hospital staffed for emergency care.
EL	Elderly waiver	One of seven Medicaid 1915(c) waivers in Iowa.
ETP	Exception to policy	Requests made by members or advocates for services that (1) are not covered by the waiver, (2) exceed the spending limit for a service, or (3) exceed the overall monthly cap for spending for the waiver.
FPL	Federal poverty level	An economic measure used to decide whether the income level of an individual or family qualifies for certain federal benefits and programs.
HCBS	Home- and community-based services	Medicaid-funded programs and services that support people with disabilities and/or behavioral health needs as well as older Iowans to live in the community. These programs include Medicaid HCBS waiver programs, Habilitation Services, Program of All-inclusive Care for the Elderly, Home Health Services, Private Duty Nursing/Personal Care Program, Hospice Services, Targeted Case Management, and Money Follows the Person.
HD	Health and Disability waiver	One of seven Medicaid 1915(c) waivers in Iowa.
HHS	Iowa Department of Health and Human Services	Formerly the Iowa Departments of Public Health (IDPH) and Human Services (DHS), HHS is Iowa’s single entity responsible for managing the state’s health and human services programs.
HIV	HIV/AIDs waiver	One of seven Medicaid 1915(c) waivers in Iowa.
HS	Habilitation services	Iowa’s 1915(i) state plan option to offer habilitation services to those not on a 1915(c) waiver.
IADL	Instrumental activity of daily living	Complex activity required for independent living, such as cleaning and housekeeping, washing laundry, managing money, managing medication, preparing meals, handling shopping, managing transportation, and using communication devices.
ICF/ID	Intermediate care facility for people with intellectual disabilities	An active, setting-based treatment for individuals with diagnoses of intellectual disabilities who need constant supervision and continuous habilitation services.
ID	Intellectual Disability waiver	One of seven Medicaid 1915(c) waivers in Iowa.
IHH	Integrated health homes	Team of professionals, including family and peer support services, working together to provide whole-person and patient-centered care for adults with a serious mental illness and children with a serious emotional disturbance. IHHs must coordinate all medical and behavioral care regardless of payer.
IMMT	Interim medical monitoring and treatment	Monitoring and treatment of a medical nature for children or adults ages 18 to 20 whose medical needs make when alternative care is unavailable, inadequate, or insufficient. IMMT services are not intended to provide day care. Instead, they supplement available resources. Services must be ordered by a physician.
LTSS	Long-term services and supports	An array of medical and personal care services for people who struggle with self-care due to aging, illness, or disability. Includes home- and community-based services and institutional-based care.

Acronym	Definition	Notes
MCO	Managed care organization	A business group that manages the delivery and costs of health care services under contract with the state.
MFP	Money Follows the Person	Transition supports for individuals with an intellectual disability or a brain injury who are transitioning from a nursing facility or an intermediate care facility for people with intellectual disabilities to a community residence. Services include funding for transition services and enhanced supports during the first year of community living, paid for by a federal grant.
MHBG	Mental Health Block Grant	Funding provided to states by the Substance Abuse and Mental Health Services Administration to target adults with serious mental illness and children with severe emotional disturbance.
MHDS	Mental Health and Disability Services	Iowa's community-based, person-centered mental health and disability services system provides locally delivered services that are regionally managed within statewide standards.
MHI	Mental health institute	State-run facilities designed to provide specialized acute, person-centered psychiatric treatment for individuals who are experiencing severe symptoms of mental illness but are unable to receive necessary evaluation or treatment services in the community.
NEMT	Non-emergency medical transportation	A Medicaid benefit that helps members get to and from appointments.
NF	Nursing facility	Health care facility for individuals who require long-term nursing or rehabilitation services.
PACE	Program of All-inclusive Care for the Elderly	Comprehensive care program that provides preventive and primary care, social services, acute care, and long-term services.
PD	Physical Disability waiver	One of seven Medicaid 1915(c) waivers in Iowa.
PDN/PC	Private Duty Nursing/Personal Cares program	Program through Early Periodic Screening, Diagnostic, and Treatment that provides private duty nursing and personal care for children younger than age 21.
PMIC	Psychiatric medical institution for children	Residential long-term care for children with mental health disorders. Different states have different names for such facilities.
PMPM	Per member per month	Method of calculating expenditures that allows comparisons of expenditures across different subgroups of members.
RC	Resource Center	A state-run intermediate care facility for people with intellectual disabilities. Iowa has two: Glenwood Resource Center and Woodward Resource Center.
RCF-PMIs	Residential care facilities for persons with mental illness	Housing and rehabilitation model for individuals with chronic mental illness, funded by the Mental Health and Disability Services regions.
SATP	Substance Abuse Treatment Program	Inpatient or outpatient treatment programs funded by Medicaid to address chemical dependency.
SCL	Supported Community Living	A service designed to assist the member with daily living needs. Assistance may include but is not limited to personal and home skills, community skills, personal needs, transportation, and treatment services.
SE	Supported employment	Individualized services that provide support to participants who need intensive, ongoing support to obtain and maintain a job because of their disabilities.
SED	Severe emotional disturbance	A categorization for children younger than age 18 who have had a diagnosable mental, behavioral, or emotional disorder that substantially interferes with or limits the child's role or functioning in family, school, or community activities.

Acronym	Definition	Notes
SIS	Supports Intensity Scale	Standardized assessment tool designed to measure the relative intensity of support needs for individuals. There is an assessment for children and another for adults. This is used in a few of Iowa's 1915(c) waiver programs.
SMI	Serious mental illness	A categorization for adults age 18 and older who have a diagnosable mental, behavioral, or emotional disorder that causes serious functional impairment that substantially interferes with or limits one or more major life activities.
SNAP	Supplemental Nutrition Assistance Program	A federal nutrition assistance program that provides benefits to individuals and families with low incomes via an Electronic Benefits Transfer card.
SNF	Skilled nursing facility	An in-patient treatment and rehabilitation center featuring licensed nurses and other medical professionals that generally supports short-term recovery from acute medical issues.

Terms used in this report

Community-based case managers, or **CBCMs**, are employees of a managed care organization (MCO) who work with its members to identify their health needs and appropriate services to address those needs. CBCMs generally facilitate access to health care within the MCO's offered services, based on a member's authorized level of care. They are also responsible for helping members find in-network providers. CBCMs may take on the role of system navigators by helping members identify helpful benefits and programs outside of the MCO's purview or by helping them apply for changes in their levels of care.

Consumers are people using community-based services (CBS). They may be members (also called **beneficiaries**) of a Medicaid managed care plan and seek payment for their CBS through the Medicaid system, or they may have other payers.

Guardians are people who have legal authority to make decisions on behalf of consumers. They may be parents or individuals who have a court-appointed relationship with consumers.

Natural supports are friends, family, caregivers, and advocates who help consumers with their health needs, although they not a formal part of the health care system. Their support is generally unpaid, though some programs may allow natural supports to be compensated for the services they provide to consumers.

Providers are individuals or organizations that provide CBS. They may also act as **system navigators**, or entities that help consumers identify programs and services for which they are eligible and can also help address consumers' concerns about their health and functioning.

Executive Summary

As many as 25 percent of Iowans have a disability, a behavioral health need, or are older adults (age 65 or older).[1] It is challenging to estimate the share of this population that needs additional supports to stay in their homes, particularly those who are eligible for publicly funded services to do so. Nonetheless, even if a minority of individuals in this group require supports today, the possibility that they will need supports in the future—and the involvement of their family members and loved ones to navigate obtaining those services and supports—means that many more Iowans will be affected by programs and policies to support community living.

Individuals who need additional services, and their families, have strengths that they bring to their communities. Many will require additional services to support independence based on their unique needs. Supports range from assistance with getting out of bed in the morning, to monitoring medications and transportation to appointments, to employment supports that allow people to pursue meaningful jobs that align with their skills and interests—all aimed at supporting inclusion and integration in communities across Iowa.

Services and supports that allow people to remain in the community are called community-based services (CBS). This evaluation report considers the complex system and range of programs that provide CBS in Iowa and identifies opportunities to more equitably and efficiently serve Iowans who want to live in communities rather than in an institution.

The Iowa Department of Health and Human Services (HHS) contracted with Mathematica and The Harkin Institute in January 2022 to conduct a systemwide assessment of the state's CBS system and develop a set of recommendations to improve how people experience and interact with this system. The assessment is grounded in a set of guiding principles that capture Iowans' vision for the ideal system, including high-quality and equitable services that are delivered in a coordinated and transparent way.

The evaluation found immediate opportunities to strengthen the foundation of the system, as well as longer-term opportunities to create a more equitable system based on people's unique strengths and needs. This evaluation maps out recommendations to be accomplished over time, but there is an urgent need for improvements for the more than 35,000 Iowans who currently rely on or are waiting on these critical services.[2]

A. Evaluation overview

Our evaluation leveraged a substantial commitment by Iowa HHS to understand how community members experience the CBS system. Through Medicaid Town Halls and other community engagement activities, HHS administrators were aware of myriad complex challenges faced by consumers and providers who support living in the community. Iowa HHS sought an external evaluation team to assess the CBS system comprehensively, because many consumers with complex challenges in health and functioning use a range of social services and supports across the state. Although the evaluation was

[1] This is an estimate based on data from multiple sources and different years. The United States Census Bureau's American Community Survey indicates that as of 2021, 226,916 Iowans under age 65 had a disability and another 548,470 were age 65 or older in 2021. The Substance Abuse and Mental Health Services Administration estimates that 162,000 Iowans in 2019 had a serious mental illness. A share of those with serious mental illness also have a disability or are over age 65 and thus would be double-counted across these sources.
[2] Iowa HHS. "Agency Dashboard Initiative: Medicaid MCO Capitation Data: November 2022." Available at https://hhs.iowa.gov/dashboard_health. Accessed January 4, 2022.

intended to focus on programs under HHS' purview, such as Medicaid, administrators recognized that many other programs and policies that support the populations of interest would be important considerations.

Our findings and recommendations were developed by assessing the information collected across evaluation activities, including an in-depth review of HHS programs, policies, and procedures; a thorough analysis of administrative data used by programs in the CBS system; and substantial input from community members—among them consumers, families, caregivers, and providers—about their positive and negative experiences with the system and their recommendations about needed system reforms.

In consultation with HHS, we focused our initial assessment on Medicaid programs and policies such as Medicaid 1915(c) waiver programs, which allow the state to offer home and community-based services (HCBS) to particular populations. Iowa currently has seven waivers, each of which has different eligibility rules, offers a different set of covered services, and uses different assessments; all of these have different processes for accessing waiver services. As we describe in this report, demand for those services exceeds the current capacity of the state to meet Iowans' needs.

Additionally, Iowa's Mental Health and Disability Service (MHDS) regions function as a critical safety net across the state for Iowans accessing CBS, including individuals who are waiting for a Medicaid waiver slot. Our initial analysis sought to understand the interplay between Medicaid and MHDS. As our work with HHS continues, we expect to broaden our investigation to assess how other programs, departments, and systems across the state affect individuals who are aging or who have disabilities or behavioral health needs.

B. Summary of findings and recommendations

Our recommendations are grounded in a set of high-level findings from our systemwide assessment, described in more detail in Chapters V, VI, and VII.

Iowa's process for managing Medicaid waiver waiting lists does not support timely, efficient, or needs-based access to appropriate services. Waiting lists for Medicaid waiver services have the potential to be an important entry point into the CBS system and can serve as a source of information about CBS needs throughout the state. Yet Iowa's first-come, first-served approach to managing waiver waiting lists and assigning waiver slots does not capture information about, nor does it prioritize, services based on need. Iowans who need intensive supports, as well as those who are not eligible for Medicaid services, can remain on Medicaid HCBS waiver waiting lists for years. Moreover, the waiting lists do not collect information that could help HHS plan for future system demands. While on the waiting list, consumers often have difficulty connecting to CBS offered outside Medicaid, and the current process does not offer referral to other sources of support.

Recommendation: **Iowa should implement streamlined screening and improved processes to better align services with people's needs.**

Subrecommendations

- Conduct a point-in-time screening for all individuals currently on an HCBS waiver waiting list.
- Implement new processes to prioritize services using a single Medicaid HCBS waiver waiting list.
- Develop infrastructure to share waiting list status with members and with other key agencies providing services, such as Mental Health and Disability Services (MHDS) regions and Area Agency on Aging (AAA)/Aging and Disability Resource Centers (ADRCs).

Medicaid HCBS waiver services often do not align with member needs, resulting in inequity and inefficiency in accessing needed services. Although Iowa's Medicaid waivers are the primary avenue for consumers to access CBS to support community living, the current waiver structure aligns eligibility to diagnosis, which means that Iowans' support needs may not fit with the services available under the waiver they are using. This disconnect creates an inequitable and inefficient allocation of services. Some diagnoses are covered by multiple waivers, meaning that consumers can be eligible for more than one waiver and can move across waivers to obtain a different service package. Others are not covered by any waiver on the basis of their diagnosis, even though their support needs require CBS to remain in the community. In addition, it is difficult to assess members' needs comprehensively because there is no single assessment used across all available waivers.

Recommendation: **Iowa should take steps to align CBS, including Medicaid HCBS waivers, to the needs of Iowans.**

Subrecommendations

- Develop a standardized, uniform assessment tool across Medicaid HCBS waivers and manage data so that information on consumers' needs can be shared with key partners.
- Evaluate options for redesigning Iowa's HCBS waivers to be aligned with members' documented needs.

Services and supports in Medicaid and the broader CBS system are difficult to navigate and access. A shortage of providers and gaps in the service continuum create barriers to receiving appropriate care in the community. Furthermore, across Iowa's CBS system, consumers and case managers have difficulty accessing information about available services and providers. This situation is exacerbated by high case manager caseloads. Collectively, these challenges leave consumers and their natural supports to navigate

a limited and complex system, resulting in delays or inability to access needed supports. These challenges also create barriers for consumers residing in institutions who are seeking to transition to the community.

Recommendation: **Iowa should maximize access to Medicaid HCBS and other CBS supports for people with long-term service and support needs.**

Subrecommendations

- Improve the public's understanding of the CBS system, available supports, and ways to access services.
- Clarify and strengthen expectations for MCOs to support individuals with long-term care needs by connecting them to available services and supports.
- Evaluate options for redesigning the way HCBS case management is provided.
- Support families involved in receiving or providing HCBS by encouraging self-direction and paying caregivers.
- Consider expanding Money Follows the Person (MFP) eligibility criteria beyond certain diagnoses to allow more transitions out of facilities for those who wish to reside in the community.

Critical to the implementation of these recommendations is the interplay between Medicaid and MHDS. Aligning MHDS and Medicaid services to better leverage public funding will create a more streamlined system and allow for maximal use of state dollars to reach the most people. As HHS makes decisions, it will be imperative to consider the implementation of these recommendations across MHDS and Medicaid. To successfully make change that improves the system, HHS will need to engage Iowans who use services, caregivers, providers, administrators, and many others to identify solutions, support implementation, and communicate about changes being made to the system.

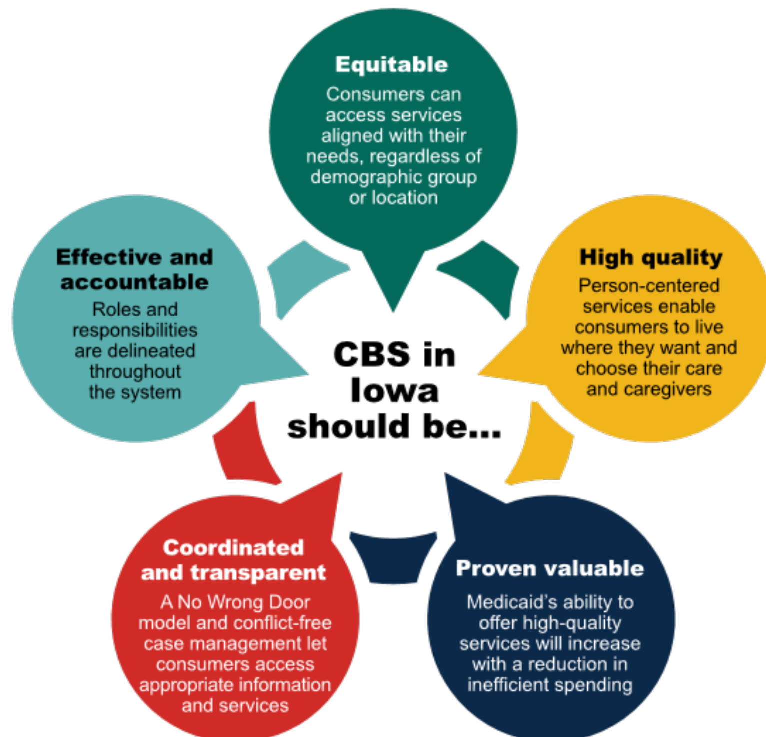
I. Introduction

Health and human services programs in Iowa are guided by a vision for society wherein individuals, families, and communities are safe, resilient, and empowered to be healthy and self-sufficient. In service of this vision, it is the mission of the Iowa Department of Health and Human Services (HHS) to provide high-quality programs and services that protect and improve the health and resiliency of the people they serve. Central within the programs and services HHS administers are supports to allow people who are aging or have disabilities or behavioral health needs to maximize their health, independence, and ability to live in the community. For many in those populations, long-term services and supports (LTSS) are a critical lifeline, and community-based services (CBS) offer supports for those who wish to remain at home and be engaged in the community.

Recognizing the complex landscape in which these services operate, Iowa HHS contracted with Mathematica and The Harkin Institute in January 2022 to lay the groundwork for a path toward improving the CBS system. The Mathematica-Harkin team[3] conducted a systemwide assessment of the state's system to support people who are aging, have disabilities, or have behavioral health needs and developed a set of recommendations to improve the way that consumers and providers experience and interact with the state's CBS system. In addition to documenting areas for improvement, we offer suggestions to build on some successful activities that could be undertaken more broadly throughout the system.

Our evaluation of Iowa's CBS system was grounded in a set of guiding principles that encapsulate Iowans' vision for the ideal system (Figure I.1). These principles align with guidelines from the Centers for Medicare & Medicaid Services (CMS), but they also reflect the articulated values of Iowans throughout the CBS system. The principles highlight a desire for a system in which high-quality services are accessed equitably, where services show proven value for supporting living in the least restrictive setting possible, and where services are delivered in a coordinated and transparent way, with efficacy and accountability throughout the system.

Figure I.1. Guiding principles for Iowa's CBS system



A. Evaluation overview

Our evaluation leveraged a substantial commitment by Iowa HHS to understand how community members experience the CBS

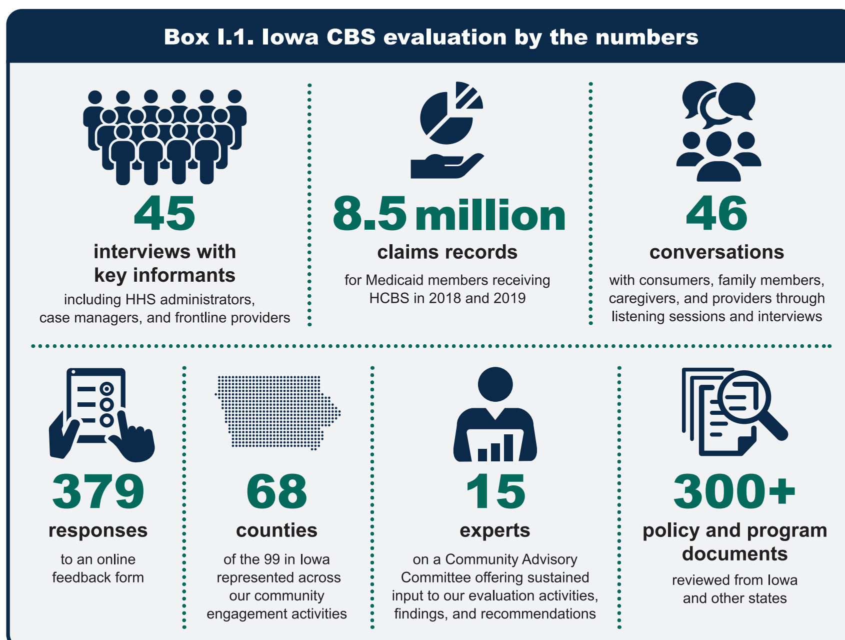
[3] A full list of contributors to this report is available before the reference section.

system. Through Medicaid Town Halls and other community engagement activities, HHS administrators were aware of myriad complex challenges faced by consumers and providers who support living in the community. Iowa HHS sought an external evaluation team to assess the CBS system comprehensively, because many consumers with complex challenges in health and functioning use a range of social services and supports across the state. Thus, although the evaluation was intended to focus on programs under HHS' purview, such as Medicaid, administrators recognized that many other programs and policies that support the populations of interest would be important considerations.

We assessed the CBS system (see Box I.1) using information gathered in the following ways:

- An in-depth **review of HHS programs, policies, and procedures**, including document reviews and staff interviews, to determine whom each program serves, how services are provided, and the incentives and disincentives built into the existing framework (described in Appendix A)
- A thorough **analysis of administrative data** used by programs in the CBS system, with a special focus on enrollment patterns and service use within the Medicaid program during 2018 and 2019, the most recent years with complete service use data available for our analysis (described in Appendix B)
- Substantial **input from community members**, including consumers, families, caregivers, and providers, about their positive and negative experiences with the system and their recommendations about needed system reforms (described in Appendix C)

Input from a Community Advisory Committee, which was composed of 15 experts with lived experience in the CBS system from across Iowa (listed in Appendix D), was critical to our analysis, interpretation of findings, and recommendations. Their suggestions and feedback are woven throughout this report. Our ultimate set of findings and recommendations were developed by comprehensively assessing the information collected across all the evaluation activities.



In consultation with HHS, we focused our initial assessment on Medicaid programs and policies, including Medicaid 1915(c) waiver programs that allow the state to offer home- and community-based services (HCBS) to particular populations. Iowa currently has seven waivers, each of which has different eligibility rules, offers a different set of covered services, assesses participants' needs differently, and has different processes surrounding accessing waiver services. As we describe in this report, demand for those services exceeds the current capacity of the state to meet Iowan's needs. Iowa's Mental Health and Disability Services (MHDS) regions function as a critical safety net across the state in accessing CBS, providing an array of services to Iowans, including individuals who are waiting for a

Medicaid waiver slot. Thus, our initial analysis also sought to understand the interplay between Medicaid and MHDS. As our work with HHS continues, we expect to broaden our investigation to assess how other programs across the state affect individuals who are aging or who have disabilities or behavioral health needs. This additional engagement may include other offices under HHS' purview, such as the Division of Family Well-being and Protection, and may also expand to include other department and systems (the aging, criminal justice, and education systems, for example).

B. Summary of findings

Our recommendations are grounded in a set of high-level findings from our systemwide assessment, described in more detail in Chapters V, VI, and VII:

- **Iowa's process for managing Medicaid waiver waiting lists does not support timely, efficient, or needs-based access to appropriate services**. Waiting lists for Medicaid waiver services—which are an important entry point into the CBS system—can serve as a source of information about CBS needs throughout the state. Yet Iowa's first-come, first-served approach to managing waiver waiting lists separately for five of its seven waiver program does not comprehensively capture information about, nor does it prioritize, services based on need. Iowans—those who need intensive supports, as well as those who are not eligible for Medicaid services—can remain on Medicaid HCBS waiver waiting lists for years. Moreover, the waiting list does not collect information that could help HHS plan for future system demands. While on the waiting list, consumers often have difficulty connecting to CBS offered outside Medicaid, and the current process does not offer referral to other sources of support.
- **Medicaid HCBS waiver services often do not align with member needs, resulting in inequity and inefficiency in accessing needed services.** Although Iowa's Medicaid waivers are the primary avenue for consumers to access CBS to support community living, the current waiver structure aligns eligibility to diagnosis, which means that Iowans' support needs may fit with the services available under the waiver they are using. This creates an inequitable and inefficient allocation of services. Some diagnoses are covered by multiple waivers, meaning that consumers can be eligible for more than one waiver and can move across waivers to obtain a different service package. Others are not covered by any waiver on the basis of their diagnosis, even though their support needs require CBS to remain in the community. In addition, it is difficult to assess members' need comprehensively because there is no single assessment used across all available waivers.
- **Services and supports in Medicaid and the broader CBS system are difficult to navigate and access.** A shortage of providers and gaps in the service continuum create barriers to receiving appropriate care in the community. Furthermore, across Iowa's CBS system, consumers and case managers have difficulty accessing information about available services and providers. This situation is exacerbated by high case manager caseloads. Collectively, these challenges leave consumers and their natural supports to navigate a limited and complex system, resulting in delays or inability to access needed supports. These challenges also create barriers for consumers residing in institutions who are seeking to transition to the community.

Across these key findings, we discovered that Iowa may be better able to leverage and coordinate with Mental Health and Disability Services (MHDS) regions to help consumers access CBS. Iowa's MHDS regions offer valuable CBS at the regional level that can augment what is available to Iowans through Medicaid waivers—including those who are waiting for waiver slots. However, Medicaid and the MHDS regions do not effectively coordinate to minimize service gaps and duplication, creating inefficiency throughout the CBS system.

C. Summary of recommendations

Findings from our evaluation of Iowa's CBS system suggest that three cross-cutting approaches can improve equity, quality, efficiency, coordination, transparency, and accountability within the system.

- **Implement streamlined screening and improved processes to better align services with people's needs** Iowa should develop an initial screening process for those on the waiting list and standardize waiver needs assessments once individuals enroll on a waiver. This will be critical for understanding needs across the system and prioritizing services, and it will support a recommendation to redesign the state's Medicaid HCBS waivers. In addition to improving initial assessments, we identified opportunities to improve the waiting list management process to better support individuals waiting for a waiver slot.
- **Align CBS services, including Medicaid HCBS waivers, to the needs of Iowans.** Reducing the number of HCBS waivers and redesigning their service packages to better align with the needs of Iowans can improve service quality and equity while reducing administrative complexity and inefficiency. We offer options for waiver redesign, based on experiences in other states, that are designed to achieve Iowans' CBS goals.
- **Maximize access to Medicaid HCBS and other CBS supports for people with long-term service and support needs.** To maximize the effectiveness of the existing CBS system, HHS should improve the public's understanding of the system and modify expectations and processes for case management to ensure enhanced navigation support within the system. Iowa should also expand on existing programs that are well-regarded by consumers and appear to be effective but underutilized, such as self-directed services and Money Follows the Person (MFP).

Critical to the implementation of these recommendations is the interplay between Medicaid and MHDS. Aligning MHDS and Medicaid services to better leverage public funding will create a more streamlined system and allow for maximal use of state dollars to reach the most people. As HHS makes decisions, it will be imperative to consider the implementation of these recommendations across MHDS and Medicaid. In our recommendations, we note specific opportunities to better align these two systems. We expect that efforts to implement these recommendations can and should start in parallel with each other. Key to decision making will be the ongoing engagement of invested Iowans across the CBS system and continued data analysis to assess the impact of recommendations.

D. Report outline

Recognizing HHS' interest in moving ahead on the process of meaningful CBS system change, we begin by presenting our recommendations in Chapter II. For those already familiar with Iowa's CBS system, it will be possible to jump directly to that chapter. For others who may be less familiar with CBS in Iowa, Chapter III provides an overview for CBS and the role of Medicaid, MHDS, and other entities in providing critical services to Iowans who are aging or have disabilities or behavioral health needs.

The findings from our systemwide assessment to support our recommendations follow. In Chapter IV, we pivot from the bird's-eye view of the CBS system to describe the user's perspective—that is, how consumers initially access the CBS system, the process to obtain HCBS through a Medicaid waiver, and the connections between those phases and facility-based LTSS. We use that framing to organize our detailed findings, which we share in Chapters V, VI, and VII. Finally, in Chapter VIII, we summarize our work to date and document our intent to support Iowa HHS in its efforts toward meaningful systems change.

II. Recommendations

Implementing specific recommendations to address the challenges we identified in the CBS system will improve Iowans' ability to access services to support living in the least restrictive setting. In the sections that follow, we provide detailed recommendations under each of the themes we identified in the previous chapter. Implementing these recommendations will require that HHS:

- **Leverage and coordinate with complementary initiatives to improve CBS.** Concurrent with our systemwide assessment, Iowa has been working on complementary initiatives to support people with disabilities, with behavioral health needs, and who are aging. For example, the state will need to respond to the Department of Justice's investigation of overinstitutionalization of individuals with IDD which will likely result in specific efforts to improve and enhance access to CBS. As HHS considers options for implementing the specific recommendations in this report, it will be important to coordinate across these initiatives to build upon successes in the system.
- **Engage Iowans across the state to shape systems change that reflects consumers' needs.** Building off a strong foundation of public engagement, it is imperative that HHS continue to engage with invested Iowans across the state as it makes decisions about which recommendations to implement. Transparency about the timeline and actors will be key to the decision-making process to leverage support from the community. HHS can capitalize on the current CBS Community Advisory Committee—consisting of consumers, caregivers, and providers—and expand it to engage additional experts across the system. Ongoing engagement with the state legislature will be critical to support the implementation of these recommendations.

Each of the subsections in this chapter focuses on a recommendation. Under each recommendation is a set of more specific sub-recommendations of the types of activities that we think HHS should consider in service of better aligning the CBS system in Iowa with established guiding principles. To be sure, meaningful systems change will involve agencies both in and outside HHS. Where possible, we consider the involvement and role of other systems to implement the recommendations. Additionally, we draw upon our review of systems change efforts in other states to offer suggestions and best practices based on those experiences.

A. Iowa should implement streamlined screening and improved processes to better align services with people's needs

Well-managed waiting lists can serve as an effective tool to fairly and accurately identify individual and systemwide needs, to plan for the future, and to effectively communicate with those in need of services. Iowa's current policies for waiting list management are not effective because of the duplication of individuals on the waiting lists and the lack of information about their needs. HHS should consider assessing the needs of those on waiting lists through a simplified screening tool to connect people to other services and prioritize individuals on the waiting list.

- ➢ **Conduct a point-in-time screening for all individuals currently on an HCBS waiver waiting list.**

Screening individuals on the HCBS waiver waiting lists will give HHS a better understanding of the needs of individuals who have requested supports to remain in the community. Gathering this type of data would give HHS a sense of the demand for services needed to support the health and independence

of Iowans who are aging or have disabilities or behavioral health needs. Additionally, it may help inform a more comprehensive HCBS waiver redesign process (outlined in recommendation C, below).

