

Vermont Home and Community- Based Services Quality Measures Stakeholder Feedback Project

Deliverable 4: Findings and Recommendations

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Introduction

The purpose of the HCBS Quality Measures Stakeholder Feedback Project was to engage a wide array of Vermonters who interact with the State’s Medicaid-funded Home and Community Based Services (HCBS) in conversations about a state-led initiative to measure the quality of these services. This included talking with people who receive these services, family caregivers, and service providers and disability advocates.

This project included 5 deliverables submitted to AHS as separate reports. The current report is Deliverable 4: Findings and Recommendations.

Deliverables	Key Activities
1. Create Stakeholder Engagement Plan	Ask questions, form core team, draft plan, Kickoff.
2. Draft Educational Materials	Find information on measures, translate for stakeholder groups, launch advisory team.
3. Revise Educational Materials Based on Feedback	Plan and launch survey and listening sessions, use existing meetings and infrastructure as much as possible.
4. Create Summary Report	Share findings and recommendations for educational materials and future stakeholder engagement.
5. Develop Train-the-Trainers Sessions	Design and lead sessions for AHS QI committee, HCBS subcommittee, AHS staff.

Overview

Stakeholder feedback was gathered through project advisory committee meetings and stakeholder forums (see report *Deliverable 1: Stakeholder Engagement Plan*).

Participants included people receiving services, family caregivers, providers, and advocates, with most feedback coming from individuals involved in the Developmental Disabilities Services (DDS) program. Fewer perspectives were represented from

Choices for Care and the Traumatic Brain Injury Program, particularly from older Vermonters and those in Home Sharing arrangements. As a result, findings may not fully reflect the experiences of all HCBS populations.

The next section shares high level findings and recommendations. The appendices include more detail for readers who want more detail from the Advisory Committee meetings (Appendix A), across the stakeholder feedback sessions (Appendix B), and separately for each stakeholder feedback session (Appendix C).

Findings

Across multiple forums stakeholders shared both deep concern about the current delivery of HCBS in Vermont and strong commitment to improving the system.

Several high-level findings cut across stakeholder groups and inform the recommendations that follow:

- **People expressed appreciation for individual staff who listen, communicate clearly, show respect, and provide genuine, person-centered support.** Services were described as working best when staff are reliable, responsive, and able to build trusting relationships.
- **At the same time frustration about providers and services was shared frequently.** Participants reported persistent workforce shortages, unfilled service hours, and difficulty finding direct support professionals. Some individuals raised concerns about residential providers' understanding of Medicaid requirements related to rights in provider-controlled settings, and people receiving DDS services reported limited access to information about their individual budgets.
- **Perceived disconnect between State quality oversight and lived experience.** Stakeholders were often unaware of Vermont's comprehensive HCBS quality strategy and questioned whether the State was doing enough to oversee service quality. Improved communication about quality assurance efforts could help close this gap and build confidence in the system.

- **Fear of retaliation and lack of trust in anonymity.** Many people receiving services are worried about providing honest feedback. They worry being honest could lead to negative consequences, such as loss of services or preferred staff. Addressing concerns about privacy, anonymity, and choice of supports during interviews is essential for collecting accurate data.
- **Participants also voiced skepticism that the State would share findings openly or use the information to drive meaningful change.** This distrust appears to be influenced by recent changes in HCBS policies, as well as the broader political and cultural climate.
- **Despite these concerns, stakeholders consistently emphasized their desire to contribute to improvement efforts.** Participants recognized the importance of engaging directly with State-led quality assurance activities and viewed their feedback as a way to influence decision-making at the highest levels.

