



Better Health Together (BHT) Meaningful Consumer Engagement Summary Report

A Summary of Consumer Input Used to Inform Medicaid Transformation Demonstration (MTD) Project Selection and Planning, and to Design BHT's Long-term Meaningful Consumer Engagement Policy and Strategy

Overview

The BHT Meaningful Consumer Engagement planning process involved several tiers of activity designed to secure input into the selection and planning of MTD projects and to yield a recommended policy and strategy for the BHT Board to consider adopting for ongoing meaningful engagement of consumers in future Accountable Community of Health (ACH) and MTD activities. This report details findings from the first phase of activity: consumer focus groups.

Methodology: Consumer Focus Groups

In total, 40 consumers participated in focus group discussions to inform the selection and planning of MTD projects for the BHT region and to provide opinions and ideas for establishing a long-term meaningful consumer engagement strategy for the activities of the ACH. The following groups were coordinated in partnership with a variety of community host organizations:

- Youth in Foster Care and/or Recently Aged Out of the Foster System (in partnership with Embrace Washington, Career Path Services, and Safety Net)
- Tribal Members and Urban Indian Community Center Visitors (in partnership with the American Indian Community Center and Empire Health Foundation)
- Rural Residents throughout North East Washington (in partnership with Rural Resources)
- Rural Residents throughout Lincoln County (in partnership with Lincoln County Health Department)
- Urban Residents throughout Spokane County (in partnership with Community Health Association of Spokane/CHAS)

Names of focus group participants are held confidential, but host organizations verified attendance and group composition has been validated for diversity to represent the following characteristics of attendees:

- Geography (rural, urban, tribal)
- Race and ethnicity
- Gender
- Age
- Health conditions
- Social determinant needs

Consumer Input Regarding Medicaid Transformation Demonstration

Consumers Define “Good Health”

In an effort to learn baseline health knowledge and self-determined health priorities, attendees were asked the open-ended questions, “what does good health mean to you/how do you define good health?” The following themes emerged:

- **PERSONAL HEALTH BEHAVIORS AND CAPACITIES:**

- All focus groups identified healthy diet and exercise as key contributor/indicator of health.
- All groups touched on healthy relationships (family, friends, marriages) as important predictors of health, and many participants referenced life purpose and/or spirituality as key drivers of well being.
- Many participants referenced the ability to do what you want/need to do in life and to take care of your family’s needs.
- Most referenced advocating for your health (asking questions, researching, learning how to navigate health care).
- A few discussed prevention (starting to care for your health young, not waiting until you are sick) and a few indicated that “not needing to go to the doctor too much” is a marker of good health.
- A few indicated that freedom from disease or chronic health conditions is a factor of health.

- **BASIC NEEDS AND SOCIAL DETERMINANTS**

- All focus groups identified access to safe, affordable, healthy housing as a critical factor for health, and a number discussed homelessness specifically as a deterrent to health.
- All groups discussed food security and healthy food as a key factor, with the most prominent observation summarized by one participant as, “you can’t be healthy without healthy food, but you can’t afford to buy healthy food and even the food banks provide some of the most unhealthy food around like unhealthy carbs and empty calories.”
- Transportation was cited as a key factor contributing to health, particularly among rural, tribal, and foster system participants, noting that you can’t access healthy food, medical appointments, or safely get around without good transportation and it is a key factor in reduced health.

