

HOMEtown Conversations Summary Report

Mathematica partnered with the Iowa Department of Health and Human Services (HHS) to host 15 public events, called HOMEtown Conversations, from October to December 2023. HOMEtown Conversations allowed HHS leadership to connect with Iowans across the state to share updates on the Hope and Opportunities in Many Environments (HOME) project, receive feedback, and answer questions from Iowans related to the community-based services redesign. The HOME team held in-person events in 12 cities across Iowa (Figure 1). Three virtual events, including one Spanish language event, also expanded participation opportunities. Some 1,169 Iowans, including 23 state legislators, attended a HOMEtown Conversation.¹

Figure 1. HOMEtown Conversations event locations



Iowans who attended HOMEtown Conversations events appreciated hearing about the HOME project directly from Medicaid leadership and generally expressed support for the changes proposed. About 94-percent of attendees who completed feedback surveys shared that they learned valuable information from the events. In addition, 86-percent said that the event met their expectations, and 89-percent believed that HHS would use their input to improve Iowa's community-based services system. Attendees also recommended that HHS continue to provide opportunities for Iowans to receive updates and provide

¹ Attendance totals reflect the combined number of attendees at all events and do not account for individuals who attended multiple events.

input as the HOME project moves forward. This report summarizes additional feedback from Iowans attending the events.

Attendees supported streamlining waivers and aligning services with need

Attendees generally supported transitioning from Iowa's current system of seven diagnosis-based waivers to fewer needs-based waivers with expanded service arrays and supported transitions between waivers. Attendees described the following challenges with the current waivers:

- **Difficulty navigating the current waiver structure.** Attendees emphasized their difficulties in differentiating between waiver offerings, matching needs to the correct waiver, and transitioning from one waiver to another as needs change.
- **Challenges interpreting administrative code.** Attendees noted that unclear language in HHS' administrative code confused providers and case managers and limited access to services for some consumers.

Attendees suggested specific services and delivery changes to consider in waiver redesign:

- Modeling service packages on the Intellectual Disability (ID) waiver's more comprehensive service package.
- Increasing access to home-delivered meals, transportation services, home modifications, consumer-directed attendant care (CDAC), homemaker, day habilitation, and supported community living services for all waiver members.
- Simplifying requirements and providing clearer information for the Consumer Choices Option (CCO) program.
- Expanding Iowa's 1915(i) habilitation financial eligibility requirements to support better employment opportunities.
- Ensuring the redesigned waiver structure considers the distinct needs of all age groups, including children and older adults, and all disability types.
- Removing IQ test scores as an eligibility requirement and broadening the array of service offerings to align waiver services with the needs of individuals with autism.

"I have a 15-year-old son with autism and ID. I love the idea of streamlining waivers... My son is complex; he's a genius at puzzles but won't respond to 'how was your day at school.' I love that we're seeing that no one size fits all. Every parent feels this way; kids don't fit into a box." ▲ —*Family caregiver, Burlington*

Attendees shared the following suggestions to facilitate a smooth transition from the current to the new proposed waiver structure:

- Communicating clearly with members, providers, and case managers how the transition to a new waiver structure would affect current waiver members' service access or waitlist position.

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- Creating robust training programs for providers and case managers to ensure they are equipped to support a wide variety of diagnoses and populations under the new waiver structure.

Attendees highlighted the need to reduce the waitlist

Attendees voiced the following challenges with the current waitlist:

- **Long wait times for services.** Attendees felt frustrated with the long wait people experience before being offered a waiver slot, the delay before receiving services, and the high number of people on the waitlist. Attendees emphasized that long waits for services can negatively impact the health and quality of life for members and family caregivers. Attendees shared dissatisfaction with the length of the Children’s Mental Health (CMH) and ID waiver waitlists.
- **Potential adverse health outcomes for older adults on a waitlist.** Although the Elderly Waiver (EW) currently has no waitlist, attendees raised concerns about older adults potentially experiencing a waitlist that would delay service access under a redesigned waiver system.
- **Minimal communication about waitlist status.** Attendees highlighted the lack of screening and limited communication for individuals on the waitlist. They expressed concern that people might spend years on a waitlist for a waiver that they are ineligible for or that does not best meet their needs, further delaying their access to services.

Attendees shared recommendations to improve a member’s waitlist experience:

- Screening waitlist members to ensure they have applied for the correct waiver.
- Providing waitlist members with accurate information about when they can expect to receive a waiver slot.
- Connecting waitlist members to available non-waiver services.
- Moving to a single waitlist with prioritization based on need, to speed up access to services for those with the highest level of need.
- Developing a prioritization approach to waitlist management that considers both need and time spent waiting.

Attendees shared suggestions for improving the accuracy and appropriateness of assessments

Attendees highlighted challenges with current assessment processes and tools:

- **Long waits prior to assessment.** Attendees noted that members experienced long wait times for level of care assessments after receiving a waiver slot, creating further delays in their access to services they need.
- **Assessments that felt too frequent.** Many attendees shared frustrations on the required frequency of assessments for waiver participants with lifelong disabilities, though they acknowledged that HHS lacks the authority to change this federal requirement.
- **Potential bias or inaccuracy in assessments.** Attendees raised concerns that MCO involvement in the assessment process may bias assessments. Several attendees also questioned the accuracy of assessments, noting that assessment results may reflect a member’s feelings toward the assessor, a desire to demonstrate independence, or the daily variation in their condition rather than true support needs.

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- **Negative psychological impacts of assessments on members.** Attendees flagged the limitations of the current assessment tools. For example, they noted that the Support Intensity Scale (SIS) is lengthy and can be retraumatizing for members.

