

Iowa Hope and Opportunity in Many Environments (HOME)

Steering Committee

Tuesday August 29, 2023

Agenda for today

Review waiver redesign survey findings

Discuss waitlist policy and procedures next steps

Update on HOMEtown Conversations

Next steps



Waiver Redesign Survey

Purpose and reach of the survey

- **Gather direct input from lowans about:**
 - The specific services people need
 - The problems they have accessing services they need
 - Suggestions to make services work better
- **Gather input from three important groups:**
 - People who use services and their caregivers (n = 254)
 - Case managers (n = 146)
 - Service providers (n = 240)
- **Use input to:**
 - Inform recommendations for waiver and case management changes
 - Engage with invested groups

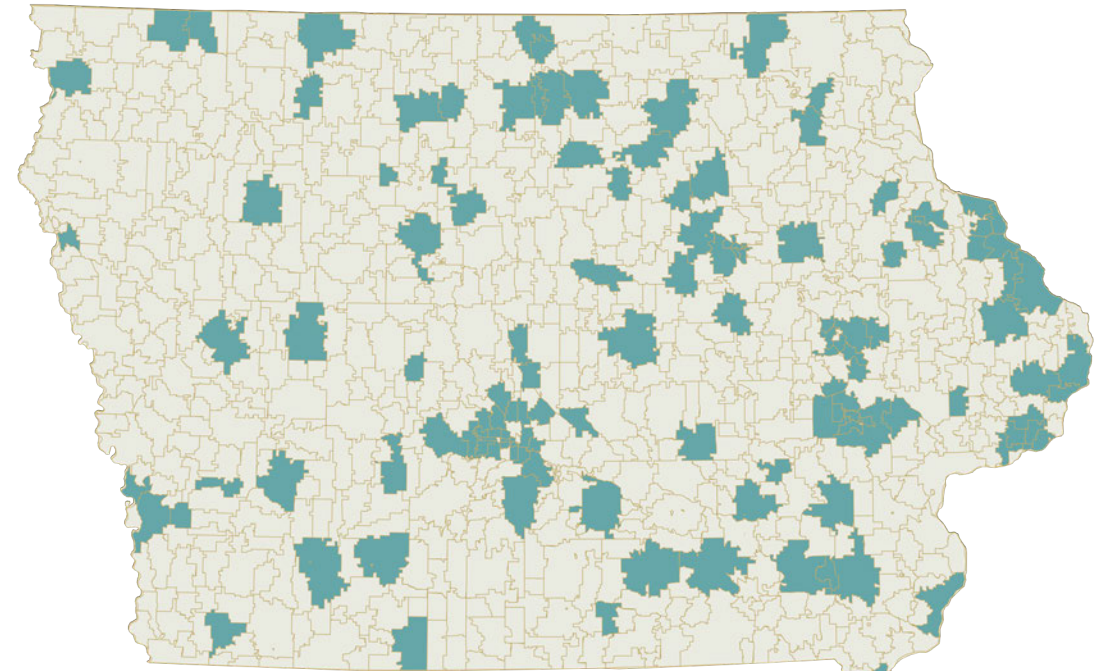


Survey respondents

People who use services and caregivers

- **254 respondents**
 - 63 people who use services
 - 191 caregivers
- **People who use services live in 133 zip codes across the state**
- **Among people who use services**
 - Average age is 32 (range 4 to 87)
 - Most are white (87%) and non-Hispanic (90%)
 - 51% are male; 46% are female

Home zip codes of people who use services
(n = 251)



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People who use services and caregivers