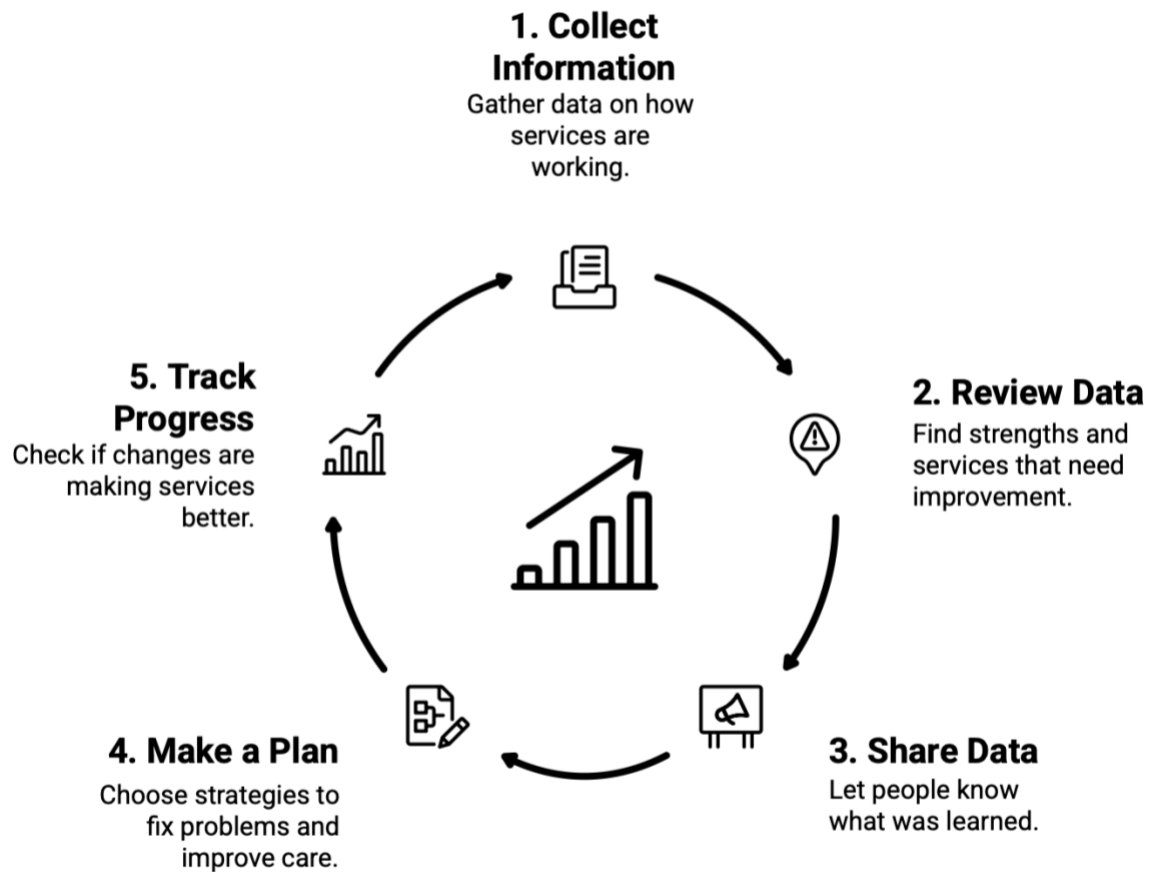
Recommendations

The partnering organizations for this project want to emphasize three broad recommendations:

1. **The quality of the data collected by the CAHPS will rely heavily on thoughtful planning, clear communication, and individualized accommodations.** There are recommendations and materials throughout this report that can assist the State in a successful rollout of the CAHPS.
2. **The Quality Assurance Activities required by CMS should be supplemented by and understood in the context of additional quality assurance work in HCBS and supplemental data collection.** Division level quality assurance work provides additional information and context so that state decision makers can translate quality assurance data into effective improvement plans. Family caregivers, providers, and advocates also have important insights that the State may wish to collect.

3. **Continue to support and fund stakeholder engagement in quality assurance activities.** As the findings section emphasizes, stakeholders have important information to share throughout any continuous quality assurance process. Their investment increases the chances of success.

More specific recommendations are organized around five steps of a continuous quality improvement process. This organization structure was chosen to provide the State with recommendations as they engage in the different aspects of CQI for HCBS Quality Measures. The steps include: Collecting information, reviewing data, sharing data, making a plan, and tracking progress.



Step 1: Collect Information

Collecting accurate and meaningful feedback requires careful planning and supports that recognize the diverse communication and processing styles of people receiving HCBS.

Recommendations:

- Use plain language in all materials and consistently check for understanding.
- Set clear expectations about the purpose of the CAHPS® survey, what anonymity means in practice, and how responses will (and will not) be used.
- Ensure participants know they can:
 - Choose a support person to be present during interviews
 - Request accommodations such as breaks, advance access to questions, or alternative response formats
- Provide training for survey participants in multiple formats (video, live, and written) on how to answer CAHPS® questions, including how to use Likert scales.
- Allow flexibility in response options when participants struggle with multi-point scales and provide interviewers with scripts to support consistent administration.
- Train interviewers using established accessibility and respectful interview practices, including presuming competence and speaking directly to the interviewee.
- Consider supplementing CAHPS® data with additional sources, such as focus groups or surveys of family caregivers, to capture information not included in standardized measures.

- **The State should add 3 to 5 questions to supplement the CAHPS®:**
 - **One open-ended question:**
For example: “Is there anything else you want to tell us about the quality of your services?”
 - **One housing question:**
For example: “Do you want or need to find a different place to live?”
 - **One relationship question:**
For example: “Do you have friends who are not paid staff or family?”
 - If the CAHPS supplemental employment module questions¹ are not used, **add one employment question:**
For example: “Do you want help finding a paid job or finding a different job from the one you are working at now?”
 - **One budget question:** (Note: May not be applicable to people in Choices for Care.)
For example: “Do you know what your budget is and how many hours of support your budget gives you?”
- The State may also wish to supplement its data collection with a **survey of family caregivers**.

¹ [CAHPS® Home- and Community-Based Services Survey: Supplemental Employment Module](#)

Step 2: Review Data

Reviewing data should go beyond technical analysis and include the perspectives of people with lived experience.

Recommendations:

- Involve people receiving services and other stakeholders in reviewing findings to help interpret patterns and validate results.
- Disaggregate data by HCBS program, disability type, support needs, or age group (for Choices for Care) to identify differences and target improvement efforts.
- Review CAHPS® results alongside other quality assurance data already collected by the State, including interviews and monitoring activities conducted by DDS and Adult Services, to provide context and set priorities.
- Examine indicators such as nonresponse or interview abandonment rates to identify potential accessibility barriers in the data collection process.

Step 3: Share Data

Transparent sharing of findings is essential to building trust and sustaining engagement.

Recommendations:

- Publicly post data and the State’s interpretation of results on an accessible website, even when findings point to areas needing improvement.
- Balance discussions of challenges with acknowledgment of strengths to provide a fair and constructive picture.
- Present findings to existing advisory committees and stakeholder groups, using plain language and accessible formats. DAIL already has a robust infrastructure for stakeholder engagement through the State Program Standing Committee for DDS, the DAIL Advisory Committee, and the Medicaid and Exchange Advisory Committee.
- Clearly describe how stakeholder input informed conclusions and next steps.

Step 4: Make a Plan

Planning for improvement should be collaborative, focused, and grounded in both data and lived experience.

Recommendations:

- Actively solicit ideas from stakeholders when identifying quality improvement strategies, operating from the assumption that all input is valuable.
- Look for underlying causes of systemic challenges while also identifying opportunities for smaller, achievable changes.
- Set and communicate clear quality targets and standards so participants understand what they should expect from HCBS providers.
- Close existing communication gaps by clearly explaining where standards exist, where they are still being developed, and how progress will be measured.

Step 5: Track Progress

Tracking progress and sharing updates reinforces accountability and strengthens trust.

Recommendations:

- Do not rely solely on large-scale surveys; use small, iterative data collection efforts to assess whether changes are having the intended effect.
- Share progress—and lack of progress—regularly and widely with stakeholders.
- Clearly connect reported outcomes to the priorities and plans that stakeholders helped develop.
- Invite stakeholders to help problem-solve when initiatives do not produce the desired results, recognizing their ongoing role as partners in quality improvement.