Developing and implementing a screening tool should be implemented in partnership with Iowa's MHDS regions and other agencies serving the populations of interest across the state, including Area Agencies on Aging (AAA) and Aging and Disability Resource Centers (ADRCs). The results of this screening could be used to refer people to different agencies that can provide support to people while they are getting on the waiting list for a Medicaid HCBS waiver. One example of a potential screening tool is the Contact Assessment tool developed by interRAI. It is designed to prioritize the urgency for comprehensive assessment and services.[4] The advantage of adopting an interRAI-based tool is that it would build off an assessment tool already used in multiple waiver programs in Iowa. Other states such as Connecticut have used the interRAI as a starting place to customize screening and assessment tools to allocate HCBS within the state.

A waiting list screening process could allow Iowa to leverage state funds to require that MHDS regions provide services for individuals on the waiver waiting list who meet a certain level of need. In addition, or alternatively, MHDS regions could be required to support people who report that they need waiver services but are found ineligible for them. Of course, this change would require expansion of MHDS eligibility criteria and supports to serve a more diverse range of needs than currently served and expand beyond the current core services.

- **Implement new processes to prioritize services using a single Medicaid HCBS waiver waiting list.**

Maintaining separate waiting lists by waiver program, as Iowa currently does, is less effective than having a single waiting list. States with a single waiting list can prioritize individuals for services based on urgency of need without having to triage across separate waiting lists, where individuals may appear multiple times. Especially in conjunction with the new screening tool mentioned above, creating a more structured management approach for a single waiting list will help prioritize services. A new management approach would include identifying populations HHS wants to prioritize for services based on certain criteria determined from information collected in the screening.

Rather than the first-come, first-served approach that Iowa currently uses to manage waiver waiting lists, other states use urgency of need to prioritize applicants on their lists. We identified promising practices based on a review of policies in Florida, Louisiana, Minnesota, Ohio, and Utah. In these states, urgency of need is defined by how soon the applicant will need services to avoid institutionalization. Urgency is based on measures of (1) functional, social, and clinical needs; (2) available housing and caregiving supports; and (3) the risk of adverse outcomes without HCBS. For individuals already in facilities, these states have reserved capacity slots to help transition these individuals, similar to Iowa's current approach for those in institutions.

Ohio offers an example of how a state screens applicants and streamlines waiting list management while continuing to operate multiple Medicaid waiver programs. Specifically, applicants no longer choose among different waivers; instead, applicants are automatically assigned to a waiver waiting list depending on their responses to a screening tool. The screening tool assesses what people will need now

[4] InterRAI. "Screeners: Contact Assessment." 2022. Available at https://interrai.org/instrument-category/screeners/. Accessed September 20, 2022.

and in the next year, then assigns them to a waiting list only if their needs cannot be met by other community-based services.

➢ **Develop infrastructure to share waiting list status with members and with other key agencies providing services, such as MHDS regions and AAA or ADRCs.**

HHS should consider infrastructure to share waiting list information both with members on the waiting list and with other CBS organizations in the state so that Iowans can get services while they wait for a waiver slot. To estimate and share the likely wait time for someone on a waiting list, HHS would need to implement new processes to manage the waiting lists, as described above. To share with other key agencies, the state would need to create a common identifier for all participants across Medicaid and MHDS. A common identifier would (1) allow for Medicaid to share with MHDS a list of individuals on the waiting list who need services in accordance what is learned during the screening step and (2) increase transparency about what services the two entities have been provided to reduce service gaps and duplication between MHDS and Medicaid. If the state acts on this recommendation, HHS should also engage other state agencies to create a more comprehensive data-sharing system across other systems, such as education and child welfare systems.

B. Iowa should take steps to align CBS, including Medicaid HCBS waivers, to the needs of Iowans

Iowa operates a set of Medicaid waiver programs to meet a variety of Medicaid enrollees' health and disability needs, recognizing that a one-size-fits-all approach is challenging. These waivers cover different services and have different monthly budget caps. This structure has resulted in people jumping across waivers. Because their diagnosis makes them eligible for multiple waivers, consumers take the first waiver slot available, only to wait for an opening on the waiver that best meets their needs. Iowa should consider restructuring its waivers, following the lead of other states. Specifically, the state should consider aligning its waivers so that they do not have gaps or overlapping eligibility criteria. Reducing the number of waivers will also simplify program administration and streamline service availability. Part of waiver redesign should include implementing one standardized assessment tool—a more robust version of the screening tool—for all waivers to determine consumers' level of care and service needs. Over time, information from a uniform assessment can be used to refine the package of HCBS available to each waiver participant.

➢ **Develop a standardized, uniform assessment tool across Medicaid HCBS waivers and manage data so that information on consumers' needs can be shared with key partners.**

HHS should develop one uniform needs assessment tool to identify the needs of Medicaid members across HCBS waivers. Ideally, this uniform assessment would augment the information collected as part of the screening tool described in recommendation A, but it would collect additional information from members. Iowa now uses a range of assessment tools across waivers, making it difficult to comprehensively assess the range of support needs across the state. HHS can further improve system functioning by sharing assessment data with partners to better understand system operations.

To streamline data collection, assessors could complete assessments using a computer or other internet-enabled device and enter data in real time. HHS would need either to consider contracting with a vendor to develop a data collection system or to identify an existing system that could be adapted for this use. At a minimum for key functionality, the system will need to have the following components: user role-

based authentication and adequate Health Insurance Portability and Accountability Act security controls; data entry forms that include skip patterns; a robust data architecture; and integration with other systems through individual unique identifiers. Ideally, the different information systems within Iowa—including those managed by state agencies, managed care organizations (MCOs), and private organizations—would use application programming interfaces (APIs) to allow the systems to communicate with one another. For example, with APIs, HHS could automate the matching of assessment data to provider payments to calculate population-level metrics that include assessment as well as information about the use of acute care services. Alternatively, APIs could be used to connect MCO-based systems to a central state system and allow access to MCO-gathered assessment data on a near real-time basis.

Other states provide models for Iowa to consider. For example, Connecticut's assessment process dovetails off of the interRAI-based screening tool the state built, as described earlier. It created a single standardized assessment tool to be used across all LTSS populations regardless of waiver or program, with a focus on consumer needs, strengths, and preferences. Minnesota developed and implemented MnCHOICES, a web-based application that integrates assessment and support planning for waiver participants. This tool eliminated the need for multiple assessments across waivers. Moreover, the single tool, designed to increase quality management, is specific to Minnesota and can be used for both programmatic and budgetary decision making. Assessors outside Minnesota's Medicaid case management system complete the assessments with members.

➢ **Evaluate options for redesigning Iowa's HCBS waivers to be aligned with members' documented needs.**

Medicaid waivers should be tailored in a way that allows individuals who wish to remain in the community to equitably access the services and supports aligned to their needs, regardless of their diagnosis. A simplified waiver structure relative to what currently exists would make it easier for Iowans to understand what services are available and allow them to plan accordingly. Judging from our assessment of the current waiver structure, the needs of the Iowa HCBS population, and practices of other states, we outline three models that HHS could consider. Under each model, HHS will need to assess:

- **Budget:** HHS will need to consider the type of budget model used to determine the total budget for waiver participants in a needs-based or age-based system. Regardless of the model, it is likely that HHS will want to update its approach to waiver budgets.
- **Timeline:** The timeline to implement these changes will vary across the approaches outlined below. Approaches 1 and 2 may be more aligned to the vision that invested Iowans have outlined, but these may take more time to implement.

States have been moving to administer a smaller number of waivers to increase administrative efficiency and improve clarity for consumers about service eligibility. In some instances, these waivers have been done by type of disability, as is the case in Iowa, but other states have structured eligibility by acuity and by age.

Additionally, these waivers have generally been designed without overlapping eligibility criteria, streamlining the eligibility process. Having mutually exclusive criteria for each waiver reduces ambiguity about available services and creates a more equitable system. Over time, the state may be able to reduce costs by ensuring that individuals maximize use of 1915(i) state plan services, which receive a higher federal medical assistance percentage for adults who are enrolled as part of the expansion

population. Analyzing the impact of this cost shift would require data culled from the waiting list screener.

Approach 1: Create three waivers with eligibility based on a person's acuity of need.

Under this approach, HHS would phase out diagnosis-based waivers and introduce three new 1915(c) waivers that align with individual need. This structure would eliminate overlapping waiver eligibility and better align service availability and spending with individual need. The three-tiered structure would have (1) a limited-supports waiver for those at low risk of institutionalization, (2) a moderate-supports waiver for those who need supports to stay in the community, and (3) an intensive-supports waiver for those with the most intensive needs.

Other states have designed their waivers in similar ways around acuity of need. For example, Tennessee uses the 1115 demonstration authority to provide HCBS to adults over age 65 with physical disabilities through its CHOICES program and assigns people to different groups depending on their eligibility for nursing home care: one group for anyone who meets nursing home level of care, a second group for those with physical disabilities and seniors who meet nursing home level of care but want to stay at home, and a third group for those who do not meet the level of need but are at risk for institutionalization. Additionally, Tennessee is actively transitioning people with intellectual and developmental disabilities from its 1915(c) waivers to Employment and Community First CHOICES (1115) program, which has five need-based benefit groups.

Alternatively, Minnesota is implementing two 1915 (c) waivers, with one waiver for people living in residential settings and one for those living independently or at home with family. While setting is not necessarily an indicator of need, we have included this approach as an innovative example. Notably, Minnesota is also implementing the use of individualized budgets, with the budgets based on the person's mix of supports and services identified by the assessment. They previously used a county-based budget method that was based on diagnosis.

Approach 2: Create two waivers with eligibility based on age.

Under this approach, HHS would introduce two new age-based 1915(c) waivers, one that serves children and one that serves adults of all ages. Again, the current 1915(c) waivers in the state would be replaced in this approach. This structure would simplify eligibility criteria, offer equitable access to services regardless of diagnosis, and clarify for consumers what they are able to receive. Importantly, HHS would need to identify population groups that get priority access to the waiver through the waiting list prioritization process, because merging waivers by age would add waiting list structures for members now eligible for two waivers that do not have a waiting list: HIV/AIDs and elderly.

Wisconsin, for example, has two 1915(c) waivers structured on the basis of age, Children's Long-Term Care Supports and the Family Care program. Anyone under age 18 who meets level of care requirements is enrolled in the children's waiver, and those meeting the requirements who are over 18 are enrolled in the Family Care program. There are two options under the Family Care program. Although individuals under both waivers receive the same set of HCBS, the Family Care Partnership program also provides acute and primary care services. The transition to this approach occurred in the 1990s, and Family Care unified service delivery across diagnoses. At the same time, Wisconsin made HCBS an entitlement program and has since eliminated its waiver waiting lists. Although Wisconsin provides waiver services similar to those Iowa provides, Wisconsin also covers additional services, among them adult family

home services, housing support services, and relocation services. The state has a third 1915(c) waiver for anyone who would like to self-direct their services and provides childcare services for children.

Approach 3: Simplify waiver structure by consolidating within the current waivers.

Under this approach, HHS would consolidate the AIDS/HIV (HIV) and Physical Disability (PD) waiver into the Health and Disability (HD) waiver. This would simplify the existing waiver structure and is less administratively burdensome to implement than the other approaches. But it likely would not completely resolve the challenge of equitable access to services and budgets across Iowa's waivers, because waiver eligibility would continue to be based on diagnosis. To better address this concern, we would recommend that Iowa consider creating individual budgets rather than a single budget cap per waiver. This kind of design would align expenditures to need, even with a diagnosis-based waiver structure.

Other states serve more than one population under the same waiver, with eligibility based on diagnosis. For example, Delaware, Nebraska, and New Mexico use diagnosis-based waivers, but each has only four or fewer waivers to serve their populations. A few of the Nebraska and New Mexico waivers use a budget methodology to cap services either through an individual budget or budget that is stratified by population or level of need. For example, New Mexico uses a leveled support method for its medically fragile waiver whereby an individual's budget is based on their support needs. Nebraska's Comprehensive Developmental Disabilities Services Waiver uses an individual budget methodology that develops a budget for each individual based on an assessment of their skills, abilities, and needs. The budget amount is determined before the service plan is developed.

C. Iowa should maximize access to Medicaid HCBS and other CBS supports for people with long-term service and support needs

Medicaid HCBS waivers are a critical resource for people with disabilities or behavioral health needs and people who are aging, but 1915(c) waivers alone cannot effectively serve everyone in Iowa, given constrained resources. Although the improvements put forth in the first recommendation are critical for aligning service packages to need, we also recommend that HHS consider opportunities to provide additional supports through other CBS programs in Iowa. Allowing consumers to access the services they need to remain in the community requires a transparent and coordinated process to connect consumers and providers and to help consumers navigate the system. Leveraging the MHDS regions when appropriate and ensuring that state plan services are being used effectively is key to this recommendation.

- **Improve the public's understanding of the CBS system, available supports, and ways to access services.**

Enhancing and expanding the resources that Iowa uses to educate consumers about services available to them would help ease consumer frustration when navigating a complex system. Iowa can leverage existing infrastructure to make improvements in this area. For example, its Compass online resource directory has been nationally spotlighted as an example of a well-designed resource to connect people to services.[5] Judging from conversations with consumers and their natural supports, however, it is unclear

[5]National Association of States United for Aging and Disability. "Complex Needs and Growing Roles: The Changing Nature of Information and Referral/Assistance." 2019. Available at http://www.advancingstates.org/sites/nasuad/files/NASUAD%20IR%20Survey%20Report%200719_web.pdf. Accessed September 16, 2022.

that Iowans are widely aware that the Iowa Compass site is a place to access information. To promote awareness and use of this tool, HHS could better publicize it after confirming that it is accessible to consumers with a range of disabling conditions and internet access options. HHS may also recommend that agencies formalize agreements with acute care settings and other referral entities to specify how information is shared, collaborate on opportunities to publicize resources, and respond to feedback from consumers about opportunities for improvement.

In addition to making information available for consumers, Iowa should consider ongoing investment into the No Wrong Door system. This would allow for efficiency of referrals, and possibly eligibility determination, for behavioral health, disability, and aging programs. It also creates a simpler process for people seeking services.[6] Implementation of a screening tool as described earlier is a step towards this streamlined approach if the results of the screener are used to connect people to resources across the LTSS system.

Massachusetts's efforts using funding from the Balancing Incentives Program illustrate another way that Iowa might improve its referral network. Specifically, Massachusetts implemented a website and call center, MassOptions, to provide connections to all types of services via a specialist who directs consumers to the right agency depending on stated needs.[7] Massachusetts expanded choice counseling, improved eligibility assistance by co-locating Medicaid eligibility with ADRCs, improved training for direct care workers, and boosted awareness about its information and referral website and call center.

- **Clarify and strengthen expectations for MCOs to support individuals with long-term care needs by connecting them to available services and supports.**

Like other states that have implemented managed care, Iowa must balance allowing MCOs the freedom to innovate with aligning MCO contract requirements to support HHS goals. A next step for Iowa HHS is to mature the relationship and measure and improve health outcomes and coordinate with social services. To do this, HHS will need to fully incorporate LTSS into MCO quality measures and financial incentives. To some extent, this has been implemented in MCO contracts to date with blended capitation rate cells for institutional LTSS and HCBS. However, other opportunities exist to accelerate rebalancing through financial incentives. If this strategy is something HHS pursues, Mathematica can offer support with prioritizing and aligning these provisions to other recommendations being implemented.

With managed care a critical component of HCBS provision in the state, HHS should focus on identifying measures and incentives to ensure accountability for outcomes. Specifically, HHS should consider:

- Clarifying responsible parties and who will be held accountable for key elements of the system while changes outlined in recommendations A and C are implemented
- Augmenting the tracking of managed care performance and ensuring that the agency has enough resources to assess compliance with contract requirements. HHS will need to leverage policy staff to provide clarity to MCOs and appropriately track the progress MCOs make toward goals

[6] Administration for Community Living. "Key Element of an NWD System of Access to LTSS for All Populations and Payers." 2016. Available at https://acl.gov/sites/default/files/programs/2016-10/NWD-National-Elements.pdf. Accessed September 27, 2022.
[7] Center for Health Care Strategies, Inc. "Strengthening Medicaid Long-Term Services and Supports in an Evolving Policy Environment: A Toolkit for States." 2019. Available at https://www.chcs.org/media/Strengthening-LTSS-Toolkit_032019.pdf. Accessed September 15, 2022.

HHS can use the current delivery system to improve supports and codify, through policy or incentives, the specific roles and responsibilities for the MCOs. Some options for doing this within managed LTSS contracts are shown in Figure II.1.

Figure II.1. Example language from other MLTSS contracts

Policy requirement	Example
Improve quality-of-care data collection and reporting	New York requires quarterly reporting on rebalancing efforts such as transitions in and out of institutions. Iowa could consider collecting and publicly reporting the Medicaid managed LTSS measures released by CMS in 2022.[a]
Provide incentives or sanctions for transitions, or both	In addition to blended capitation rates, states have other financial incentives or sanctions for transitions. Ohio provides three months of enhanced payments after someone transitions from an institution to the community, and reduces payments for three months if a beneficiary enters an institution. Hawaii rewards and sanctions MCOs that meet or don't meet HCBS community capacity requirements, respectively. They require that MCO rewards be in part passed on to providers, but MCOs cannot pass along sanctions.
External review of care plans with reduction, suspension, or termination of services	Kansas has ADRCs review MCO care plans that result in a reduction or suspension of services. The review process and criteria are publicly available to make the process more transparent while being reviewed by an independent body.
Waiting list service provision and reporting	Kansas MCOs are required to report the number of people (1) in institutions while on waiver waiting lists, (2) who move off and on waiting lists (and the reason for the move), and (3) on a waiting list but receiving HCBS through managed care.
Requirements for case management	Massachusetts' Senior Care Options program requires certain qualifications for case managers. In this program, MCOs are required to contract case management responsibility to local Aging Services Access Points. These requirements are a bachelor's degree in social work or human services, two years of experience, and other trainings.
Case management ratios	Tennessee sets specific caseload requirements for those in institutional settings, transitioning from institutional settings, receiving HCBS, and at risk of institutionalization. For example, in 2017, Tennessee's HCBS average ratio was 1:46, with a 1:66 maximum. There are penalties if ratios are not met. Additionally, Tennessee applies the case management ratio for HCBS to individuals who have been assessed as candidates for moving out of institutions to increase the support during the transition period.[b]
Partnerships with community-based agencies	Oregon requires its MCOs and LTSS providers to share best practices, processes, and expectations for engaging beneficiaries in care planning. Oregon does not include LTSS in its managed care program; rather, it serves as a model for enhancing partnerships with MCOs and community groups.
Network adequacy	In addition to time and distance standards for network adequacy, states can: • Measure the amount of time between HCBS authorization and receipt of services • Measure the amount of HCBS authorized compared to what is delivered[c]

[a] Centers for Medicare and Medicaid Services. "Medicaid Managed Long-Term Services and Supports (MLTSS) Measures Technical Specifications and Resource Manual." 2022. Available at https://www.medicaid.gov/media/3396. Accessed September 22, 2022.

[b] Community Living Policy Center, University of California San Francisco. "Managed Long-Term Services and Supports: Assessment, Authorization, and Case Management in State MLTSS Systems." November 2017. Available at https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/MLTSS%20Assessment%20Authorization%20Planning%20Management%2011-13-17.pdf. Accessed September 15, 2022.

[c] Community Living Policy Center, University of California San Francisco. "Managed Long-Term Services and Supports: Assessing Provider Network Adequacy." December 2018. Available at https://heller.brandeis.edu/community-living-policy/images/pdfpublications/2018decembermltss-assessing-provider-network-adequacy.pdf. Accessed September 22, 2022.

- **Evaluate options for redesigning the way HCBS case management is provided.**

Iowa has an opportunity to reconsider how HCBS case management is delivered in the state. Currently, Iowa's MCOs are responsible for providing case management for those enrolled in managed care. In addition, MHDS regions, AAA/ADRCs, and institutions also provide some level of case management for people with disabilities, who have behavioral health needs, and who are aging. Improving the quality and stability of case management across these systems may support a more streamlined and easily navigable system. States with managed LTSS choose to either keep case management in the MCO, contract for it outside the MCO, or create a hybrid model with responsibility shared between MCOs and community organizations.[8] When considering any of the case management approaches detailed in this section, HHS will need to consider:

- Contracting out case management to local entities increases connections to local community partners and agencies familiar with local resources, whereas keeping it internal allows for better communication between MCO departments.
- MCOs cannot contract out to entities that do not have enough staff or supporting infrastructure in place, so outsourcing case management responsibilities will require an investment in supporting local entities to build capacity.

Approach 1: Identify the requirements to be applied to case management entities across the state.

With this approach, HHS and its partners would develop requirements for all entities that provide case management, which could include specific training requirements, licensure, or partnerships with local entities. This option might include MCO case managers, facility case managers, targeted case management case managers, and other entities that provide case management. Implementing this approach would require clearly defined roles, responsibilities, and coordination when people transition between different components of the system, such as from MHDS to a Medicaid waiver or from an institution to a community setting. HHS could implement financial incentives to ensure MCOs are fulfilling their case management duties.

Minnesota had this kind of distributed case management model, in which many different entities are responsible for case management across the system. Although this action was not taken specifically for LTSS, in 2019 Minnesota mapped out a way to standardize case management across all Medicaid case management entities. For each service component—that is, assess, plan, refer, and monitor—Minnesota outlined expectations and standards that every case manager must comply with.[9] The goal is that regardless of where someone receives case management, beneficiaries know what to expect and what they can rely on.

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[8] Community Living Policy Center, University of California San Francisco. "Managed Long-Term Services and Supports: Assessment, Authorization, and Case Management in State MLTSS Systems." November 2017. Available at https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/MLTSS%20Assessment%20Authorization%20Planning%20Management%2011-13-17.pdf. Accessed September 15, 2022.

[9] Minnesota Department of Human Services. "Case Management Redesign: Draft Service Design." January 2019. Available at https://mn.gov/dhs/assets/cm-redesign-draft-service-design-12.05.2019_tcm1053-412417.pdf Accessed September 15, 2022.

Approach 2: Offer MCOs the opportunity to outsource case management to the MHDS regions, AAAs, or other local entities.

With this approach, HHS would require MCOs to partner with regional entities already in place to provide some, or all, case management for people receiving HCBS. Case management costs would be included in the MCO capitated rate as they are now, but the MCOs would contract out to the MHDS regions, the AAAs or ADRCs, or both. This option would engage the MHDS regions and the AAAs or ADRCs in the system and strengthen partnerships, while delegating case management to regional or local entities that may be more attuned to what services are available at the local level. During the transition to managed care, HHS did allow MCOs to contract with entities that previously provided case management.

North Carolina is in the process of shifting to managed care and implementing tailored plans for people with intensive behavioral health and intellectual and developmental disability needs. One of the state's nine core principles for case management is that care managers should be embedded in provider organizations when possible, and that they should live near and be actively engaged in beneficiaries' communities. These tailored plans will be carried out as health homes and follow federal health home guidelines. They can employ case managers, contract with organizations that obtain case management agency certification through the state (such as those that provide services to people with intellectual or developmental disabilities or with behavioral health needs), or they can contract with advanced medical homes (serving those in their standard plans) if they meet certain requirements. The state provides oversight and payment to the plans, and it certifies case management agencies and advanced medical homes. Tailored plans will receive a capitated payment that includes case management, but they can also submit claims for engagement activities to outreach to beneficiaries who are not actively engaged.[10]

Another example of this type of approach is in Ohio, where Medicaid-Medicare plans for dually eligible individuals are required to contract with AAAs to provide case management for adults ages 60 and older. These plans are allowed to contract out case management for other populations as well.

- **Support families involved in receiving or providing HCBS by encouraging self-direction and paying caregivers.**

Self-directed services like the Consumer Choices Option (CCO) and Consumer-Directed Attendant Care (CDAC) programs are well-regarded by invested Iowans. With known provider shortages in Iowa and across the country, HHS should promote self-direction for consumers as a way to serve additional people in the community. This could be especially valuable in rural areas, where the supply of direct care workers is inadequate. To leverage self-directed services, HHS should create a training for case managers using the CCO and ensure there is clear information about how to enroll in and effectively use CCO. Further, building on the flexibilities implemented during the pandemic, HHS could design a caregiver service and benefit package to allow spouses and parents to receive payment to reduce the amount of unpaid caregiving.[11] This option would include engaging caregivers to ensure the package supports caregivers and does not place undue burden on them and their families.

[10] North Carolina Department of Health and Human Services. "North Carolina's Care Management Strategy for Behavioral Health and Intellectual/Developmental Disability Tailored Plans." May 2019. Available at https://files.nc.gov/ncHHS/TailoredPlan-CareManagement-PolicyPaper-FINAL-20180529.pdf. Accessed September 15, 2022.

[11] HHS. "Appendix K: Emergency Preparedness and Response and COVID-19 Addendum." 2020. Available at https://www.medicaid.gov/state-resource-center/downloads/ia-combined-appendix-k-appvl.pdf. Accessed September 15, 2022.

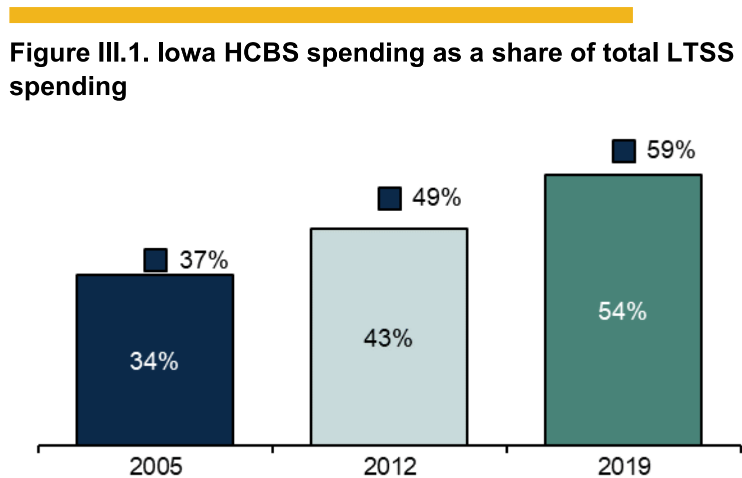
- **Consider expanding MFP eligibility criteria beyond certain diagnoses to allow more transitions out of facilities for those who wish to reside in the community.**

The transitions support that MFP offers generally receives positive feedback from Iowans. However, eligibility for MFP in Iowa is limited to individuals with an intellectual disability or brain injury. This means that Iowa misses the opportunity to use some of the additional funding offered by the federal MFP program to help Iowans who are aging or who have another disability and might be able to benefit from MFP. HHS could consider expanding MFP eligibility to allow all people whose needs can be met via Medicaid HCBS waiver services to transition out of facilities with support from the MFP program. Alternatively, or additionally, the results of the recommended waiting list screening may help identify priority populations to serve with MFP funds. MCOs could also be required to financially support this program and support the expanded transition benefits for those leaving institutions for community-based settings. Regardless of whether the program is expanded, HHS should clarify the responsibilities of the MFP program and MCO case managers for supporting transitions to best meet the needs of Iowans transitioning out of facilities.

III. The Iowa LTSS Landscape

For many people who are aging or who have disabilities or behavioral health needs, CBS are critical supports allowing them to remain in their homes and be integrated into their communities. Facility residence may be necessary in some cases, but policy shifts over the past decades have focused on providing LTSS in the community instead of in facilities whenever possible. To a large extent, this change reflects a recognition that individual preference in living arrangements is critical. The U.S. Supreme Court's 1999 Olmstead decision required that CBS be made available so that people can live in the least restrictive setting of their choosing. There are also financial incentives for making this shift, with HCBS generally found to be less expensive per member than LTSS provided in nursing homes and other long-term care institutions.[12]

Figure III.1. Iowa HCBS spending as a share of total LTSS spending



Source: 2005 data from Wenzlow et al. (2016); 2012 fiscal year data from Lewis et al. (2019); 2019 fiscal year data from Murray et al. (2021).

Note: Bars reflect the share of Iowa's Medicaid LTSS expenditures devoted to HCBS; the squares represent the same statistic at the national level across all states.

Like other states, Iowa has shifted its state Medicaid spending away from institutional LTSS spending toward HCBS (see the bars in Figure III.1). From 2005 through 2019 (the last year of available data), the proportion of LTSS expenditures spent on HCBS increased from 34 percent to 54 percent. The share of Iowa's LTSS expenditures on HCBS has been just below the national average (shown as dark blue squares in Figure III.1), though generally the state is following the national trend. Yet, state investments in recent years for HCBS lag behind those for facility care. From 2013 through 2022, appropriations to nursing facilities have increased by double those for HCBS. In 2022 alone, Medicaid appropriations to nursing facilities increased by $19.1 million while HCBS appropriations increased by $11.0 million.[13]

A. CBS funding and governance in Iowa

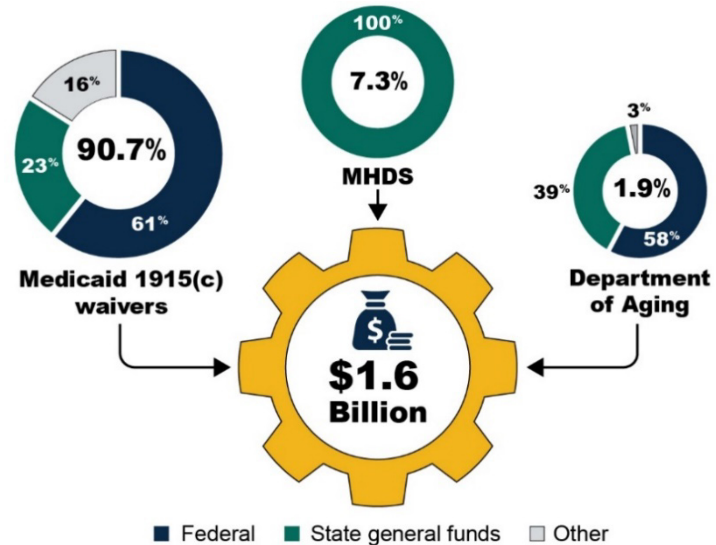
Medicaid is the primary, though not the only, funder of CBS in Iowa for Iowans with disabilities or behavioral health needs and those who are aging. As Iowa HHS implements system changes to Medicaid, as described above, it will be important to assess the impact of these changes on other state programs and, more importantly, to learn how to work with other supports in the system to create a streamlined system of care.

