

Iowa Community-Based Services Evaluation

Findings About Iowans with Disability, Behavioral Health, and Aging Needs

January 2023

Contents

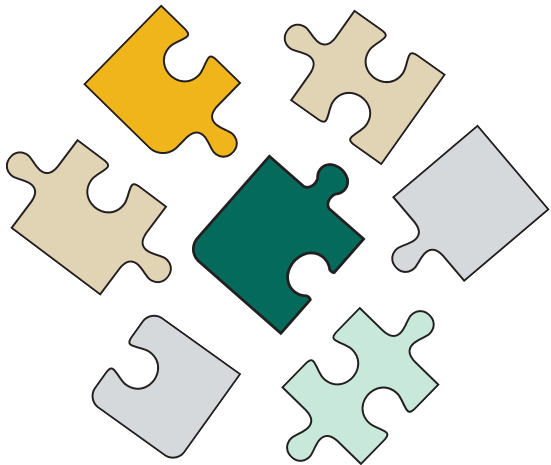
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I. Evaluation Takeaways

About the evaluation

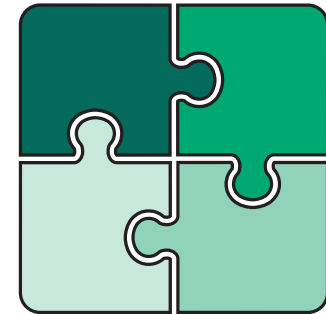
The community-based services (CBS) system is working more for some people than for others. This creates inefficiencies and inequities.



We evaluated the parts of the system to learn what works well and what does not.



We found that Iowa should align services with people's needs. This will help the system work better for everyone.



What did the evaluation show?



Iowa's Health and Human Services (HHS) process for managing Medicaid waiver waiting lists does not support timely, efficient, or needs-based access to appropriate services.

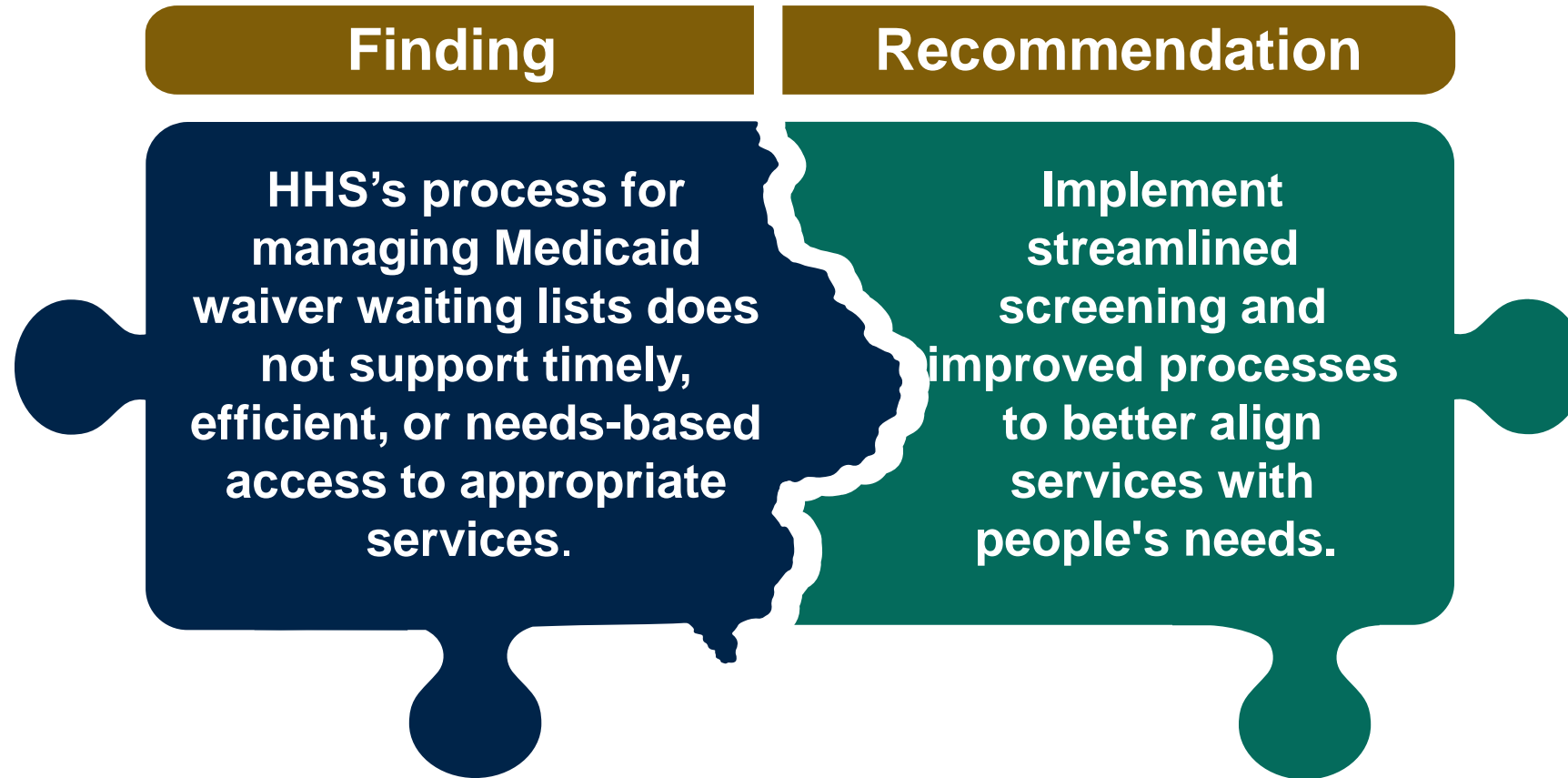


Services provided by Medicaid for home- and community-based services (HCBS) waivers often do not align with member needs, resulting in inequity and inefficiency in accessing needed services.