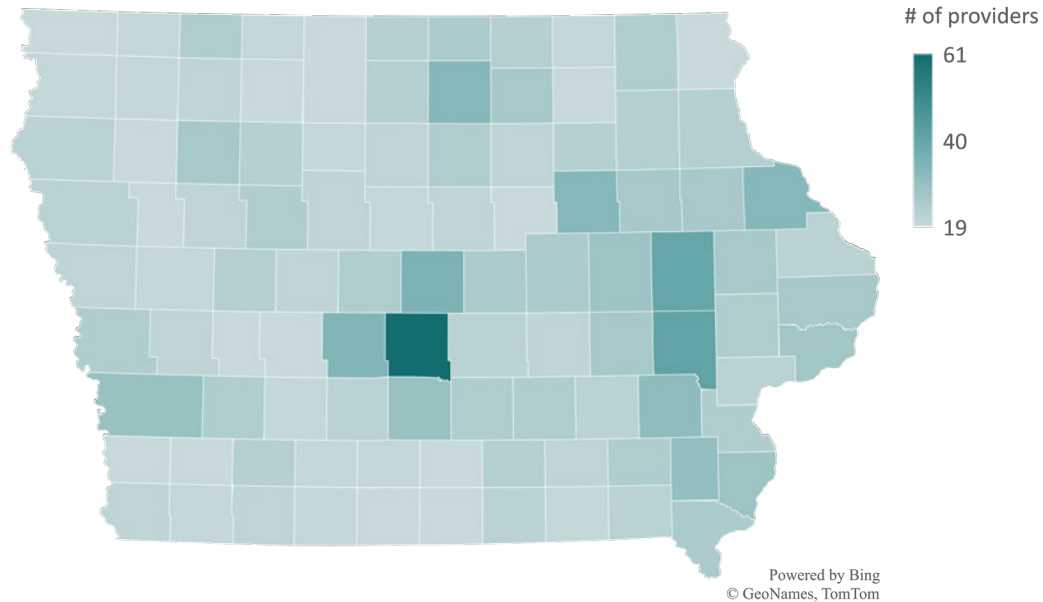
- **81% of people who use services are currently enrolled in a waiver**
- **14% of people who use services are on a waitlist**
 - Most commonly, waitlists for Intellectual disability waiver (51%), Health & disability waiver (29%)
- **9% of people who use services are enrolled in Habilitation Services Program**
- **58% of people who use services have more than one source of insurance**
 - Most commonly, private insurance (69%) and Medicare (55%)

Waiver enrollment among people who use services

Waiver	% of respondents (n = 207)
Intellectual Disability	57%
Health & Disability	21%
Brain Injury	9%
I don't know or other	5%
Elderly	3%
Physical Disability	3%
Children's Mental Health	2%

Providers

Counties where providers provide services
(n = 240)



16 providers provide services in all counties

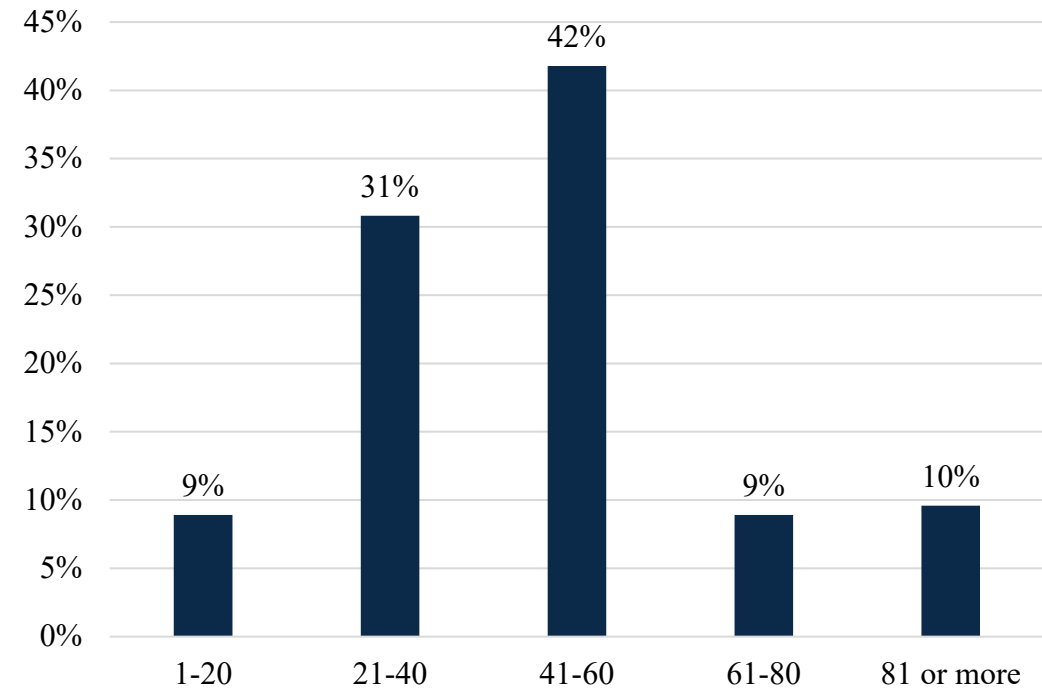
Most commonly provided services

Service	% of providers (n = 240)
Supported Community Living	62%
Day Habilitation	35%
Supported Employment	27%
Respite	24%
Nonmedical Transportation	23%
Mental Health Services	23%