Appendix A. Advisory Committee Meetings

Meeting #1, Nov. 28, 2025

At the first meeting, the VTDDC Executive Director provided an overview of this stakeholder engagement process. This included: Why CMS was requiring new quality assurance activities; what data was being collected and how this is being done; and what the CAHPS® Survey is. The group generated a list of clarifying questions. These questions are a good indicator of the type of information that service participants are likely to want when first hearing about this quality review. Project staff agreed to bring answers to the committee's questions at the next meeting.

Meeting #2, Dec. 5, 2025

The second meeting focused on the process of taking the CAHPS® Survey. Committee members raised concerns about each step in the interview process.

- Step 1. When first learning that you have been selected for the CAHPS, service participants and family caregivers may think this is a scam. The information must come from a trusted source and be reinforced by case managers and provider agency staff. Providers on the Advisory Committee stressed the need for clear communication with all parties – service participants, provider agency staff, guardian/parents, and case managers.
- Step 2. People must be able to pick who supports them during the interview. Participants expressed distrust that their anonymity would be protected. They said that if a paid support provider – including a shared living provider – is present, that paid provider may share what they have said about services and staff. This concern was similar to issues raised in the stakeholder feedback sessions.

- Step 3. Participants need the State to be clear about the fact that taking the CAHPS may help the system improve, but it will not address a subject's specific issues with their services. This may be difficult for some service participants to understand.
- Step 4. The CAHPS® survey is long and may be taxing for individuals being interviewed. Accommodations must include having the questions ahead of time if desired, taking breaks, and spreading the interview over two sessions if needed.
- Step 5. The State must make the data and findings publicly available. There was considerable skepticism that the State would share data that would reflect unfavorably on specific provider agencies or on the HCBS service delivery system.

Meeting #3, Dec. 12, 2025

In the third meeting, Committee members dug deeper into how quality is best assessed. This raised issues for them about whether the CAHPS® Survey will give accurate and full picture of the quality of HCBS services. Key points include the following:

- Positivity Bias: Committee members were concerned that service recipients will report higher satisfaction than might be merited because they are not aware of what the standards for services are or should be. This is especially likely in the DDS system of care, where many HCBS participants have historically not known what their individual service agreement entitles them to in terms of hours of direct support². Additionally, if you have always experienced service hours a

² With the introduction of payment reform and independent case management on Oct. 1, 2025, this is expected to change. In Choices for Care, HCBS recipients appear to be aware of the support hours they should receive.

certain way – for example, you accompany your Direct Support Provider (DSP) on their errands rather than doing something in the community that you choose -- you are not likely to see this as an indicator of poor quality.

Another committee member pointed out that family caregivers may shield individuals from fully understanding that they should be receiving more support hours, rather than letting their son or daughter feel stressed or disappointed.

Alternatively, the caregiver may step in to provide the missing service, something that happens frequently to this parent.

- Failure to address issues that are the most important to service participants and family caregivers: Committee members identified several important issues that are top of mind for DDS participants – specifically, housing and housing choice; employment and jobs that align with personal interests and provide opportunities for advancement; and rights conferred by the Medicaid Setting Rule when living in a provider-controlled residence. These rights include privacy in one’s room, the ability to have guests including overnight guests, choice and control over one’s schedule, and access to food that the individual prefers at all times. Unfortunately, we did not have a wide enough sample of Choices for Care participants to assess whether compliance with the CMS Settings Rule is also of concern in this program.

Meeting #4, Jan. 2, 2026

During the fourth meeting, Committee members focused on providing feedback on the draft educational materials – specifically pages 5-13 of the draft booklet. Detailed feedback is reflected in the revisions made to this document before its final submission. General feedback included the following:

- As planned by the project staff, information covered in pages 5-13 would be better presented as a website. As a website, more detailed explanations can appear on pages behind an overview.

- Information must be provided in plain language with less jargon, shorter sentences, and familiar vocabulary. This helps all readers.
- Alternative formats, especially short videos, are desirable.
- Graphics that rely on abstract symbols (icons) are hard to understand.

Meeting #5, Jan. 16, 2026

The fifth meeting focused on reviewing the key themes and recommendations of the Advisory Group. These are found in Section 6 of this report. The Committee's findings were consistent with the concerns and ideas that emerged from stakeholder feedback sessions.

Appendix B. Summary of Themes

Across Stakeholder Feedback Sessions

Comments from stakeholders fell into three broad categories:

1. Concerns about the process of data collection, especially when interviewing people using the CAHPS® Survey.
2. Areas important to HCBS quality not included in the Vermont HCBS Measure Set.
3. Concerns about the current state of HCBS in Vermont. Participants shared some of these issues so that the State may be better prepared for what it will hear.

Category 1: Data Collection Process

Barriers to honest feedback

Stakeholders in Developmental Disability Services (DDS) said there are many reasons why people taking the CAHPS® Survey may not feel it is safe to say what they think about their services. This did not appear to be a concern for people in Choices for Care, though the sample size was very small.

- **Fear of getting in trouble:** Many people in DDSD said they are afraid that if they tell the truth, staff might get upset or their services could be taken away.
- **Worry about privacy:** People are worried that what they say will not stay private. They fear their comments will be shared with agencies, and that staff will figure out who spoke up, even if names are not used.
- **Who is present:** The person should be encouraged to do the interview without providers being present. Currently, DDSD quality assurance staff often interview people who get services in the presence of their providers.
- **Safety and mandated reporting:** Some people are afraid that talking about past mental health crises could lead to being hospitalized against their will. Others are confused about privacy when the interviewer is also a mandated reporter. People

want the State to describe the steps that will be taken if a person reports abuse or neglect. They also want to know if the interviewer will make sure that a person is safe before ending the interview.