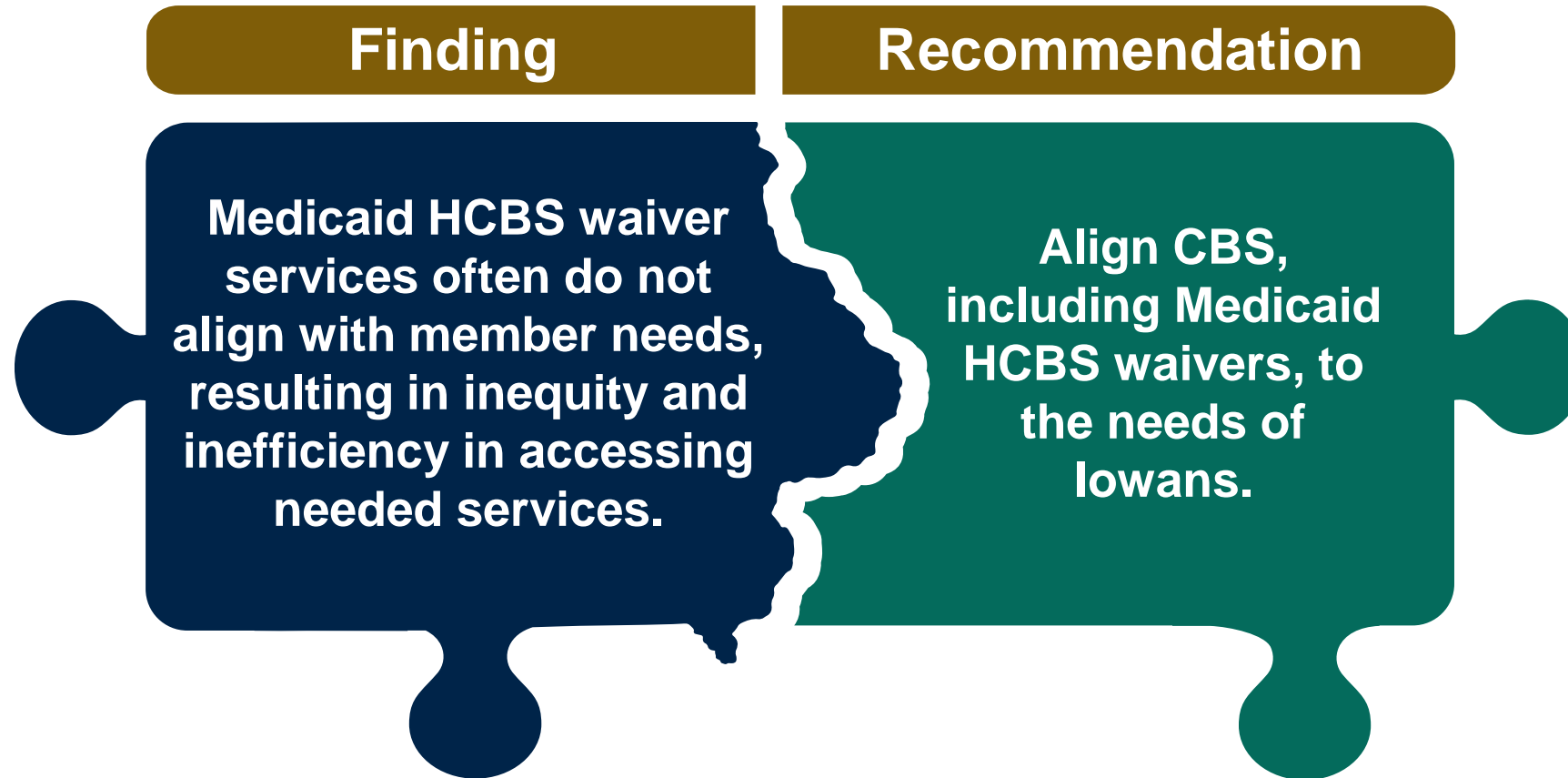


Services and supports offered in Medicaid and the broader CBS system are difficult to navigate and access.

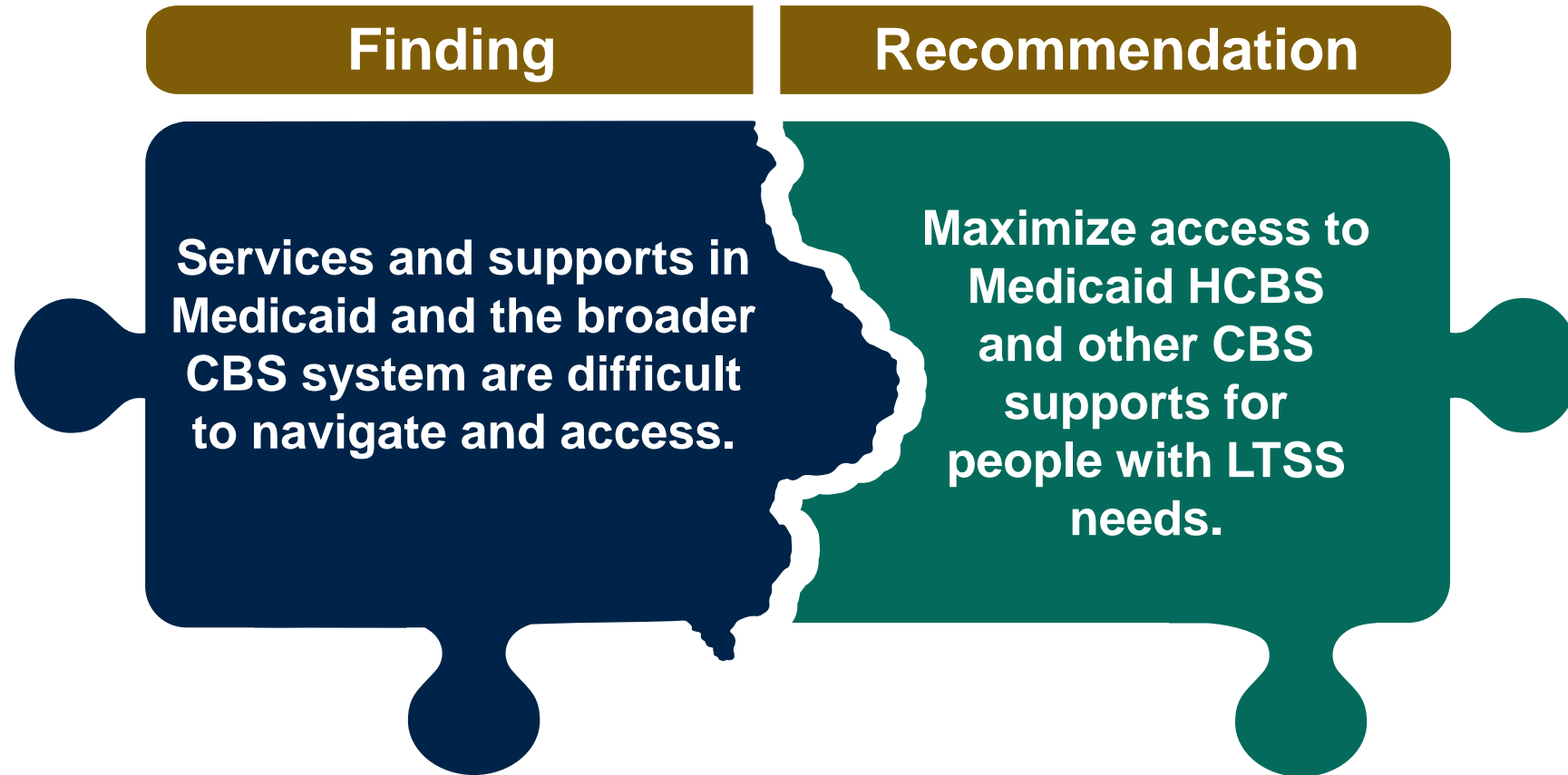
How can Iowa HHS better support people when they begin to need HCBS?