- Rural, tribal, and foster system participants all discussed the need for sufficient financial resources to meet your basic needs and to access healthy foods and health services.
- **ACCESS TO APPROPRIATE HEALTH CARE**
 - All groups noted that access to health care was important, particularly citing “regular checkups, immunizations, and preventive care like mammograms,” as important to health.
 - All groups referenced access to necessary prescription medications, particularly for chronic conditions (such as diabetes), and the difficulty getting the right medications in the right amounts at the right time as a challenge. Prescriptions were heavily discussed in the Tribal group.
 - Several groups had robust discussions about knowing how/when/where to get appropriate care, and knowing how to use your coverage (indicating that it requires lots of time, work, and self-advocacy to utilize Medicaid benefits).
 - All groups noted that oral health was important, though they focused more on access to dental treatment, restoration, and the challenge in finding providers who would take Medicaid and affording services that Medicaid won’t pay for (dentures, crowns) as a significant barrier to health.
- **BEHAVIORAL HEALTH AND SUBSTANCE USE, STRESS, EMOTIONAL WELLBEING**
 - Behavioral health was a dominant topic of conversation in every group, with participants suggesting that:
 - People don’t talk about it enough and/or there is stigma regarding mental health and addiction.
 - There are insufficient resources to meet the needs (insurance coverage for various services, lack of trusted service providers particularly in rural and tribal areas.
 - Family trauma and historical trauma create significant health challenges particularly for youth in foster care/aging out and among Tribal populations.
 - Access to substance abuse treatment is wholly inadequate across the board (lack of immediate access, lack of coverage, lack of culturally-appropriate options).
 - The opioid epidemic has had a profound and personal impact on most attendees (either personally or family and friends).
 - The response to this epidemic is causing stigma in rural communities (e.g., community members feeling judged and labeled as drug seekers when they have documented issues).
 - The lack of provider choice, treatment delays, and coverage issues make successful treatment difficult.
- **SIMILARITIES AND DIFFERENCES AMONG GROUPS:**
 - Rural residents and Tribal populations focused far more than their urban counterparts on:
 - Basic needs and social determinants issues (housing, transportation, food security, healthy food access).
 - Lack of health care provider choice, the importance of (and lack of) trusted health care relationships, and the need for more access to immediate, tailored (culturally, individually) behavioral health and substance abuse treatment.
 - Youth in Foster Care/Aging Out and Tribal populations focused on behavioral health challenges, addiction, and other issues related to family and historical trauma.

- Rural residents focused more heavily on utilizing trusted relationships (family, friends, neighbors) to help answer health questions, connect one another to community supports.
- Urban residents focused more heavily on self-advocacy to ask providers questions, seek out coverage and care options through their MCOs, and research health and health care options through various resources online.
- All focus groups demonstrated an immediate and robust tendency to collectively problem-solve health or health care challenges, and to share resources with and coach one another when a member noted a health or health care problem (e.g., problems getting access to dental care, challenges with prescription medications and coverages, difficulty with behavioral health or addiction treatment access).

Consumers Explore Health Care, Health Care Challenges, and Health Care System Ideas

Once participants were grounded in their open-ended thoughts on health and health-care, they were asked the following open-ended questions:

- “What does good health CARE mean to you?”
- “What gets in the way of getting the health care you need?”
- “What health or health care access supports do you wish you had for you or your family?”
- “If you had a magic wand to make any change you wanted in the health care system, what would you change to make health care easier to get and health easier to keep?”

These conversations yielded the following themes:

- **PRESCRIPTION ACCESS:**

- Participants cited challenges getting prescription medications needed for chronic conditions (diabetes, Parkinson’s), with delays, multiple trips to the pharmacy, uncovered items, having to get prescriptions from pharmacies outside of their neighborhoods because of insurance coverage, and going days without needed prescriptions due to MCO approval processes. Many participants shared some version of this comment, “It is so hard to get approval for the right medications, even if you have something like diabetes.”
- Their primary concerns dealt with the approval process, changes in formularies, and cost of medications and supplies (e.g., syringes, diabetes testing supplies). One participant shared that family members and friends sought out “donations” of prescriptions and supplies for her from other community members or gave her medications and supplies left when another individual passed away, as they knew she didn’t have access to what she needed on a regular basis.

- **DENTAL HEALTH ACCESS:**

- Dental health was raised in all focus groups, with concerns regarding finding dentists who take Medicaid, getting care for uncovered dental needs (dentures, oral surgery, crowns), and the need for rural residents to drive to urban centers to find providers who will take Medicaid.
- Participants noted that they were “waiting for teeth to fall out” or “walking around in constant pain” because of oral health issues.