[12] Hargan, E.D. "Report to the President and Congress: The Money Follows the Person (MFP) Rebalancing Demonstration." Washington, D.C.: U.S. Department of Health and Human Services, 2017. Available at: https://medicaid.gov/sites/default/files/2019-12/mfp-rtc.pdf. Accessed September 15, 2022.
[13] Iowa Fiscal Services Division. "Health and Human Services Appropriations Bill House File 891." 2021. Available at https://www.legis.iowa.gov/docs/publications/NOBA/1221139.pdf. Accessed January 27, 2023.

In fiscal year 2022, $1.6 billion dollars were spent on community supports through the Department of Aging, Medicaid waivers, and MHDS regions (Figure III.2). The 1915(c) waivers, which make up just over 90 percent of CBS expenditures in the system map, were the focus of our evaluation. The MHDS regions and the Department of Aging also play critical roles in supporting those who are aging or with disabilities by providing a limited set of services to those who are eligible and by supporting system navigation. Each of these funding sources receives state general funds. In addition, the Department of Aging and Medicaid are supported with federal funds.

Iowa also leverages funding from the Mental Health Block Grant (MHBG), Substance Abuse Treatment Program (SATP), vocational rehabilitation, and other federal- and state-funded programs. Although not included in the financial map, the funds help provide a robust set of supports for people with disabilities or behavioral health needs, and for those who are aging. In addition, child welfare and criminal justice programs may provide services to Iowans who may also interact with Medicaid and other programs.

Figure III.2. CBS spending in Iowa



Source: *Iowa Budget Report, Fiscal Year 2023*. 2022. Available at https://dom.iowa.gov/sites/default/files/documents/2022/01/fy23_bbb_final_with_cover.pdf. Accessed January 12, 2023; and Iowa HHS. (2ncy Dashboard. Available at: https://hhs.iowa.gov/dashboard_welcome. Accessed January 12, 2023.

Note: The Medicaid 1915(c) waiver expenditures shown above are MCO total waiver capitation expenses for state fiscal year 2022. Fee-for-service expenditures are not included. To calculate the state and federal split for Medicaid, we used the federal and state expenditures for the Health Program provided in the HHS Agency Dashboard Fiscal tab for fiscal year 2020, which was the most recent year available in the dashboard.

Iowa Medicaid is responsible for a majority of LTSS service provision in the state. Medicaid waiver programs, described in Section III.B, are the primary vehicle by which people access HCBS. Iowa Medicaid also oversees LTSS in facilities, described in Section III.C. In Section III.D, we highlight other entities that offer HCBS in Iowa, including the state's MHDS regions. These regions provide locally delivered services to adults and children with mental health and disability needs.

Since 2016, Iowa Medicaid has contracted with MCOs to administer its Medicaid managed care program, Iowa Health Link. MCOs are contracted to do the following:

- Conduct administrative oversight to determine member levels of care
- Approve and deny authorization for services
- Determine whether members meet medical necessity for the services they wish to receive
- Provide case management services to members to aid their system navigation and care coordination

Blended capitation rates are used to incentivize MCOs in Iowa to promote community-based care, but there are some notable exceptions. A blended rate is when the state pays the same capitation to MCOs for everyone in LTSS, regardless of setting. Because HCBS costs MCOs less than institutional care, they are incentivized to provide community supports and take a financial loss for people in institutional care.

The case management teams within the MCOs are intentionally separated from the staff who make decisions about service authorizations, which promotes conflict-free case management. Medicaid members interact with MCO case managers to develop service plans aligned to their care needs. These case managers should assist beneficiaries by educating them about their authorized benefits, helping them find CBS providers, and assisting them with applications for higher levels of care, such as institutional placement. While the state has outlined expectations to the above for case management within the MCOs, stakeholders often bring case management up as a challenge within the managed care system.

During the period of our initial analysis (in 2022, through August 31), two managed care organizations, Amerigroup and Iowa Total Care, provided care statewide, with Amerigroup managing 58 percent of the population and Iowa Total Care the remaining 42 percent.[14] Iowa's managed care arrangement is fully integrated, with payments for physical health, behavioral health, and LTSS services and needs. These entities receive a per member per month (PMPM) capitated payment to administer services, including LTSS.

B. HCBS through Iowa Medicaid waivers and state plan options

HCBS through Medicaid are not available to all beneficiaries in the state, but rather only for those who meet certain eligibility criteria. States request and receive approval from the U.S. Department of Health and Human Services to operate waivers that differ from typical Medicaid state plan services. Under these 1915(c) waivers, states can offer HCBS to individuals meeting an institutional level of care who would like to remain in the community. States have the flexibility to limit and target enrollment in 1915(c) waiver programs (see Box III.1).

Currently, more than 25,000 Iowans rely on seven Medicaid 1915(c) waivers to provide HCBS:

- HIV/AIDS waiver (HIV)
- Brain Injury waiver (BI)
- Children's Mental Health waiver (CMH)
- Elderly waiver (EL)
- Health and Disability waiver (HD)

Box III.1. What are Medicaid 1915(c) waivers?

- The waivers offer HCBS to groups of Medicaid members with high level-of-care needs as an alternative to living in an institution.
- Waiver services do not cost more than providing these services in an institution.
- The waivers permit states to target specific populations (for example, based on disability) and have enrollment caps (unlike the Medicaid state plan).
- Waivers cover services to avoid institutional care, including case management, home health aide and personal care, adult day health, habilitation, and respite care.
- Services follow a care plan that is individualized and person-centered.
- The waivers are initially approved for three years, with the ability to extend in five-year increments.
- The waivers are allowed through Section 1915 of the Social Security Act.

Source: CMS (2022); Medicaid and CHIP Payment and Access Commission (2022).

[14] Molina Healthcare was awarded a new managed care contract on September 1, 2022.

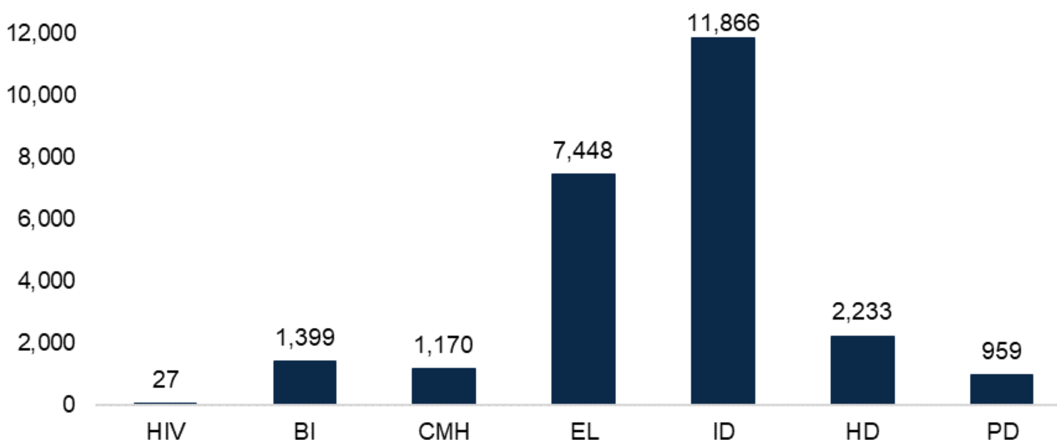
- Intellectual Disability waiver (ID)
- Physical Disability waiver (PD)

These waivers vary in their size (Figure III.3) because of differing eligibility requirements and the number of Medicaid members who can be served under each program (slot cap). Some of the waivers hold additional slots available for individuals leaving facility-based care. The waivers also differ in that five of the seven waivers have a waiting list and the other two do not (Appendix Table E.1). The EL waiver is the only waiver that does not cap enrollment; thus, it is the only waiver whose enrollment and expenditures increase annually to meet the needs of Iowa's aging population.

The waivers also offer a different set of services meant to target the needs of individuals with specific diagnoses (see Appendix Table E.2). Some services are covered broadly, such as respite (available on six of seven waivers); other services, such as day habilitation, are available on only one waiver. Generally, the ID waiver has the most robust service package and its recipients have the highest PMPM spending ($6,021 in 2020). Members on the PD and CMH waivers have fewer service offerings and lower PMPM spending ($4,379 and $3,515 in 2020, respectively).[15]

In addition, in 2021, 6,937 individuals with chronic mental illness received habilitation services from Iowa's 1915(i) state plan option. Under Section 1915(i), states can expand their offering of HCBS using an amendment to the Medicaid state plan. For this specific set of habilitation services, Iowa has waived the Medicaid provision that services must be accessible to all individuals by limiting access to only those with a mental health diagnosis who have a household income under 150 percent of the federal poverty level (FPL) and who meet specific needs-based eligibility criteria and have certain risk factors.[16] Under the state plan option, these services must be available to anyone who meets these criteria and the program therefore does not have a waiting list.

Figure III.3. Enrollment in Iowa's Medicaid 1915(c) waivers in January 2022



Source: Iowa waiver waiting list numbers as of January 2022, based on an Iowa HHS report in September 2022. Available at https://hhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs. Accessed September 15, 2022.

[15] Iowa Fiscal Services Division. "Medicaid HCBS Waivers." August 2021. Available at https://www.legis.iowa.gov/docs/publications/FTNO/1226368.pdf. Accessed September 15, 2022.
[16] Iowa HHS. "State Plan Home- and Community-Based Services (HCBS) Habilitation Program Information Packet." May 2022. Available at https://hhs.iowa.gov/sites/default/files/Comm531.pdf. Accessed September 15, 2022.

In addition to the waivers just mentioned, Iowa offers CBS to support individuals with disabilities or behavioral health needs and people who are aging with a set of services available through the Medicaid state plan and other programs. These include the following:

- **Community-based neurobehavioral rehabilitation services (CNRS):** Specialized category of neuro-rehabilitation services provided by a multidisciplinary team to address cognitive, medical, behavioral, and psychosocial challenges, as well as the physical manifestations of acquired brain injury. These services are available for individuals residing in a three- to five-bed residential care facility that meets certain requirements.
- **Home health services:** Services provided to children and adults through home health agencies that provide skilled nursing, home health aide, or occupational, physical, and speech therapy.
- **Integrated health homes (IHH):** Team of professionals, including family and peer support services, work together to provide whole-person, patient-centered care for adults with a serious mental illness (SMI) and children with a serious emotional disturbance (SED). IHH must coordinate all medical and behavioral care regardless of the funding source.
- **Money Follows the Person (MFP):** Supports for individuals with ID or a brain injury who are transitioning from a nursing facility or intermediate care facility for people with intellectual disabilities (ICF/ID) to the community. Services include funding for transition services and enhanced supports during the first year of community living, paid for by a federal grant.
- **Private Duty Nursing/Personal Cares (PDN/PC) program:** Program through Early Periodic Screening, Diagnostic, and Treatment that provides private duty nursing and personal care for children younger than age 21. Up to 16 hours of care is provided per day.
- **Program of All-inclusive Care for the Elderly (PACE):** Comprehensive care program that provides preventive and primary care, social services, acute care, and long-term services for frail individuals. Participants typically receive care at a day center staffed by a team of health care professionals.

C. Institutional LTSS in Iowa's Medicaid program

Although the focus of our work is on services provided in the community, Iowans face challenges transitioning from institutional care to a community residence. Our evaluation primarily focused on settings that had been found to have difficult transitions or had been identified as pain points for Iowans, including: ICF/IDs, mental health institutions (MHIs), nursing facilities (NFs), and psychiatric medical institutions for children (PMICs).

- **ICF/IDs** provide active, setting-based treatment for individuals who need constant supervision and continuous habilitation services. Iowa has over 100 private ICF/ID providers, and the state operates two: Glenwood Resource Center and Woodward Resource Center.
- **MHIs** are state-run facilities designed to provide specialized acute, person-centered psychiatric treatment for individuals experiencing severe symptoms of mental illness who are unable to receive necessary evaluation or treatment services in the community. Iowa has two remaining MHIs following the closure of two other facilities in 2015.
- **NFs** are settings for intensive medical care and personal assistance, where individuals may receive short-term skilled nursing and rehabilitation or long-term care when they are medically stable but unable to live at home because the supports they need to conduct their activities of daily living are not available in the community.

- **PMICs** are privately run institutions that provide continuous care and diagnostic or long-term psychiatric services to people younger than age 21. PMICs may provide mental health or substance use services. As of 2020, there were 28 licensed PMICs in the state.

As shown in Table III.1, these facilities serve people across Iowa with a range of complex challenges. Accordingly, they vary in terms of their capacity and likelihood of transitions into and out of the community.

Table III.1. Medicaid LTSS facilities in Iowa

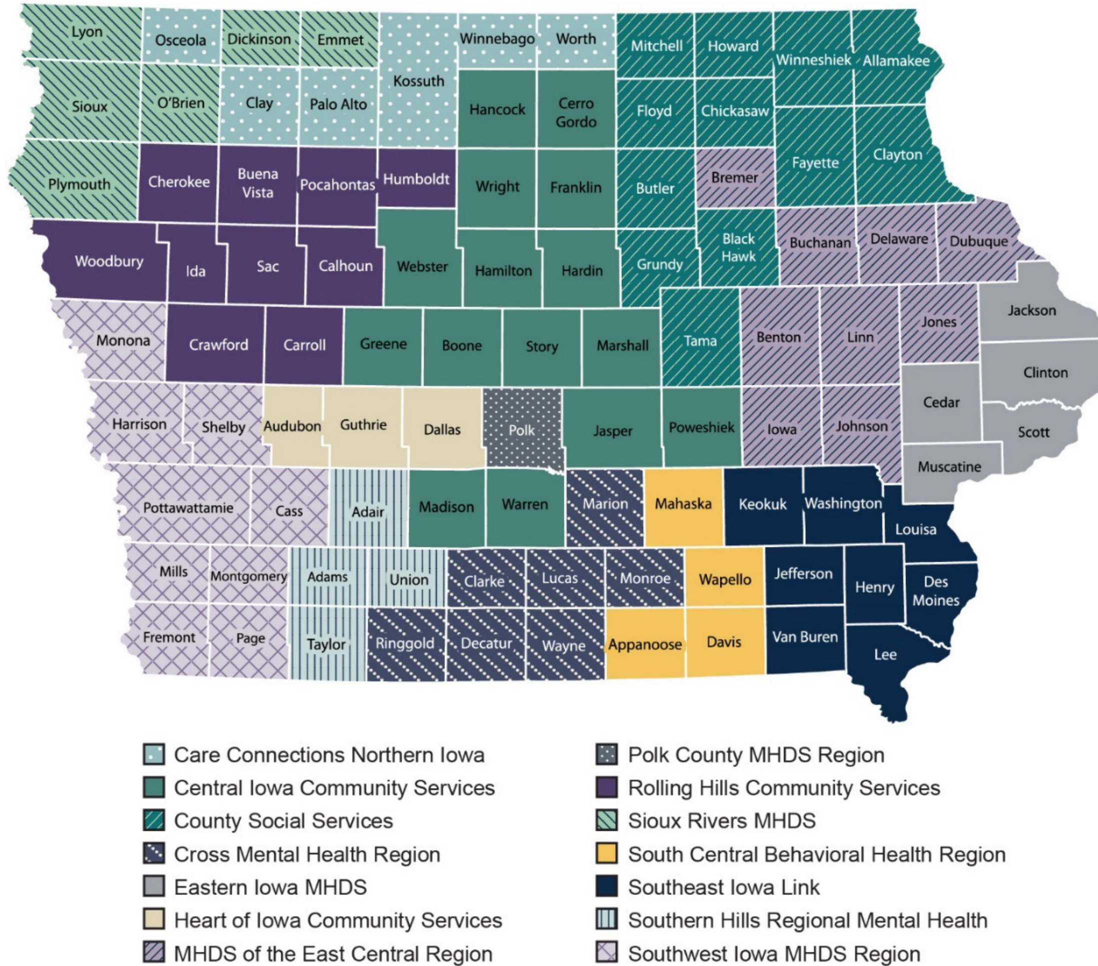
	ICF/ID	MHI	NF	PMIC
Population served	Individuals with severe intellectual disabilities	Adults and children with severe symptoms of mental illness	Adults who require nursing care and other services in addition to room and board because of a mental or physical condition	Children younger than age 21 with psychiatric conditions
Number of beds	2,927	64 adult beds, 28 children or adolescent beds	29,320	452
Average length of stay	11.4 years	Unknown	Unknown	31–90 days
MCO oversight	Yes	No	No	Yes

Source: Iowa Legislature (n.d.); Iowa HHS (2016); Iowa HHS (2021); Iowa HHS (2022).

D. CBS in Iowa beyond Medicaid

The impact of MHDS on the CBS landscape in Iowa is outsized relative to its financial footprint, which is just 7 percent of the total CBS budget. Although MHDS does not have the same level of expenditures as Medicaid's spending on HCBS, MHDS regions are an important part of Iowa's system of supports for consumers with disabilities and behavioral health needs. Iowa's 99 counties are divided into 14 MHDS regions (see Figure III.4). Each region is tasked with providing local access to mental health and disability services for Iowans.

Figure III.4. MHDS regions



Source: HHS, "Iowa Mental Health and Disability Services Regions: Statewide Report SFY2021." 2022.

Note: Appendix Table E.3 contains a list of the MHDS regions and counties that align with this map.

In addition to being responsible for the development of and access to a set of core services (see Box III.2), the regions contract with local providers to make sure that the core set of services are available to residents of the region, regardless of the potential payment source for the services. Many of the core services that regions provide are comparable to those that Medicaid HCBS waivers cover. However, it is hard to compare Medicaid and MHDS services because each uses its own set of billing codes and service requirements. Thus, two services may seem similar in name but are functionally different when provided.

Box III.2. Iowa MHDS core services

- Treatment to improve a person's conditions
- Crisis response
- Support for employment
- Support for community living
- Recovery services
- Service coordination

Source: Iowa Code 2022, Section 331.397.

The MHDS regions are required to fund services for eligible adults diagnosed with a mental illness or intellectual disability who live at or below 150 percent of the federal poverty level (FPL) and children with SED who live at or below 500 percent of the FPL. Eligibility for MHDS payment requires that recipients either not be enrolled in Medicaid or, if Medicaid enrolled, that MHDS pays for services that are not covered by Medicaid. In 2021, the regions served 27,990 (unduplicated) people. Among those served in 2021—including those with a dual diagnosis—96 percent of consumers served by MHDS had a mental illness, 5 percent had an intellectual disability, and 3 percent had a developmental disability.[17]

Regions can tailor their services to certain groups. They are also able to provide services to populations who meet specific requirements, including those with brain injuries or developmental disabilities or children who have needs beyond SED. Some regions provide select services for those who are involved with the justice system. Each region independently decides the populations served and services provided beyond the core services and eligibility requirements. This design allows regions to tailor services to the needy populations in their communities and take into consideration the capacity of the provider network in their region.

Historically, each county levied local taxes to supplement behavioral health services in their local communities. This system became regionally based in 2014 to address equity issues across the state. In July 2022, the funding structure for MHDS changed when Senate File 619 went into effect, which moved funding to the state and tried to solve gaps in services that could be attributed to differences in local property taxes. This came with a per capita general fund appropriation, totaling just over $121 million in 2023.[18] Keeping the regional structure, state funding will be distributed based on population and demand for services. MHDS regions are intended to be the payers of last resort in Iowa by acting as a safety net when Medicaid funding isn't available.

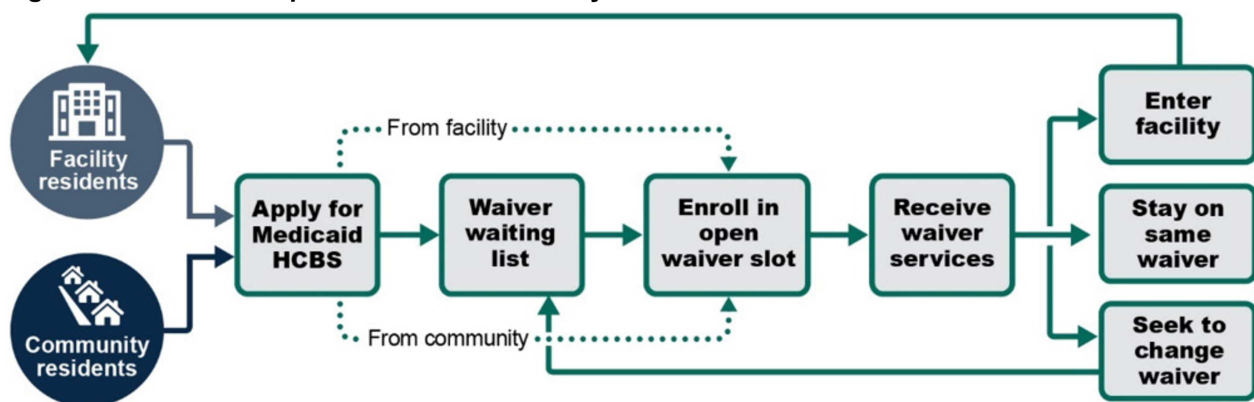
[17] Iowa HHS. "Iowa Mental Health and Disability Services Regions: Statewide Report SFY2021." July 2022. Available at https://hhs.iowa.gov/sites/default/files/SFY2021_MHDS_Regions_Statewide_Dashboard_FINAL.pdf?090120221437. Accessed September 15, 2022.
[18] Iowa Legislative Services Agency. "Fiscal Note: Fiscal Services Division – Senate File 619." 2019. Available at: https://www.legis.iowa.gov/docs/publications/FN/1222907.pdf. Accessed January 27, 2023.

IV. Iowans' Journeys Through the LTSS System

Our evaluation found that Iowa's CBS system currently falls short of its guiding principles at various places along the consumer experience in accessing HCBS and LTSS through Medicaid. Because individuals do not interact with the aggregate landscape documented in the previous chapter, we use consumer experience framing to document our findings in the chapters that follow.

Figure IV.1 shows the most common pathways to accessing HCBS. This diagram was informed by an understanding of Iowa policies and our conversations with Iowans across the state who have disabilities or behavioral health needs or who are aging. These trajectories follow a similar—but not identical—path. Individual paths are not always as linear as the figure shows, but for purposes of illustration, we demonstrate common pathways moving horizontally from left to right. With Medicaid HCBS as the core of CBS in Iowa, most individual trajectories in the system begin when consumers try to access Medicaid services. The figure shows that individuals enter the CBS system either from facilities or as residents in the community. As discussed below, facility transitions are especially important in the current system.

Figure IV.1. Iowans' experiences in the LTSS system



A. Iowans entering the HCBS system

Entering the HCBS system encompasses applying for Medicaid HCBS via a 1915(c) waiver and spending time on a waiver waiting list before being enrolled in a waiver program. Whether in a facility or community setting, the first step to accessing HCBS is to apply for services through Medicaid. Finding out about waivers and applying for them is not always transparent, so many consumers rely on tips from friends and relatives to make the process easier. This graphic assumes that Iowans in facilities aim to exit an institution, but not all may want, or be able, to exit because of their needs, individual or family preferences, or the lack of community supports.

Those who qualify for the HIV and EL waivers can receive a waiver slot immediately, because these programs do not have waiting lists. For those who apply for the BI, CMH, HD, ID, and PD waivers, however, individuals enter a waiting list in most cases. In Chapter V, we summarize our findings related to system entry for those who begin their HCBS journey through a waiver waiting list. In a few cases, individuals are able to bypass the waiting list or shorten their wait. For those coming from an institution, reserved capacity slots may be available for individuals on the BI, CMH, and ID waivers. For those applying to the ID or BI waiver, a priority needs assessment allows some applicants to move to the front of the line.

Alicia, a 24-year-old woman with a disability that limits her mobility, recognized that her disability was increasingly interfering with her ability to live independently. She applied for the PD and HD waivers in Iowa Medicaid about three years ago. She heard from people she knew that the HD waiver would likely provide more of the types of services she needed, but that the waiting list was longer than for the PD waiver. She applied for both, figuring she would take what she could get. Like others we spoke with, she told us that the application process was challenging. She could not tell where she was on the waiting list, was told her application got lost multiple times, and had to fill out the same forms again and again.

About a year and a half ago, Alicia briefly had a slot on the PD waiver—but then learned that her college savings meant that she did not meet the asset limits for Medicaid and she lost her slot. She's since used her savings so that she will be eligible for the HD waiver when a slot opens. In the meantime, she's relied on friends to help with her daily care needs and uses county transit services when she can, but she misses her independence. ***Asked when she thinks she might get a waiver slot, Alicia said, "I honestly quit asking about a year ago. It takes up too much time to even find an answer."***

Listening session participant (name and details have been changed to protect privacy)

B. HCBS after enrollment on a Medicaid waiver

As shown in Figure IV.1, leaving a waiver waiting list occurs when (1) individuals are offered a slot and enroll or (2) individuals enter a facility because they are unable to remain living in the community. Once they enroll in a waiver, most Iowa Medicaid members will remain in that waiver moving forward. Once someone is determined eligible for the waiver, an MCO case manager develops a service plan by using a person-centered planning process with an interdisciplinary team. The service plan outlines the supports and services needed for each member within the service and budgetary constraints of the waiver.

Even so, those using waiver services may remain on the waiting list for another waiver. They may initially accept a slot in one waiver but believe that another waiver better meets their needs, based on a recommendation from their case manager, someone in the community, or by learning about other services. Staying on one waiting list while using services through a different 1915(c) waiver occurs if (1) another waiver covers services the member needs that they cannot access through their current waiver or (2) another waiver has a higher monthly spending cap for residing in the community.

In Chapter VI, we discuss our findings regarding the ways in which Iowans navigate the HCBS system in the state and the challenges that they and providers identify with system complexities and care coordination.

Dale, a 67-year-old Iowan, has not had a break in seven years from being the primary caregiver for his 33-year-old son, Jared. Jared currently receives HCBS through Medicaid's ID waiver. Yet as they age, Dale and his wife, Judy, are struggling with providing the level of care Jared needs while dealing with their own declining health. They worry that the ID waiver services won't be sufficient to keep Jared from having to move to a facility once they are unable to care for him. Facing the future, Dale remarks, ***"I think there's definitely, for us, a bias towards institutional services. And that's always been tough to overcome and continue to say, you know, my son deserves to live in his own home, in his community, and to be around family."***

Listening session participant (name and details have been changed to protect privacy)

C. Transitions between HCBS and facility LTSS

HCBS are designed to help individuals with complex needs reside in the setting of their choosing—often in their home or that of a loved one. Yet, for many, the threat of facility entry is a constant worry. Figure IV.1 shows that transitions out of facilities can start the HCBS journey for some, and that transitions into facilities can occur at several points in the HCBS journey. Iowans who wait many months or years on the waiver waiting lists may enter facilities when they are unable to access the services they need, either because they are not eligible for them or the service is not available in their community. Because reserved capacity slots offer faster access to waivers, some in the community told us about considering facility placement as an option—though not a palatable one—to access HCBS more quickly. Even Iowans already receiving services face challenges accessing the care they need to remain at home. Iowans residing in facilities also can face difficulties in accessing community-based supports, which frequently lengthens their facility stay. We discuss transitions to and from facilities in parts of Chapters V and VI.

Julie's daughter, Molly, has complex behavioral health needs. She lived in an institution for four years, without input from the family about where she should live. Julie told us, "The state had to take custody because that was the only way we could get her mental health services." After years in the facility, Molly was ready to transition back to the community, and now lives in foster care. ***The most challenging part of her daughter's transition from the institution was establishing community services****. "She is close to 18 and struggling and is likely to end up homeless if we don't have the right services in place," Julie said.*

Interview with evaluation team (name and details have been changed to protect privacy)

V. Supporting Iowans Entering the HCBS System

Like other states, Iowa's waivers have capacity and funding constraints so these services cannot be offered to everyone. For many Iowans on waiver waiting lists, the wait is uncertain, and it can be challenging to access necessary supports while waiting for a slot to open. Addressing waiting lists for waivers and services was one of the two most frequently cited improvements that Iowans would make to the CBS system, according to respondents to the online feedback form.

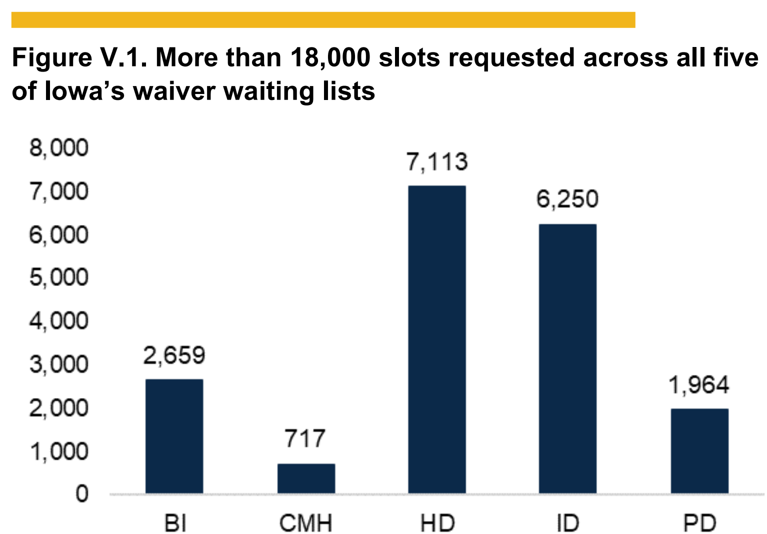
In this chapter, we discuss our findings related to system entry:

- Iowa's first-come, first-served approach to waiver waiting lists means that individual waits can be lengthy, even when consumers need intense supports. In addition, HHS knows relatively little about the support needs of those not yet on a waiver, which makes planning for the future needs of Iowans challenging.
- Of the five waivers with a waiting list, consumers on three of them—BI, HD, and ID—accrue more inpatient and emergency department (ED) costs compared with consumers already on that waiver. While total PMPM provider payments are higher for those on a waiver, these higher payments reflect the HCBS services not accessible to those on the waiting list.
- Iowans have difficulty connecting to needed supports while on a waiver waiting list, and there is no proactive referral system to connect them with available services.