How can Iowa HHS improve waiver assessments and service offerings?



How can Iowa HHS enhance access to services for people already enrolled in a waiver?





II. Evaluation Approach

Who is leading the work?

Funder



Provide high-quality programs and services that protect and improve the health and resiliency of individuals, families, and communities.

Contractor



Subcontractor



Subcontractor



What is Iowa HHS trying to address?

- **Improving equitable access to high-quality, community-based behavioral health, disability, and aging services through Medicaid and other programs in the state**
 - Addressing gaps and inequities in services
 - Reducing inefficiencies in the system
 - Improving service delivery

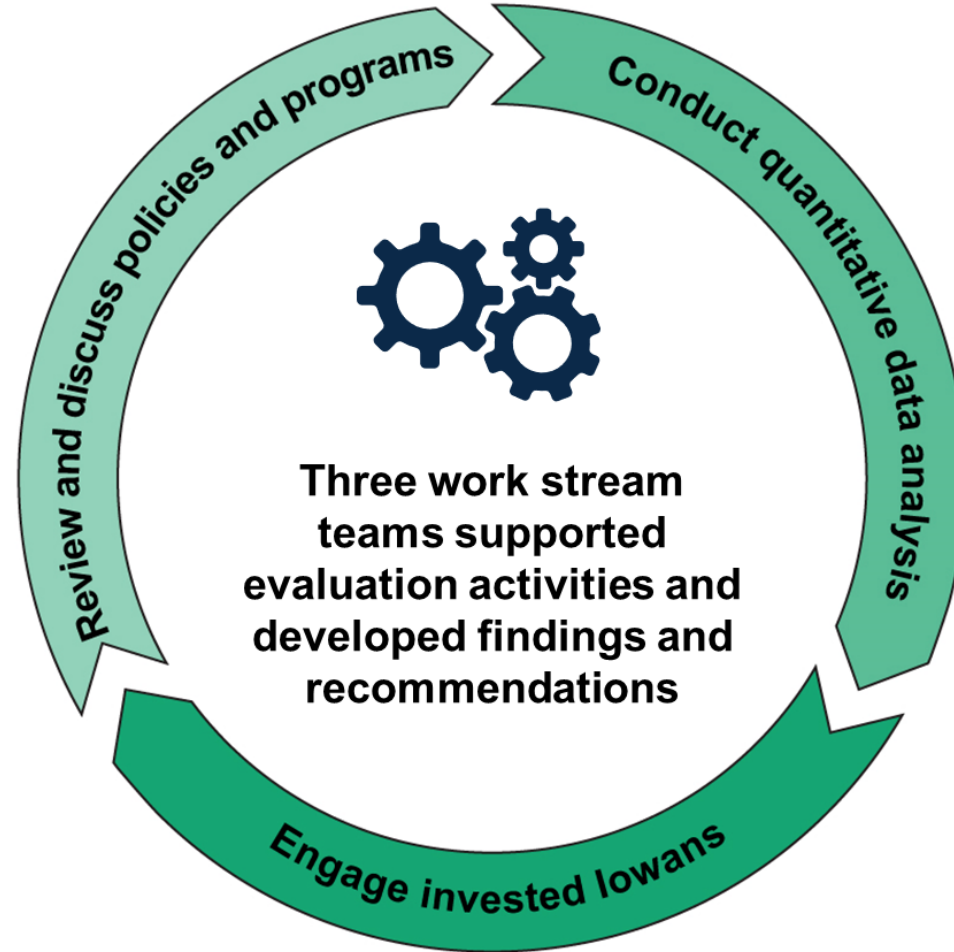
What principles guided the work?

- The evaluation team worked closely with invested Iowans, including HHS staff and the advisory committee
- Together, they developed five guiding principles



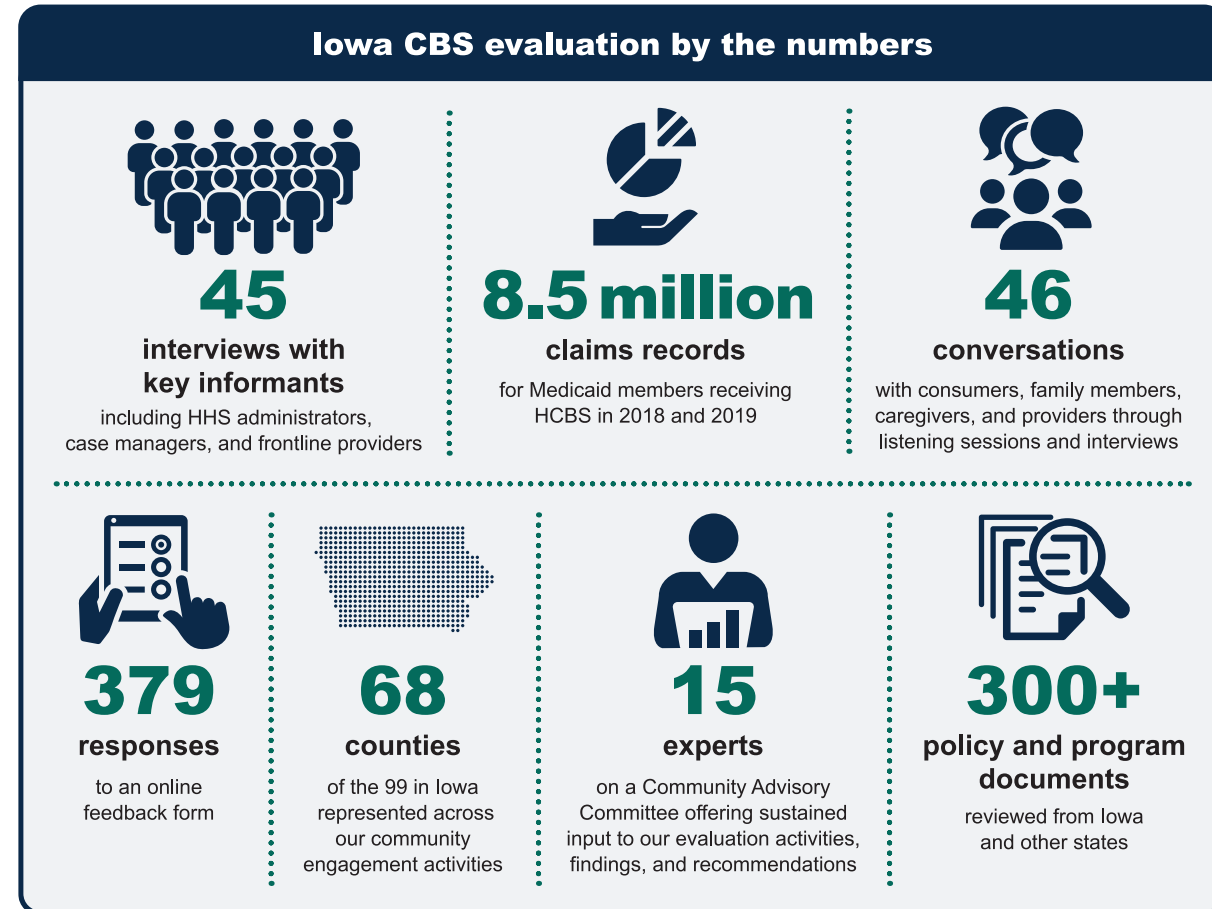
Source: Figure I.1. Guiding principles for Iowa's CBS system (from the Evaluation Report).