- **Transparency:** People worry that the State will not share what it learns from the interviews, especially if there are serious problems with services. People want the State to clearly explain how the information will be used and how the results will be shared with them and with the public. This skepticism was common across both DDSD and Choices for Care. Both service participants and family caregivers voiced concern that this process would not lead to genuine improvements.

Providers want to be sure that they receive the data set that is specific to their agency so that they can develop internal strategies to make improvements. However, the pool of responses for a given agency needs to be large enough so that individual answers cannot be identified. This may be a problem for smaller agencies.

Accommodations

- Is there a formal process used by CAHPS interviewers to ask people ahead of time what accommodations they need to participate in an interview?
- People would like to be able to bring notes with them to the interview. This will help them remember the answers they formed during a prep session. (People [use this accommodation](#) when voting or going to the doctor).
- People asked to receive the questions ahead of time, both in writing and as a recording. This is an important accommodation for people who use augmentative and alternative communication, and for people who may process information differently.
- During the interview, participants want the questions available in writing to follow along, using an accessible format and font.
- Several participants said they would feel more comfortable if the interview were conducted by someone who also has I/DD.

- People asked for a slower pace. They requested quiet, private rooms where no one else can hear.

Other Process Concerns

- **Confusion about confidentiality / anonymity:** Many people find it hard to trust that the interview is anonymous because the State uses their name and relies on providers to schedule the interview. This lack of trust was expressed by participants in both Developmental Disability Services and Choices for Care.
- The **CAHPS® survey seems to be best suited for people getting Personal Care Attendant services.** It is not as good a match for people who get DDS.
- **Hard to access:** People said the survey is too long, not written in plain language, and hard for people who type to communicate or use assistive technology. Participants want to know that they can take breaks or finish the interview over more than one session.
- **Choosing your own support person:** Participants want to pick who supports them during the interview, such as a peer, friend, or family member, instead of having agency staff in the room.
- **No open-ended questions:** The survey does not give people space to explain their answers in their own words. It is hard to talk about the quality of services by only choosing yes/no or number-scale answers. This concern was voiced by both service participants and family caregivers
- **Scaled questions are confusing:** Some people may need help in plain language to understand how to answer scale questions (like always, usually, sometimes, never).
- **CMS recommendation to have alternative scales is also concerning.** There is concern that changing four choices into only two takes away people's choices instead of making things easier to understand. It is an important principle of plain language that information is not taken away but rather translated into simpler sentences and vocabulary. However, the guidance for the CAHPS® Survey directs interviewers to rephrase scaled questions as just two options:

“Mostly yes, or mostly no.” An alternative to this alternative is to have clearer instructions, and perhaps visual or other aids to clearly explain the original scale choices.

- **Family voices are missing:** The CAHPS interview is directed to the person receiving services. Family caregivers often see things differently. For example, one parent said her son might say his living situation is fine, but his parents—who are in their 70s—know this situation is not sustainable.
- **Situations where family are paid caregivers:** It is more common in Choices for Care for a parent or spouse to be paid as a caregiver. There is confusion about whether a service participant should answer CAHPS questions about a paid family caregiver. Talking about a paid family caregiver increases concerns about confidentiality.
- **Knowing what to expect:** Participants said they need plain-language explanations ahead of time about what stays private and what must be reported, so they can decide what feels safe to share.
- **Provider concerns:** Providers said that assisting in scheduling interviews and answering questions from service participants will add to their administrative workload. For the rollout of the CAHPS® Survey, providers said the need: (1) Plenty of advanced notice from the State; and (2) Clear communication from the State, including messaging that they can share with service recipients and caregivers. The State should provide information that explains why someone might want to participate in the CAHPS.

Category 2: Areas of HCBS Quality Not Addressed in CAHPS

- **The CAHPS® survey does not ask** about some big issues that affect people’s quality of life. For example, it does not ask if people have choices about where they live, if they understand their budget and services, or if they know their rights when providers control their housing and support.
- **Inclusion in decision-making:** People often described feeling left out of meetings about their services. Some believe providers meet without them, make decisions

“behind closed doors,” and then expect the person to agree in follow-up meetings. The CAHPS does not address this core right.

- **HCBS Settings Rule and Access Rules:** The survey may not fully capture HCBS rights. For example, it may ask whether a person gets food when they are hungry, but the Settings Rule also includes the right to choose where to eat (including in their room) and to have choice about what they eat.
- **Choice of staff:** CAHPS asks how staff treat the individual. However, CMS rules also emphasize the person’s right to choose their staff, which is not addressed in the CAHPS.
- **Following the person-centered plan:** Participants emphasized that staff should follow the goals in the person-centered plan, but this is not clearly asked in the CAHPS® Survey.
- **Looking out for others:** Some participants said that people who can speak up often watch out for people who cannot. They suggested adding a question about observations of how respectfully staff treat other people, not only the respondent.
- **Privacy and confidentiality:** Survey questions about privacy appear limited (for example, privacy while dressing). A major concern is privacy around personal information and confidentiality—including fears of staff talking about people or sharing information without permission. Another confusing factor is that some people have been interviewed in the past about their services as part of other quality assurance activities. Interviews conducted by the DDS Division are not anonymous.
- **Role confusion:** Even a year from now, some participants may still confuse roles (for example, a service coordinator from the provider agency vs. case manager from Benchmark or Columbus). Interviewers may need prompts and follow-up questions to clarify who the person is talking about.
- **Integrated community access:** The Settings Rule focuses on access to places and activities that people without disabilities enjoy. The survey may ask whether someone “goes out in the community.” However, people may count segregated activities like a day program as a community outing. They may also count

activities that they did not choose -- for example, errands that the service provider needs to run -- as “being in the community.” Interviewers may need follow-up prompts to clarify whether activities are truly integrated, community opportunities that the service participant has chosen.