A. Iowa's approach to managing waiver waiting lists means that it is difficult to assess the unmet need for waiver slots

The capacity of Iowa's 1915(c) waivers does not support all the people in the state who would like to access HCBS. As of June 2022, there were more than 18,000 waiver slots requested across all five waivers (Figure V.1). Demand for waiver services, as represented by the number on a waiver waiting list, has grown considerably in recent years. All the waiting lists, except for CMH, have grown by at least 50 percent since 2019.[19] The ID and BI waiting lists have experienced the fastest growth, each approximately doubling in size over the last three years. It is hard to pinpoint one reason for the growth, which likely reflects a combination of factors, including longer periods of

Figure V.1. More than 18,000 slots requested across all five of Iowa's waiver waiting lists



Source: Iowa waiver waiting list number as of January 2022, based on an Iowa HHS report in September 2022. Available at https://hhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs. Accessed January 12, 2023.

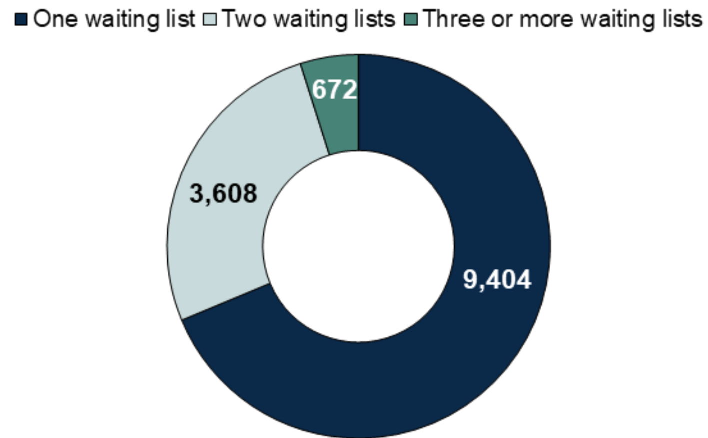
[19] Iowa HHS provided historical monthly slot and waiting list data to Mathematica in July 2022. This statistic reflects the change in waiting lists from January 2019 to January 2022.

waiver enrollment resulting from greater longevity, better awareness of the waivers, and aging caregivers who are no longer able to provide care for their loved ones and must turn to Medicaid supports.

Publicly reported waiting list statistics overstate true demand for waiver services.

The published waiting lists in Iowa are not an accurate representation of need for waiver services. The total number on each waiting list does not account for those on multiple waiting lists (Figure V.2). The approximately 18,000 waiver waiting lists slots across all five waiting lists in June 2022 were held by 13,864 individuals. Among individuals on multiple waiting lists, nearly 9 in 10 are on the HD waiting list. Of individuals on the HD waiting list, about 40 percent are also on the ID waiver waiting list and another 40 percent are on the PD waiting list.

Figure V.2. Nearly one in three individuals on a waiver waiting list are on more than one list



Source: Point-in-time data about the Iowa waiver waiting lists provided by HHS in June 2022.

Note: We conducted a similar analysis on the 5,758 individuals we observed on a waiver waiting list in December 2018, the month of data we analyze in the next section. At that time, 25 percent (1,426 individuals) were on two or more waiting lists, whereas nearly 31 percent were on two or more waiting lists in June 2022.

Demand for waiver services is also overstated because about 10 percent of those on a waiver waiting list in December 2018 were already receiving services from another Medicaid 1915(c) waiver (and an additional 5 percent or so were receiving 1915(i) habilitation services).[20] The overlap of waivers and waiting lists provides some insight into people's understanding of waiver services:

- Seventy-five percent of those on the PD waiver and on a waiting list for another waiver were on the HD waiver waiting list, reflecting similar diagnostic eligibility criteria. However, the HD waiver has a higher monthly cap for spending and a more generous array of services.
- Almost all of those on the HD waiver were waiting for either a BI or ID waiver slot, with a slightly higher share on the ID waiver waiting list. Again, this reflects an overlap in diagnostic criteria and the hope of waiver enrollees to move to a waiver with more services.
- Relatively few BI or CMH waiver participants were on a waiting list compared with PD and HD waiver participants. These waivers are already more generous than either the PD or HD waivers, but among those few on waiting lists, almost all were on the ID waiver waiting list.

Waiting list and waiver patterns reflect, in part, consumers' determination that the services available on another waiver are more aligned with their needs. Knowing that waiting lists can be long, Iowans will seek services from multiple waivers at the same time and accept the first waiver slot available to them.

[20] Based on data from December 2018 to align with information reported later.

They then remain on the other waiting list or start the process to apply for another waiver that is better aligned with their needs.

Waits to receive waiver slots are lengthy and slots are not always accepted once offered.

Waiver slots are limited, and demand is high, which results in people often waiting many years to receive a waiver slot. Data from HHS for those on the waiting list in June 2022 show that BI and ID waivers have waits of about five years, followed by the HD waiver with a four-year wait and the PD waiver with a two-year wait.[21] Iowans on the waiting list have little to no information about the length of their wait, and HHS does not have a process to estimate the length of the wait. HHS does publish a report that shows the next application date for the next available slot. We heard from Iowans who were frustrated with a lack of transparency about their application status. Iowa does not offer applicants a way to predict their likely waiting time on this list, such as a way for consumers to check their status and make sure that submitted materials have been received.

Iowa is just one of seven states, as of 2020, that does not screen for eligibility before placement on a waiting list (Box V.1 contains common strategies used by a selection of other states). Only the BI and ID waiver waiting lists offer emergent and urgent needs screenings that applicants can voluntarily complete. The remaining waivers do not screen applicants about their functional or health needs until slots become available, and they assign slots on a first-come, first-served basis. As a result, Iowa has little insight into the needs of most consumers on the waiting lists. The BI waiver screening is relatively new and has a low response rate. In January 2022, Iowa mailed screenings to the entire waiting list. In June 2022, only 3.6 percent on the BI waiting list had completed the assessment, and 2.4 percent on the ID waiting list had completed the assessment. It is unclear why the response was so low.

Box V.1. Ways that other states prioritize their HCBS waiver waiting lists

We conducted an evidence scan of common strategies used in six states* to identify how other states manage their waiver waiting lists. These included the following:

- Assessing individuals for eligibility and need before placing them on a waiting list
- Identifying one waiver that will best meet an applicant's needs and assigning them to that waiting list
- Prioritizing the waiting list by risk of institutionalization to support diversion from institutions, based on functional and social needs, available community supports, and risk of adverse outcomes

Source: Medicaid and CHIP Payment and Access Commission (2020).

* Florida, Louisiana, Minnesota, Ohio, Utah, and Wisconsin.

Once Iowa HHS attempts to contact waiting list applicants about available slots, many of the applicants are either unreachable, ineligible (due to not having turned in the correct paperwork or not having the right level of need), or deceased. The average acceptance rate for a slot from 2019 and 2020 was 44 percent for all waivers, ranging from a low of 25.5 percent for the HIV waiver to a high of 68.5 percent for the ID waiver.

Between 2019 and 2021, 5,938 waiver slots were offered that did not result in waiver enrollment. Across all five waivers, the most common reason for not enrolling was that the applicant did not provide adequate information to complete the application or could not be reached (Table V.1). Our conversations with HHS staff and community members uncovered logistical problems with relying on mail to confirm

[21] Iowa HHS. "2022 Monthly Slot and Waiting List Summary." 2022. Available at https://hhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs. Accessed September 15, 2022.

applicant interest and with burdensome administrative application steps. Almost equally as likely were issues with eligibility: applicants were determined to not need the level of care provided by a particular waiver, did not meet Medicaid eligibility requirements, or were too old or did not have the right diagnoses for the waiver program. This can lead to frustration for people who waited months or years only to find out they were not eligible for the program in the first place. In some instances, the applicant had died, and a few had moved into a facility.

Table V.1. Reasons open waiver slots were not accepted

Categories	BI	CMH	HD	ID	PD
Total	332	1,354	1,545	648	2,021
Inadequate applicant information or cannot be reached	56	783	127	271	897
Eligibility-related issues					
Incorrect level of care	42	196	204	60	408
Does not meet financial eligibility requirements	5	1	5	11	16
Does not meet demographic/diagnostic requirements	11	187	444	29	211
Applicant died	178	1	697	101	347
Resides in an institution	5	20	4	26	11
Removed per applicant request	21	143	55	107	75
Other or no reason given	14	23	9	43	56

Source: Iowa waiver unaccepted slot information provided in July 2022 by HHS.

Note: The table includes all cases in 2019, 2020, or 2021 (calendar years) in which a waiver slot became available but was not filled by the next applicant. Cells with fewer than 10 occurrences have been masked to preserve confidentiality. We do not report on the HIV waiver because only 38 total cases occurred and none of the cells was large enough to report individually.

B. Provider payments on behalf of Iowans on a given waiver show different patterns than for those on that waiver's waiting list

Being on a waiver offers Medicaid members the opportunity to access many HCBS that are not available through the Medicaid state plan. We therefore sought to understand whether payments made to providers on behalf of Medicaid members differed between those on a waiver compared to those on the waiver's waiting list

We found meaningful differences in PMPM provider payments by service category between waiver and waiting list members (Table V.2). Members on a waiver had greater total Medicaid provider payments on average than those on the analogous waiting list. For example, total payments for members on the BI waiver averaged $3,127, whereas total payments for those on the analogous waiting list averaged $1,933.

The primary driver of the higher total provider payments across waivers and waiting lists was HCBS. For instance, there is a $3,021 difference in average HCBS spending between those on the ID waiver and the ID waitlist. The difference in HCBS provider payments between waivers and waiting lists is consistent with the availability the lack of available HCBS through the state plan. Based on our inspection of the data, individuals on waiting lists often accessed state plan habilitation services; we also saw a few instances of individuals accessing round-the-clock and transportation services after institutional stays, a point we return to later.

We did observe higher PMPM provider payments in some categories for those on the waiting list. For example, inpatient spending and ED spending were lower for members on the BI, HD, and ID waivers relative to members on the waiting lists for those waivers. It is possible that spending in these categories would be lower if these members were eligible for HCBS with a waiver slot, though we cannot determine that with certainty. This pattern was not present for those on the PD or CMH waiver and waiting list. This could in part reflect the role of private insurance payments for ED visits and inpatient stays, especially for youth on the CMH waiting lists, who may be able to leverage their parents' private insurance. We did not have access to data to allow us to conclude this definitively.

Finally, we also found that the average institutional cost for those on a waiver was lower than for those on a waiting list. Institutional costs are lower for those on a waiver in part because waiver eligibility ends after 120 days in a facility.[22] We explored the data and found that almost all individuals who stayed in a facility for more than a month were not simultaneously on a waiver. The exceptions to this were rare and mostly habilitation or a single day assignment to a waiver. Additionally, institutional costs for those on a waiting list who experience a facility stay are quite high and drive up the average costs in those categories, even if a minority of those on the waiting list are in a facility.

Table V.2. PMPM provider payments, by service category

	Number of members	NF	MHI	HCBS	ICF/ID	ED	Inpatient	Other institutional	Outpatient behavioral health	Other outpatient	BHIS	B3	PMIC	Total
Waiver														
HIV	31	$13	–	$701	–	$32	$265	–	$3	$382	–	–	–	$1,396
BI	1,444	$28	–	$1,851	$1	$19	$66	$0	$9	$973	$177	$0	$1	$3,127
CMH	998	–	$9	$821	–	$23	$92	–	$167	$376	$6	-	$106	$1,600
EL	8,303	$134	–	$527	–	$15	$26	$0	$1	$326	$2	$0	–	$1,033
HD	2,341	$57	–	$823	–	$18	$93	–	$32	$1,414	$8	$1	–	$2,445
PD	1,092	$78	–	$382	–	$64	$183	$0	$6	$679	$0	$2	–	$1,394
ID	12,184	$8	$5	$3,296	$9	$12	$30	$3	$28	$398	$7	$2	$2	$3,800
Waiting list														
BI	1,057	$570	$22	$219	$35	$39	$265	$1	$14	$488	$147	$1	$127	$1,933
CMH	1,677	$20	$27	$121	$30	$26	$77	$0	$128	$186	$23	$0	$259	$904
HD	3,358	$165	$2	$143	$17	$31	$180	$0	$28	$454	$11	$2	$2	$1,038
PD	1,836	$171	$13	$101	$7	$53	$210	$1	$5	$405	$18	$3	–	$987
ID	2,765	$133	$3	$275	$99	$21	$91	$2	$55	$345	$24	$1	$75	$1,127

Source: Iowa Medicaid encounter data.

Note: The payment amounts include all members enrolled in a waiver or on a waiting list at any time during the 2018 calendar year. The amounts include payments for up to 12 months after we first observed someone in a waiver or on a waiting list in 2018. Consumers in the waiting list rows were not enrolled in any waiver during the 12-month follow-up period. Individuals on multiple waiting lists are included in multiple waiting list rows. Categories of payments are based on an HCBS taxonomy described in Appendix B. The totals may not equal the sum of the columns in a given row due to rounding. Cells with a $0 did have payments, but those payments were so minor that the average PMPM amount was less than $0.50. Cells with a dash had no payments in that service category.

BHIS = behavioral health intervention service; B3 = 1915(b)(3) services.

[22] Iowa HHS. "Medicaid Waiver Services." December 2022. Available at https://www.legis.iowa.gov/docs/iac/chapter/441.83.pdf. Accessed January 5, 2023.

The differences between waiting list and waiver spending may reflect CBS provided by natural supports—individuals on the waiting list may rely more on family and unpaid caregivers for services they could receive if on the waiver. It also could be that these individuals might be receiving services from MHDS, which can provide CBS to those on a waiver waiting list. Notably, HCBS spending alone does not always explain the gap between those on the waiver and those on the corresponding waiting list. Without knowing more about the demographics, health status, and needs of members in both groups, it is difficult to determine the cause of this pattern. Because waiting list participants may be relatively early in their CBS journey, it may be that a better comparison of PMPM payments for those on the waiting list would be more recent waiver enrollees. In other words, we cannot conclude from the data presented in Table V.2. that provider payments would be higher or lower for the same person if enrolled in a waiver rather than on a waiting list.

C. Iowans have difficulty connecting to needed supports while on a waiver waiting list

Iowans shared that they struggled to learn about waiver services and how to apply for a waiver. A common theme from the listening sessions is that families need more consistent information to understand what services are available, who qualifies for them, and how to access them. They told us they often learned about potential services for which they could be eligible through word of mouth, from friends or family with lived experience.

Accessing non-Medicaid CBS relies on individuals tracking down available supports.

While waiting for waiver services, some Iowans may be able to turn to other supports offered throughout the state to meet their CBS needs. Services might be available from a range of state agencies, including the MHDS regions, Iowa vocational rehabilitation services, child welfare, or the Department of Aging. As a part of its participation in the Balancing Incentive Program, Iowa was required to create a No Wrong Door system that facilitates access to the right supports regardless of where someone has their initial system interaction.

Our interviews with consumers in Iowa indicate that the state currently does not have an effective No Wrong Door model, which would allow them to access needed information, referrals, and services without regard to the state agency or other organization in the system that they initially contacted for support. Instead, we heard how consumers feel that they are left to navigate the web of services and supports on their own to find services that might be available to meet their needs. This sentiment aligns with a 2020 analysis that ranked Iowa 44th among states in its implementation of the No Wrong Door system in 2020, with a score of 43 percent compared with a 66 percent national average.[23]

One part of the CBS service network in Iowa is the MHDS regions, at least for those who have disabling conditions aligned with MHDS' eligibility requirements. With limited state funding for CBS services, coordination between MHDS and Medicaid is important to maximizing CBS offerings. In particular, services covered by Medicaid receive a federal match, whereas MHDS services are purely state-funded. Iowa can maximize funding available for CBS by relying on Medicaid services that bring in the federal match to the extent possible.

[23] Lewin Group. "Aging and Disability Resource Center/No Wrong Door Functions: A Leading Indicator in the 2020 Long-Term Services and Supports State Scorecard." 2020. Available at https://www.longtermscorecard.org/~/media/Microsite/Files/2020/ADRC_NWD%202020%20Key%20Takeaways.pdf. Accessed September 15, 2022.

Yet, there is little communication or coordination among the MHDS regions and Medicaid. Our analysis of linked MHDS data and Medicaid enrollment records for two MHDS regions support this claim to some extent. While the experiences of two regions are not representative of all regions, linked data can show the types of coordination challenges that might exist in the state.

About three-fourths of MHDS participants in both regions were Medicaid members.[24] Some MHDS participants had access to Medicaid HCBS through a waiver, 15 percent of MHDS participants in Region A and 19 percent in Region B. Similarly, less than 5 percent were on a waiver waiting list in either region. MHDS supports may be an especially effective option for Medicaid members waiting for a waiver slot to open up, but we found that only a small minority of MHDS participants were on such a list.

A Medicaid identification number is the best way for MHDS regions to know whether consumers they serve are also eligible for Medicaid. We found that in most cases, MHDS regions do not have the Medicaid identification number, even for those who were Medicaid members. Between 33 and 43 percent of MHDS participants had a candidate Medicaid ID number listed in their MHDS data. In both regions, no more than 3 percent of participants who reported a Medicaid ID number could not be verified in the Medicaid enrollment data.

Table V.3. Medicaid enrollment and Medicaid ID verification for MHDS participants

	Region A		Region B	
	Number	Percentage	Number	Percentage
All participants	2,458	-	4,929	-
Participants enrolled in Medicaid	1,966	79	3,657	74
Participants enrolled in a waiver	379	15	958	19
Participants on a waiting list	73	3	186	4
Participants with a verified Medicaid ID in MHDS data	822	33	2,114	43
Participants with an unverified Medicaid ID in MHDS data	64	3	101	2

Source: MHDS data from Regions A and B; Iowa Medicaid enrollment data, waiver enrollment data, and waiting list status information.

Note: This table reports Medicaid enrollment data, waiver enrollment, waiting list status, and Medicaid ID validation information for MHDS participants in two regions. Mathematica linked MHDS participant data provided by the regions to Iowa Medicaid enrollment data. The waiver status information is from 2019, and the waiting list status information is from 2021. The MHDS data are from 2019 through October 2022. If someone spent time on a waiver and waiting list in 2018 and 2019, they are reported in the waiver category only. Verified Medicaid IDs are those in the MHDS data that are identical to a Medicaid ID in the enrollment data. Unverified Medicaid IDs in the MHDS data do not have an identical Medicaid ID in the enrollment data.

We also considered Medicaid waiver and waiting list participants in counties represented by these two MHDS regions to determine how many of those members were also receiving MHDS services. Of the total number of people living in Region A that are on a waiver, about 19 percent also received MHDS services. For those on a waiting list, 18 percent received MHDS services. This is similar to Region B, in

[24] It is important to note, as documented in the table note, that the time periods of these data do not align perfectly, and it is possible that the Medicaid enrollment status that we used was different by the time period of MHDS data that we received. More information about these files is available in Section D of Appendix B.

which 15 percent of people in the region on a waiver received MHDS services and 14 percent of those on a waiting list. While the difference in the time periods of the source data is important here, the fact that very few new waiver slots have been filled since 2018 because very few people have moved off of waivers during this time suggests that the general magnitude of these numbers is still informative.

Region A gave us data on the expenditures of their MHDS region by service category, which allowed us to assess potential overlap in spending across MHDS and Medicaid. While total expenditures were highest for participants who were not on a waiver or a waiting list, average MHDS expenditures are highest for those on a waiver waiting list. This is consistent with individuals on waiting lists having unmet CBS needs.

We found that across these groups, many of the services provided by MHDS regions are also covered by Medicaid. This is especially notable among Medicaid waiver members, for whom 67 percent of expenditures were in categories where Medicaid also has covered services through the state plan or a waiver program. Among those enrolled in a waiver, most of the MHDS spending was on psychotherapeutic support services. It is important to note that data do not allow us to say with certainty that the MHDS-covered services would have been covered by Medicaid; it is possible that MHDS is effectively offering wrap-around coverage to Medicaid beneficiaries in these instances. Interestingly, about half of MHDS expenditures for the waiting list group were for services without a Medicaid equivalent. The service categories with the largest expenditure category among this group were for residential care facility for people with mental illness.

Table V.4. Expenditures for Medicaid members in Region A by service category

	Medicaid waiver members	Waiver waiting list members	Other Medicaid members	Not Enrolled in Medicaid
Number of participants	379	73	1514	519
Total expenditures	$1,348,472	$269,933	$2,378,142	$943,203
Average expenditure per participant	$3,558	$3,698	$1,571	$1,817
Expenditures by category				
MHDS service with a Medicaid state plan equivalent	67%	41%	63%	33%
MHDS services with a Medicaid waiver service equivalent	4%	12%	4%	2%
MHDS services without a Medicaid equivalent	29%	48%	34%	65%

Source: MHDS data are from Region A; Iowa Medicaid enrollment data, waiver enrollment data, and waitlist status information.

Note: This table reports MHDS expenditures by category for Medicaid members served by Region A. The table reports expenditures by category as a percentage of total expenditures. Expenditures by category were provided by the MHDS region and we identified which of these services had a similar Medicaid state plan or waiver service equivalent. In some cases, these services are not identical in name but are functionally equivalent in meeting member's needs.

Our analysis suggests that with additional analysis, we could further highlight opportunities to improve coordination between MHDS and Medicaid, both in terms of knowing who is accessing services from both programs and in coordinating spending across programs.

Information sharing across agencies in Iowa limits cross-program utilization.

"The system is incredibly fragmented and difficult to navigate and understand. And that's coming from someone that doesn't have a disability and has consistent transportation. I can't imagine navigating these things with additional challenges."

Listening session participant

Iowa's agencies currently do not have a mechanism for sharing information with one another. Being able to do so would allow agencies to (1) better coordinate services across multiple programs and (2) identify gaps in services and supports that consumers might be able to access if connected to other programs. For example, a single state identifier (for example, an identification number like a Social Security number that is consistent across programs) and collection of programmatic information at the state level would also allow Iowa to identify service gaps and duplication and identify common cross-program interactions, and then to consider ways to streamline and improve information and service delivery. In that system, a case manager would be able to determine that a person was accessing both waiver and MHDS services, and the case manager could then work to consolidate and coordinate services with a person-centered care plan, better maximizing existing state resources. With a centralized database, state agencies could compile, store, and update the benefits already received or requested by an individual (including federal disability benefits, Medicare, Medicaid [waiver and waiting list], as well as Supplemental Nutrition Assistance Program [SNAP], housing, and other social services). If information were stored centrally, consumers and natural supports could reduce the amount of time they spend tracking down information and providing the same information across fragmented programs.

Most Iowans on Medicaid are not receiving HCBS before entering a facility.

Without needed CBS, individuals may enter an institution. Some medical conditions undoubtedly warrant facility entry, yet we heard from families in listening sessions that they faced situations in which they felt the only way to get essential services for a family member was to place them in an institution.

Using Medicaid encounter data, we found that most consumers who ultimately entered an institution in 2018 were known to Medicaid, but most were neither accessing HCBS nor on a waiver waiting list. Less than 27 percent were enrolled in a 1915(c) waiver or receiving habilitation services through the 1915(i) state plan option in the six months before entry (Table V.5). Between 5 and 16 percent were on a waiver waiting list. But the majority—between 58 and 78 percent—were on Medicaid but not enrolled in a waiver, receiving state plan habilitation services, or on a waiver waiting list.

The path to nursing facility entry followed a different pattern. Just under two-thirds (63 percent) of people who entered nursing facilities in 2018 were enrolled in Medicaid in the prior six months. This low rate of Medicaid coverage before entering nursing facility care is likely related to the state's Medicaid spend-down requirement, which allows consumers with Medicare coverage to meet the Medicaid income limits by deducting their medical expenses from their income. This issue suggests that NF diversion would also necessitate coordination with Medicare in many cases.

Table V.5. Percentage of consumers who in 2018 were enrolled in Medicaid, receiving HCBS via a 1915(c) waiver or the 1915(i) state plan option, or on a waiver waiting list before entering an institution

Institution type	Number entering an institution	Enrolled in Medicaid six months before institution entry (%)	On a waiver or state plan habilitation six months before institution entry (%)	On a waiver waiting list six months before institution entry (%)
ICF/ID	101	99	26	15
MHI	306	96	13	5
PMIC	604	82	7	16
NF	6,437	63	25	2

Source: Iowa Medicaid encounter data.

Note: This table shows the count of consumers who entered institutions during the 2018 calendar year and their Medicaid, waiver, 1915(i) state plan habilitation and waiting list statuses in the six months before entry. The table presents only the first institutional stay in 2018 for those with multiple institutionalizations. The counts excluded consumers who were in another institution (ICF/ID, MHI, PMIC, NF, SNF, or hospice) six months before entry. Members who were enrolled in a waiver and on at least one waiting list in the six months before entry to institutional care were classified as on a waiver and were not counted as being on a waiting list.

D. Key takeaways

While a more streamlined waiting list process would not eliminate the need for a waiting list, it would allow Iowa HHS to assess and prioritize services for those entering the CBS system, and it would increase coordination and transparency across agencies and for people who need support. A single waiting list and improved screening processes would support future planning at HHS as they consider how to best serve those who are and will be receiving HCBS services. Our evaluation found that the current waiting list process does not accurately represent current needs, as people are on multiple waiting lists and some on the waiting list are already on a different waiver. In addition to altering the current waiting list processes, we recommend implementing a process to collect information about the needs of people requesting services. Further, our initial analysis to link MHDS and Medicaid data found that there is duplication in services among those enrolled in Medicaid and receiving MHDS services, which suggests the state could better leverage state resources by sharing information between these two entities. As part of an improved waiting list process, Iowa HHS can make referrals to non-Medicaid CBS to support people while they are on the waiting list and make better linkages between MHDS regions and Medicaid operations.

VI. Aligning Waiver Structure and Assessments to Meet Iowans' Needs

Iowa's seven 1915(c) waivers use a one-size-fits-all per diagnosis approach to meet the needs of those who need support to live in the community (Appendix Table E.1). Although the waivers were designed to meet a broad range of needs, they fail to account for variation in needs within diagnostic groups and are inaccessible to people with other diagnoses. In addition, the waiver system does not have a uniform approach to assessing need across waivers, adding further barriers to delivering needs-based services.

In this chapter, we discuss our findings related to:

- The current waiver structure in which eligibility is diagnosis-based rather than needs-based which means that many Iowans cannot access services essential for them to remain in the community
- The current assessment process makes it difficult to comprehensively assess member needs across waivers

A. The current waiver structure means that individuals with similar HCBS needs but different diagnoses may not be able to access the same supports

Waivers based on diagnosis do not reflect the reality facing many people with disabling conditions, functional impairments or behavioral health needs. For example, two people with multiple sclerosis may have very different support needs, with one nearly fully independent and the other requiring intensive supports to remain in the community. Conversely, two people with different diagnoses may have similar support needs—for example, a person with multiple sclerosis and a person who is blind might both need home-delivered meals.

> *"It's not so much a challenge as it is kind of dumbfounding, the categorical nature of these waivers. We actually had to switch from the brain injury waiver to the intellectual disability waiver so we could access day habilitation. But in doing that, we lost home and vehicle modifications. And I think it's almost designed to weed out people so they just give up. But I don't give up."*
>
> Listening session participant

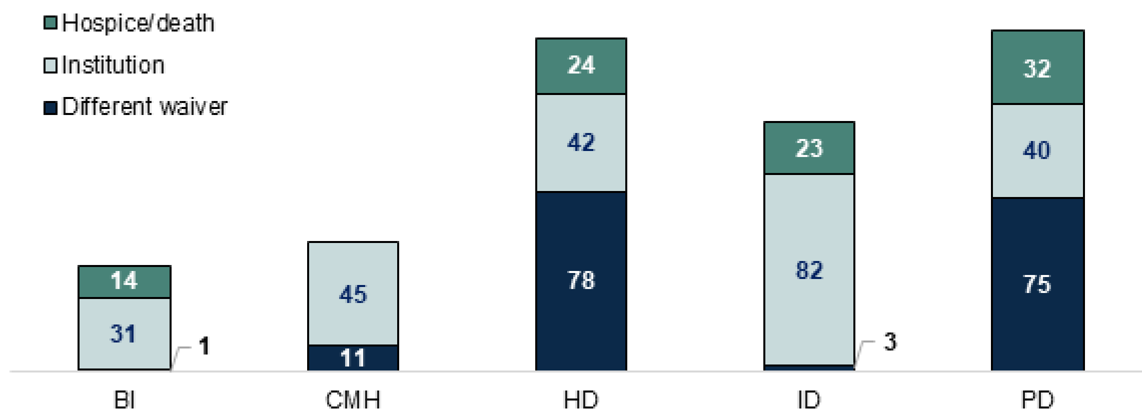
The current waiver eligibility criteria in Iowa are based on disabling condition and do not account for the variation in need among members. There are differences in available services and spending caps across the seven HCBS waivers (Appendix Table E.2). For example, the PD waiver covers six services while the ID waiver covers fifteen services. Individuals on the ID waiver have access to home health aides, interim medical monitoring and treatment, nursing, and vocational services, whereas individuals on the PD waiver do not. In addition, three waivers (BI, EL, and ID) do not have spending limits and the others have monthly maximum spending amounts. As of July 2021, the PD waiver had a monthly cap of $730.90 (excluding the onetime costs of home and vehicle modifications) and the HD waiver was capped at either $959.50, $2,792.65, or $3,742.93, depending upon the level of care required.[25]

[25] Iowa HHS. "Medicaid LTSS Program Comparison Chart." July 2021. Available at https://hhs.iowa.gov/sites/default/files/LTSS_Program_Comparison_Chart.pdf?072620211457. Accessed September 15, 2022.

Given the differences that exist in spending caps and services across the seven HCBS waivers, waiver enrollees with similar needs may not have access to the same types and amounts of services. Indeed, service expenditures (measured via provider payments) vary by waiver. Notably, the average HCBS payment per person (shown in Table VI.2) for all Medicaid-funded services was more than eight times larger for people enrolled in the ID waiver compared to those enrolled in the PD waiver. These differences could be driven by the different service offerings, differences in budget restrictions across waivers, or differences in utilization (perhaps driven by need or appropriateness of service offerings). It is unclear if these different levels of spending are appropriate based on total spending alone. However, there is a perception among community members and HHS that some members with low need are receiving many services and funds, while some with high needs are not receiving services they need to live successfully in the community.

Some individuals with co-occurring conditions or whose conditions span multiple waivers (like PD and HD, or BI and ID) reported that they accepted a slot in a lower-resourced waiver as a stopgap to meet some of their needs until they can transfer to a higher-resourced waiver. Our analysis of Medicaid data confirms that people on lower-resourced waivers are most likely to transfer to another waiver (Figure VI.1). For example, 44 percent of members who disenrolled from the PD waiver left for another waiver, as did 54 percent of those who disenrolled from the HD waiver. In contrast, just 1 percent and 2 percent of those who disenrolled from the ID and BI waivers, respectively, left for other waivers.