How was the work designed in Year 1?



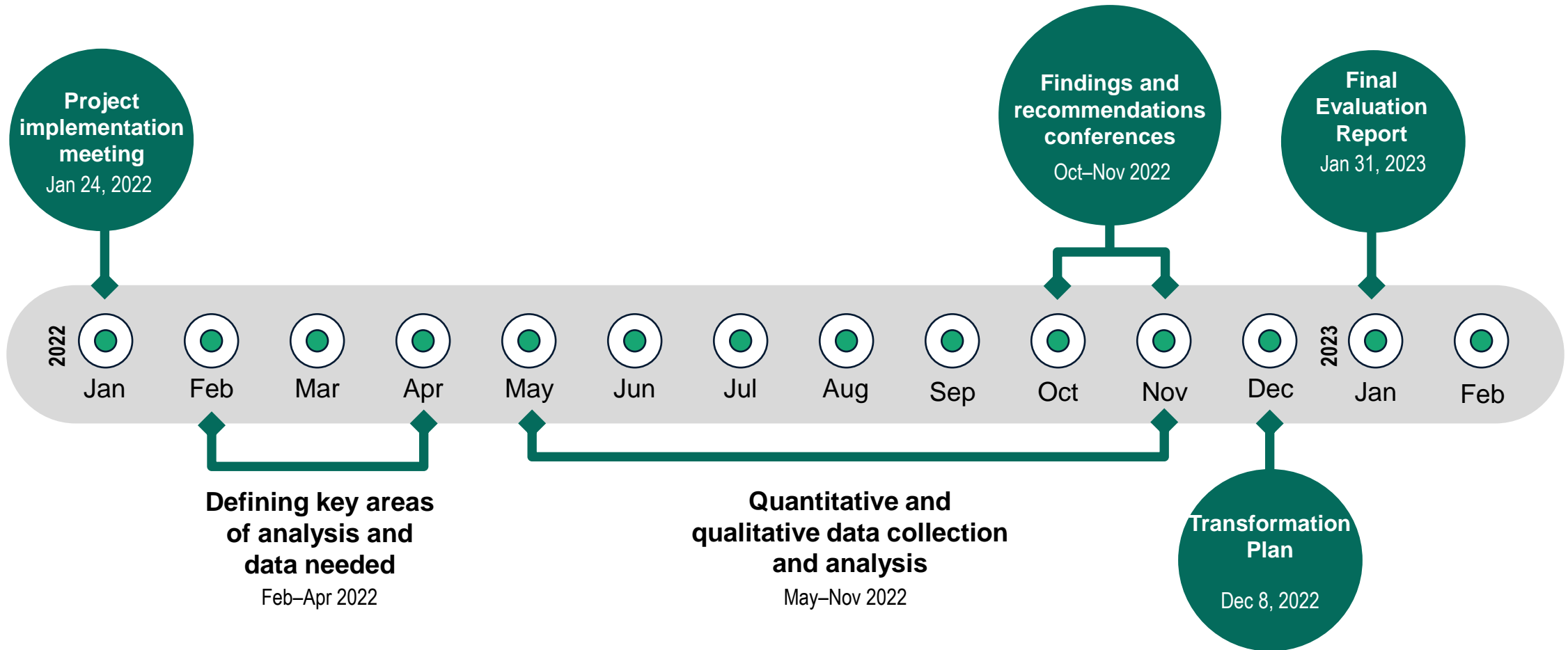
What did the team accomplish in Year 1?

- The three work stream teams analyzed the system
- The evaluation informed the findings and recommendations



Source: Box I.1. Iowa CBS evaluation by the numbers (from the Evaluation Report).

What was the timeline for the work?





III. Findings and Recommendations



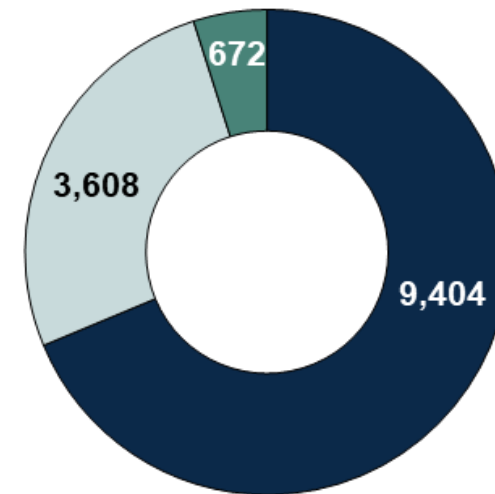
Findings: Accessing Waiver Services

The number of people requesting waiver slots overstates the true demand for services

- **13,000 Iowans requested more than 18,000 slots across Iowa's waiver waiting lists in 2022**
- **Nearly one in three people are on more than one waiver waiting list**

Number of people on one or more waiver waiting list

■ One waiting list □ Two waiting lists ■ Three or more waiting lists



Source: Figure V.2. Point-in-time data about the Iowa waiver waiting lists provided by HHS in June 2022 (from the Evaluation Report).

Emergency department and inpatient costs are higher for those on a waiting list than on a waiver

- **People on waiting lists accrued higher costs in some payment categories, such as emergency department care and inpatient care**
- **People on waiting lists had lower total Medicaid spending per member per month (PMPM) than those on the waivers because they lacked access to HCBS**

Note: We compared those on the waiting list to those on a waiver; we did not compare those on a waiting list, living in an institution with those on a waiting list, living in the community.

The system is not designed to coordinate MHDS and Medicaid services

- About 75 percent of MHDS participants were enrolled in Medicaid yet less than 5 percent were on a waiver waiting list
- MHDS spending is higher for those on a waiver or waiting list compared to other Medicaid enrollees or those not on Medicaid

Medicaid enrollment and Medicaid ID verification for MHDS participants

	Region A		Region C	
	Number	%	Number	%
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%

Source: Table V.3. MHDS data from Region A and Region B and Iowa Medicaid enrollment data (from the Evaluation Report).