Case managers

- **Tenure as a case manager**
 - 1-2 years (9%)
 - 3-4 years (11%)
 - More than 5 years (80%)

Current number of members on caseload (n = 146)





Experience with waiver services

Services people reported are difficult to access

“I need this service, but I do not receive it” (n = 254)

- Home-Delivered Meals (83%)
- Interim Medical Monitoring and Treatment (71%)
- Nutritional Counseling (66%)
- Prevocational Services (60%)
- CDAC – Skilled (59%)

“It's hard for me to clean my kitchen because I can't stand for long periods of time; it's hard for me to carry heavy groceries upstairs; I would like Meals on Wheels but I don't qualify for free meals.”
– Person who uses services

Note: We excluded respondents who said they do not need this service, don't know if they need it, or prefer not to say

Barriers to accessing needed services

Top barriers

- I didn't know about this service / I don't know how to access this service
- I can't find providers in my area
- It is not covered under the waiver/program that I am enrolled in
- I am currently on a waitlist for a waiver so I can receive this service
- I can't find a provider who is trained to meet my specialized needs

Services that don't meet peoples' needs

“I receive this service, but it does not fully meet my needs” (n = 254)

- Home and/or Vehicle Accessibility Adaptations (30%)
- Assistive Devices (29%)
- Nursing (25%)
- CDAC – Unskilled (22%)
- Self-Directed Personal Care (22%)

“My daughter's platform lift broke and this was the only way in and out of our home. We could not find a provider who was willing to complete a repair until they received approval from the MCO. This takes weeks!”
- Caregiver

Note: We excluded respondents who said they do not need this service, don't know if they need it, or prefer not to say

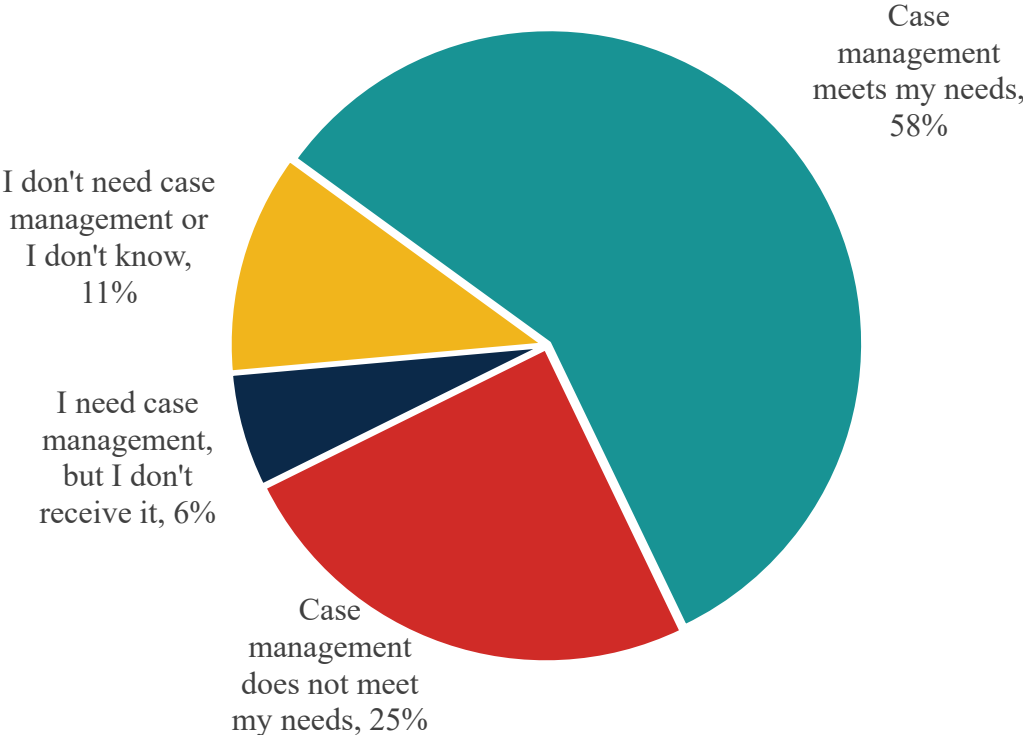
Reasons services don't meet peoples' needs