Category 3: Overall Quality Issues with HCBS

- **Not knowing what “good support” looks like:** Some family members said they don’t know what quality support is supposed to look like because they have never experienced it. Others, including service participants, shared that they don’t know what the standards of care are. This makes it hard to know what to report or how to rate one’s services.
- **People who get HCBS clearly described high quality services as:** Treat us with respect and realize we are intelligent. Slow down, take time out to understand us. Avoid judging. Care about us. Have kindness towards us. Do not have too much negativity around us. Be honest and reliable. Understand our rights. Meet our needs. Follow our goals in our individual service agreement (ISA). Help us make informed decisions, not make decisions for us. Nothing about us without us. Support us to advocate for ourselves. Support us to access the same opportunities as people without disabilities.
- **There are differences** in how people in DDS describe quality services and how people in Choices for Care describe quality services. For example, while both groups said respect is important, people in Choices for Care said respect is shown by being on time, following the directions of service recipients, and consistency in the staff that the agency sends. People in DDS were more likely to think of respect in terms of good communication and support to make one’s own choices (see above).
- **Unmet needs:** Families shared that some people only receive a small fraction of the hours for which their son or daughter is approved. For example, one parent said her family member is approved for 25 hours/week but typically receives only 3 hours/week. Others said they have not gotten any services at all for years.

- **Lack of training:** Family caregivers said that staff and agencies often do not work well together. One person said, “the right hand does not know what the left hand is doing.” Families also shared that many staff are not trained to support people with serious medical or mental health needs. Parents said they feel exhausted trying to manage care on their own. They often coordinate doctors, programs, and services because agencies do not have enough specialists trained to manage complex medical and/or mental health needs.
- **Communication problems:** Families said agency leaders and case managers often give different answers about housing and available services, which makes things confusing and stressful.
- **Transparency around individual budgets:** Caregivers and self-advocates want to know their real budgets. They also want an easy way to share feedback about providers—like a “Yelp-style” system where people can rate services. People in Choices for Care seem to have a better understanding of their individual budget.
- **Outdated System Model:** Some self-advocates described Vermont's system as outdated, focusing on "taking care of" people rather than supporting personal choice and independence.
- **HCBS Rule Violations:** During almost all of the GMSA focus groups, people shared examples of rights violations, including unjustified restrictions on community access, food choices, and having visitors.

Appendix C. Summaries of Stakeholder Feedback from Each Session

The purpose of this appendix is to summarize feedback from each stakeholder feedback session for this project.

GMSA Leadership Retreat (May 20-21, 2025)

Attendance: 25 Peer Leaders with IDD representing 16 local self-advocacy groups gathered for a two-day retreat.

We imagine a world where people with disabilities are treated with dignity, respect, and fairness – not judged, ignored, or treated as second class. In this future, our rights are respected, and we do not have to fight to get what we need.

People are listened to and believed. Doctors, police, service providers, and community members understand how we communicate and respect our lived experiences. Abuse is taken seriously. Everyone has enough time to understand information, ask questions, and speak up for themselves.

We live the lives we choose – where and how we want – with strong circles of support. We feel safe and welcome in our communities. Transportation, therapy, health care, education, and basic needs like food are easy to access.

People with autism and LGBTQIA+ identities are respected and celebrated. There is no stigma. No one is talked down to or treated differently because of disability. Feel bad about yourself because you have a disability instead you feel proud, confident, and positive self-belief.

We have equal chances for relationships, marriage, parenting, friendship, learning, faith, and fun. We have jobs we enjoy that use our talents – not jobs chosen for us because of low expectations. Our goals are possible. We are happy where we live.

Everyone learns how to advocate – generation after generation. Friendly debates are welcome. Different ideas are respected. People trust each other, communicate with kindness, and use more positive words than negative ones. Most of all, we belong. People know us. We are respected. We have the same rights as everyone else – and we are free to be ourselves.

Vermont Developmental Disabilities Council Meeting (September 25, 2025)

Meeting Attendance: 12 Governor-appointed members who are self-advocates (4) or family members (8); and 4 allies from non-profit disability organizations.

Purpose: This was the inaugural meeting for Council members to develop their next Five-Year State Plan. The Executive Director provided an overview of current issues in (1) Vermont HCBS generally and (2) Housing and Residential Services specifically. She invited Council members to contribute to a SWOT analysis mapping the Strengths, Weaknesses, Opportunities, and Threats for each of the two topics.

Key Finding – Change is destabilizing. Members described a system of care undergoing tremendous change. New federal rules, the restructuring of agency payments, workforce shortages, and federal cuts to Medicaid and HUD are some of the factors threatening the stability of Vermont’s HCBS system.

Key Finding – opportunities to advance quality in HCBS. Many of these changes are supported by the Council as long-overdue – for example, independent case management is a necessary condition for ensuring that people can advocate for the services they need. Council members see opportunities to improve HCBS through data collection, cost-based rates, greater transparency, and more quality oversight.

GMSA Board Meeting October 27, 2025

Attendance: 17 people with IDD participated in this focus group about people's quality concerns.

The group talked about the need to mobilize, speak up, and involve more people (including high school students).

Stigma and safety: One advocate raised concern about increased stigma and misinformation about autism, and another participant connected that to other groups facing stigma (LGBTQ+ people, immigrants). The group emphasized the need to fight stigma through strong peer support.

Peer-to-peer support must continue (and grow):

- One speaker said peer-to-peer education about HCBS rules/rights needs to keep going after current grant money ends, and that both people with IDD and providers need ongoing education.
- Another participant added that peer support and lived experience are essential for connection and inclusion work.
- A third member said the impact should be stronger, including making sure providers know the rules so they can't claim ignorance.

Examples of rights problems in services/supports:

- A participant gave examples of people being restricted from community access and not being able to choose the food they want even when room-and-board money is supposed to cover food.
- There was discussion that people may fear retaliation for "rocking the boat," especially when staffing is limited.

Medicaid anxiety: A member shared worry about Medicaid during a government shutdown and fears of losing services. Another noted administrative barriers could increase (like needing to re-apply more often), and people may need more help not to fall off coverage.