Figure VI.1. Waiver exits in 2018 followed by entry into hospice or death, entry into institutional care, or transition to another waiver



Source: Iowa Medicaid encounter data.

Note: This figure shows deaths and hospice care, institutionalizations, and waiver transitions 12 months after waiver exit for waiver exits in the 2018 calendar year. We excluded the HIV waiver from this figure because very few transitions occurred and the EL waiver because its age restriction made transitions to other waivers rare. We do not show the exact number in the BI or ID waivers who moved to a different waiver to protect privacy, as the number in those categories is less than 10 members. Transitions across the three categories shown represented 2.1 percent of total members on the BI waiver, 7.1 percent of those on the CMH waiver, 11.5 percent of those on the HD waiver, 0.7 percent of those on the ID waiver, and 14.7 percent of those on the PD waiver. The remaining transitions were to other outcomes or could not be categorized based on available data.

To better understand how waiver enrollment might affect service use, we compared provider payments by service category for people who transferred from one waiver to another (Table VI.1). We assume that an

individual's needs do not immediately change as they move from one waiver to another (especially given the long first-come, first-served wait for a slot to open), so we can compare payments and service patterns before and after a waiver transfer to assess how service use varies for one person based on what services are available by waiver. Of course, it is also possible that needs change over time, given the duration of waiver waiting list, but we cannot ascertain that from the available data.

Among the 38 people in Table VI.1 who transferred from the PD waiver to the HD waiver (which has a higher budget cap than the PD waiver) in 2018, payments across all HCBS categories grew. For example, average PMPM HCBS payments were $74 on the PD waiver compared with $580 after transferring to the HD waiver. Similarly, total HCBS payments increased, as did payments for many other categories of medical services after the transfer from HD to either BI or ID waivers, neither of which have monthly budget caps. We did not find that reductions in PMPM provider payments were uniform for ED visits or other services such as inpatient or outpatient care.

Exceptions to policy (ETPs) offer another indication that waivers are not meeting the needs of enrollees. ETPs allow members to obtain services not covered by the waiver or to exceed the monthly spending limit set by the waiver. In fiscal year 2021, HHS reviewed 474 ETP requests for waiver enrollees, most of which were to exceed spending caps. Of these, 429 ETP requests (90.5 percent) were approved. The waivers with the most ETP requests relative to waiver enrollment were the CMH and PD waivers, suggesting that those waivers may have a high proportion of enrollees for whom the waiver does not align with participant need. We also found that 26 percent of ETPs requested an increase in the waiver spending cap, 26 percent requested coverage for respite services, and 9 percent of requested provider rate increases above the standard rate.

Table VI.1. PMPM provider payments in 2018 and 2019 for people transferring across waivers in 2018

Service category	Original waiver: PD	New waiver: HD	Original waiver: HD	New waiver: BI	Original waiver: HD	New waiver: ID
Number of members	**38**	**38**	**12**	**12**	**12**	**12**
Emergency department	$25	$20	$10	$26	–	$2
Inpatient	$133	$33	$120	$1	–	–
Outpatient behavioral health	$4	$3	–	$1	$293	$138
Other outpatient	$653	$671	$698	$1,494	$858	$994
HCBS	$74	$580	$302	$865	$96	$1,025
Caregiver support	–	$1	$29	$384	$36	$240
Case management	–	–	$1	$57	–	$149
Day services	–	$8	–	–	–	$203
Equipment, technology, and modifications	$9	$66	$2	$35	–	–
Home-based services	–	$16	$63	$7	–	–
Home-delivered meals and nutrition	–	$161	–	–	–	–
Mental and behavioral health	–	-	$3	–	$13	$29
Round-the-clock services	–	-	–	$41	–	$346
Services supporting self-direction	$43	$183	$185	$324	$20	$49
Transportation	$22	$146	$19	$17	$26	$9
Total	$890	$1,316	$1,130	$2,388	$1,247	$2,159

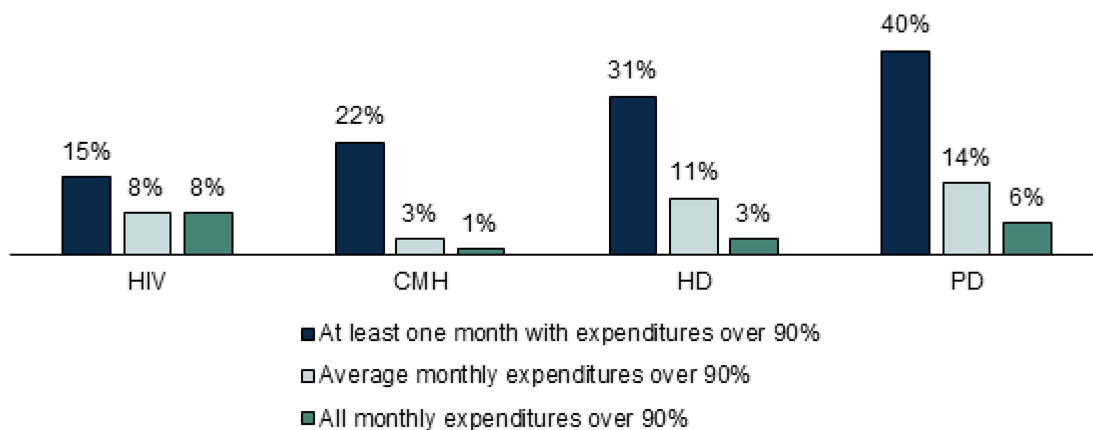
Source: Iowa Medicaid encounter data.

Note: This table describes PMPM provider payment patterns by category for individuals who transferred from one waiver to another waiver during the 2018 calendar year. We describe three transfers: PD to HD, HD to BI, and HD to ID. Though the transfers occurred sometime during the 2018 calendar year, the payments on which the PMPM calculations were based span the 2018 and 2019 calendar years. Cells with dashes had no payments for that category for that waiver.

Another way to examine the alignment of member needs with waiver services is to look at the share of waiver participants whose provider payments approach the waiver's monthly spending cap. Members with expenditures above 90 percent of the waiver limit could indicate that members need the full amount of available services, or the waiver service array is not meeting some people's needs

Among the four waivers with a cap, 15 to 40 percent of people enrolled for at least six months in 2018 had provider payments that were 90 percent or more of the budget limit in one or more months (Figure VI.2). Fewer than 15 percent of waiver participants had average provider payments across all months they were enrolled that were 90 percent or more of the waiver cap. Of course, lower levels of expenditures may not simply reflect lower need and may instead reflect limited availability of service providers or difficulty accessing services.

Figure VI.2. Percentage of waiver recipients with provider payments above 90 percent of the monthly spending limit



Source: Iowa Medicaid encounter data.

Note: For the four waivers with monthly budget caps, this figure shows how often monthly provider payments exceeded 90 percent of the budget limit during the 2018 calendar year. We report three statistics: (1) the percentage of waiver participants whose payments exceeded the threshold for at least one month (any month), (2) the percentage whose average monthly payments exceeded the threshold (average month), and (3) the percentage whose payments exceeded the threshold in every month observed (all months). The analysis includes only waiver participants who were enrolled for at least six months during the 2018 calendar year (26 people enrolled in the HIV waiver, 832 people in the CMH waiver, 2,091 people in the HD waiver, and 906 people in the PD waiver). The CMH, PD, and HD waivers also offer home modifications, but those costs are not included in the budget caps for those waivers.

While we most commonly heard about members seeking to transfer from one waiver to another, it is important to recognize that diagnosis-based waiver eligibility means that some who need HCBS support cannot access it. For example, HHS administrators stated that people with autism spectrum disorders who do not have co-occurring intellectual disabilities are often unable to access HCBS because they do not qualify for the ID waiver on the basis of their diagnosis.[26] This type of diagnosis barrier leaves people

[26] Iowa HHS. "Medicaid HCBS Program Comparison Chart." May 2018. Available at https://publications.iowa.gov/32939/1/Medicaid_HCBS_Program_Comparison_Chart.pdf. Accessed September 15, 72022.

with autism spectrum disorders without access to HCBS options available to individuals with intellectual or developmental disabilities, even if they could benefit from such services.

B. The current assessment process makes it difficult to comprehensively assess member need.

The current HCBS waiver assessment tools do not provide a uniform measure of need, making it challenging to understand how needs vary across waivers. As shown in Table VI.2, Iowa uses a variety of assessment tools across waivers and by age. Each tool is designed to measure a range of needs, including support with activities of daily living (ADLs), instrumental activities of daily living (IADLs), behavioral needs, medical and health needs, and more. But because the content and wording of questions in each assessment varies, considering needs across waivers is not straightforward.

For adults, there is no single assessment tool used across all waivers. The interRAI–Home Care (HC) is used for adults on the EL, HIV, BI, HD, and PD waivers, and the Supports Intensity Scale (SIS) for Children and Adults is used for the ID waiver. Participants not on a waiver who are receiving state plan habilitation services are assessed using a separate tool, the Level of Care Utilization System (LOCUS)/Comprehensive Assessment and Social History (CASH). A range of assessment tools are used to evaluate children, and these differ from the tools used to evaluate adults on the same waiver, reflecting notable differences in functional demands for youth and adults. However, there is one assessment tool used for all waivers for which children are eligible: the Case Management Comprehensive Assessment.

Table VI.2. Assessment tools used by Iowa's HCBS waivers

Tool	Ages	HIV	BI	CMH	HD	EL	ID	PD	HS
Adults									
Supports Intensity Scale (SIS) for Adults	16+						X		
interRAI–HC	21+	X	X		X	X		X	
interRAI–Community Mental Health	19–64							X	
Level of Care Utilization System (LOCUS)/ Comprehensive Assessment and Social History (CASH)	19+								X
Children									
Supports Intensity Scale (SIS) for Children	5–15					n.a.	X	n.a.	
Case Management Comprehensive Assessment	0–3	X	X	X	X	n.a.	X	n.a.	
interRAI–Pediatric Home Care (PEDS-HC)	4–20	X	X		X	n.a.		X	
interRAI–Child and Youth Mental Health (ChYMH)	4–20			X		n.a.		X	
Child and Adolescent LOCUS/CASH	4–18					n.a.		n.a.	X

Source: Iowa Medicaid Information Letter No. 2088-MC-FFS.

Note: Those under age 18 are not eligible for the PD waiver. Those under 65 are not eligible for the EL waiver. In 2019, the time period for our analysis, the state used the interRAI – Community Mental Health assessment for those 19 and older on the PD waiver and receiving habilitation services.

n.a.= not applicable.

In talking with Iowans, we heard concerns that members with more significant needs were drawn to particular waivers because those waivers more generously covered certain services. We also heard concerns that even when members on different waivers had the same level of need, levels of utilization may be different because of waiver structure and not totally correlated to necessary supports. Because

each assessment collects different elements to measure member need, it is difficult to make comparisons across waiver populations when different assessments are used. Nonetheless, we used available assessment data for adult waiver participants in 2019 to better understand members' needs while they are living in the community and the relationship between that need and provider payments across waivers.

We were able to make direct comparisons of adult participants on the BI, EL, HD, and PD waivers since all participants on those waivers are assessed using the interRAI-HC. Section C of Appendix B provides many additional details about the data we received, our assessment of the extent to which the available data reflect the full population of waiver participants, and more details about the measures of need we selected to consider in our analysis. That appendix also contains additional measures of need related to cognition as well as statistics on individual IADLs and ADLs included in these summary measures.

Using the data available in the interRAI-HC, we present information on two summary measures of need related to independent living:

- The number of IADLs for which a member's capacity to complete a task required significant assistance, as recorded by staff administering the survey.[27] IADLs are generally somewhat complex daily tasks such as preparing meals, doing ordinary housework, managing a flight of stairs, shopping in a store, or navigating transportation; we had information on these five activities, documented in Appendix B.
- The number of ADLs for which a member performed the task with significant assistance, as recorded by staff administering the survey. ADLs are activities necessary for living independently, such as eating, bathing, dressing, and using the toilet; we had information on 10 of these activities, documented in Appendix B. In addition to these ADLs, we included an additional measure indicating needing significant assistance in managing medication.[28]

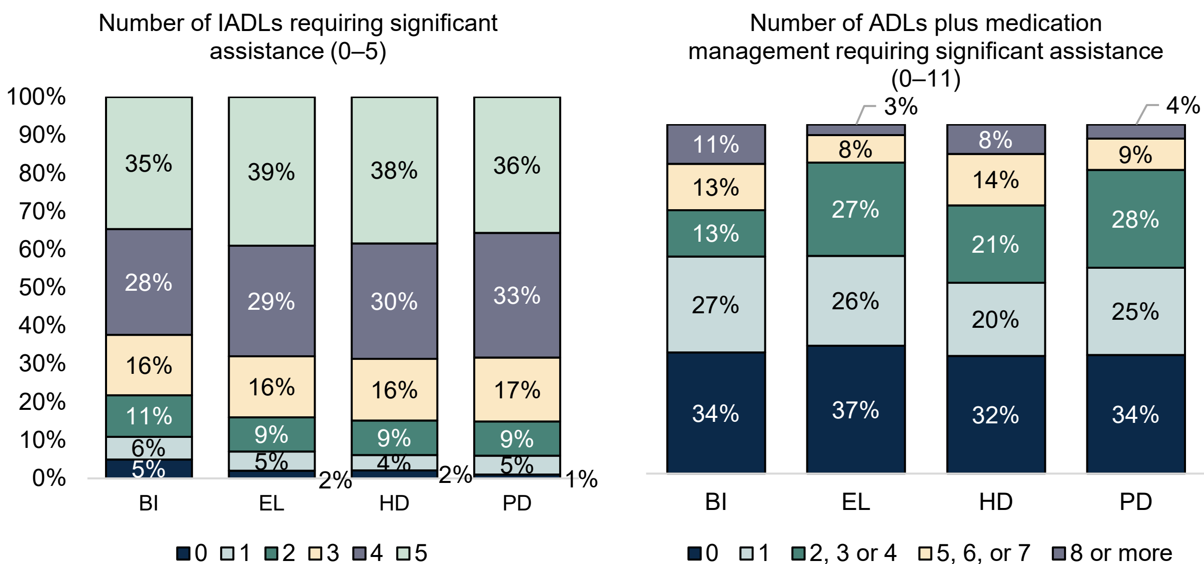
It is important to note that our measure of significant assistance is useful as a metric highlighting some key differences across waiver programs, but it does not fully capture member need holistically. For example, a person who requires limited assistance on all 11 ADLs may require as much HCBS as someone who requires significant assistance on 3 ADLs, but the former would appear to not have significant assistance needs according to our definition. Additionally, it is important to note that the capacity to perform IADLs or ADLs with significant assistance does not necessarily mean that such support is available to a waiver participant. Waiver members may have significant assistance needs, but may perform these activities without significant assistance if support is not available. We discuss provider availability issues in Iowa in more detail in the next chapter.

Looking across participants in the waivers using the interRAI-HC, we do not see that participants with the highest support needs are concentrated in a particular waiver. Starting with the left panel of Figure VI.3, we see that the distribution of participants who required significant assistance with IADLs was relatively similar. Most participants in each waiver require significant assistance to complete at least 2 of the IADLs

[27] The interRAI-HC collects information on whether individuals can complete IADLs and ADLs (0) independently; (1) with setup help only; (2) with supervision; (3) with limited assistance/help on some occasions; (4) extensive assistance/needs support, but can complete at least 50 percent of the task on their own; (5) maximal assistance/can complete less than 50 percent of the task on their own; or (6) total dependence. We considered those in categories 4, 5, or 6 to require significant assistance. As we describe in Appendix B. we use a capacity-based measure for IADLs (e.g., the individual has the capacity to complete the task) while we use a performance-based measure for ADLs (e.g., the individual actually completed the task), consistent with the interRAI-HC assessment tool.
[28] Technically, medication management is an IADL, but because it is critical to remaining independent for many, it is sometimes included with ADLs.

in our measure, and many require assistance with all five of the IADLs we considered, based on an assessment of the capacity to complete these activities. The right panel of the same figure considers significant assistance needs using the ADL plus medication management measure. Again, we see that the distribution of need is similar across waivers, with more participants needing support with at least one of the eleven measures we considered. Notably, about one-third of participants for whom we had complete IADL data available did not require significant assistance to complete any IADLs, and a similar share of those with complete ADL data did not require significant assistance to complete any ADLs. It is important to note that (1) participants might have required lower levels of support under the "significant" threshold we used and (2) a person without significant assistance needs on one of our summary measures might have had needs on the other measure, or on cognitive tasks or other measures collected in the interRAI-HC that we did not fully investigate.

Figure VI.3. Share of participants by waiver requiring significant assistance to complete daily living activities



Source: The InterRAI-HC assessments provided by Iowa Total Care and Amerigroup were completed in 2019 and linked to Medicaid encounter data from 2019.

Note: The analysis was limited to waiver participants with available assessment data on all of the measures in each summary score, as described in Appendix B, Section C. Percentages may not sum to 100 due to rounding.

Disaggregating waiver participants by significant assistance needs allows us to better answer two questions: (1) Within a given waiver, do provider payments increase with intensity of need? and (2) Across waivers, do provider payments look comparable for members with similar levels of support needs? Figure VI.4 helps us answer these questions. In general, we see that the answer to the first question is yes, a higher number of IADLs and ADLs requiring significant assistance needs was generally correlated with higher total and HCBS provider payments. This pattern was least likely to be the case for the BI waiver, where payments were higher for those with fewer IADL and ADL support needs. This pattern of expenditures may reflect members with lower levels of assistance needed across many IADLs or IADLs (in other words, a large number of IADLs or ADLs requiring support just under the level of

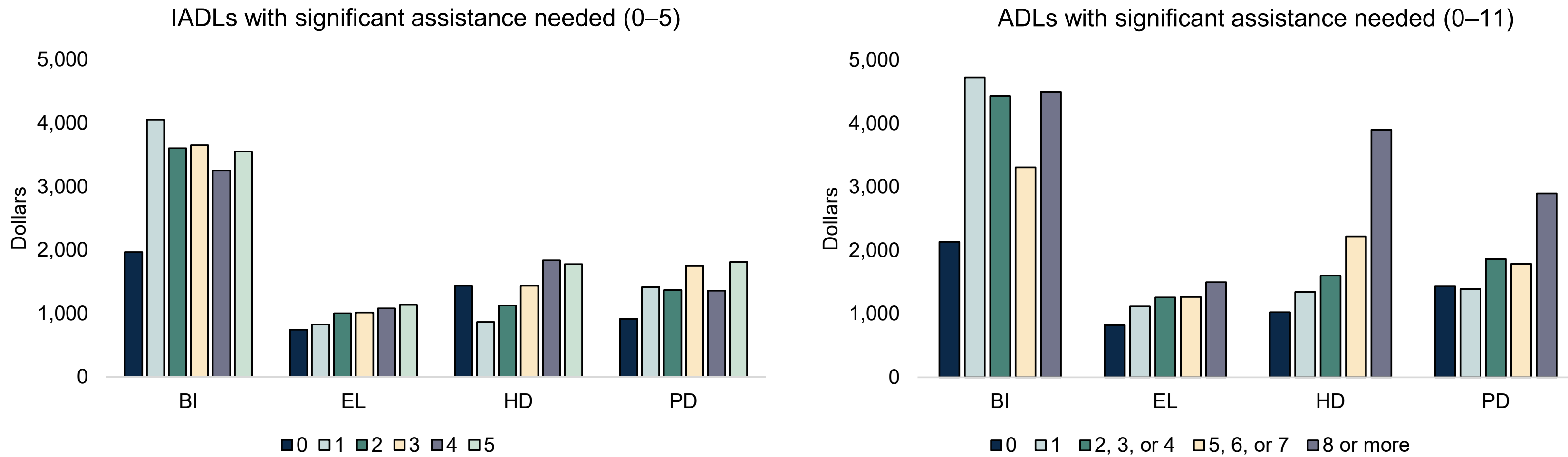
significant assistance). It is also possible that members have support needs for activities not included in those we measured or require supports for cognitive difficulties that are not adequately reflected in the IADL and ADL measures.[29]

Looking across waiver participants with the same level of support needs—at least on the measures we include from the interRAI-HC—we see that PMPM provider payments vary across waivers. We continue to find that holding level of assistance constant, provider payments were generally highest for individuals in the BI waiver, followed by those in HD, then PD and EL waivers. This is consistent with anecdotes we heard from community members that services on waiver programs are not always aligned to need and that some waivers support participants with the same needs more generously than other waivers. It is important to caveat that the measures of need we considered from the interRAI-HC in isolation do not fully capture overall support needs—cognitive difficulties not manifested in the selected IADL or ADL measures, the availability of family supports, and other health considerations are critical to HCBS need in a way that is difficult to capture in a single summary measure.

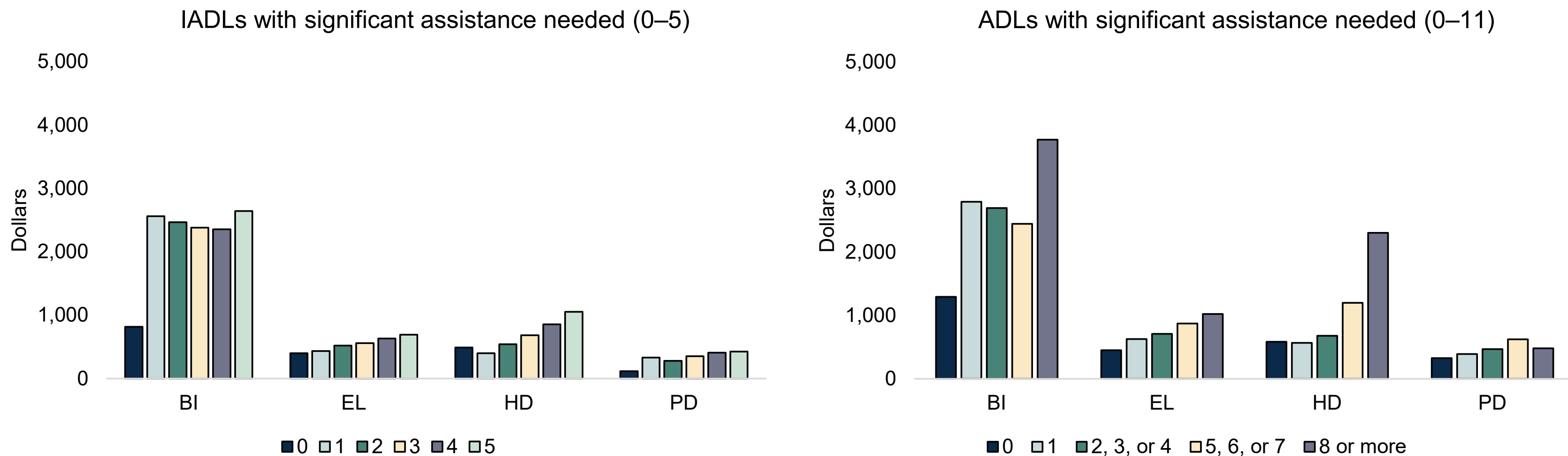
[29] We found that total provider payments were higher for those who were moderately or severely impaired in daily decision making relative to those who were not, though HCBS provider payments were about the same across those groups (and we did not assess the correlation between that measure and assistance needs for ADLs or IADLs).

Figure VI.4. Patterns of PMPM provider payments, by waiver and number of IADLs and ADLs requiring significant assistance

Panel A. Total PMPM provider payments in 2019



Panel B. HCBS PMPM provider payments in 2019



Source: InterRAI-HC assessments provided by Iowa Total Care and Amerigroup were completed in 2019 and linked to Medicaid encounter data from 2019. The analysis was limited to waiver participants with an assessment, as described in Appendix B, Section C.

Absent from the previous analysis are participants from the ID waiver, which has the most members and reflects a large share of total and HCBS provider payments in Iowa. The ID waiver, unlike other waivers for adults in Iowa, assesses participants using the SIS-A. Phased in starting in 2018, HHS began using SIS-A scores to calculate tiered rates for ID waiver participants. We used the SIS-A summary needs score to conduct an analysis for ID waiver participants similar to that for other waivers. Because the SIS collects information on a set of metrics different from the one for interRAI-HC and constructs its own index, however, the measures do not align to the interRAI-HC measures. Moreover, as we discuss in Appendix B, the SIS-A assessments were available for only a minority of adult participants in 2019 for a few reasons. The findings related to the SIS should therefore be interpreted with some caution.

Table VI.3 shows the distribution of scores among the 471 ID waiver participants with a 2019 SIS-A assessment who had a Support Needs Index score. It is important to note that in total, only 482 participants—or 4.7 percent of adult ID waiver participants in 2019—had a SIS-A assessment, and not all of those had a Support Needs Index score available. While the share of participants with an assessment is small, the characteristics of those with an assessment looked quite similar to those without (Appendix Table B.4).

Unlike the other waivers, within the ID waiver, the evidence suggests payments are not uniformly related to this measure of need. Table VI.3 is stratified on the Support Needs Index using cutpoints specified by the SIS, as documented in the table notes. Among participants in the highest index score category (116 and higher), we see that PMPM HCBS and total provider payments are lower than for those with Support Needs Index scores in other categories. Because provider payments can have a wide range and the number of observations in that highest category of need is small, it may be the case that the individuals in this group are not typical of all ID participants. We do see that for lower Support Needs Index scores, PMPM provider payments generally increase with need. The lack of a strong relationship in the ID waiver could be the SIS-A Support Needs Index measure isn't sensitive or those with a score are unique and their needs are not well-captured by the Support Needs Index.

Table VI.3. Distribution of SIS-A assessment scores and PMPM provider payments, 2019

SIS-A Summary Needs Index score[a]	Share of participants with score in range	Total provider payments ($, PMPM)	HCBS provider payments ($, PMPM)
Less than 89	19.1	2,119	1,865
90–101	35.4	4,187	3,782
102–115	40.6	6,635	6,172
116 or more	4.9	5,722	4,991

Source: SIS-A assessment data provided by Amerigroup and Iowa Total Care that were completed in 2019 linked to Medicaid encounter data from 2019.

Note: The analysis was limited to waiver participants with available assessment data, as described in Appendix B, Section C.

[a] These cut points are generally based on definitions in the SIS-A scoring framework. Per that framework, scores less than 89 are generally in the 1st to 20th percentiles, scores from 90 to 101 are approximately the 21st through 50th percentile, from 102 to 115 are the 51st through 80th percentile, from 124 to 131 are the 91st to 98th percentile, and 132 or more are the 99th percentile. We had to aggregate the responses in the upper categories to protect confidentiality, as very few participants had scores in the 124–131 and 132 or more categories.

C. Key takeaways

A waiver structure focused on identifying and meeting people's needs, regardless of their diagnosis, would be better than the current structure at helping Iowans remain in the community, improve equitable access, and increase administrative efficiency. Currently, the system places a high level of burden on Iowans to identify and access the services they need to stay in the community, such as transferring between waivers and requesting exceptions to policy on the basis of their unique needs. Our analysis of payments across waivers shows that services may not be allocated equitably across those with similar needs. This creates unnecessary inefficiencies for Iowa Medicaid in administering waivers and supporting transitions between waivers, and creates additional stressors for families and caregivers trying to access services. We recommend redesigning the waiver structure to allow individuals to get services based on their need, not their diagnosis. The use of different assessments across waiver programs and by age makes it more complicated to assess individuals' needs as they age and move across waivers over time, and for the state to have a comprehensive assessment of systemwide need. A redesigned system, including standardization of the assessment process to determine waiver and service eligibility, would allow a comprehensive assessment of need across populations.

VII. Accessing Services in Iowa's LTSS System

Iowans who are offered and accept a waiver slot can receive designated Medicaid-covered HCBS, but our evaluation revealed that many continue to experience difficulties accessing the services they need. For some, the difficulties stem from limitations in the services that waivers offer; for others, the challenges relate to provider capacity and navigating a complex system to access waiver services or other CBS. Challenges with accessing services in the community may mean that people have to enter institutions so their needs can be met.

In this chapter, we discuss our findings related to accessing CBS:

- Access to CBS is limited by gaps in the service array and provider capacity constraints. Self-directed services that are available in some waivers, which might help offset certain types of provider shortages, are well-regarded by members, but seem to be underutilized.
- Iowans find it difficult to find clear and consistent information about their service options from providers, case managers, and HHS.
- Limited access to CBS services can lead to longer than desired stays in facilities. MFP is well regarded in Iowa as a source of effective transition support, but its current eligibility criteria limit the population who can use it.

A. The service array combined with provider capacity constraints limit the availability of community-based supports for many Iowans using CBS

Iowans residing in the community often struggle to access needed services. When asked about their biggest challenge in accessing CBS, 77 percent of respondents to the online feedback form identified waiting lists for service access and waiver enrollment. Although we are not able to distinguish between those reasons, we heard from many Iowans about gaps in available CBS and a shortage of available CBS providers, especially in rural areas. The inability to obtain services may negatively affect consumers' health and well-being and create burdens on family and caregivers.

Gaps in the continuum of service availability create challenges for remaining in the community.

HHS administrators, providers, consumers, and caregivers identified gaps in Iowa's service continuum for individuals using waiver services. The most notable gaps affect individuals with intellectual or developmental disabilities, youth, and those with co-occurring behavioral and physical health issues. In addition, many consumers face transportation challenges that limit their ability to get to and from providers and to live fully in the community. We heard about particular challenges with:

- **Residential crisis services for members with intellectual or developmental disabilities on the ID waiver.** ID waiver members can access long-term supportive housing in the community outside their family home using waiver housing, which blends a place of care with Supported Community Living (SCL), a service that is designed to support safety, finances, housekeeping, and other services. Yet these homes are generally staffed with a single direct service professional supervising four residents. Residents' behaviors need to be relatively stable for a single staff member to adequately support all residents. If a resident's behavior becomes unstable, often police or crisis services are called and an assessment is completed to determine whether institutionalization is needed. Iowans reported that residential crisis services—such as a hospital diversion program—for ID waiver members could

prevent unnecessary institutionalizations, prevent loss of placement in HCBS waiver homes, and support the intellectual disability direct care workforce during times of greater stress for residents.

- **Youth-specific crisis and psychiatric stabilization services.** Children experiencing an acute mental health crisis have limited crisis service options, especially outside traditional weekday business hours. Iowa has crisis stabilization and services for children, but these services are often not accessible and are inconsistently provided across the state. Rather, many youth in crisis turn to a local emergency department. In some cases, they travel out of state for needed supports or turn to institutional care when community supports are not available.