- **Home & Vehicle Accessibility Adaptations and Assistive Devices**
 - The modification or device I need isn't covered
 - It takes too long to get the modification/ device
 - It is difficult to get the modification/ device fixed when it needs repairs
 - When the modification/device breaks, I don't have a back-up

- **Nursing, CDAC (unskilled) and Self-Directed Personal Care**
 - I don't receive this service for as many hours as I need
 - This service helps me with some things, but not everything I need
 - I can't find a provider in my area
 - I can't find a provider who is trained to meet my specialized needs

People who use services' experiences with case management

Experience with case management
(n = 254)



Reasons case management does not meet the needs of people who use services

- My case manager helps with some things, but not everything I need (62%)
- My case manager doesn't understand the services available on my waiver (32%)
- My case manager is slow to respond (30%)
- My case manager doesn't understand my specific needs (27%)

Case managers' familiarity with waiver services

Proportion of case managers who said they were “very familiar” with the services offered and process for helping beneficiaries get on each waiver (n = 146)

- Intellectual Disability Waiver (79%)
- Elderly Waiver (73%)
- Brain Injury Waiver (69%)
- Health and Disability Waiver (64%)
- Physical Disability Waiver (60%)
- Children’s Mental Health Waiver (14%)
- HIV/AIDS Waiver (12%)

Services that case managers find most difficult for beneficiaries to access

“If individuals need this service, I have difficulty helping them access it” (n = 146)

- Home and/or Vehicle Accessibility Adaptations (55%)
- Chore Services, Homemaker, or Senior Companion (51%)
- Home Health Aide (50%)
- Nursing (48%)
- Specialized Medical Equipment (46%)



Cross-cutting themes

Provider workforce challenges

Themes

- Lack of providers and staff, and high staff turnover, were major concerns voiced by all groups of respondents
- Respondents said low reimbursement rates for services leading to low payment for staff contributes to this issue
- Providers expressed that the process of getting reimbursed is complex and time-consuming, which may defer providers from offering services

Provider workforce challenges

“I’m tired and struggling....if we don’t find staff and schedule staff ourselves, then we [caregivers] pick up the slack. I don’t know how to fix that and **get tired recruiting help but then don’t have help.**” - Caregiver

“If waiver rates were consistently raised providers would not have the critical swings in openings. **If there are no staff, there are no services.** If people can't get routine COLA raises they will quit and work in an industry where they can.”
- Provider

Accessing services is complicated and burdensome

Themes

- The length of waitlists was a major concern raised by respondents from all groups
- Respondents also expressed that processes for applying for waivers and accessing services is too complex and time-consuming

Accessing services is complicated and burdensome

“[We need] reasonable waitlist time for families with an infant and toddler with disabilities who needs these services. Parents are learning and navigating the world of having a child with disabilities and their medical bills are piling up and they are not receiving any assistance that they deserve.”
- Caregiver

“I spend way too many hours coordinating and working on [CCO] that it almost makes it not worth having the service. **It makes my life more difficult at times than being supportive.**”
- Caregiver

MCO challenges

Themes

- Respondents across all groups expressed concerns that MCO requirements and processes are burdensome
- Many caregivers and people who use services raised concerns about MCO service limits, denials, and grievance and appeals processes

MCO challenges

“The amount of paperwork required by MCOs...is leading to high turnover and lack of knowledge left in the field. The processes and workflows and steps and systems are incredibly time consuming which takes case managers away from doing what they were trained to do which is with be with and help people, not paperwork.” – Case manager

“The MCO [should] have to follow a clear set of rules, like a set amount of hours for each service, rather than the MCO just saying ‘no, we are not going to cover that.’ **Members should not need to appeal everything** and go to hearing for every request.” - Caregiver