Transportation, work, and daily-life barriers:

- One person described transportation breakdowns keeping people from community life and services not meeting needs, especially for autistic people and people with behavioral/mental health needs.
- Another shared struggles with transportation, reduced support hours, loss of food stamps due to working, and stress about family members needing more help.
- A third individual described problems at work and wanting more hours. Another member added that this person currently doesn't receive services but likely needs support.

Family and relationships: A participant shared a major barrier to seeing her sister (who lives in shared living). Another member framed this as a basic right to see the people you want to see.

Housing: One advocate described years of unsafe housing (mold, mice, high costs) before finally getting Section 8 after a long wait, and another participant noted people are sometimes discouraged from getting on housing waitlists.

Immigration/ICE concern + independence: Two members expressed fear about ICE encounters, especially for people with disabilities who may have communication barriers. One also wants to live on his own and raised questions connected to family/guardianship and moving.

GMSA One-Day-Conference in Montpelier, VT (November 3, 2025)

27 adults with IDD participated in a focus group about rating services.

- The focus group revealed a shared belief that rating services is fundamentally important. For many, it's a crucial tool for agencies themselves. **"It is very important so agencies know what is working and if something is not working, they can correct it,"** one person stated, explaining that these insights allow for practical changes, from changing staff to changing what we do every day. These ratings help agencies

“spot where they need to do more training” and understand their own strengths and weaknesses, which is also vital for the state to oversee care and ensure people are receiving their services.

- For individuals receiving care, the process carries deep personal weight. One contributor emphasized, **“Rating my services is important so my family knows I am safe.”** Others pointed out the need for these assessments to clearly demonstrate **“where shortcomings are such as better meaningful employment and educational opportunities”** and to make undeniable **“how short staffing is impacting the individuals with disabilities.”** They highlighted specific gaps, noting **“we need better support to understand social security and other benefit programs because not all agencies have trained staff to help with those areas.”**
- A powerful theme was the essential role of lived experience. **“Ask us because we are the experts. We are there 24/7,”** was a direct call for inclusion. This aligns with the perspective of a disability rights advocate, who stated, **“For GMSA the satisfaction of the disability community is our #1 concern. As a disability rights organization we need to set a good example by asking people about their services.”**
- Finally, there was reflective insight into why this external prompting is sometimes necessary: **“We are disabled. We might need help to reflect on our services because we don't immediately pay attention to it, to the quality of our services.”** Together, these comments form a narrative that sees service ratings as a multifaceted tool for accountability, improvement, safety, advocacy, and authentic inclusion.

GMSA One-Day-Conference in Burke, VT (November 12, 2025)

17 adults with IDD participated in a focus group about rating services.

- There are a lot of reasons why we need to rate our services. First, it's important because **“the state and government need to track the quality of something they fund.”** They—and we—need to know if we are actually getting the support we're meant to have. At its heart, it's **“to make sure you are getting the right services provided by staff.”**

- For us personally, it's vital. "Because we need to know if our services are working for us." It's true: "If you don't stop and think about your supports, you might not know what is actually working for you. If we don't think about them critically, we can't really answer that." You have to advocate for yourself—"you want what is right for yourself, if they gave you the wrong staff, you can tell them to put them somewhere else." And when you find the right fit, you want to protect it. Like one person said, "I like the staff I have now and if the agency puts a monkey wrench in it—it is not okay." Because, while "some of the staff are helpful," the surveys really "show your coordinator which staff are the right fit or maybe it is the wrong fit."
- The act of reviewing services is powerful. "When we are given the opportunity to rate our services it allows a person to start speaking up for themselves."
- Finally, it's bigger than just us. "When new clients are trying to get services, they will get an idea about agencies from people who do surveys." Our voices create a roadmap for others. "It is important to do surveys because some of us don't get what we want out of our services. This is important feedback for people coming into services."

VTDDC Council Retreat (Nov 15, 2026)

This session provided direct feedback from individuals receiving services, revealing a wide range of living experiences.

- **Safety Concerns:** One participant described an unsafe environment in a group home where staff were distracted by phones while a housemate became violent.
- **Barriers to Independence:** Some individuals want to live more independently but feel they are not being given the support or training to learn necessary life skills like cooking.
- **System Comparison:** A participant who recently moved from Maryland noted that Vermont's system "feels like it's still the 90's," focusing more on "taking care of people" rather than supporting personal choice.

GMSA One-Day-Conference in Manchester, VT (November 18, 2025)

24 adults with IDD participated in a focus group about rating services.

- Direct support staff said, simply put, **“we need to know what you need and what works for you.”** This feedback is important in so many ways. The whole concept of person-centered planning—services tailored just for you—falls apart without it. **“We can't do that without feedback from you.”**
- The rest of the comments are from people with IDD. For agencies, it's a guide. “Agencies need to know what to do more of.” And we want to say, “thanks for supporting us out in the community and in the workforce, a thank you for everything.” But it's also a vital check: “Is this agency a good and safe place to work for? It is a safety thing.” When staff are respected and secure, we are too.
- Looking ahead, “the ways to move forward for the future we will need to know what to do and how to help people. The state needs to know what to do, how to move forward in the future.” It all comes back to one goal: “to support our services, to support me better.” This process affirms that “our opinions, my opinion matters.” When it works, it's wonderful. “I am happy with the people on my team, they respect me, and some day down the road I will accomplish things. Every day is a step-by-step process.”
- But there are real frustrations that this feedback must address. There's a “lack of transparency on the part of the state about what is going on with our services.” And this painful question hangs in the air: “Why is it that agencies get all this money and we are not getting services?”
- Our voices in these surveys carry all of this—the gratitude, the needs, the hopes, and the rightful demands for accountability. They are the bridge between the life we have and the life we deserve.

GMSA One-Day-Conference in Burlington, VT (November 21, 2025)

33 adults with IDD participated in a focus group about rating services.