"It is hard to get adequate help when you need it. When a person is in crisis, especially if they are a minor, there are so few options, few open beds, few providers. I truly feel like if we can help be ahead of the program with more … programs, more counseling and therapy, quality of life services, etc., that we can make an impact in the number of mental health crises that we see and hopefully see more open beds, fewer suicides and more people living meaningful and healthy lives."

Response to online feedback form

- **Services to better support Iowans with co-occurring intellectual or developmental disabilities and behavioral health issues.** There are notable gaps for individuals with co-occurring behavioral health conditions and brain injury, people with intellectual disabilities and skilled nursing needs, and those with co-occurring behavioral health needs and intellectual or developmental disabilities. Providers report that they do not have the training and experience to provide appropriate care for such co-occurring conditions. When poorly managed, such situations may lead to unnecessary hospitalizations and law enforcement involvement, according to an HHS administrator.
- **Transportation.** Many Iowans live in non-urban settings with limited or no public transit services, meaning that they must rely on other forms of transportation to engage in the community. While Non-Emergency Medical Transportation (NEMT) is an available benefit to individuals on the 1915(c) waivers within Iowa, only 31 percent of waiver enrollees used NEMT in 2020.[30] Members, caregivers, and providers mentioned a range of challenges with accessing NEMT. They shared that the needed transportation services are rarely available, are unreliable or inaccessible, and have insufficient coverage areas. For those with mobility limitations, these options can be especially difficult to navigate, as accessible transit can be limited. An inability to use transportation services to access medical appointments is a key barrier to receiving community-based care.

[30] See Table B1.9c in Becerra, X. "Report to Congress: Non-Emergency Medical Transportation in Medicaid, 2018–2020." 2021. Available at https://www.medicaid.gov/medicaid/benefits/downloads/nemt-rtc.pdf. Accessed September 15, 2022.

Insufficient provider availability creates barriers to remaining in the community.

Even when the specified waiver services and budget align with a participant's needs, provider availability can be a significant challenge to accessing care in the community. A "lack of staff or training for staff" was the second most frequently cited item on the feedback form in response to a question asking about the greatest challenge in accessing CBS. We heard that many Iowans attribute provider availability issues in part to current reimbursement rates.

Box VII.1. Iowa HHS' recent efforts to address provider shortages

- Used American Rescue Plan Act of 2021 funding to increase payments to agencies that employ direct service staff.
- Created a reimbursement rate structure to incentivize home health care providers located in rural areas.
- Developed a loan repayment program for students who work in an underserved area after they graduate as a mental health professional.

Source: Iowa HHS. "American Rescue Plan Act (ARPA) 2021." 2022. Available at https://hhs.iowa.gov/ime/about/initiatives/ARPA. Accessed January 13, 2023.

Being unable to access services affects both consumers and their families and loved ones. For example, respite services are covered by all the waivers except one, but caregivers reported that respite service was often inaccessible because of provider availability issues. When a consumer is living in the community without sufficient supports, family members usually serve as unpaid caregivers and care coordinators, and it is they who take on navigating authorization and approval issues with the MCOs. HHS is aware of these issues that consumers and their families raise; Box VII.1 highlights some of the recent efforts the department has made to address this issue.

Provider accessibility challenges are often most acute in rural areas. Given Iowa's large land area, it can be burdensome for members to travel to providers, which may require more than an hour-long drive for basic health care services. Moreover, members routinely reported issues with finding providers in rural areas who accept Medicaid, and providers reported that they find it too costly to drive to rural areas to deliver services.

"Staffing shortages make it increasingly difficult for parents of children with disabilities to hold a career. Although we can get approved for services, we can't get them covered, meaning that parents have to take time off work to provide nursing care, transportation, and other services directly. The time off of work can be covered by [Family Medical Leave Act] to an extent. But that is unpaid and has a down-spiraling effect on the financial circumstances and resources for the household."

"Chronic turnover and lack of staff prevent me from living a fully independent life in the community."

Responses to online feedback form

Employers have reportedly responded to low reimbursement rates by reducing staffing, increasing staff caseloads, and reducing staff development efforts. Together, these approaches lead to undertrained providers, staff burnout, and eventually staff turnover, which exacerbates capacity issues. In addition, when community providers operate have few staff supporting many members, their ability to respond to members in crisis and ensure a safe environment for their staff and members is limited.

Providers may use their discretion when accepting Medicaid members, which can mean that some populations can find it difficult to identify qualified providers. Care is especially difficult to identify for individuals on the sex

offender registry, who are not allowed to use group-based community services, and for members with a history of aggressive behaviors or destruction, who have difficulty finding service providers and housing options in the community. In talking with providers, we also learned that some believe they have insufficient staffing and training to be able to successfully serve those with the most complex needs. As a result, providers may select members with less complex care needs, creating an underserved population with a high level of service needs.

To encourage providers to serve ID waiver participants who have higher levels of need, several years ago Iowa developed tiered payments for services paid on a daily rate (such as SCL) in accordance with SIS ratings.[31] An unintended consequence of this policy is that now some providers reportedly accept only members at the highest rating to maximize their revenue, while others refer members with higher ratings to facilities because they do not feel qualified to serve them in the community. Additionally, the SIS assessment that is used to set rates is completed every three years or following a significant change (though off-year assessments are also completed in the interim). Community members expressed concern about using a point-in-time assessment as a basis for long-term funding because members' needs can change rapidly.

The information we heard from invested Iowans across the LTSS landscape on provider availability stands in contrast to the quarterly MCO service network analysis reports.[32] This analysis indicates that the state maintains a sufficient provider network, with MCOs reporting 100 percent network adequacy for most LTSS services in 2022. It is important to note, however, that network adequacy standards apply only to services to which the member travels, when many CBS (SCL or home health aides, for example) are provided in individuals' homes. Finally, network adequacy considers only the presence of an available provider: It does not account for providers with a waiting list or providers who are selective about the LTSS populations they serve. As a result, adherence to the contracted network adequacy standards does not mean that individuals receive the care in their homes that is needed to sustain community living.

Self-directed services already available in Iowa HCBS offer an alternative means of service access, but these are potentially underutilized.

In the face of provider shortages and difficulty in finding providers, consumer-directed services were reported as a bright spot by consumers we spoke with. These services enable members to lead their care plan by allowing them to directly hire their own attendants to help with daily activities through the Consumer Directed Attendant Care (CDAC) program or control a targeted amount of Medicaid dollars to hire caregivers or purchase goods through the Consumer Choices Option (CCO) (see Box VII.1).

There appear to be opportunities to better leverage the successes of CCO and CDAC. CCO is used by a minority of members (23 percent of those in the BI waiver and only 3 percent each in the HIV and EL waivers; Table VII.2). A higher share of Medicaid members use CDAC rather than CCO, but the share varies widely across the waivers, ranging from as high as about 60 percent of participants in the HIV and PD waivers to less than 10 percent for ID waiver participants.

[31] Iowa HHS. "HCBS ID Waiver Tiered Rates FAQ." n.d. Available at https://hhs.iowa.gov/ime/providers/csrp/fee-schedule/hcbs-id-tiered-rates-faq. Accessed September 15, 2022.
[32] Iowa HHS. "Managed Care Network Geographic Access Reports." September 2022. Available at https://hhs.iowa.gov/ime/about/performance-data-GeoAccess. Accessed September 15, 2022.

Box VII.2. Consumer-directed HCBS in Iowa Medicaid waivers

Iowa Medicaid members in a 1915(c) waiver can self-direct a portion of their care, except those in the CMH wavier.

CDAC allows members to hire two caregivers of their choosing (though members cannot set the wage rates for providers). Members can hire for unskilled services (for self-care tasks that the member would do independently, if able) and skilled services (under the supervision of a licensed medical professional).

CCO gives members both hiring and budget authority for a select set of waiver services. The number of services that can be self-directed varies by waiver—as few as four on the PD waiver and as many as nine on the HIV waiver.

Despite positive reports about the option to self-direct services, several members reported difficulty with accessing and understanding information on service availability, coverage, and reimbursement policies. Members stated that low wages and reimbursement rates for CCO and CDAC providers reduced the effectiveness of these programs, although they may help address provider access issues because they allow members to hire and pay family or friends as caregivers. Members also described routinely seeking ETPs to go above established rates to pay for their CCO services.

Table VII.1. Share of waiver participants using CCO and CDAC in 2018, by waiver

Waiver	Participants using CCO (%)	Participants using CDAC (%)
HIV	3	61
BI	23	33
EL	3	48
HD	18	38
ID	15	9
PD	4	58

Source: Iowa Medicaid encounter data.

Note: We identified members using CCO through a combination of service and provider codes provided by Iowa DHS. CDAC services were identified using service codes from the fee schedule. CDAC and CCO categories are not mutually exclusive; a person using CCO can also use CDAC services and may be counted in both columns in the table.

B. Consumers face challenges navigating a complicated system and find it difficult to obtain clear, correct, and consistent information

MCO case managers and care coordinators are responsible for assisting members in identifying providers, covered services, and other supports. Iowans nevertheless reported that navigating the system is challenging. More than half of respondents to the feedback form indicated that information about services and supports was hard to access. This challenge resonated even among those with ample experience with the system. One consumer we spoke with—a person on a waiver who is a direct service provider and is also a caregiver to two of her children with disabilities—shared that even she has difficulty navigating the system and receiving approval for needed services.

"Case managers … end up running into endless obstacles of services being unavailable."

"I have been trying to get services [for] over two years ... and have still found services lacking. In fact, most of them I can't even get information on unless I go to three or four different people on the phone, each giving a different answer."

Responses to online feedback form

Generally, communication issues and knowledge gaps among MCO case managers, care coordinators, and consumers can cause delays in accessing care, which can lead to unnecessary acute care and facility entry. Even short of that, it can lead to time and psychic burden on consumers and providers. It can also create a burden on family members to serve as care coordinators and take on the navigation of authorization and approval issues with the MCOs.

Accessing information to find available HCBS providers is challenging.

Even when providers are available, the information necessary to find and contact them can be frustratingly difficult to access. MCO case managers have difficulty locating service providers because no mechanism is in place through which providers can share information with the MCOs about openings and capacity. This obligates MCO caseworkers to make many phone calls to find appropriate referrals for members. In addition, MCO case managers are often not well equipped or trained to offer connections outside of Medicaid-funded entities, such as to MHDS, substance use, or aging services. This means that even after entering a waiver, other services and supports in the broader CBS system may remain out of reach without concerted individual navigation efforts.

"There's no one that says, 'Here are all of the possible services available to you under Medicaid.' You know, you need someone to, like, guide you through, to listen to what's going on, and figure out what program or what waiver or what might be good for you. And every now and then someone throws you a new golden nugget that you don't even know about at the time. But the comprehensiveness of what do you need, let's find a program that matches, there's not usually someone to walk you through that very well."

Listening session participant

Consumers also face difficulties in identifying providers, in part because of challenges with accessing knowledgeable case managers. The MCOs in Iowa are not required to have a certain ratio of members to case managers, and case managers often have large numbers of members to support. Members report difficulty with getting in touch with case managers, with having their phone calls returned, and with the lack of case manager continuity. In addition, online tools that MCOs

offer to help members find providers often lack links to providers' websites, lists of services available, and information about whether providers are accepting new patients. The online tools also do not allow consumers to narrow searches to services covered by HCBS waivers, making it challenging to quickly identify covered service providers.

In some cases, informational challenges can create barriers to receiving the appropriate level of care. For example, PMIC entry requires that the member or their caregiver demonstrate that they exhausted all outpatient and community-based services. MCOs can help identify potential providers and share contact information, but their policies preclude them from calling or making appointments on behalf of members. This means that during times of crisis, family caregivers often must dedicate substantial time and resources to use providers' directories to track down those who can provide sufficient documentation for the PMIC.

The system lacks continuity of care for individuals moving across the service continuum.

As health needs evolve and providers change, Iowans report that care trajectories were frequently disrupted because a person's case manager changed. This can happen because case management is often tied to a specific provider or service, and case managers do not always follow people as they move through the system.

"We were once switched to a different case manager for about a year and didn't have any contact with her. Please continue to keep the case managers as long as possible so they know the situation and can provide better solutions."

Response to online feedback form

MFP illustrates that consumers can experience difficulties with accessing continuous care even in a program that is generally well-regarded for supporting transitions to the community. Key informants reported that MFP transition support services provided effective system navigation, but these navigators were only available for the first year post-transition. Members experience this as being "passed off" from one support provider to another, while they would have preferred to have consistent long-term system navigation help that moves with the individual through the system.

Moving across other programs in the CBS system can generate similar consumer experiences. One MHDS region administrator discussed the importance of having a consistent caseworker who follows members throughout transitions between places of care and even funding sources. They noted, "You have to stick with them.... If we start out with you, we're going to follow you until you don't need [us] anymore." In addition, because Medicaid providers do not share a data system, consumers must continually repeat their medical history whenever they change providers—resulting in an inefficient use of time because information already "in the system" must be shared again, leaving less time for getting needed care.

C. The current HCBS landscape in Iowa can lead to longer-than-desired facility stays

The challenges described earlier in this chapter regarding service access and system navigation can lead to facility entry and may lengthen the stays in facilities. Facility stays should last only as long as medically necessary, and transitions to the community should occur in accordance with the individual's preferences. Nonetheless, misaligned incentives and the lack of available HCBS and providers can mean that stays are longer than desired. Not only does this outcome violate Olmstead provisions, it also means

that facility beds are not being efficiently allocated, as those who could live in the community are occupying beds that could have been used by those who need institutional-level care. This misallocation of facility beds puts additional demands on the CBS system.

Facility transitions can be delayed because of difficulty in finding and coordinating with HCBS providers.

Transition planners at PMICs, the two state resource centers, and MHIs reported difficulty in finding community providers to serve would-be transitioners, causing their return to the community to be delayed. An MHI administrator shared that staff make 70 to 100 phone calls per transitioning patient to find community-based placements for discharge. Facility-based social workers can create transition plans that identify the receiving providers and the services needed to return to community living, but there is no systematic way for facilities to identify providers who have openings.

Iowa also does not have a centralized way for HHS to communicate with its facility and MCO partners about openings in other systems that could be helpful for discharge planning. For example, key informants at PMICs and MCOs shared that they do not have access to foster care system information that would help facilitate the placement of children into the foster care system when they exit a PMIC, if they are unable to return to their home.

Once a community provider is located, billing policies prevent them from receiving payment for an institutionalized individual before that patient is discharged. Specifically, waiver services cannot be billed and reimbursed while a person is in an inpatient setting or in an institution,[33] which disincentivizes community-based providers from establishing contact and rapport with an individual who is transitioning out of a facility. A noted exception to this policy is for those individuals who are leaving the state resource centers and who use MFP. These individuals can be served by their facility and a community-based provider at the same time, paid for by MFP, which allows the community staff to learn from the facility staff and for the individual to experience their new environment prior to transition. In the listening sessions, providers almost universally mentioned MFP as a strength for connecting people to services when they leave institutions. This pre-transition connection increases both patient and provider confidence in the transition and can shorten the time between facility departure and receipt of CBS.

Low rates of waiver service uptake among those who leave institutions may suggest challenges in accessing HCBS.

We found that fewer than 5 percent of people leaving ICF/ID, MHIs, PMICs, and NFs enrolled in a waiver or received 1915(i) state plan habilitation services within 30 days of leaving an institution (Table VII.2). In the first full year after leaving an institution, fewer than 42 percent enrolled in a waiver or received state plan habilitation services.

As shown in Table VII.2, a higher proportion of members accessed HCBS than were enrolled in a waiver or state plan habilitation at each point in time we considered. This suggests that members are receiving a limited set of community services after leaving an institution, in some cases through MFP. Individuals accessing HCBS while not enrolled in a waiver or state habilitation services commonly received round-the-clock care or transportation services. Still, it is notable that even at a full year after leaving a facility, many had not accessed HCBS and the majority were not enrolled in a waiver or state habilitation services.

[33] Iowa Administrative Code. "Chapter 83: Medicaid Waiver Services." 2022. Available at https://www.legis.iowa.gov/docs/iac/chapter/09-07-2022.441.83.pdf. Accessed September 15, 2022.

Table VII.2. Waiver enrollment or state plan habilitation services use and HCBS utilization for members exiting an institution in 2018

Institution type	Number exiting institution	Waiver or state plan habilitation enrollment within 30 days (%)	Any HCBS use within 30 days (%)	Waiver or state plan habilitation enrollment within six months (%)	Any HCBS use within six months (%)	Waiver or state plan habilitation enrollment within one year (%)	Any HCBS use within one year (%)
ICF/ID	105	1	46	3	57	41	61
MHI	322	4	9	7	18	12	25
PMIC	688	4	7	10	16	16	23
NF	4,337	4	21	9	31	10	34

Source: Iowa Medicaid encounter data.

Note: This table shows waiver enrollment, 1915(i) state plan habilitation service use, and HCBS utilization among people who exited an institution during the 2018 calendar year and remained alive for 30 days. Types of HCBS utilization included in the table are caregiver support; case management; day services; equipment, technology, and modifications; home-based services; home-delivered meals and nutrition; mental and behavioral health; round-the-clock services; services supporting self-direction; supported employment; and transportation.

It is unclear why enrollment in a waiver or state plan habilitation is relatively low among people transitioning out of institutions, because there is no waiting list for state plan habilitation services and several waivers reserve slots for those exiting institutions. The low rate of waiver or state plan habilitation uptake suggests that consumers leaving an institution may encounter barriers to enrollment because they are not aware of the waiver and state plan habilitation services or do not know about the availability of those options.

D. Key takeaways

Strengthening components of the CBS system will increase access to high-quality care and services that have proven value for keeping people in the community. Current gaps in the CBS system mean that people must access facility-based care, even in situations when people want to remain in community. This task includes shoring up navigation supports so people know what services are available and how to access them across all CBS programs in Iowa; it also means ensuring that people have strong case management support while they are on a waiver. Further, we recommend that policies and programs that support families be taken into consideration: for example, consider ways to expand self-direction and other caregiver support programs, and make MFP available broadly for those who want to move to a community setting. Without a CBS system that meets people's needs, families and caregivers will undoubtedly experience undue stress as they try to navigate the system, which can lead to unnecessary institutionalizations.

VIII. Conclusion

People across Iowa share the goal that individuals will be able to live in communities that support their health, well-being, and safety, and that the system should maximize their independence and ability to live in the community. As this assessment has demonstrated, a range of services and supports are available to Iowans who are aging, who have disabilities, or who have behavioral health needs. Although these programs are providing vital services to some, there are real opportunities to improve the structure and operations of programs and services for Iowans with long-term care needs, which would make services more accessible, efficient, and impactful.

As the HHS, consumers, and other invested Iowans embark on efforts to redesign the CBS system to equitably meet consumer needs and to enact the recommendations proposed in this report, it will be important to align these efforts with the guiding principles of HHS, including its commitment to the following:

- **Data-driven decision making:** We make informed, data-driven, and evidence-based decisions to drive quality and improve results.
- **Accountability:** We use public resources responsibly to improve lives through the programs and services we provide.
- **Integrity:** We generate trust through honest, respectful, and reliable work that we can be proud of.
- **Equity:** We actively identify and remove barriers to access and inclusion so that we can give all individuals an opportunity to succeed.
- **Communication:** We communicate in a thoughtful and coordinated way to ensure that individuals are well informed about our work.
- **Collaboration:** We facilitate meaningful partnerships that focus on the voices of the individuals and communities we serve.

Redesigning systems is challenging work. There is substantial energy and enthusiasm in Iowa for this effort, and we are confident that with vision, commitment, and dedicated resources, the state of Iowa will be successful.

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Appendix A. Overview of Program and Policy Review Activities

The program and policy analysis comprised three phases. In the first, we aimed to learn about the landscape of Iowa's service delivery system through a literature review and collection and analysis of program operation information. Next, we identified successes and challenges within the core of the CBS system—focusing on IME- and MHDS-funded programs—through a series of 27 interviews with program administrators and policy experts within Iowa HHS and MCOs. Finally, following those interviews, our team conducted a series of data collection, analysis, and research tasks aimed at better understanding system challenges, including barriers to waiver entry, waiver structure, and transitions in and out of facility levels of care.

A. Assessing the CBS landscape (February–April 2022)

To understand the policy landscape in Iowa, our team conducted a high-level review of programs concerning behavioral health, disability, aging, criminal justice, and children and youth, which stem from a set HHS recommended. Our goal was to understand program eligibility, funding sources, and the scope and scale of operations. Figure A.1 shows the entities we researched.

Figure A.1. Entities, programs, and policies initially considered

Disability and behavioral health	Aging	Criminal justice	Children and youth
• Medicaid 1915(c) and 1915(i) waivers • MFP, PACE • Medicaid-funded institutional LTSS • Mental Health and Disabilities Services (MHDS) • Substance Abuse Prevention and Treatment Block Grant (SAPT) • Iowa Provider Network • Mental Health Block Grant • Community Mental Health Centers (CMHCs)	• Commission on Aging • Iowa Department on Aging • Area Agencies on Aging (AAA) • Aging and Disabilities Resource Center (ADRC) • Program for All-Inclusive Care for the Elderly (PACE)	• Juvenille Justice • Community Based Corrections • Quasi-Incarceration Residential Facilities • Institutions (Prisons) • Reentry Planning • Behavioral Health Medication Voucher Program	• Child Welfare • Iowa's Area Education Agencies

Next, the team worked with staff from HHS to refine the scope of the evaluation to focus on LTSS programs and services. Based on HHS guidance, the primary focus of the evaluation was on HCBS programs (e.g., 1915[c] waivers, PACE, MFP, and 1915[i] habilitation services), waiting lists for 1915(c) waivers, and institutional LTSS (ICF/ID, MHI, PMIC, NF) services. MHDS region-funded services were a secondary focus of the evaluation.

To establish more in-depth knowledge of the programs of interest, we requested detailed information from Iowa Medicaid and MHDS staff on the purpose of the programs and program enrollees, funding, service use, and spending.

B. Identifying system challenges and successes (March–April 2022)

To learn about the challenges and successes of the LTSS system, we conducted 27 virtual interviews with key program administrators and policy experts. These included Iowa Medicaid bureau chiefs, policy specialists and other managers; MHDS staff within HHS; and directors and other leaders in Iowa's MCOs.

Over the course of two months, we had open-ended discussions with key informants about successes, challenges, and opportunities for improvement. We asked questions such as the following:

- What are Iowa's biggest successes in providing high-quality long-term services and support in home- and community-based settings?
- What are some of the biggest challenges?
- Are there any services and supports that are generally unavailable to people with disabilities, behavioral health needs, and elderly people that, if added to the LTSS system, would lead to better care in home- and community-based settings?
- To what extent is access to and receipt of HCBS equitable by geography, disabling condition, or other consumer characteristics?
- Do you have any suggestions that would improve the experiences of people with disabilities and behavioral health needs in accessing high-quality HCBS?

We identified key themes that emerged from the interviews and shared summary findings with HHS.

C. Analyzing system challenges (May–August 2022)

We worked with staff from HHS to identify key system challenges that warranted additional analysis: waiver entry, waiver structure, and transitions in and out of facility-based care. We developed distinct analysis plans to learn more about each challenge and to identify successful strategies.

Waiver entry analysis. The goal of the waiver entry analysis was to understand how Iowa's waiver entry and waiting list policies compare with policies in similar states. We began by reviewing Iowa waiver amendment applications for each of the seven 1915(c) waivers to document waiver policies related to eligibility, waiting lists, and reserve capacity slots. We reviewed previous and current waiver application forms, emergent and urgent needs assessment forms, and interviews with Iowans about their application experiences. We also visited an Iowa HHS office to ask about the application process.

For comparative purposes, we studied six other states: Florida, Louisiana, Minnesota, Ohio, Utah, and Wisconsin. We selected these states because they employed a variety of strategies related to waiver waiting lists, and several were located near Iowa or had similar geography. We examined two aspects of these strategies that might serve as possible models for Iowa to consider: (1) waiting list reduction strategies and (2) approaches to serving people while they are on a waiver waiting list.

Waiver structure analysis. We conducted a waiver structure analysis to better understand how Iowans on waivers accessed needed medical and social services, and how their access compared to similar people

in other states. First, we reviewed the most recent CMS 372 Report and waiver application for each of the seven HCBS waivers to document features such as enrollment limits, maximum allowable expenditures, average expenditures, and services, among other features. We then analyzed Medicaid data (described in Appendix B) to describe annual service-specific utilization and provider payments for each waiver. We also analyzed exceptions to policy requests to try to understand where covered waiver services may not meet the needs of enrollees. In addition, we created a crosswalk between MHDS and waiver services to identify potential gaps in services, complementary services, and duplication of services.

To understand alternative approaches, we analyzed waiver redesign and waiver structures in four other states: Louisiana, Michigan, Ohio, and Tennessee. We searched for states that could provide examples of waivers based on acuity, 1915(i) state plan amendments for behavioral health, 1115 demonstration waivers that include LTSS, 1915(c) waivers, and managed LTSS. In the four selected states, we reviewed CMS 372 Reports and waiver applications to document waiver features. We also reviewed summary documents, stakeholder feedback, and news articles to identify more details about the motivation for redesign, goals of the redesign, effectiveness in achieving goals, and stakeholder perceptions.

Transitions analysis. The objectives of the transitions analysis were to determine barriers to transitions in and out of facilities, to understand the policy and programmatic incentives for facility-based care, and to learn what facilitates successful transitions between levels of care. To achieve these objectives, we undertook a literature review, conducted qualitative interviews, and researched transition policies and processes in other states.

Our literature review aimed to deepen our understanding of ICF/IDs, PMICs, and MHIs. We reviewed HHS materials, program descriptions, meeting minutes, and Medicaid policy manuals to learn about the facilities, their referral processes, and the processes for transitions back to the community. We also researched state policies and programs that facilitate movement in and out of Iowa’s institutions, such as MFP and Iowa’s managed care contracts.

We then conducted interviews with 23 key informants, focusing on transitions. Some of these interviews were with individuals we met during our first round. We also expanded discussions to MHDS staff throughout the regions; met with additional MCO staff across the state; and had conversations with private entities, with a focus on behavioral health services. We selected interviewees on the basis of their firsthand knowledge of transitions between community and facility-based care, and we sought to represent a variety of institutional settings. We analyzed interview responses for content related to incentives for facility-based care, incentives for community-based care, challenges with transitions out of facilities, challenges with referrals to facilities, and facilitators of transitions into and out of facilities. We further categorized information on incentives depending on who was influenced by the incentive and the nature of the incentive (political, financial, medical, or social).

Finally, to identify promising practices in institutional transitions in other states, we conducted document reviews and convened an internal working group of state Medicaid policy experts at Mathematica. We also researched topics that included braided funding, community-based service standards in rural communities, system navigation, ways to leverage MCOs, and ways to improve the beneficiary system navigation experience.

Appendix B. Quantitative Data Analysis and Methods

To triangulate what we heard from invested Iowans, we conducted analyses of quantitative data from various sources to produce summary statistics throughout our evaluation. Our analyses focused primarily on Medicaid encounter data describing the enrollment and service receipt of members requiring HCBS or other LTSS, but also included other waiver and waiting list information the state provided. In this appendix we describe in detail the data we received and how we transformed them to conduct our analyses.

A. Medicaid claims data analysis

The quantitative analyses in this report relied primarily on Iowa Medicaid encounter data. HHS regularly receives program data from the two MCOs that serve state Medicaid members and then processes the data into a usable format.

Record selection

In April 2022, Mathematica requested Medicaid data for all beneficiaries who had any of the following statuses during the 2018 or 2019 calendar years (the primary reference period for this data analysis to avoid issues of incomplete data in more recent years):

1. Were enrolled in any one of the HCBS programs, including a section 1915(c) waiver program, PACE, MFP, or 1915(i) habilitation services
2. Used other HCBS program services, such as Community-Based Neurobehavioral Rehabilitation Services, Home Health Services, Hospice Services, Private Duty Nursing/Personal Care Program, Case Management
3. Used institutional LTSS, such as nursing facility, ICF/ID, MHI, or PMIC
4. Were on a waiting list for one or more section 1915(c) waiver programs

For these members, we requested data from January 2017 through June 2021—providing at least 12 months of data before and after that spell for each person in the 24-month reference period. The data elements requested included information about demographics and geographic location (such as gender, age, death status, race, and county of residence), Medicare enrollment, Medicaid enrollment (such as start date and MCO plan identifier), Medicaid enrollment-based programs (such as 1915[c] waiver programs and 1915[i] habilitation services), Medicaid claims (institutional/residential, inpatient, and other types of provider payments), and waiver waiting list information.

It is important to note that the provider payment statistics presented in this report do not include services covered by Medicare, and therefore understate the federally paid health services that members received. Most (67 percent) of the Medicaid beneficiaries in Iowa are also enrolled in Medicare. Benefit coverage varies across Medicare and Medicaid. For example, Medicaid covers LTSS, including all long-term needs, whereas Medicare provides only limited, short-term LTSS coverage. However, some services such as inpatient stays or emergency department visits are covered by both programs. By statute, Medicaid is the "payer of last resort," which means that Medicaid pays for a service only if no other third party covers that service. When Medicare and Medicaid both cover a service, Medicare pays for it. Thus, provider payments in the Medicaid data reflect amounts paid only by Medicaid.

Between June and August 2022, HHS provided Mathematica with data extracts. In the extracts, program eligibility started on the first day of a month and ended on the last day, allowing us to organize the data with one line per member per month. The extracts contained information from encounter records only and did not contain information about services provided under the fee-for-service system. Mathematica received the encounter data in a series of pipe delimited text files, analyzed the data using SQL (Structured Query Analysis), and analyzed output using Tableau and Excel.

We received additional waiting list data from the state, which we linked to Medicaid encounter data in support of the analysis. Specifically, each file that HHS provided included a snapshot of waiting list status for all waivers at a certain point in time. Among the data elements were an identifier, type of waiver, date of waiting list entry, date of birth, and county. We used information in these files to calculate waiting list spans and then linked the waiting list spans to records in the Medicaid data extract.