Case management challenges

Themes

- People who use services and caregivers voiced concerns around case management, specifically:
 - Lack of training and knowledge among case managers
 - Case manager turnover
 - Concerns that case management under MCOs is not conflict-free and is poorer quality

Case management challenges

“It is a conflict of interest for case management to be coming from the same umbrella as the purse strings. MCO case managers are not advocating for what services individuals need, **they are advocating for what services will save their employer a dollar.**” - Caregiver

“In addition to the more constant flux of CMs...**case managers don't have the training on the variety of provider and program options available** to be able to offer choices to people they serve.” - Caregiver

Need for information and resources about accessing services

Themes

- “I didn’t know about this service / I don’t know how to access this service” is the top barrier to accessing needed services for people who use services
- People who use services and caregivers expressed a need for streamlined online resources and systems that help individuals to easily connect with a live person by telephone

Need for information and resources about accessing services

“[We need] a **searchable catalog** of what's available and how to access the service.” - Caregiver

“**It is difficult [for clients] to connect with their Medicaid worker or a live person to answer questions or get information.** Many times, clients have to wait on hold for up to an hour or more only to be told they need to be reconnected to another department, which leads to incredible frustration.”
- Case manager

Importance and value of HCBS services

“We would be in serious distress as a family without the brain injury waiver, Medicaid, and our child’s residential facility. **Our child’s care, health, and quality of life have all been positively impacted because of these services.**” - Caregiver

“**The waiver has provided my daughter so many options.** She has been able to live with two roommates in an apartment and she is very happy.” - Caregiver

“I am so happy that we receive respite. **It is life changing.**”
- Caregiver



Questions?

Questions?

- **What stands out to you?**
 - What resonates?
 - What was surprising?
- **Is there anything you expected to see, but didn't?**
- **What else should we know?**



Waitlist Policy and Procedures

Waitlist business process map (BPM)