Key takeaways

- **People are on waiver waiting lists for many years; the waivers do not have enough slots to serve everyone**
- **High institutional spending for those on the waiting lists suggests Iowa could better serve people in the community, in the ways they prefer**
- **Iowans have a hard time connecting to needed supports while on the waiting list**

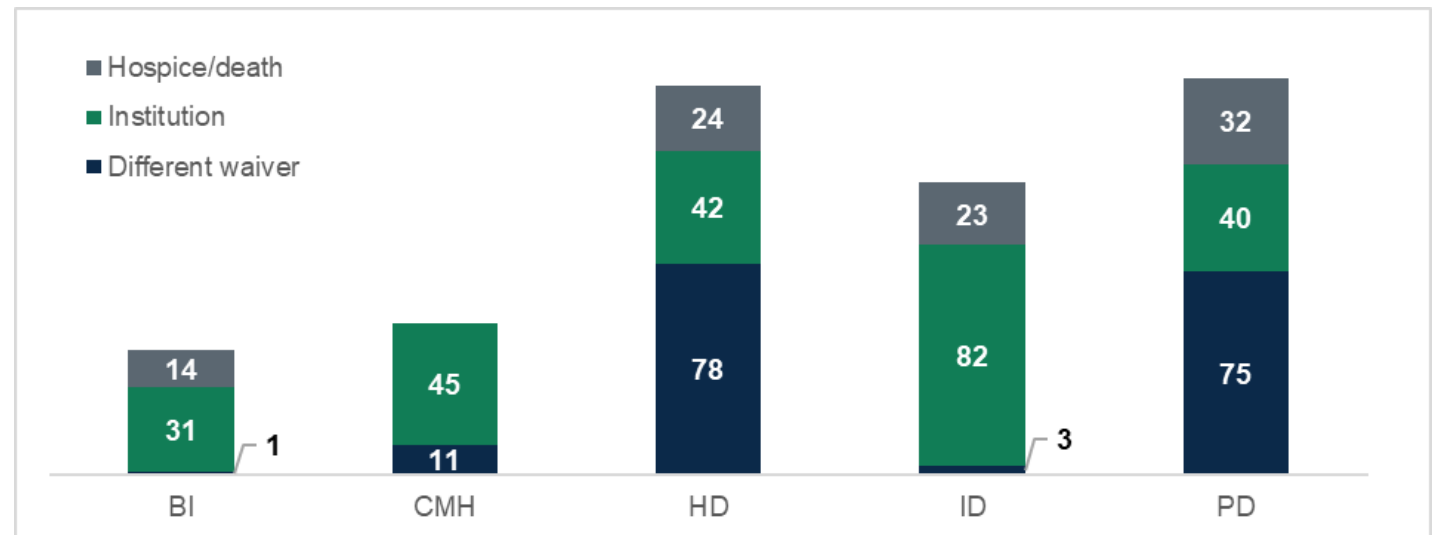


Findings: Challenges of the Current Waiver Structure

The waiver structure introduces inequities and inefficiencies into the system

- People with similar HCBS needs but different diagnoses are not able to access the same supports
- People move between waivers to try to access the services they need

Number of waiver exits to an institution, another waiver, or hospice/death

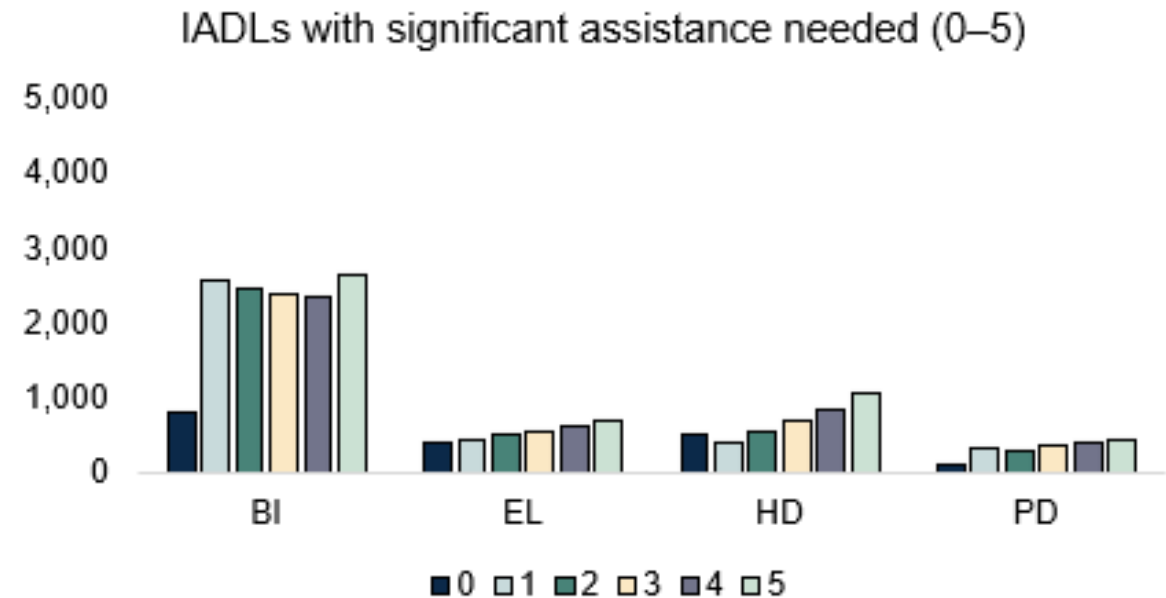


Source: Exhibit VI.1. Iowa Medicaid encounter data from 2018 (from the Evaluation Report). Waivers names are defined in the appendix.

The assessment process does not allow for measurement of need across waivers

- Iowa uses seven different assessment tools for its 1915(c) waivers
- Provider payments are inconsistent for people with the same level of need across waivers

HCBS PMPM provider payments in 2019



Source: Exhibit VI.4, Panel B, from the Evaluation Report. Iowa Medicaid encounter data from 2019 and interRAI assessment data from 2019. Waivers names are defined in the appendix.

Waivers are not meeting needs



“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



Key takeaways

- **The waiver system is not aligned with lowans' need, creating inequities and inefficiencies in the system**
- **People with the same level of need across different waivers have different provider payment amounts**
- **Community members shared that the waivers are not meeting their needs, and it is frustrating and exhausting to try to access what they need**



Findings: Transitions Between Institutions and Community Settings

There are gaps in the continuum of care

- **Services that are unavailable or difficult to access include:**
 - Residential crisis services for members on the Intellectual Disability (ID) waiver with intellectual or developmental disabilities
 - Youth-specific crisis and psychiatric stabilization services
 - Services to support those with co-occurring conditions
 - Transportation services
- **Service gaps, coupled with provider shortages, create challenges for accessing services to remain the community**

There is not enough support to navigate the complexities of the CBS system

- **Consumers face challenges navigating the system, such as the inability to find clear and consistent information**
- **Members' case managers change frequently, which interrupts care**

“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.”