Service categorization

We created an analytic file from the data extracts for our Medicaid data analysis. The analytic file included all members who met the sample selection criteria above based on program enrollment or service receipt in 2018 or 2019. We developed logic to create a service categorization of provider payments to map them to different types of service use (Table B.1). The logic relied mostly on claim type, provider type, and procedure codes to categorize claims. Any remaining inpatient, long-term care, or outpatient claims that were not classified into one of the categories listed in Table B.1 were characterized as inpatient unclassified, other institutional, or outpatient unclassified.

Table B.1. Data elements used for identifying relevant service categories

Service category	Data elements used
Inpatient, nursing facility, mental health facility, PMIC, ICF	Claim type and provider type
ED	Procedure code Revenue center code
HCBS[a,b]	Procedure code and modifier Waiver type (waiver)
Outpatient behavioral health, B3	Procedure code and modifier
BHIS[b]	Procedure code and modifier Waiver type (null)

Source: Mathematica's analysis of Iowa Medicaid encounter data.

Note: Any claims not classified into one of these defined categories were classified as inpatient unclassified, other institutional, or outpatient unclassified, depending on the claim type code.

[a] HCBS include any services approved for Iowa's section 1915(c) waiver programs or habilitation state plan program.

[b] Several services are covered under both HCBS and BHIS, so we used the waiver type variable on claims to distinguish whether a claim with a relevant procedure code should be categorized as HCBS or BHIS.

We also mapped the list of HCBS procedure codes to relevant taxonomy categories to report more detailed information about HCBS (Table B.2).[34] The HCBS taxonomy categories included caregiver support; case management; day services; equipment, technology, and modifications; home-based services; home-delivered meals and nutrition; mental and behavioral health; round-the-clock services; services supporting self-direction; supported employment; and transportation.

[34] For more information, see https://wms-mmdl.cms.gov/WMS/help/TaxonomyCategoryDefinitions.pdf.

Table B.2. Categories of services included in HCBS

Category	Examples of services included
Caregiver support	Respite, in-home family therapy
Case management	
Day services	Adult day care, day habilitation
Equipment, technology, and modifications	Assistive devices, home and vehicle modification, specialized medical equipment
Home-based services	Home health aide, chore services, homemaker services, home-based habilitation, nursing
Home-delivered meals and nutrition	
Mental and behavioral health	Behavioral programming, counseling (individual and group)
Round-the-clock services	Supported community living
Services supporting self-direction	Consumer-directed attendant care, financial management services
Supported employment	
Transportation	Individual or group trips, wheelchair van trips

Data analysis

We used the analytic file and other quantitative data to conduct a variety of Medicaid analyses, including those described in this report, to answer key questions and provide context for policy recommendations. For the analyses, we created a series of tables that describe key outcomes across waiver, waiting list, and institutional populations, and conducted other analyses identified across work streams as being useful to the evaluation. The analyses often included the creation of descriptive statistics—counts, percentages, means, medians, and so on—or tabulations. At the bottom of each table or figure in this report is a description of the data source and a note explaining what the figure examines. Most tables and figures focus on data from the 2018 and 2019 calendar years to avoid drawing policy conclusions from data collected during the COVID-19 pandemic, beginning in the United States in March 2020.

The HCBS utilization information for the 1915(c) waiver programs in the encounter data Mathematica received aligns reasonably well with external benchmarks. We compared waiver member counts and provider payments in the encounter data to information from the CMS 372 annual reports (Table B.3). For all but the PD waiver, member counts did not differ by more than 16 percentage points. Similarly, for four of the seven waivers, HCBS payments did not vary by more than 7 percentage points. Differences between the two data sources are likely attributable to differences in how members were grouped into waiver programs. In the encounter data, we attributed someone to a waiver and tracked their 2018–2019 payments if they enrolled in the waiver at any point in 2018, which is not necessarily how the 372 reports classified waiver participation. It is noteworthy that statistics for HCBS utilization for the HIV and ID waivers, which have limited beneficiary turnover relative to the other waivers, are the most consistent across data sources. The differences in percentages reported in Table B.3 suggest that the statistics in this report are reasonably accurate presentations of HCBS utilization across Iowa's 1915(c) waiver programs relative to other external sources.

Table B.3. Comparison of HCBS data for Medicaid 1915(c) waiver programs in encounter data and CMS 372 annual reports

	2018 CMS 372 data		2018–2019 Iowa Medicaid encounter data		Percentage difference	
	N	Annualized per member per month payments	N	Annualized per member per month payments	N	Annualized per member per month payments
HIV	32	$8,954	31	$8,412	–3%	–6%
BI	1,265	$26,166	1,444	$22,212	14%	–15%
CMH	921	$8,711	998	$9,852	8%	13%
EL	9,903	$5,372	8,303	$6,324	–16%	18%
HD	2,166	$9,280	2,341	$9,876	8%	6%
PD	813	$4,906	1,092	$4,584	34%	–7%
ID	12,646	$40,645	12,184	$39,552	–4%	–3%

Source: Iowa Medicaid encounter data; Ross, J., K. Liao, and A. Wysocki. "Medicaid Section 1915(c) Waiver Programs Annual Expenditures and Beneficiaries Report: Analysis of CMS 372 Annual Reports, 2017–2018." Chicago, IL: Mathematica, 2021.

Note: This table shows waiver counts and annualized spending for Iowa's 1915(c) waiver programs from two data sources: the Medicaid encounter data Iowa provided to Mathematica and 372 reports sent by Iowa to CMS. The last two columns report the percentage difference in member counts and HCBS spending, respectively, across data sources.

B. Analysis of Medicaid waiver waiting list data

In addition to the Medicaid encounter data analysis, we conducted an analysis of HCBS waiver waiting lists using three additional types of waiting list data. First, we analyzed aggregate waiver-specific waiting list counts from the monthly updated, publicly available Monthly Slot and Waiting List Summary posted on the HHS website. This source provided current waiting list counts, and archived versions allowed us to measure historical waiting list counts going back to January 2018. Second, HHS provided two sets of files related to waiver waiting lists. This were two individual-level data extracts for people on the waiver waiting lists on April 25, 2022, and June 28, 2022, respectively. The data elements included an identifier, type of waiver, date of waiting list entry, date of birth, and county. The data files also contained emergent and urgent needs assessment scores for individuals on the BI and ID waiver waiting lists. The identifiers in the waiting list data files were not sufficient to link the records to Medicaid encounter data. We used the available data to document the extent to which people were on multiple waivers and had emergent and urgent needs, as well as waiting list churn.

HHS also provided a waiver slot data file with information about why HCBS waiver slots offered between 2019 and 2021 were declined. The data file contains an identifier, type of waiver, date the slot was offered, and the reason it was not assigned. We received and analyzed the waiver slot data in Microsoft Excel.

C. Analysis of waiver assessment data

We requested assessment data from 2019 for adult waiver participants from two MCOs, Iowa Total Care and Amerigroup, who were in operation during our evaluation analysis period and still in operation to

date. These assessments included the interRAI-HC for adult members on the HIV, BI, HD, PD, and EL waivers and the SIS-A for adult members on the ID waiver. We excluded the relatively few Medicaid members in fee-for-service during this period, for purposes of linking to the encounter data used elsewhere in this report.

Each MCO provided the assessment data they had available from 2019. After linking to encounter data, we determined that we received assessment data for about one-half to two-thirds of participants on the BI, EL, HD and PD waivers, and approximately 5 percent of those on the ID waiver. There are a few reasons that assessment data were not available for a share of waiver participants in that year. The primary reason is that in 2019, United Healthcare was the MCO serving a majority of HCBS members in Iowa in the first half of the year. We do not have assessment data for any members whose assessments were completed by that MCO in the first six months of the year. Additionally, the SIS-A is administered on a three-year cycle and Iowa assessed most members in 2017 for purposes of implementing tiered rates in the ID waiver. Thus, relatively few members were due their next SIS-A assessment in 2019.

Table B.4 compares a few characteristics of members for whom we received assessment data relative to members for whom we did not. Based on these comparisons, we believe that the analysis based on available assessment data may be reasonably reflective of the experience of all waiver participants. Note that because of the relatively few members in the HIV waiver, we did not include that waiver in our analysis to avoid releasing identifiable information for small groups. Among members assessed using the interRAI-HC, we found that based on sex, members with assessments were quite similar to members without assessment data available. The mean age was also similar by assessment status in the EL and PD waivers. Yet for the BI and HD waivers, we found a 8.2 and 12.4-year difference between groups, respectively. Despite those demographic differences, we found that total provider payments and HCBS payments were similar by assessment status in most waivers. One notable exception was the HD waiver, where those with assessments had total PMPM payments that were $460 lower and HCBS PMPM payments that were $152 lower than those without assessments. Despite relatively fewer assessments completed in 2019 for ID waiver participants, we found that participants with and without SIS-A assessments looked quite similar on the measures we included.

Even for those with an assessment completed in 2019, not all participants had complete data on all of the individual activity measures we considered. Tables B.5 and B.6 show detailed information on some cognition-based measures of need as well as IADLs and ADLs requiring significant assistance, as contained in the interRAI-HC assessments (aggregated versions of this information are used in Figure VI.3).[35] In these tables, we limit our analysis to participants for whom information was available on all of the relevant measures (e.g., IADL percentages are limited to the waiver participants with data on all five IADLs).

To create a summary measure of need, we generated a count of the number of IADL capacity-based limitations (from 0 to 5) and the number of ADL performance-based limitations (from 0 to 11, for 10 ADLs and an additional measure of medication management). We also considered a version of these counts for all participants with an assessment (not shown); the distribution of total number of activities

[35] The data we received from the MCOs contained two different IADL measures—capacity to complete an activity and performance of a particular activity. Far fewer respondents had performance-based measures available, and the assessment tool we received suggested that capacity-based measures were part of the standard form. As such, we report on capacity to complete IADLs, whereas ADL measures are performance-based (consistent with the assessment tool). In general, we saw that in most cases, performance to complete an activity was generally at the same level or a lower level of independence than captured by the capacity-based measure.

requiring significant assistance seemed relatively close to the ones shown. Thus, our hypothesis is that missing data elements indicate that the individual did not require supports on that particular measure, prompting the person completing the assessment to leave that element blank.

We then sought to connect significance of need to provider payments, using summary measures for the number of activities requiring significant assistance. In Tables B.7 and B.8, we used those summary measures and then linked to the encounter data to calculate total and HCBS PMPM payments from 2019 (aggregate measures of this information are used in Figure VI.4). To be consistent with Tables B.5 and B.6, we limited this analysis to participants with complete information on the IADL and ADL measures. We found similar PMPM payment patterns within and across waivers when we included all participants with an assessment. In that case, though, we implicitly assumed that no information about a given ADL or IADL was equivalent to not having a significant assistance need. Because we could not verify that was the case, we prefer the version presented below.

Table B.4. Comparison of characteristics of adult waiver participants with and without an assessment in 2019

	BI	EL	HD	PD	ID
Total number of adult waiver participants in 2019	1,538	9,550	2,540	1,283	10,250
Received 2019 assessment					
Number of members	782	4,887	1,238	770	482
Mean age (years)	38.4	77.4	34.9	54.0	39.4
Male (%)	62.1	28.0	54.2	35.3	54.6
Mean total provider payments (PMPM, $)	3,587	1,087	2,424	1,616	4,825
Mean HCBS provider payments (PMPM, $)	2,101	640	872	416	4,393
Did not receive 2019 assessment					
Number of members	756	4,663	1,302	513	9,768
Mean age (years)	30.2	78.2	22.5	52.9	39.4
Male (%)	60.0	62.1	59.1	36.2	56.8
Mean total provider payments (PMPM, $)	3,409	1,013	2,884	1,443	4,888
Mean HCBS provider payments (PMPM, $)	2,042	581	1,030	464	4,521

Source: Assessment data on waiver participants in 2019 provided by Iowa Total Care and Amerigroup in August 2022.

Note: The BI, EL, HD, and PD waivers use the interRAI-HC; the ID waiver uses the SIS-A. The ID waiver statistics exclude participants who were younger than age 18 on December 31, 2019 (the ID waiver serves people younger than age 18, but we only received SIS-A assessments for people ages 18 and older). Provider payment amounts were measured in 2019.

Table B.5. Cognitive tasks and IADLs requiring significant assistance in 2019, by waiver

	BI	EL	HD	PD
Cognition and memory				
Problems with short-term, procedural or situational memory	76%	61%	44%	57%
Number of participants with complete data	613	4,758	835	739
Disordered thinking or awareness	85%	62%	70%	72%
Number of participants with complete data	774	4,830	1,226	763
Declining thinking/awareness, mental status, or decision making	14%	12%	10%	14%
Number of participants with complete data	564	4,807	752	757
IADLs (capacity to complete)[a]				
Number of participants with complete IADL assessment data	561	4,794	729	742
IADLs requiring significant assistance				
Meal preparation	75%	79%	81%	79%
Ordinary housework	84%	95%	93%	96%
Stairs	49%	62%	60%	61%
Shopping	81%	82%	84%	82%
Transportation	72%	66%	66%	65%
Number of IADLs requiring significant assistance				
0	5%	2%	2%	1%
1	6%	5%	4%	5%
2	11%	9%	9%	9%
3	16%	16%	16%	17%
4	28%	29%	30%	33%
5	35%	39%	38%	36%

Source: 2019 InterRAI-HC assessment data from two managed care organizations; Iowa Medicaid encounter data.

Note: The statistics exclude observations with any missing assessment data of that type.

[a] Each of the individual IADL measures and the summary score in this table is limited to participants for whom complete IADL information (on all five measures) was available, as shown in the table.

Table B.6. ADLs and medication management requiring significant assistance in 2019, by waiver

	BI	EL	HD	PD
Number of participants with complete medication and ADL assessment data[a]	358	3,217	538	530
Medication management requires significant assistance	53%	39%	32%	32%
ADLs requiring significant assistance				
Bathing/bath transfer	38%	46%	53%	49%
Personal hygiene	26%	17%	31%	20%
Dressing upper body	24%	15%	29%	15%
Dressing lower body	30%	22%	41%	25%
Walking	8%	5%	9%	5%
Locomotion	9%	5%	9%	5%
Transfer toilet	17%	6%	20%	8%
Toilet use	19%	7%	24%	10%
Bed mobility	15%	5%	24%	9%
Eating	6%	2%	10%	3%
Number of ADLs or medication management requiring significant assistance				
0	34%	37%	32%	34%
1	27%	26%	20%	25%
2	5%	15%	9%	14%
3	6%	7%	7%	9%
4	2%	5%	5%	5%
5	5%	4%	5%	4%
6	4%	2%	5%	3%
7	4%	2%	4%	2%
8	4%	1%	5%	0%
9	3%	1%	5%	2%
10	3%	1%	2%	1%
11	1%	0%	1%	0%

Source: 2019 InterRAI-HC assessment data from two managed care organizations; Iowa Medicaid encounter data.

Note: The statistics exclude observations with any missing assessment data of that type. We added medication management to the count of ADLs because proper medication management is critical to basic self-care.

[a] Each of the individual IADL measures and the summary score in this table is limited to participants for whom complete IADL information (on all five measures) was available, as shown in the table.

Table B.7. Mean total PMPM provider payments and cognitive, IADL, and ADL support needs in 2019, by waiver

	BI	EL	HD	PD
Number of participants with complete IADL assessment data	561	4,794	729	742
Number of IADLs requiring significant assistance (capacity measure)				
0	$1,966	$745	$1,436	$914
1	$4,054	$826	$864	$1,414
2	$3,601	$1,002	$1,130	$1,367
3	$3,649	$1,015	$1,437	$1,755
4	$3,252	$1,081	$1,838	$1,361
5	$3,552	$1,137	$1,777	$1,812
Number of participants with complete medication and ADL assessment data	358	3,217	538	530
Number of ADLs or medication management requiring significant assistance				
0	$2,136	$826	$1,027	$1,440
1	$4,723	$1,117	$1,342	$1,391
2	$4,953	$1,241	$1,256	$1,826
3	$4,532	$1,246	$1,707	$1,819
4	$2,882	$1,329	$2,100	$2,047
5	$3,225	$1,300	$1,789	$1,484
6	$3,605	$1,303	$2,456	$1,948
7	$3,074	$1,146	$2,425	$2,201
8	$4,836	$1,509	$3,292	$5,392
9	$4,868	$1,478	$5,093	$2,859
10	$3,345	$1,505	$3,746	$1,337
11	$5,041	$1,509	$2,614	$3,719

Source: InterRAI-HC assessment data from two managed care organizations; Iowa Medicaid encounter data

Note: Provider payments were measured in 2019. The table is limited to participants for whom complete IADL information (for the IADL panel) or complete ADL information (for the ADL panel) was available, as shown in Tables B.5 and B.6, respectively. We added medication management to the count of ADLs because proper medication management is critical to basic self-care.

Table B.8. Mean HCBS PMPM provider payments and cognitive, IADL, and ADL support needs in 2019, by waiver

	BI	EL	HD	PD
Number of participants with complete IADL assessment data	561	4,794	729	742
Number of IADLs requiring significant assistance (capacity measure)				
0	$818	$402	$489	$115
1	$2,562	$434	$400	$330
2	$2,468	$519	$540	$282
3	$2,382	$558	$682	$352
4	$2,354	$631	$855	$410
5	$2,641	$693	$1,055	$425
Number of participants with complete medication and ADL assessment data	358	3,217	538	530
Number of ADLs or medication management requiring significant assistance				
0	$1,293	$451	$582	$325
1	$2,791	$627	$566	$391
2	$3,001	$696	$641	$444
3	$2,896	$697	$633	$493
4	$1,377	$765	$818	$500
5	$2,458	$845	$1,125	$564
6	$2,877	$907	$1,325	$726
7	$1,930	$888	$1,131	$589
8	$4,124	$937	$1,811	$1,408
9	$4,093	$882	$3,314	$509
10	$2,557	$1,189	$1,689	$124
11	$4,524	$1,156	$1,907	$438

Source: InterRAI-HC assessment data from two managed care organizations; Iowa Medicaid encounter data

Note: Provider payments were measured in 2019. The table is limited to participants for whom complete IADL information (for the IADL panel) or complete ADL information (for the ADL panel) was available, as shown in Tables B.5 and B.6, respectively. We added medication management to the count of ADLs because proper medication management is critical to basic self-care.

Table B.9. Mean PMPM provider payments by SIS-A Support Needs Index score in 2019

	N	Total payments	HCBS payments
Total	471	$4,860	$4,444
Less than 90	90	$2,119	$1,865
90-101	167	$4,187	$3,782
102-115	191	$6,635	$6,172
116-123	19	$6,128	$5,413
124-131	3	$3,189	$2,177
Greater than 131	1	$5,607	$5,422

Source: SIS-A assessment data from two managed care organizations; Iowa Medicaid encounter data

Note: Provider payments were measured in 2019. We omitted 11 people with a SIS-A assessment from this table because their payment information was not available or they were not enrolled in the ID waiver in 2019.

D. Linking MHDS and Medicaid data to understand CBS provision in Iowa

Using data provided from two MHDS regions we compared MHDS enrollment and spending to similar information in the Medicaid enrollment records. To facilitate this analysis, we linked together data from two different sources: MHDS administrative data and Medicaid enrollment information.

To conduct this analysis, we used personal identifying information provided by the regions including first name, last name, and date of birth to link to Medicaid enrollment records. The Medicaid records also included Medicaid IDs that we were able to compare to the self-reported information that the regions had collected from their participants. After matching on other characteristics, we were able to use the Medicaid records to verify the accuracy of the self-reported Medicaid IDs. We received data from both MHDS regions that covered enrollment. Region A also provided some application dates and expenditure amounts and categories from January 2019 through October 2022. Unfortunately, our data request to the regions did not permit a complete concurrent comparison in both MHDS and Medicaid, given that our request to HHS was for Medicaid waiver enrollment information for participants interacting with those programs in 2018 and 2019. Our Medicaid waiver waiting list enrollment data was from a point in time dataset provided by HHS in 2022.

Appendix C. Summary of Community Engagement Activities

Understanding the lived experiences of staff who offer services and people who use services that support community living is critical to understanding current program operations and assessing opportunities for improvement. We sought to obtain the perspectives of a range of invested Iowans through conversations with consumers, family members and caregivers, frontline staff, and staff from advocacy and service organizations.

We pursued three sets of data collection activities for this task: listening sessions across the state and virtually, an online feedback form to solicit opinions and perspectives, and interviews with consumers and family members. We obtained approval from an institutional review board (Health Media Lab) for all activities.

A. Listening sessions

Approach. We conducted 90-minute listening sessions with consumers, parents and family members of consumers, and providers to solicit information about successes and challenges in accessing CBS. To find participants, we conducted email outreach to providers and organizations across the state, asking them to recruit participants for specific sessions. In addition, The Harkin Institute and HHS advertised the sessions on websites and through social media. As an incentive, we offered a $25 gift card for attending a session. Potential participants called or emailed The Harkin Institute to sign up and were required to complete a written consent form. The goal was to enroll up to eight people for each session, with an expectation that around four to six people would attend.

Staff from The Harkin Institute conducted the listening sessions from July through November 2022 across the state, as well as in Des Moines and virtually (Table C.1). We conducted 39 sessions that included 143 participants, for an average of 3.7 participants per session. We recorded all sessions, and we included captioning along with American Sign Language interpreters.

Protocol. Staff followed a protocol to guide the conversations, with different protocols for (1) consumers, (2) parents and family members of consumers, and (3) provider staff. The protocols included questions on current service use; use of Medicaid and waiver services; challenges with using, accessing, or keeping services; experiences transitioning into and out of institutions; and broader concerns with CBS and solutions to those concerns.

Analysis. The data collected through the listening sessions informed the report in two ways. First, we compiled notes from each session to quickly identify themes and issues that emerged. This information allowed our team to keep abreast of what we learned from the sessions. Second, we conducted an analysis to identify common themes and issues, that is, those that emerged across the multiple sessions conducted with consumers, parents and family members, and providers, along with consumers from specific non-English-speaking populations (Tables C.2a–C.2d). We also identified quotes that reflected these common themes and issues to include in the report. Third, we asked participants during the sessions from September 16 through November 2022 to rank five broad CBS topic areas in order of importance, with 1 being most important and 5 being least important. This approach allowed us to get a sense of what areas they wanted to prioritize in CBS changes. The topic areas that emerged were:

- **Topic 1:** Community members need to be able to provide input into the CBS system design, and it's not clear how that system works

- **Topic 2:** The waiver system isn't based on people's needs
- **Topic 3:** It's hard to get the right services because the system is disorganized and doesn't support people and their family members
- **Topic 4:** There are not enough services
- **Topic 5:** People can't leave institutions when they're ready or avoid them when they want to

Table C.3 presents the results from this exercise, with responses shown for all participants and separately for (1) consumers and family members and (2) providers. Both groups ranked the topics similarly: most important was topic 3.

Table C.1. Listening sessions conducted from July through November 2022

Date	Location	Focus	Number of participants
Northeast Iowa (Cedar Rapids, Dubuque, Independence, Mason City, Waterloo)			
July 7	Waterloo	Consumers	1
July 8	Mason City	Providers	2
July 9	Cedar Rapids	Consumers	1
July 14	Virtual	Parents and family members of consumers	2
July 14	Des Moines	Providers	2
July 27	Waterloo	Providers and parents of consumers	6
July 28	Waterloo	Providers	6
July 28	Waterloo	Professional guardians	2
Northwest Iowa (Denison, Estherville, Fort Dodge, Rock Valley, Sioux City, Spencer, Storm Lake)			
August 4	Sioux City	Parents and family members of consumers	1
August 5	Rock Valley	Providers	2
August 5	Spencer	Providers and parents of consumers	4
August 5	Carroll	Providers	5
August 10	Virtual	Parents of consumers	1
August 10	Des Moines	Providers	2
Southeast Iowa (Burlington, Columbus Junction, Davenport, Fort Madison, Iowa City, Muscatine, Ottumwa)			
September 9	Virtual	Providers	5
September 13	Altoona	Providers and consumers	10
September 16	Burlington	Providers	1
September 16	Fort Madison	Providers	1
September 16	Muscatine	Providers	2
September 16	Columbus Junction	Spanish-speaking consumers	8
September 17	Ottumwa	Parents and family members of consumers	3
September 17	Des Moines	Providers and family members of consumers	3
September 26	Des Moines	Burmese consumers	7
September 28	Des Moines	Providers	4
September 29	Des Moines	Providers	5

Table C.1 (*continued*)

Date	Location	Focus	Number of participants
Southwest Iowa (Atlantic, Clarinda, Council Bluffs, Creston, Shenandoah)			
October 5	Virtual, Des Moines	Parents and family members of consumers	1
October 5	Virtual	Parents of consumers	3
October 17	Clear Lake	Providers	4
October 18	Cedar Rapids	Consumers	1
October 19	Burlington	Providers	7
October 19	Burlington	Providers	4
October 19	Des Moines	Providers	6
October 19	Des Moines	Providers	6
October 26	Council Bluffs	Providers	1
October 27	Atlantic	Consumers	2
November 2	Davenport	Providers	3
November 2	Davenport	Providers	11
November 7	Virtual	Family members of consumers	3
November 10	Creston	Family members of consumers	5

Table C.2a. Themes identified in listening sessions regarding service access, by respondent type

Group	Service access themes
Consumers	**Strengths** • None noted **Challenges** • People do not know about all of the available services • Difficulties include access to keeping a waiver and a lack of support in understanding Medicaid rules to keep eligibility • Access to CCO, as case managers are not knowledgeable about it • Hard to access services if experiencing homelessness • Time on waiting list without services is excessive
Parents and family members	**Strengths** • When case management is consistent, families have positive experiences with service connections • School and medical providers are good sources of service referrals **Challenges** • Families struggle to find staff to provide BHIS, respite, transportation, and other services • Some services are available, but difficult to use because of red tape • Transportation is a challenge in many parts of the state • People spend a lot of time on waiting lists before receiving services, and their conditions may regress • Assessments are not always accurate • Even after getting on a waiver, families don't know what services are available to them and how to access them, or who to contact when they have issues with services • CCO is a popular service, but families feel like they have to fight to get services, that case managers are not well-trained in CCO, and that case managers often try to talk families out of using it • Each MCO and different case managers within the same MCO interpret the Iowa code differently, thus making it difficult for families to access needed services • Most families get their information from other families, not through case managers • Case managers offer little follow-through, communication, or support • Families struggle to navigate the HHS website and would like electronic application forms for waivers, electronic communication, and document sharing
Providers	**Strengths** • Strong referral networks/partners with hospital and medical systems **Challenges** • MCOs are rigid in their policies around respite minutes, transportation, and other services • "Use it or lose it" rules incentivize wasting resources to maintain services • Payment rates are too low to cover all needed services • Lack of beds or other locations for high-needs diagnoses, especially for mental health and significant intellectual disabilities coupled with behavioral challenges. Providers would like to offer these services but cannot afford to because of low payment rates. • Reassessing individuals creates routine busy work • The process for accessing services is time consuming and involves a lot of red tape, which takes time away from providing needed services • More services are denied under the MCOs than were when services were managed by the state • The waiting list is too long • People who need services get no assistance in applying for them; although providers may fill that gap, they are not reimbursed for such activities • The process of securing services is slow because the request must go through several reviews before the authorization is approved • Rural communities don't have as many resources and services as larger communities have, especially for specialists • The SIS is not an accurate basis for funding

Table C.2a (*continued*)

Group	Service access themes
Communities whose first language is not English	**Strengths** • None noted **Challenges** • Families who do not speak English encounter language barriers with HHS phone calls, voice messages, and letters, and specific outreach attempts are ineffective and reflect a lack of awareness of the needs of language minority groups • Renewal forms for Medicaid, which are in English, are not always sent on time • If phone calls from HHS are not answered, community members encounter difficulties in returning the call because of the steps they must follow and the language barrier • Community members lack information about potential waiver services: of the 17 services listed on the handout, all participants in one listening session had heard of 6 services, at least one person had heard of 3 services, and no one had heard of the remaining 8 services • Community members lack information about services covered (such as how long the health plan issued during the pandemic will continue and for whom it will continue) and the costs associated with ambulances

Source: Listening sessions, July through November 2022.

Table C.2b. Themes identified in listening sessions regarding service quality

Group	Service quality themes
Consumers	**Strength** • Once CCO is set up, consumers see it as a strength **Challenges** • Systems need to use the same language to mean the same thing to make it more understandable • The systems are “too picky”: if a person says one thing wrong or uses the wrong word, they could get denied for services and must start over again • Consumers lack assistive technology and equipment • Transportation is a major challenge regarding availability, who qualifies, limited hours, and fixed routes
Parents and family members	**Strengths** • Families generally like CCO • Respite belongs in both a “strength” and “challenge” category: families like the service when it’s working, but often do not have enough providers in rural areas **Challenges** • Staff often present as unqualified or disinterested in the work • Families report often receiving misinformation and multiple messages from different staff in the same office • The system is very complex: families struggle to navigate it before giving up on some things completely • Families feel overburdened with documentation • CCO started with families helping to set up caregiver wages and hours, but when the MCOs came in, that approach changed; families are not told about the Upper Cap Rate, which can be used when the regular rate is not enough to secure staff to meet their needs • MCOs have misconstrued identifying the person’s natural supports as a way to better understand the person’s situation; rather, they use natural supports to limit service hours • There is confusion about whether parents, siblings, and guardians can get paid to provide services under CCO • Because of high caseloads and turnover, case managers do not get to know the person • Home and vehicle modification rules are too rigid

Table C.2b (*continued*)

<table>
<tr><th>Group</th><th>Service quality themes</th></tr>
<tr><td>Providers</td><td>Strength
Many providers feel that current HHS leadership is on their side and supportive
Challenges
Transportation options are limited in rural areas and represent major obstacles in both rural and urban communities; rates do not allow the agency to buy accessible vehicles, and public transportation is either nonexistent, unreliable, dangerous, or limited in hours and routes
Many frontline staff lack the training needed to be successful
Providers cannot compete with the higher wages at other jobs with less stress and risk
High ratios of individuals to staff in many settings hold individuals back from community engagement
Case managers need more training
Individuals with disabilities are being put in day habilitation rather than employment or other services
Different documentation requirements for MCOs, Fee for Service, and Iowa Vocational Rehabilitation Services create red tape and are difficult to manage
When the SIS assessment is not accurate (that is, it doesn’t reflect a person’s true needs), people have to be turned away from programs because they can’t be served at the lower-tier payment rate indicated by the inaccurate score
Providers are not paid what it costs to provide a service and no longer can show the actual cost from which to negotiate with the MCOs
Finding adequate staff to provide services is a major issue
Redundant documentation (being asked for the same documentation multiple times) is a problem
The bureaucracy gets in the way of creativity and out-of-the-box thinking, thereby creating rigidity in services and a lack of individualized, person-centered services
Funding for employment services through the waivers are tied to utilization, not outcomes
People are opting to attend day habilitation services because they have no other options during the day (such as employment and individualized services)
Juvenile court offices report that HHS used to be more collaborative, and they could get a Child in Need of Assistance determination document or otherwise protect a child and provide services to the family; now, however, they perceive that HHS is no longer a partner in this process
Integrated Health Homes are not understood and seem to be another level of bureaucracy</td></tr>
<tr><td>Communities whose first language is not English</td><td>Strength
Medicaid works well for hospital and clinic visits: people believe they are healthier because they go to the doctor when they are sick, and the cost would prohibit them from going if they did not have Medicaid
Challenge
Not feeling comfortable talking with Medicaid staff</td></tr>
</table>

Source: Listening sessions, July through November 2022.