- Direct support staff said we do this for so many reasons, but they all connect. It starts with the basics: **“So, they can get more money to support our programs so we can do more.”** Funding fuels our ability **“to make improvements.”** But those improvements aren't random; they must come from the true purpose, which is **“to hear people’s voices”** so we can genuinely **“improve people's lives and make things better.”**
- The rest of the comments are from people with IDD. It's also about the day-to-day security of having real support. It means **“to be able to call them and ask questions if we are having a difficult time. When we have a problem to be able to get in contact with people we work with.”** This is how we **“get good support in your community”** and how we can **“let other people know you are getting good support to be out in the community.”**
- Our feedback isn't just for our agencies; it's a direct line to those in power. It's **“to tell the state so they know if we are getting the proper services. If we are not, then the state can look into it.”** This accountability is more urgent than ever. **“We need to voice when it is working and how important our services are especially with the Medicaid cuts that may be coming.”** The stakes are terrifyingly high. **“If we lose services, it will be a black hole.”**
- We know what we're talking about. **“Maggie from Bernie Sanders's office visited our group and was surprised at how much we know about our rights and getting services.”** Our knowledge is our power, and reporting is how we use it. Ultimately, we have to speak up because of the **“lack of transparency on the part of the state about what is going on with our services.”** In the silence, our needs can be forgotten. In raising our voices, we fight for our lives.

GMSA Two Virtual Focus Groups held on November 22 & 24, 2025.

29 adults with IDD participated in a focus group about concerns with CAHPS.

- We're all wrestling with the same heavy question: what's the worst that could happen if we speak up honestly? There's a shared fear that agencies will find out who said what comments. **"I think having it go back to your service provider or going back to staff,"** one person says, and the room agrees with a chorus of "Yeah," and **"Going back to staff. What you said will get back to people."**
- This fear has real consequences. Some worry about retaliation; "I think, you know, from what I see, it's about not being taken seriously," says a speaker, voicing a deep frustration with the state. "They come and ask you questions and they don't take you seriously, literally. They just say things just to get you off their back... when you ask for help or ask for services, they'll just toss you aside." Others fear more direct fallout: "That my services get worse, or they would fire staff," or the paralyzing anxiety that speaking up could be used as a reason for cuts, especially with rumors of "big Medicaid cuts." "I'm afraid what I say will be used to cut our services, that would suck," one person admits, articulating a terror many feel about losing the lifelines that allow them to be in the community.
- The core issue is a breakdown in communication and power. People feel talked over, not collaborated with. **"A lot of times, I feel like people are talking for me and talking at me, not talking *with* me,"** one person shares. This leads to a stifling silence, where individuals **"have not wanted to say anything when they have their staff around so they wouldn't upset 'em,"** worrying a truthful critique could strain a vital relationship.
- Yet, within this fear, there is a clear blueprint for courage. The group identifies what they need to feel safe enough to be honest. They ask for preparation: **"Maybe write down your answers with somebody... work on it together."** They demand transparency and confidentiality: **"I think there should be something in writing that the conversation should be not going anywhere... it needs to be confidential."** And

they want the process to be a real dialogue, not an interrogation. They want **"the opportunity for us to ask questions as well."**

- Ultimately, their goal isn't just to complain, but to fix things—together. As one speaker perfectly captures this balanced hope: **"If there's something you don't like about your services, I want them to know that you don't like it and have them see if they could help you fix it... with you, not at you."** They speak up not to cause trouble, but because they believe in the promise of their services and are advocating to protect and improve them for everyone.

GMSA Virtual Focus Groups held on December 2, 2025.

8 peer trainers with IDD participated in a virtual focus group about concerns mandated reporting.

- The rules for mandated reporting often leave us feeling trapped and unheard. We understand you want to keep us safe but it creates a profound **loss of control**. Our private traumas become public within our agencies, as rules require reports to travel "up the chain of command," breaching our confidentiality. Because of this, **"the last place they would go for help would be their agency."**
- This breach erodes the very trust we need to be safe. The act of reporting can feel like a betrayal by staff we rely on, and we fear judgment or blame if an incident happened while we were, for example, drinking or with the "wrong people."
- Our deepest fear is that a report will trigger severe consequences that strip away our hard-won independence. We worry about being moved to a more restrictive setting, having a financial payee assigned, or worst of all, being placed under a guardianship by a court.
- What we need is **choice and self-determination**, especially after a crisis like sexual assault. We emphasize that **"people should have the choice to talk to a mandated or a non-mandated reporter."** We need access to confidential hotlines where we can speak freely. Above all, we want to be in charge: **"I would rather make the**

report myself; Be there to give support but let me do the talking." We ask for transparency from staff: **"Let me know ahead of time if they have to report."**

- We also see practical flaws in the system that make reporting seem futile or unfair. With APS substantiating less than 20% of cases, we wonder if the risk to our autonomy is **"worth it."** The separate pathway—reporting to APS instead of police—feels discriminatory and less effective. We are left in the dark about outcomes, lacking transparency.
- Ultimately, we find the experience deeply violating and stigmatizing, as **"having everyone in the whole world know your business is stigmatizing and uncomfortable."** While we understand the need for protection, the current climate of mandated reporting creates fear and disempowerment. We request a system that finally prioritizes our **choice, confidentiality, and control.**

GMSA Two Virtual Focus Groups held on December 9 & 10, 2025

20 adults with IDD participated in a focus group about concerns with CAHPS. A few people were at both sessions.

- The group's voices came together to paint a clear and deeply personal picture of what makes a supportive service—and what makes a respectful interview. It all starts with being seen as a whole person. **"I want them to see me as me as a regular person and not a person with a disability to be judged,"** one person stated, a sentiment echoed by others who asked for **"love," "kindness,"** and **"patience."** This respect must extend to every part of their lives, including **"respect my religion"** and, powerfully, **"Please respect my imagination."**
- Communication is a major theme, filled with both frustration and hope. Many experienced being talked about, not with. **"Conversations about my life happened behind closed doors,"** someone shared, while another cited the old adage: **"nothing about us without us."** This lack of transparency erodes trust. To build it back,

interviewers need to **"not put words in our mouths,"** use **"plain language,"** and provide questions ahead of time so people can prepare with someone they trust.