— Response to online feedback form



An inadequate CBS system leads to increased institutional care

- **Service gaps, provider shortages, and inefficient system navigation lead to facility-based care**
- **Challenges accessing CBS may contribute to low enrollment in a waiver**

Percent of people who exit institutions and enroll in waiver or state plan habilitation within 30 days, six months, and one year

Institution type	Number exiting institution	Waiver or state plan habilitation enrollment within 30 days	Waiver or state plan habilitation enrollment within six months	Waiver or state plan habilitation enrollment within one year
ICF/ID	105	1%	3%	41%
MHI	322	4%	7%	12%
PMIC	688	4%	10%	16%
NF	4337	4%	9%	10%

Source: Adapted version of Table VII.2 with Iowa Medicaid encounter data from 2018 (from the Evaluation Report). Institution types are defined in the appendix.

Key takeaways

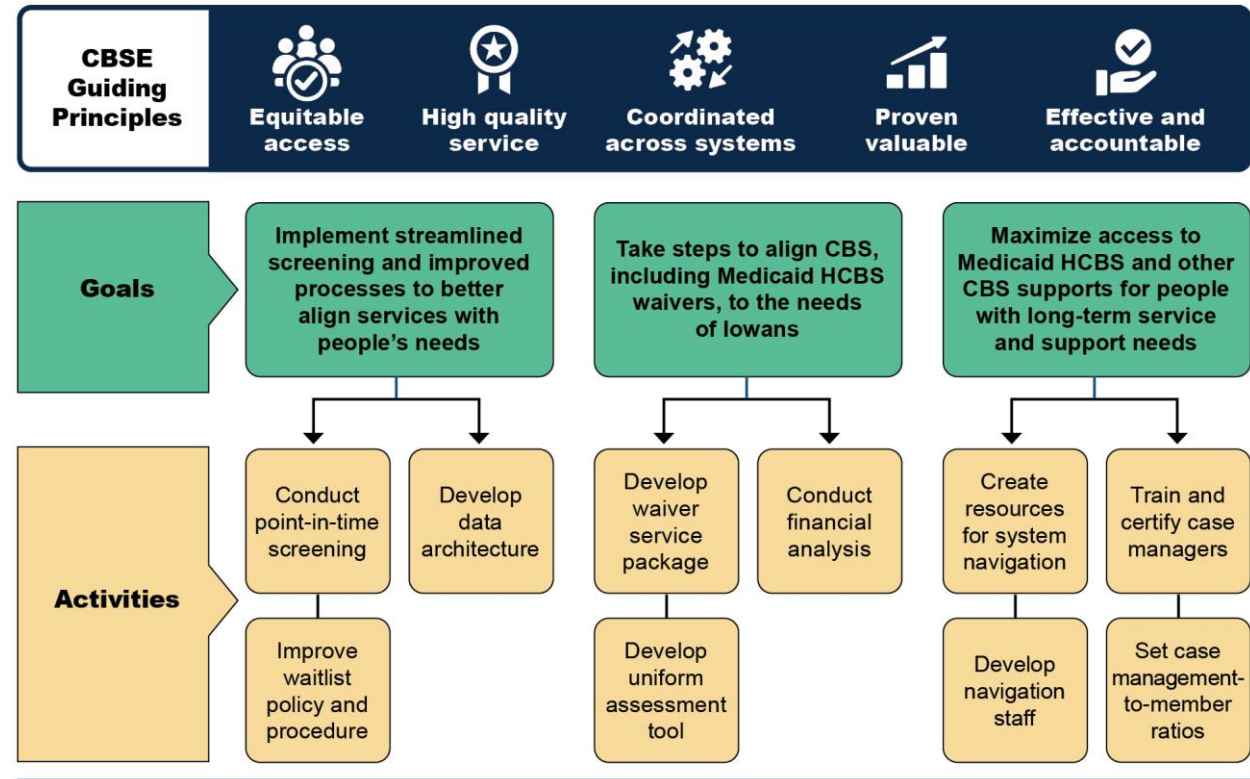
- **lowans cannot access some services, or there are not enough providers to furnish community services**
- **lowans cannot get the information they need about the CBS system and available services to meet their needs**
- **lowans turn to facility-based care when they can't get their needs met in the community**



IV. Next Steps for Implementation

How will Iowa HHS act on the recommendations?

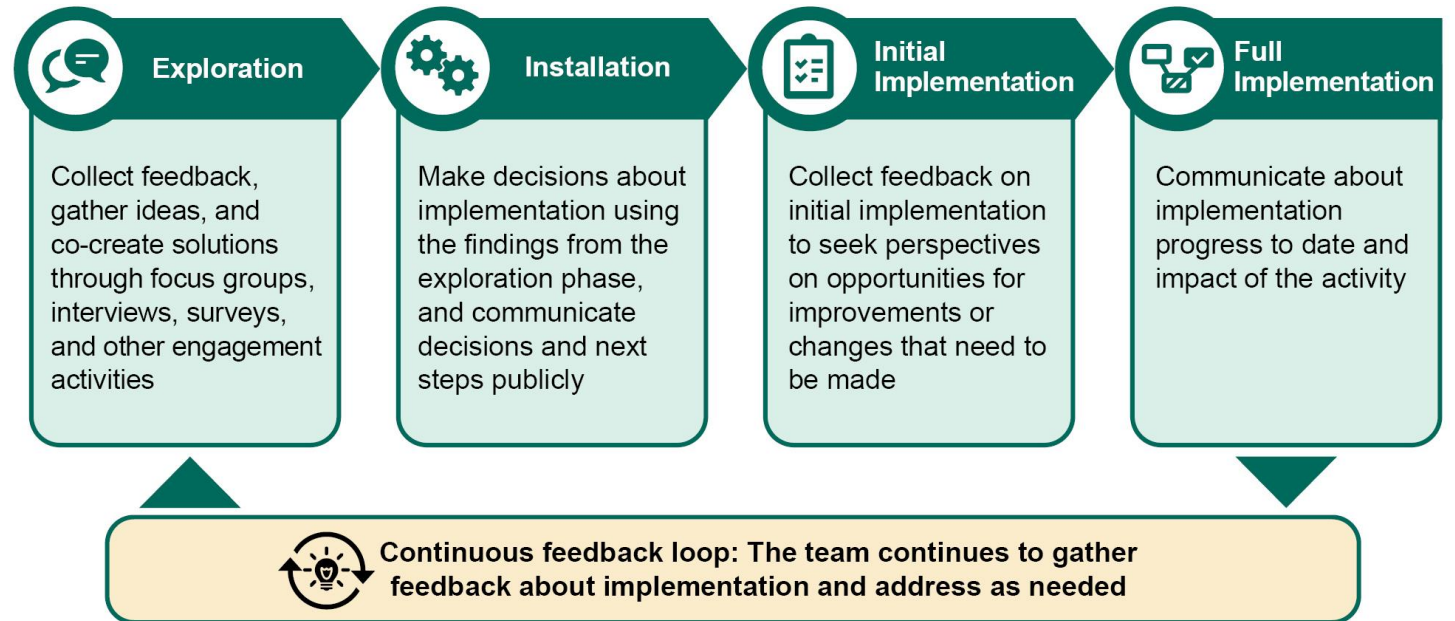
- Identify activities to support each recommendation
- Prioritize activities based on timing and resource constraints



Source: Exhibit II.1. Iowa CBSE Transformation Plan Framework (from the Transformation Plan).