- Attendees frequently stated, “I’ve called dentist after dentist trying to find someone who would see me.”
- Only one group focused a very brief discussion on preventive dental health or oral hygiene, yet all groups focused primarily on the need for/lack of access to treatment for severe dental issues resulting from lack of appropriate preventive care.
- **VISION CARE:**
 - Vision care, particularly glasses, were discussed at every focus group. Participants expressed frustration with difficulty accessing adequate care and hardware, and relayed that they experienced challenges with what they perceived were vision coverage changes.
 - Numerous attendees indicated they had only been able to secure glasses because charitable or clinic special programs helped them do so.
- **TIMELY, TAILORED, AND APPROPRIATE BEHAVIORAL HEALTH AND ADDICTION TREATMENT**
 - Behavioral health needs were discussed across all groups, focusing on a range of behavioral health issues, including stress, depression, anxiety, marital and parenting issues, trauma, mental illness, and substance abuse.
 - Destigmatizing behavioral health diagnoses was referenced repeatedly, with participants showing a clear awareness that “mental health is as important as physical health, but no one really talks about it and no one really treats it.” Fear of repercussions can also keep people from seeking help, as expressed by one individual who stated, “I had postpartum depression but didn’t go get help because I was afraid CPS would take my baby away.”
 - Lack of behavioral health providers, lack of integration between primary care and behavioral health, and lack of appropriate coverage for behavioral health services or needs were repeatedly cited throughout all groups.
 - Addiction and substance abuse treatment was discussed at length in all groups, with a high percentage of individuals self-disclosing addictions themselves or among loved ones. One of the most significant concerns in all groups was the lack of timely and comprehensive access to substance abuse treatment, with comments such as:
 - “State insurance pays for you to take all the drugs but won’t pay to help you get off of them.”
 - “Getting the drugs is easy. Getting help to get off of them isn’t.”
 - “If someone is ready for treatment there should be an option for treatment because if they don’t go now they won’t go in 2 months when there is an opening.”
 - “Treatment needs to be longer and involve more supports and counseling”
 - Rural residents indicated they felt stigmatized, judged, or labeled as drug seekers in their communities even though they have genuine chronic conditions that require options for pain control, and that they feel they have no real options for help with chronic pain.
- **A CALL FOR TRUE WHOLE-PERSON CARE**

- All groups indicated the need for true whole-person care that focuses on physical, mental, dental, vision, prescription, and social supports (housing, transportation, food, care coordination) that help people get and stay healthy. One group summed it up with the following statement, “Make the medical home a reality.”
- Several groups focused on complementary, alternative, and other medical treatments (nutritionists, massage, acupuncture, chiropractic) that would help them stay healthy from a preventive standpoint and/or in lieu of medications, yet these services are either not covered or not available in certain areas (e.g., rural). One participant summed this up stating, “give us other options than just the prescription or the knife.”
- **COVERAGE CHALLENGES:**
 - Many attendees expressed challenges understanding their coverage and how and where to access care. One participant noted, “why are there so many insurance companies and why is my coverage changing all the time? All of the insurance companies have different ways of doing things and it makes it hard to get the care I need.”
 - Rural participants expressed frustration trying to access the care they need across county lines, where different MCOs might have different provider panels. More than one individual indicated having to enroll in a different MCO to access needed care for a chronic issue or to seek treatment in a different county, and then re-enrolled in the previous MCO when they returned to reside in their own county.
 - Rural participants expressed frustration with MCOs “who don’t understand what it’s like in the rural counties...they don’t know what we have or don’t have here, or what it’s like to try to get care here. They’re just reading from a script.”
 - Respondents from most focus groups indicated that they regularly have to “jump through so many hoops” to work with their insurance companies and get the care they need, and that they spend “hours on the phone” trying to get answers, referrals, coverage information, authorizations, and provider names. One rural participant noted, “by the time you get the authorization you are much more sick than you would have been if you could have just gone in when the doctor suggested the treatment.”
 - There were divided responses among focus group participants regarding whether they felt they received good care and/or lesser care because they were on Apple Health:
 - Participants connected to larger health system providers reported easier access and better satisfaction (in their words “better quality care”) than those in with smaller systems or seeing individual providers.
 - Participants seeking physical health care services reported easier access and better satisfaction (again, in their words, “better quality care”) than those seeking dental or mental health services, with one attendee noting, “some types of providers that accept Apple Health aren’t as good...it seems like they are lower end providers or someone who is just learning.”
 - Participants in rural areas reported a perception of more stigma, judgement, or disrespect toward those covered by Medicaid.
- **LACK OF PROVIDERS/ IMPORTANCE OF TRUSTING RELATIONSHIPS WITH PROVIDERS**