- A significant worry hangs over the conversation: the fear of retaliation. People are terrified that honesty could lead to **"poor services or worse staffing"** or that their directness could be pathologized. **"I worry they're gonna think that I'm just being a danger to myself and others, and they will involuntarily admit me,"** one person said, recalling the trauma of past institutionalization.
- Yet there are bright spots—stories of staff who show up with reliability and shared connection. **"I really like my community worker. We have a lot in common... if she's not going to be at work, she lets me know,"** one person shared. Another found common ground in shared heritage: **"he is Greek as well, so we have something common there to be able to talk about."** These relationships are built on **"honesty"** and the simple, profound act of listening. As one person noted about a good staff member, **"Well, he listens when I talk. And it is okay if I don't want to talk."**
- The group's final plea is for interviewers who can truly understand. Many suggested that an interviewer with a disability or neurodivergence would create an immediate, safer empathy. **"If I had an interviewer who also had autism, then it would be easier for them to understand what I'm talking about,"** one person said. Ultimately, they are asking for a partnership—to be included, believed, and supported in their full humanity, without fear.

VTDDC Family Caregiver Mid-Day Session (Dec 11, 2025)

This session highlighted a profound **lack of services**, with some families receiving few to no hours despite having high-need authorizations. There was a significant lack of trust in agencies, with one parent noting they feel they must "solve their own problems" and then educate agency staff.

- **Key Issues:** Participants emphasized that "quantity" of hours is just as important as quality, as many authorized hours go unfilled due to a lack of staff.

- **Agency Constraints:** Concerns were raised that agencies are "handcuffed" by an inability to pay livable wages.
- **Clinical Needs:** Families with an adult with co-occurring psychiatric disabilities expressed a desperate need for more clinical support, such as psychiatrists and Board-Certified Behavior Analysts (BCBAs).

VTDDC Family Caregiver Evening Session (Dec 11, 2025)

Caregivers in this session defined quality primarily through the lens of **staffing stability and expertise**. Participants expressed frustration over agencies "shuffling" staff, which causes distress for individuals with high needs or transition anxiety.

- **Key Issues:** Families noted a lack of training for staff dealing with medically fragile or nonverbal individuals.
- **Systemic Gaps:** Aging parents expressed deep concern about what will happen to their adult children when they can no longer provide care, citing a lack of supported housing options in Vermont.
- **Financial Impact:** Some parents in their 50s and 60s reported having to leave the workforce to provide the 24/7 care that the state is currently unable to fulfill.

GMSA Virtual Focus Group on Confidentiality and Mandated Reporting (December 15, 2025)

16 people with IDD participated.

- A central question was posed: What does confidentiality mean in these interviews? One advocate defined it clearly: "Confidentiality is keeping what you say private... That means not telling others what you said. Or not telling others you've said something." The group agreed that this privacy was essential, with members emphasizing the need to protect identifiable details. As one person stated, this means "keeping your name out of it... your name, where you live, Social Security

number... anything that could be used to identify someone." There was a thoughtful debate about whether naming an agency would break confidentiality, with one participant arguing, "We want the agency to improve. That's what the goal is, really," while others worried it could lead to identification.

- Practical suggestions for ensuring privacy emerged. People stressed the need for a private setting for interviews, noting that **"Certain apartments or offices have paper thin walls."** The idea of using a "cheat sheet" in plain language was raised, so individuals could bring notes to remember what they wanted to discuss. This was deemed vital, as one member shared, **"I need my ipad or I'm not gonna remember, I'm gonna freeze up in the interview."**
- The dialogue then turned to the more complex topic of mandated reporters. The group learned that the interviewers themselves would be mandated reporters. While recognizing the protective intent, concerns surfaced. A major point of consensus was the need for clarity and empowering education on this subject.
- The group passionately advocated for self-determination in the reporting process. One leader highlighted a key principle: "GMSA advocates for a person who would like to do the reporting themselves to APS and not just letting the interviewer take over the process." This approach, they noted, both empowers the individual and protects their privacy under APS rules.
- To teach these critical concepts, the group brainstormed engaging, accessible methods, and rejecting lectures. Suggestions included interactive role-plays and plain-language videos to demonstrate scenarios. The need for a clear, "plain language" description of the APS process and steps was emphasized.
- The discussion closed by acknowledging the delicate balance they must prepare for: understanding that their feedback is generally confidential, but that disclosures of harm trigger a mandated report. The goal, as one facilitator summarized, is to equip people with knowledge so they can navigate this balance and speak their truth. The shared mission became clear: to create supportive, clear, and empowering resources so everyone feels prepared and in control for the 2027 interviews.

VTDDC DDS Provider Session (Jan 19, 2026)

Executive Directors from two major agencies discussed the upcoming implementation of the **CAHPS (Consumer Assessment of Healthcare Providers and Systems)** survey.

- **Provider Needs:** They requested clear communication and "plain language" scripts from the State to help explain the survey to participants who may feel "bombarded" by recent system changes.
- **Transparency:** Providers advocated for data to be shared and disaggregated by agency so they can use the feedback to make tangible improvements.

VTDDC Flexible Choices / Choices for Care Session (Jan 23, 2026)

Participants who self-manage their care discussed the practical barriers to the CAHPS® Survey including 5 Choices for Care service participants & 1 family caregiver.

- **Survey Privacy:** A major concern was that participants would not feel safe being honest about staff if that same staff member was present to help them take the survey.
- **Accessibility:** Participants noted that the "4-point Likert scale" used in the survey is confusing and suggested that questions be provided in advance for those who use typing to communicate.
- **Paid family caregivers:** This group is more likely to use paid family caregivers as their primary support. There were questions about how this type of provider is handled in the CAHPS. A service participant is very unlikely to feel comfortable rating the care provided by a parent or spouse.

Quality Metrics: For this group, quality is defined by staff being respectful, showing up on time, and following the specific care instructions provided by the participant.