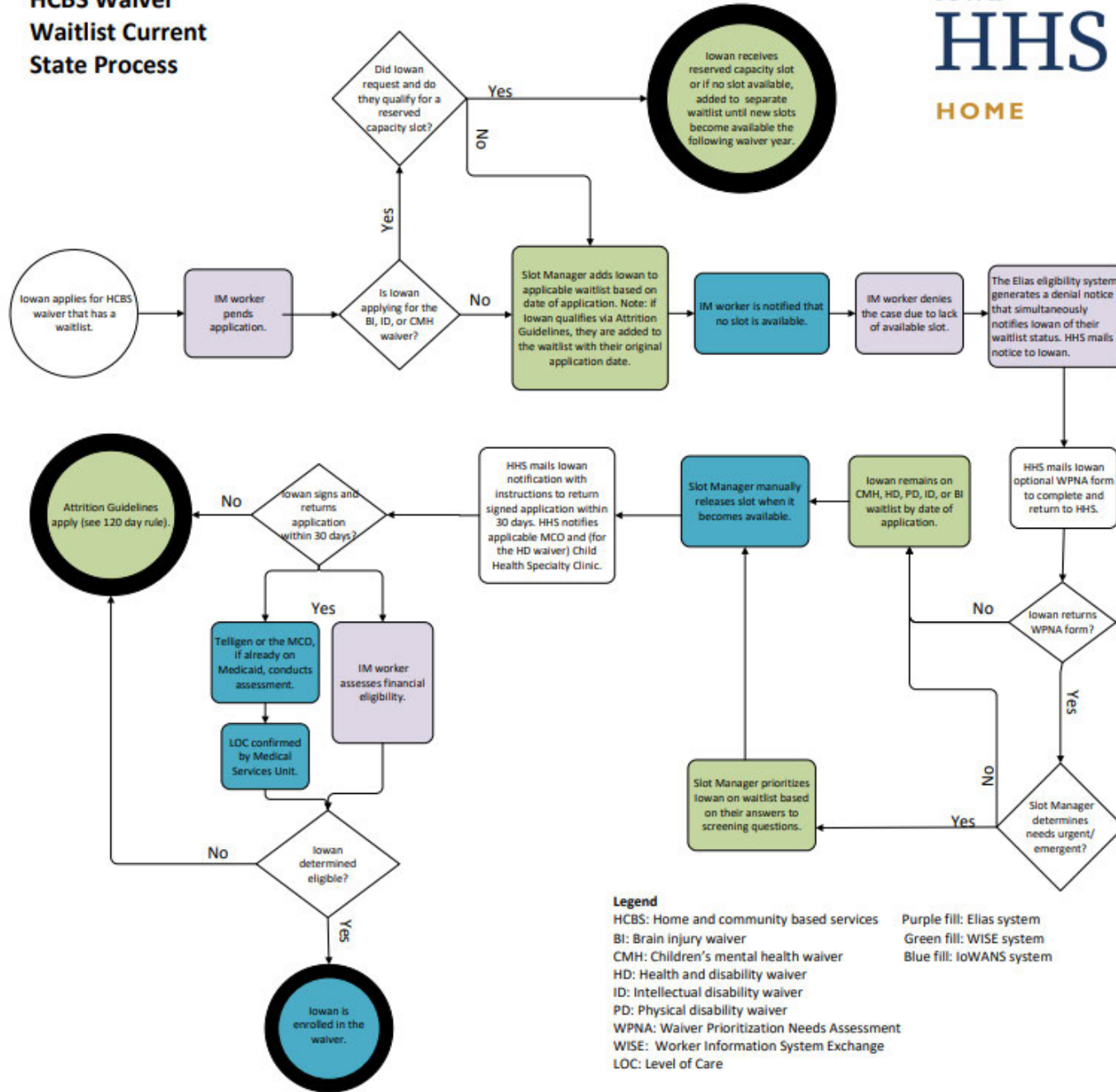
- **Process**

- Weekly meetings with HHS workgroup to discuss their process
- Final version shows each step between application and waiver enrollment

- **Next Steps**

- Use this BPM with HHS workgroup to identify opportunities for improvement
- Consider pain points for Iowans and how to improve process

HCBS Waiver Waitlist Current State Process



- Legend**
- HCBS: Home and community based services
 - BI: Brain injury waiver
 - CMH: Children’s mental health waiver
 - HD: Health and disability waiver
 - ID: Intellectual disability waiver
 - PD: Physical disability waiver
 - WPNA: Waiver Prioritization Needs Assessment
 - WISE: Worker Information System Exchange
 - LOC: Level of Care
 - Purple fill: Elias system
 - Green fill: WISE system
 - Blue fill: IoWANS system

Stakeholder interviews

- **Goal**

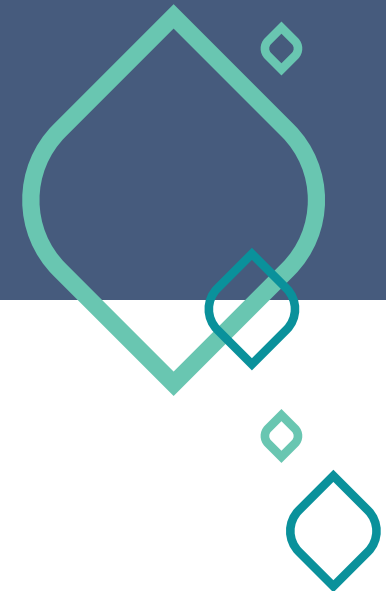
- Build on the community engagement work from last year
- Provide context for how Iowans feel about the waitlist process
- Identify areas for opportunity and improvement

- **Population**

- 40 Iowans who have submitted an expression of interest (EOI) through HHS website
- Personal experience or experience as a caregiver with HCBS waiver waitlists

- **Next Steps**

- Reach out and schedule interviews
- Harkin to conduct interviews in September



Questions?



HOMEtown Conversations

Renamed Roadshows: HOMEtown Conversations

- Your feedback on the name for these events across Iowa helped us choose an official name: HOMEtown Conversations!
- Schedule change: Events will be in late October and November
- Steering committee input is informing HOMEtown materials
- We'd love your help getting the word out

Request for volunteers for HOMEtown Video

- Considering creating a 5-minute video for the HOMEtown Conversation events
- Highlight personal stories from Iowans about the importance of improving the state's CBS system.
- Volunteer to participate in 15 minute virtual interview
- Email Kimberly or respond in the chat if you are interested or have questions.

Next Steps: Meeting cadence and materials

- We will send the August meeting summary in about one week
- Meetings will be held on the last Tuesday of every month
 - Next meeting is on September 26 from 3-4:30 pm (CST)



Other questions?