- Tribal participants noted lack of culturally-sensitive treatment options as a barrier to good care, particularly regarding behavioral health and addiction/recovery needs for adults, but also noting that they need more trusted providers who treat them holistically and in culturally-appropriate, community- and family-centered ways.
 - Rural residents indicated lack of providers was a significant barrier to good health care for them, citing lack of local access to providers such as pediatrics, obstetrics, cardiac, behavioral health, and dental providers.
 - Participants often cited the need to establish trusting relationships with providers in order to have good health and health care experiences. This is particularly difficult in rural communities, with what they described as an “exodus” of providers and an “ongoing challenge to” draw specialists, behavioral health, and even primary care providers to rural communities. One participant noted, “when you only have one option for counseling in your town and you don’t trust them, your only option is to not get the care you need.” Rural residents repeatedly reported driving 60 to 100 miles to see a different provider that they trusted.
 - Attendees indicated they prefer to have a health care team that knows them, such as the same nurse or medical assistant who talks to them every time, and the same provider who knows their history. One person stated, “it makes me feel like a member of my own health care team.” Most groups noted that this is often not the case, though, with staff turnover and changes in health care delivery models.
- **DELAYS IN ACCESS TO CARE/INABILITY TO BE TREATED FOR MORE THAN ONE ISSUE**
 - Participants across all focus groups indicated challenges due to delayed access to care, even when primary care relationships exist. One attendee shared, “Even though I have a primary care provider I like and who is really good, it can take months to get in to see them.”
 - Attendees in all groups expressed frustration at being treated for only one issue at a visit, necessitating additional visits for other conditions or concerns. This becomes a tremendous burden for time, finances, child care, transportation, and health issue exacerbation. One participant noted, “when I go in for my arm, they can’t see me for something else and then it’s another month before they can see me again and we have to pay for 2 visits instead of one.” Another noted, “it’s all related, it’s all in the same body but they are only allowed to treat one body part or issue at a time because of time and money.”
 - Groups noted that getting referrals to and appointments with specialists is exceptionally challenging. One participant noted, “It took me 7 weeks to get in to see someone for my neck, and that was after my doctor knew that something was definitely wrong.”
 - Participants indicated frustration with the limited amount of time they see providers, and that “administration makes them see a certain number of people per day so they can’t really focus on me and what I need.”
 - **TRANSPORTATION CHALLENGES:**
 - Rural participants reported transportation challenges as a huge issue to accessing care, including distance travelled to get care, lack of special mobility supports for those with

chronic issues, and feeling they were judged by others for using public or special clinic or social service support transportation.

- Foster youth and tribal members also referenced transportation challenges as barriers to health and access to health care.