Attendees supported moving to a single, uniform assessment, but they also raised concerns about the feasibility of identifying a single assessment tool that would be appropriate for all disability types. They provided several recommendations for improving the assessments:

- Selecting an assessment tool that accurately assesses needs for diverse groups and disability types, is a reasonable length, holistically evaluates support needs, and does not retraumatize members.
- Improving assessment training for providers and assessors.
- Divorcing assessors from payors to avoid conflicts of interest.

Many attendees voiced frustration with provider shortages and emphasized the need to address shortages to achieve the goals of HOME

Attendees noted that provider shortages across the state limited lowans' access to needed services. These shortages leave many members with unmet needs even when they are eligible for services, have received a waiver slot, and are able to get a referral.

- **Provider shortages are causing gaps in care, even when someone is eligible for the services and coverage.** Attendees noted that achieving the stated goals of the HOME project would require increasing provider capacity, particularly if the redesigned waiver structure is intended to expand service access.
- **Attendees emphasized the especially severe provider shortages in rural areas that result in unmet service needs for rural lowans and increased strain on family caregivers.** Attendees also highlighted shortages in certain specialties, such as providers with expertise in managing nonverbal members or potentially violent behaviors.
- **Attendees discussed lack of awareness of HCBS career pathways, limited training opportunities, low wages, and stressful working conditions as contributing to the state's provider shortages.** Some attendees noted that wages for direct care jobs start out low and have very little wage growth. This makes it difficult to recruit and retain a healthy workforce.

"What are we doing about the lack of direct care workers, the shortage, and reimbursement levels? Because I really think that's the essence of the problem." — lowan who uses community-based services, Council Bluffs

Attendees suggested several strategies to increase provider capacity:

- Raising wages for direct care workers to attract more people to the profession and increase retention
- Increasing Medicaid provider reimbursement rates to allow providers to cover the cost of providing HCBS and offer competitive wages.
- Reducing Medicaid providers' administrative burden to increase capacity.

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- Strengthening recruitment and training activities to address workforce shortages: increasing recruitment efforts in middle and high schools, partnering with educational institutions to increase training opportunities, expanding apprenticeship programs and emphasizing the social impact and importance of HCBS career opportunities.
 - Increasing opportunities for family caregivers to be paid as providers, considering peer support approaches to service delivery, and expanding virtual service delivery to increase service access given workforce shortages.

lowans expressed dissatisfaction with how challenging it is to learn about and get connected to community-based services and shared suggestions for making the system easier to navigate

Attendees raised several challenges related to systems navigation:

- **Difficulty finding out about benefits and services.** Even those who should be well equipped to navigate the system, such as providers or experienced advocates, described struggling to identify appropriate Medicaid benefits and secure services.
- **Hard-to-navigate online communications.** Attendees shared that finding information about benefits and services online is difficult and time consuming. The difficulty adds to caregiver strain and delays accessing needed services.
- **Insufficient systems navigation support.** Attendees called for more hands-on assistance with learning about available services and benefits, completing applications, and getting connected to providers—especially because local HHS offices do not assist with waiver applications. Attendees specifically stressed the need to strengthen systems navigation support for individuals who have recently received a diagnosis and those with serious physical or mental health problems.

“We get frustrated as providers going into the home to get people the services they need. The stress of trying to figure out the system and what you can and can’t do; it shouldn’t stress [lowans who use community-based services] out like that.” —*Provider, Osceola*

Attendees recommended several improvements to systems navigation:

- Making online communications materials easier to locate and understand so that lowans can easily find information about available Medicaid and non-Medicaid community-based services and benefits programs.
- Creating a “systems navigator” role to provide information about services, provide support with application processes and eligibility requirements and facilitate referrals to needed services and supports.
- Connecting consumers and family members with a systems navigator in healthcare settings at the time of diagnosis.
- Improving collaboration with schools and Area Education Agencies to connect students and families with information about services.

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- Leveraging Aging and Disability Resource Centers (ADRCs), 211, Unite Us, Iowa Unite, Community Action and Area Agencies on Aging (AAAs) to support a more coordinated systems navigation process.

Attendees shared frustrations with case manager turnover and high caseloads; they supported plans to improve case management through training and modified ratios

Although attendees shared their appreciation for the critical role case managers play in ensuring that members receive needed services, many members and family members were dissatisfied with the case management support they receive. The attendees highlighted the following issues:

- **Excessive caseloads, administrative burden, and high turnover.** Attendees expressed frustration with case managers' limited availability to connect with members and resolve issues. They also described high case manager turnover as harmful to members. Attendees noted that high caseloads and time-consuming administrative responsibilities limited case managers' time with members and increased case manager turnover.
- **Inadequate case manager training.** Attendees expressed frustration with case managers' inability to resolve issues with services and limited knowledge of benefits and eligibility requirements. They noted that gaps in case manager knowledge may cause delays in access to services.

Attendees recommended improvements to case management:

- Reducing case management ratios to increase case managers' capacity to support member needs
- Streamlining administrative burden to enable case managers to spend more time working directly with members.
- Strengthening training for case managers, particularly on the eligibility requirements for different waiver programs

"The administrative burden put on by the state to local agencies that provide community-based care coordination is so heavy that it leaves little time for care coordinators to be in front of members." —*Provider, Cedar Rapids* ▲

Conclusion

More than one thousand Iowans attended a HOMEtown Conversation event to learn about the HOME project and share feedback on how HHS can improve access to high-quality community-based services. The input Iowans provided during HOMEtown Conversations will be used to inform decision-making across the HOME project. These decisions may include changes to Iowa's waiver structure, waitlist management, assessment protocol, case management policy, systems navigation infrastructure, provider needs assessment and more. Moving forward from these events, HHS will build on HOMEtown Conversations by continuing to share updates on HOME activities, decisions, timelines, and opportunities to weigh in on key decisions throughout the project.