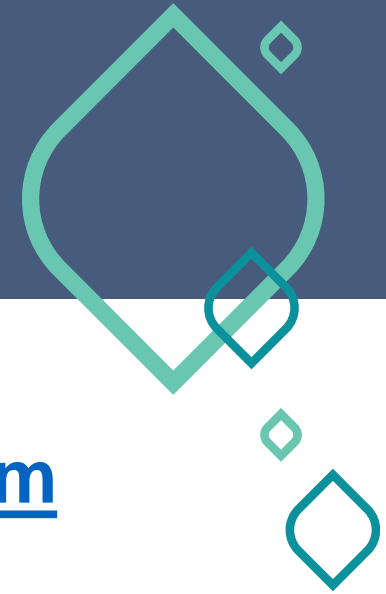
How will Iowa HHS seek feedback and communicate updates to Invested Iowans?

- Each activity will move through four stages
- We will seek feedback from Invested Iowans and provide updates during each stage of the feedback loop



Source: Exhibit III.1. Continuous feedback loop (from the Transformation Plan).

Thank you!



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Appendix A. Subrecommendations

Iowa HHS' process for Medicaid waiver waiting lists is not timely, efficient, or needs based

- **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).

Iowa HHS' Medicaid HCBS waiver services often do not align with member needs

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

Iowa HHS' Medicaid services and supports and the CBS system are difficult to navigate and access

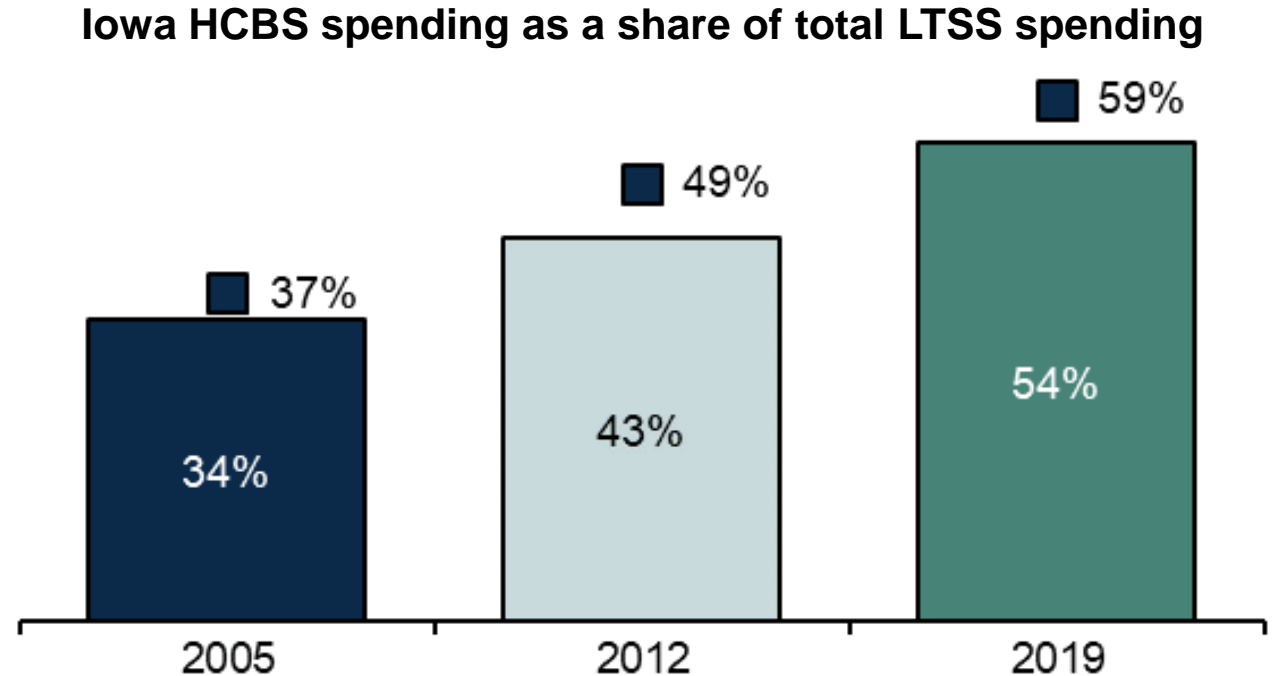
- **Recommendation:** Iowa should maximize access to Medicaid HCBS and other CBS supports for people with long-term service and support needs.
- **Subrecommendations**
 - Improve the public's understanding of the CBS system, available supports, and ways to access services.
 - Clarify and strengthen expectations 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.



Appendix B. Landscape of Long-term Services and Supports

Iowa HHS has shifted Medicaid spending away from institutional LTSS spending toward HCBS

- From 2005 to 2019, the proportion of LTSS expenditures spent on HCBS increased from 34 percent to 54 percent
- The share of Iowa's LTSS expenditures on HCBS was below the national average

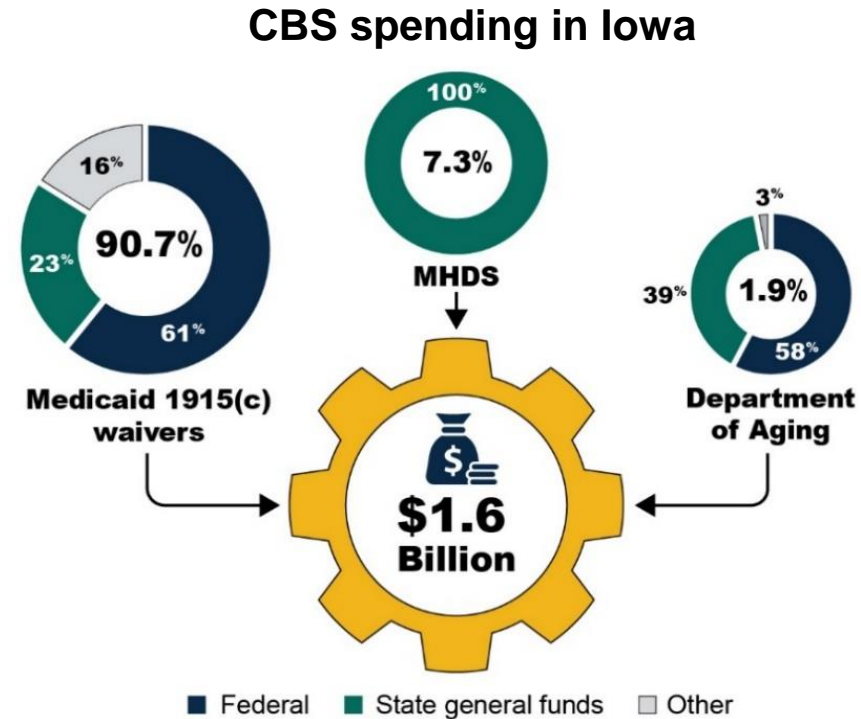


Sources: Figure III.1 from the Evaluation Report with data from (1) 2005 data from Wenzlow et al. (2016); (2) 2012 fiscal year data from Lewis et al. (2019); and (3) 2019 fiscal year data from Murray et al. (2021).