Table C.2c. Themes identified in listening sessions regarding transitions

Group	Transition themes
Consumers	**Strengths** • None noted **Challenges** • Leaving institutions involves a lot of red tape, and that process can take a long time • Consumers encounter a lack of communication regarding the process of leaving correctional institutions
Parents and family members	**Strengths** • Families appreciate MFP • Families generally feel that there is a (positive) gradual transition to the community from an institution that helps make the process manageable **Challenges** • Families are extremely frustrated when their family member is discharged because they are not making sufficient progress while in the institution • Families have a general frustration about the lack of transparency and communication while their loved one is in institutional care and sometimes during the transition process • Case managers focus too much on paperwork rather than on helping • Case managers are not involved or supportive of moves from the institutions, with families and guardians even being told to “leave it alone,” meaning do not pursue trying to get your loved one out • Family members feel they are the ones looking for community placements, not the case managers • The waiting list makes families use institutions, as there are no services they can access in the community
Providers	**Strengths** • Providers almost universally name MFP as a strength **Challenges** • Community providers do not get the full picture of a person from institution staff; instead, they receive only part of the story just to move residents into the community, resulting in inappropriate placements • Institution staff need education about community options for their residents when preparing for discharge • Community-based staff need training to work with people leaving institutions • People could leave institutions sooner if they had better case managers and the agency had the funds to hire and train staff
Communities whose first language is not English	None of the participants had experience with transitions from an institution

Source: Listening sessions, July through November 2022.

Table C.2d. Themes identified in listening sessions regarding offered recommendations

Group	Recommendations
Consumers	• Although consumers did not offer any specific solutions, they wanted changes to the implementation of the waiting list and to funding • Direct support staff should be paid more • Focus on keeping people healthy, such as eating right • Services should be easier to get • The services that are available should be publicized more, as people don't know what is available
Parents and family members	• Offer more education around CCO • Redesign waiver services to be based on needs, not diagnoses • Increase transportation support and reimbursement for families that have to travel farther or more frequently due to the significance of the disability • Give parents more control and pay them to provide services themselves • Consider including more services (chore services such as laundry service, cleaning service, and meal service) under respite • Create a shared portal where all specialists can access information about a person • Staff should be paid more and trained better so they will stay in the field and provide quality services • Establish a standard place where families can get correct, consistent information • Move case management from MCOs to another provider to reduce the conflict of interest and increase transparency
Providers	• Reassess the respite process • Pay families to provide care in home • Unify, or at least align, system documentation so that providers are not reporting the same information to multiple offices in different formats • Inform people of their existing options • Adjust assessment timelines so that individuals with static, significant conditions do not need to prove they have significant disabilities • Incentivize local transportation options or invest in local and regional transportation support • Consider various sources of information in assessments • Make training for MCOs, HHS, providers, and case managers consistent • Use data to make decisions • Increase the wages and benefits of community-based staff to be comparable to state institution staff • Create a local or regional information hub to serve as a centralized source of information and resources • All MCOs should have the same processes and operate similarly • The state plan habilitation program is not meeting service needs
Communities whose first language is not English	• Include coverage for dental care • HHS should hire staff who are more courteous and treat people the same, and who speak Spanish and other languages—using an interpreter is not the same as having a staff person who speaks the language • Small towns should have medical offices set up for x-rays and laboratories so that individuals living in small towns would not have to travel so far • Provide information in videos using other spoken languages and American Sign Language

Source: Listening sessions, July through November 2022.

Table C.3. Rankings of CBS topics by listening session participants

Group	Number of responses	Topic 1: Community input	Topic 2: Waiver system	Topic 3: Hard to get the right services	Topic 4: Not enough services	Topic 5: Institutions
Consumers and family members	25	2.84	2.92	1.96	2.84	4.32
Providers	44	3.41	3.25	1.73	2.45	4.14
All participants	69	3.20	3.13	1.81	2.59	4.20

Note: Participants ranked each topic from 1 (most important) to 5 (least important).

Source: Listening sessions, September 16 through November 2022.

Limitations. The data collected from the listening sessions are not representative of the general population of people using services, parents and family members, or providers. Those who signed up to participate might be those who are particularly active or concerned about CBS, and our outreach efforts may have missed people who do not use services, who do not use the providers we included in our analysis, or who do not have ready access to the internet or social media.

We found it challenging to secure participation from consumers in the listening sessions, and offer some additional context, lessons learned, and potential strategies to address the challenges we encountered. We recruited participants for these sessions by sending emails to service providers, advocacy groups, and stakeholder organizations. We also shared the informational/registration flyer broadly. We shared schedules and registration information across The Harkin Institute's social media platforms and reshared when other organizations and providers posted about the listening sessions on their social media. When participants registered, they received a welcome email with more information.

As the sessions continued, we found that working with service providers to recruit consumer participants yielded better results. As we host community engagement activities in 2023, we will consider different recruitment strategies to collect feedback from consumers. One challenge with the listening sessions was that, to protect confidentiality, the location of each session could be shared only after a participant registered. We received feedback that potential participants could not confidently register for sessions without knowing the location. Providers also shared that many participants found the process of emailing or calling The Harkin Institute to register confusing.

We found that in many parts of the state, people sent a representative to our session to learn more about it and report back to peers, who later decided they would like to participate, but often after we had concluded sessions in their area. We had more success when we worked with a trusted third party—such as a provider or advocacy group—to set up sessions for consumers. We had a very high turnout by holding sessions at the "Make Your Mark!" and the Iowa Association of People Supporting Employment First conferences.

Moving forward, in addition to improving the registration process, we will also work with contacts at local service providers and statewide organizations such as Iowa's Association of People Supporting Employment First, the Iowa Association of Community Providers, the Developmental Disabilities Council, and Iowa's ASK (Access for Special Kids) Resource Center. Likewise, rather than scheduling standalone events, we will identify more innovative strategies to meet participants in their locations to make participating more comfortable and convenient.

B. Online feedback form

Approach. We created an online feedback form to understand the experiences of a wider group of Iowans than those able to attend a scheduled 90-minute listening session. The Harkin Institute and HHS conducted outreach to Iowans to encourage them to visit the website and complete the form. HHS included a link to the form on its web page dedicated to the evaluation. All respondents were anonymous unless participants chose to identify themselves. We shared the online feedback form using the QuestionPro platform from July 5 through August 31, 2022, and obtained 379 complete responses (which we defined as any record with responses after the first question).[36] Respondents had the following characteristics:

- **Location:** Thirty percent reported living in an urban area, 24 percent reported living in a suburban area, 29 percent reported living in a rural area, and 17 percent did not respond to the location question. We received responses from people residing in 68 of Iowa's 99 counties.
- **Gender:** Sixty-two percent identified as female, 15 percent identified as male, and 24 percent provided either another response or no response.
- **Race and ethnicity:** Sixty-nine percent reported being white non-Hispanic, 7 percent another race or Hispanic, and 25 percent did not provide a response.
- **Age:** Six percent of respondents were ages 65 or older, 41 percent were ages 40 to 64, 31 percent were ages 18 to 39, and 21 percent did not report their age.
- **Disability:** Seventeen percent of respondents identified as having a disability.
- **Type:** We received responses from 142 providers, 40 members (people enrolled in Medicaid), 61 consumers, and 157 caregivers. People could report more than one category.

Protocol. The online feedback form had six questions, which were a mix of open-ended and closed questions:

1. What are the greatest strengths of Iowa's CBS for people with behavioral health, disability, and aging needs and their families?
2. What else should we know about the strengths of CBS in Iowa?
3. What are the greatest challenges for people with behavioral health, disability, and aging needs and their families in accessing CBS that helps them live, work, and enjoy themselves in the community?
4. What else should we know about the challenges of CBS in Iowa?
5. If you could change one thing about Iowa's CBS related to behavioral health, disability, and aging, what would it be?
6. What else would you like to tell us about your experience with CBS in Iowa?

In addition, we asked about various demographic and background characteristics and whether they would be interested in talking about their experiences further.

Analysis. We used two types of analyses for the data collected through the online feedback form. First, we coded responses to open-ended questions into broad categories of themes. Second, we calculated

[36] We excluded 274 records that had no responses or were either duplicates, responded only to the first question, or whose qualitative responses did not correspond to the question (such as random letters or information about Iowa's economy).

descriptive statistics (means, percentages, and counts) to describe responses. We further examined these descriptive statistics by respondent type to observe differences across perspectives. Figures C.1. and C.2 present information from all respondents regarding their responses to the strengths and challenges, respectively, of Iowa's CBS. Tables C.4–C6 provide a count of the responses to three of the open-ended questions as coded into broad categories. We present this information for all responses and separately for consumers, parents and family members of consumers, and providers.

Limitations. The limitations to the analyses using data from the online feedback form are similar to those of the listening sessions. First, the data are not representative of all Iowans and reflect only the people who responded to the invitation to provide their feedback on CBS. Second, the overall statistics predominantly reflect the perspectives of providers and parents or family members of consumers rather than the perspectives of consumers.

C. Individual interviews

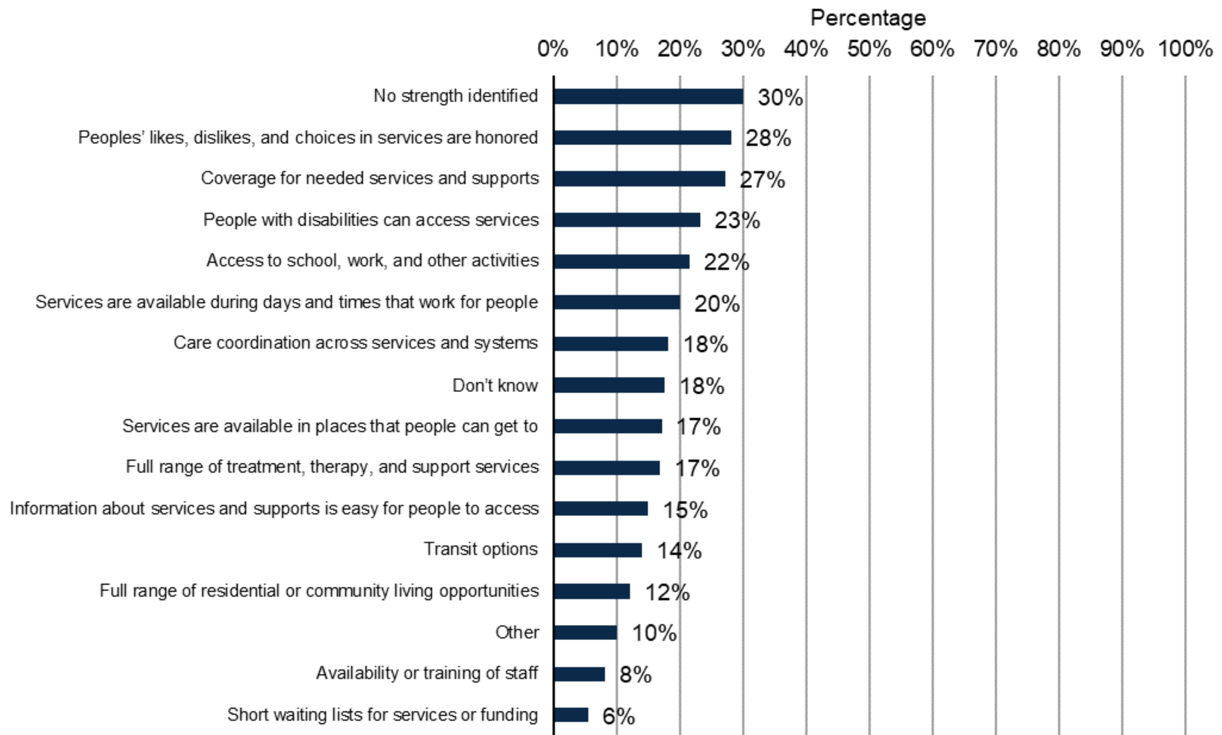
Approach. Our third community engagement activity involved 30- to 60-minute semi-structured interviews held in September 2022 with 11 consumers and parents to obtain an in-depth understanding of their experiences using CBS. We conducted interviews for two reasons: (1) to fill gaps in our knowledge about specific experiences with waivers and transitions between institutional care and HCBS; and (2) to obtain more detailed information from consumers, because we received fewer responses than expected from the listening sessions and online feedback form. We drew a sample of 16 people from the online feedback form who indicated that they were interested in being contacted for further information, provided their contact information, and noted in their responses specific service use, waiver use, and institutional care. All participants provided written consent before the interview and received a $25 gift card for their participation.

Protocol. The protocol included questions within three domains. The first domain included questions on service use, such as whether they found the service useful and whether they encountered difficulties with services, unmet needs, and unpaid help from family and friends. The second domain asked about experiences with learning about, applying for, and using waivers. The third domain addressed issues about entering institutional care (such as learning about this form of care, admission processes, and what this level of care involved) and transitioning from an institution to the community (such as why they left and their access to CBS after leaving).

Analysis. We used the information gained through the interviews to develop vignettes describing peoples' experiences with CBS (particularly with waivers) and institutions and to identify quotes to illustrate and support findings in the report.

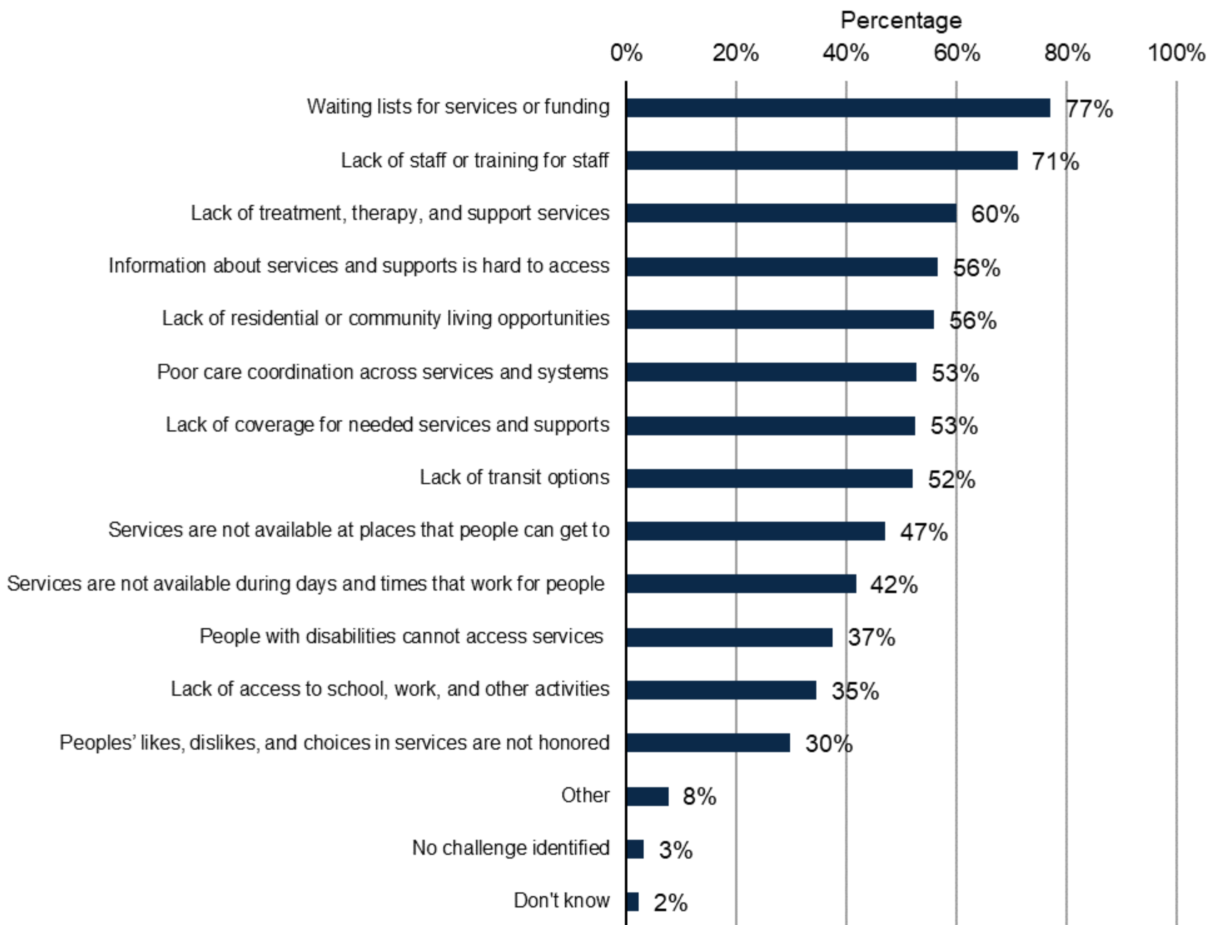
Limitations. Although the interviews provided a unique, in-depth understanding of respondents' use of services, waivers, and institutions, the information reflects only the experiences of sample members, not the experiences of all Iowans.

Figure C.1. Strengths of Iowa's CBS system, as reported by Iowans



Source: Online feedback form, July and August 2022. N = 379 respondents.

Figure C.2. Challenges of Iowa's CBS system, as reported by Iowans



Source: Online feedback form, July and August 2022. N = 379 respondents.

Table C.4. Categories of responses to the question, "What else should we know about the strengths of these CBS in Iowa?"

Response category	Consumers	Family members and caregivers	Service providers	All responses
Total respondents	**61**	**157**	**142**	**379**
Respondents who answered the question	**41**	**102**	**75**	**223**
Respondent stated that the system has no strengths	17	33	33	78
Response did not fit into a category or was not applicable to the question	6	21	10	43
Some waiting lists/services/providers/regions work better than others	5	23	10	43
Compassionate, resourceful staff and providers	4	11	13	28
Services support community integration	5	10	7	21
Service and program information is accessible	3	1	1	5
Schools offer key support	0	2	0	3

Source: Online feedback form, July and August 2022.

Note: Responses to the question were coded into the categories listed.

Table C.5. Categories of responses to the question, "What else should we know about the challenges of these CBS in Iowa?"

Response category	Consumers	Family members and caregivers	Service providers	All responses
Total respondents	**61**	**157**	**142**	**379**
Respondents who answered the question	**35**	**114**	**84**	**243**
Cumbersome application/complex and fragmented system to navigate	12	36	16	61
Response did not fit into a category or was not applicable to the question	8	24	7	45
Wait times to access waiver services	10	15	17	43
Few available providers, low provider reimbursement rates	4	11	20	39
Staffing shortages, low wages	5	10	16	34
Rural areas lack services, resources, transportation, and qualified staff	1	16	16	29
Insufficient crisis services and inadequate provider training to address complex needs	1	7	13	28
Lack of oversight and accountability for managed care	3	13	8	21
Lack of transportation services	6	4	11	19
Lack of safety net services, family caregivers must fill gaps	0	7	3	10
Insufficient care coordination across services	0	4	1	5
Not enough training for staff or specialized staff	1	2	0	5
Some waiting lists/services/providers/regions work better than others	0	1	1	3
Insufficient funding for services/staff/providers	0	1	1	1

Source: Online feedback form, July and August 2022.

Note: Responses to the question were coded into the categories listed. Responses could have more than one category.

Table C.6. Categories of responses to the question, "If you could change one thing about Iowa's CBS related to behavioral health, disability, and aging, what would it be?"

Response category	Consumers	Family members and caregivers	Service providers	All responses
Total respondents	**61**	**157**	**142**	**379**
Respondents who answered the question	**47**	**138**	**114**	**287**
Decrease wait times to access waiver services	2	18	18	44
Increase the number of providers or the provider reimbursement rates	3	19	27	42
Address the staffing shortages or increase staff wages	5	20	15	40
Response did not fit into a category or was not applicable to the question	7	19	3	31
Standardize across waiting lists, services, providers, or regions	7	13	13	30
Increase accountability in managed care and ensure case managers are knowledgeable and responsive	1	12	7	21
Increase funding for services/staff/providers	2	11	15	19
Improve crisis services and provider training to address complex needs	1	7	10	17
Increase training for staff or specialized staff	3	6	4	14
Improve care coordination between services	2	6	6	12
Implement more services to support community integration	2	6	2	9
Offer better transportation services	2	3	5	8
Improve rural areas' access to services, resources, transportation, and qualified staff	0	6	4	8
Make service and program information more accessible	2	3	2	7
Strengthen safety net services so that family caregivers do not have to fill gaps	0	2	3	6
Ensure that staff and providers are compassionate and resourceful	4	3	0	5

Source: Online feedback form, July and August 2022.

Note: Responses to the question were coded into the categories listed. Responses could have more than one category.

Appendix D. Community Advisory Committee

A critical guide to our work was input from members of a Community Advisory Committee, who provided consistent expertise related to living in Iowa with a disability or behavioral health need or as an aging adult. This committee was composed of individuals from across the state, reflecting a range of perspectives and experiences with the CBS system.

A. Process for soliciting initial members

We sought an advisory committee with lived experience engaging with Iowa's Medicaid; MHDS; and the delivery system for community-based behavioral health, disability, and aging services, or some combination thereof. To the extent possible, we solicited geographic diversity in panelists, though it was not possible to canvass the entire state's experience. The final committee comprised five members with children who utilize services, five members who utilize services themselves, and five members who either advocate for or work within the HCBS system (see Box D1 for their names). Of the members who utilize services themselves, committee members had lived experience accessing services using the HD, EL, and PD waivers. Two members were also on a waiting list for a waiver during their time on the committee. Of the members who either advocate for or work within the HCBS system, one is a member of an advocacy group, two members have MCO case management experience, one member works for a MHDS region, and one member works with CCO supports.

Box D1. Advisory committee members

- Darci Alt
- Christofer Burrows
- Kyla Claussen
- Becky Coffin
- Matt Conaway
- Garret Frey
- Elaine Gartelos
- Shelley Jaspering
- Kay Marcel
- Leah Price
- Janet Smith
- Bill Stumpf
- Alex Watters
- Ruth Wilson
- Nicole Woodley

Note: Committee members granted their permission to share their full names to acknowledge their valuable contributions.

B. Meeting facilitation and logistics

We scheduled six advisory committee meetings during the systemwide evaluation. We convened the Community Advisory Committee for virtual 90-minute meetings in April, May, July, August, October, and November 2022. Although meeting content varied, the first part of each meeting generally involved an update on evaluation activities and progress made since the last meeting. During the second portion of each meeting, we solicited advisory committee member expertise and experience on topics that surfaced as part of the evaluation. A summary of meeting themes from each session was developed, shared with committee members and HHS, and made available upon request to Iowans. The evaluation team provided a $50 gift card or check after each meeting as a token of our appreciation for their time.

Appendix E. Supplementary Tables

Table E.1. Description of HCBS coverage availability in Iowa Medicaid's 1915(c) waivers and 1915(i) state plan option

Program (acronym used in this report)	Eligibility requirement	Slot cap	Reserved capacity slots	Waiting list
HIV/AIDS 1915(c) waiver (HIV)	Diagnosis of HIV/AIDS	37	n.a.	No
Brain Injury 1915(c) waiver (BI)	Brain injury diagnosis as set forth in rule 441—83.81(249A)	1,580	45	Yes
Children's Mental Health 1915(c) waiver (CMH)	Diagnosis of serious emotional disturbance (SED)	1,313	20	Yes
Elderly 1915(c) waiver (EL)	Age 65 or over	7,930	n.a.	No
Intellectual Disability 1915(c) waiver (ID)	Primary disability of intellectual disability determined by a psychologist or psychiatrist	13,172	422	Yes
Health and Disability 1915(c) waiver (HD)	Blind or disabled and Supplemental Security Income (SSI)–related coverage groups	2,950	0	Yes
Physical Disability (PD)	Physical disability as determined by Disability Determination Services	1,317	0	Yes
1915(i) Habilitation Services (HS)	Chronic mental illness	n.a.	n.a.	No

Source: Iowa HHS (2022). "Iowa Home- and Community-Based Services Provider Manual." Available at https://hhs.iowa.gov/sites/default/files/HCBS.pdf?072120221255. Accessed September 15, 2022.

n.a. = not applicable.

Table E.2. HCBS covered by Iowa's 1915(c) waivers, by waiver

	Service maximum	HIV	BI	CMH	EL	ID	HD	PD
Monthly spending cap		$1,943.43	None	$2,077.57*	None	None	NF: $993.56** SNF: $2,891.79** ICF/ID: $3,875.80**	$730.90**
Service								
Adult daycare	None	X	X		X	X	X	
Assistive devices	$119.72 per device				X			
Assisted living	None				X			
Behavioral programming			X					
Case management	None		X		X			
Chore	None				X			
Consumer Choices Option (CCO)	Monthly budget determined by MCO	X	X		X	X	X	X
Consumer Directed Attendant Care (CDAC)	Monthly budget determined by MCO	X	X		X	X	X	X
Counseling	None	X					X	
Day habilitation	None for member services; family training option limited to 10 hours per month					X		
Emergency response	12 months of service per fiscal year		X		X	X	X	X
Environmental modifications and adaptive devices	Up to $6,592.66 per year			X				
Family and community support	None			X				

Table E.2 (*continued*)

	Service maximum	HIV	BI	CMH	EL	ID	HD	PD
Family counseling and training	None		X					
Home-delivered meals	14 meals per week	X			X		X.	
Home health aide	Varies by waiver	X—no max			X—no max	X—14 hours per week	X—no max	
Homemaker	None	X			X		X	
Home/vehicle modifications	Varies by waiver		X—up to $6,592.66 per year		X—$1,098.78 lifetime benefit	X—$5,493.88 lifetime benefit	X—up to $6,592.66 per year	X—up to $6,592.66 per year
In-home family therapy	None			X				
Interim medical monitoring and treatment (IMMT)	12 hours per day		X			X	X	
Mental health outreach	None				X			
Nursing	Varies by waiver	X—no max			X—8 visits per month (intermediate level of care); No max for skilled level of cared	X—10 hours per week	X—no max	
Nutritional counseling	None				X		X	
Prevocational services	34 hours in 90 days for career exploration		X			X		
Respite: individualized, group, specialized	Varies by waiver	X—14 consecutive days of 24-hour respite***	X—limited to 72 continuous hours in facility setting	X—14 consecutive days of 24-hour respite***	X—14 consecutive days of 24-hour respite***	X—14 consecutive days of 24-hour respite	X—14 consecutive days of 24-hour respite***	
Senior companion	None				X			
Supported Community Living (SCL)	None		X			X		

Table E.2 (*continued*)

	Service maximum	HIV	BI	CMH	EL	ID	HD	PD
Specialized medical equipment	Up to $6,592.22 per year		X					X
Supported community living: Residential-based for children	None					X		
Supported employment (SE)	Tiered payment authorization based on group size and visits per month		X			X		
Transportation	None		X		X	X		X

* Excludes cost of environmental modification.

** Excludes costs of home and vehicle modifications.

*** Respite services provided to three or more individuals for a period exceeding 24 consecutive hours for individuals who require nursing care because of a mental or physical condition must be provided by a licensed health care facility, as described in the Iowa Code, chapter 135C.

Sources: HHS (May 2022). "Home- and Community-Based Services AIDS/HIV Waiver Information Packet." Available at https://hhs.iowa.gov/sites/default/files/Comm527.pdf?091420221515. Accessed September 15, 2022.

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HHS (May 2022). "Home- and Community-Based Services Intellectual Disability Waiver Information Packet." Available at https://hhs.iowa.gov/sites/default/files/Comm511.pdf?091420221433. Accessed September 15, 2022.

HHS (May 2022). "Home- and Community-Based Services Physical Disability Waiver Information Packet." Available at https://hhs.iowa.gov/sites/default/files/Comm528.pdf?091420221447. Accessed September 15, 2022.

HHS (July 2021). "Medical LTSS Program Comparison Chart." Available at https://hhs.iowa.gov/sites/default/files/LTSS_Program_Comparison_Chart.pdf?072620211457. Accessed September 15, 2022.

Table E.3. MHDS regions and counties within them

MHDS region	County
Care Connections Northern Iowa	Clay, Kossuth, Osceola, Palo Alto, Winnebago, Worth
Central Iowa Community Services	Boone, Cerro Gordo, Franklin, Greene, Hamilton, Hancock, Hardin, Jasper, Madison, Marshall, Poweshiek, Story, Warren, Webster, Wright
County Social Services	Allamakee, Black Hawk, Butler, Chickasaw, Clayton, Fayette, Floyd, Grundy, Howard, Mitchell, Tama, Winneshiek
Cross Mental Health Region	Clarke, Decatur, Lucas, Marion, Monroe, Ringgold, Wayne
Eastern Iowa MHDS	Cedar, Clinton, Jackson, Muscatine, Scott
Heart of Iowa Community Services	Audubon, Dallas, Guthrie
MHDS of the East Central Region	Benton, Bremer, Buchanan, Delaware, Dubuque, Iowa, Johnson, Jones, Linn
Polk County MHDS Region	Polk
Rolling Hills Community Services	Buena Vista, Calhoun, Carroll, Cherokee, Crawford, Humboldt, Ida, Pocahontas, Sac, Woodbury
Sioux River MHDS	Dickinson, Emmet, Lyon, O'Brien, Plymouth, Sioux
South Central Behavioral Health Region	Appanoose, Davis, Mahaska, Wapello
Southeast Iowa Link	Des Moines, Henry, Jefferson, Keokuk, Lee, Louisa, Van Buren, Washington
Southern Hills Regional Mental Health	Adair, Adams, Taylor, Union
Southwest Iowa MHDS Region	Cass, Fremont, Harrison, Mills, Monona, Montgomery, Page, Pottawattamie, Shelby

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