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.

Medicaid is the primary funder of LTSS in Iowa

- In fiscal year 2022, Iowa spent \$1.6 billion on community supports through the Department of Aging, Medicaid waivers, and MHDS regions



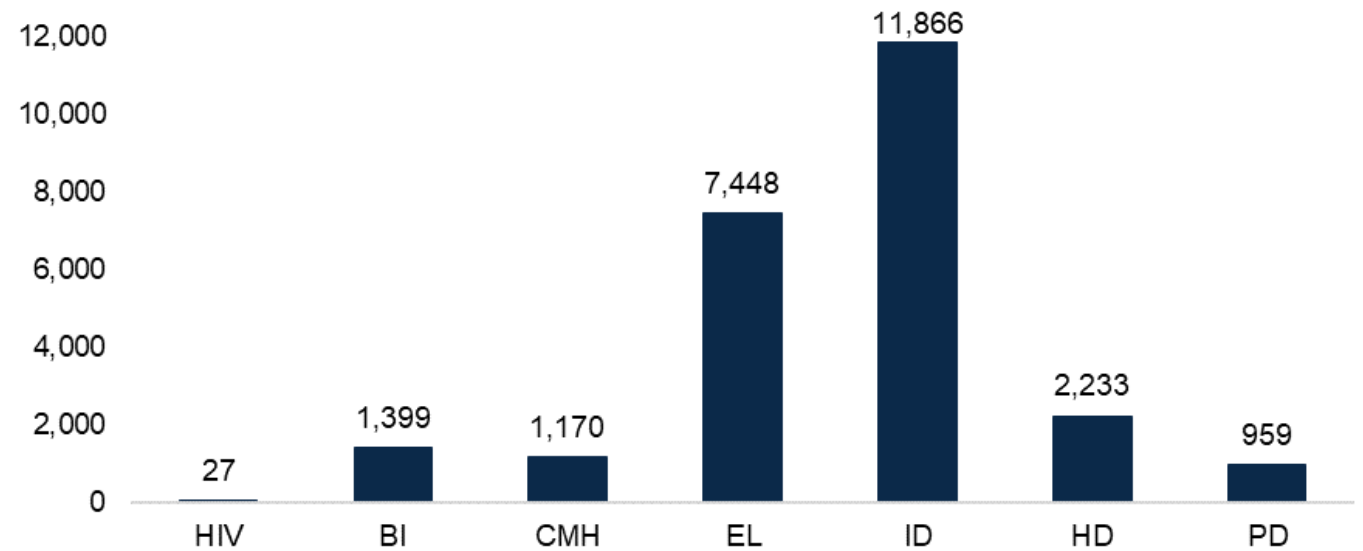
Source: Figure III.2 from the Evaluation Report with data from (1) Budget Report, Fiscal Year 2023, 2022.; and (1) Iowa HHS. (2022 Dashboard).

Note: Medicaid 1915(c) waiver expenditures are the MCO total waiver capitation expenses for SFY22. This does not include fee-for-service expenditures. To calculate the state and federal split for Medicaid, the team used federal and state expenditures data from the Health Program HHS Agency Dashboard Fiscal tab for FY2020, the most recent year available.

More than 25,000 Iowans use HCBS through seven Medicaid 1915(c) waivers

- **Waivers vary in size, services offered, and maximum monthly expenditures**

Number of Iowans enrolled in the state's seven Medicaid 1915(c) waivers in January 2022



Source: Figure III.3 with Iowa waiver waiting list numbers as of January 2022, based on an Iowa HHS report in September 2022 (from the Evaluation Report). Waivers names are defined in the appendix.

Iowans face challenges transitioning from institutional care to a community residence

- Institutions in Iowa serve people with a range of complex challenges
- People who enter an institution and have more complex needs than their peers are less likely to transition back to the community

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 across all institutions of that type	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: Table III.1 (1) Iowa Legislature (n.d.); (2) Iowa HHS (2016); (3) Iowa HHS (2016); (4) Iowa HHS (2022) from the Evaluation Report. Facility names are defined in the appendix.

Entering the HCBS system in Iowa is confusing

- **The various eligibility requirements make the process of entering Iowa's HCBS system confusing**
- **Once enrolled in a waiver, most members remain in that waiver; however, even those using waiver services may remain on the waiting list for another waiver**
- **Iowans who wait months or years on waiver waiting lists may enter facilities when they are unable to access the services they need**
- **Because reserved capacity slots offer faster access to waivers, some in the community consider facility placement as an option to access HCBS more quickly**



Appendix C. Acronyms

Acronyms, A through H

Acronym	Definition	Notes
BI	Brain Injury waiver	One of seven Medicaid 1915(c) waivers in Iowa.
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, rather than in facilities or institutional settings. This includes home- and community-based services funded by Medicaid as well as services funded through Iowa's Mental Health and Disability Services system, the Department of Aging, and other programs in the state.
CMH	Children's Mental Health waiver	One of seven Medicaid 1915(c) waivers in Iowa.
EL	Elderly waiver	One of seven Medicaid 1915(c) waivers in Iowa.
HCBS	home- and community-based services	Medicaid-funded programs and services that help people with disabilities or behavioral health needs, as well as older Iowans, 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.

Acronyms, H through M

Acronym	Definition	Notes
HIV	AIDS/HIV waiver	One of seven Medicaid 1915(c) waivers in Iowa.
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 facility for people 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.
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.
MCO	managed care organization	A business group that manages the delivery and costs of health care under contract with the state.
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 people who are having severe symptoms of mental illness but are unable to receive evaluation or treatment in the community.

Acronyms, N through Z

Acronym	Definition	Notes
NF	nursing facility	Health care facility for people who require long-term nursing or rehabilitation services.
PD	Physical Disability waiver	One of seven Medicaid 1915(c) waivers in Iowa.
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 enables comparisons of expenditures across different subgroups of members.