- **CARE COORDINATION AND ACCESS SUPPORT**

- All focus groups discussed the challenges in securing the care they needed, ranging from finding providers, to coordinating referrals, to understanding their benefits, to dealing with multiple social determinants needs. Attendees shared,
 - “It’s hard to know where to start...who do you go to get guidance?”
 - “Patients don’t always speak or understand the medical lingo and doctors don’t always convey it well,” suggesting that having an advocate as a “translator” would be helpful.
 - “We need someone to help us communicate with our providers, to help them understand us and to help us understand them.”
- Several groups had lengthy discussions on how helpful it would be to have a “hub” or a “resource center” where you could go to ask questions, get information, find referrals, or get support for needed services.
- Getting referrals and authorizations was a challenge for many, describing “jumping through so many hoops” and lengthy delays to get care. Some participants noted having help with this (several rural participants had support from a referral specialist), but most indicated this is a challenging process that simply requires them to stay on the phone or research online for hours.
- Across all groups attendees indicated a significant need to have access to care coordinators or community health workers who could help them understand their coverage, access care, and gain referrals and approvals for services and medications.
- A high percentage of participants wanted help knowing which providers took their insurance and how to get in to see them.

- **FINANCIAL BURDENS DELAYING ACCESS TO CARE OR RESULTING FROM CARE**

- Several people noted that they didn’t seek care they needed because they were afraid of the cost and/or didn’t know if their insurance would cover it.
- Others were surprised by what they described as “balance bills” for services they had received that they thought were covered but weren’t, or in instances where they had sought care and only part of it was covered (e.g., an ED visit where the hospital bill was paid but the physician bill wasn’t because the physician was not contracted with the MCO). They noted these situations destabilize their basic needs and make them less likely to seek care in the future.
- One suggested (and others agreed) that this is another issue that could be addressed through care coordination or advocates who could help coach patients on how to ask questions about their coverage, bills, and how to navigate charity care and requested write-offs.

- **A REQUEST FOR MORE HEALTH SERVICES, COACHING, AND SUPPORT FOR YOUTH IN FOSTER CARE/AGING OUT**

- Youth in the foster system shared several specific needs, including:
 - More and better behavioral health supports for trauma, depression, anxiety, family dysfunction, because in the words of one attendee, “we are emotional wrecks due to the reasons we are in foster care.” Several agreed with the notion that their health (mental and physical) has been compromised because “we have been let down by the system so many times.”
 - All participants around the table agreed with this and all offered concerns about the quality of behavioral health care services, with one noting, “I felt like a lab rat,” another stating, “I lied to them because they I knew what they wanted me to say and they treated me like a number...people don’t ask ‘why did you steal that car?’ they just check things off a list and don’t get to know you...everyone is unique and should be treated that way,” and another suggesting that, “I had to drive to Liberty Lake to get a good counselor...what if I didn’t have transportation?”
 - Several suggested that peer supports would be beneficial, as well, for mentorship, coaching, and sharing resources by people who know what you’ve gone through. One attendee stated, “It takes one to know one.”
 - Better training and more supports for foster parents and social workers to create healthy environments and help kids/young adults be healthy and learn how to be healthy on our own.
 - Help learning about their coverage and care when they transition out of the foster system, with one participant stating, “Instead of a huge packet of information I don’t understand, help me transition to understand how to use my health coverage and get the care I need.” Others shared the following requests:
 - “We need doctors who don’t use big words and who explain things in real terms”
 - “I need someone who can help me understand coverage and access”
 - “You need someone who can grab your hand and help you.”

- **A REQUEST FOR MORE CULTURALLY-APPROPRIATE, HOLISTIC CARE FOR TRIBAL MEMBERS**

- The Tribal focus group was very clear that the health care system is not effective for them.
- One participant summed this up with the following statement: “We are in a system that wasn’t made for us...we’re not all the same. We are counted in the census but we are not treated appropriately especially for things like diabetes and heart issues that they know we are more likely to have. We need more native caseworkers, more access to services for physical and mental health. Diabetes, drugs, depression, suicide, hopelessness...all of these things are killing us.”
- The rest of the group affirmed the above and agreed that health care for tribal members must be holistic, attend to the family/community and spiritual aspects of the culture, and address historical trauma that is contributing to health issues.

Consumer Input Regarding Long-term Meaningful Consumer Engagement Strategy

Consumers were guided through a variety of questions to assess how they thought BHT could most meaningfully engage with them regarding the MTD and the long-term activities of the ACH. The following themes emerged.

- The most common feedback we received was gratitude for asking for their input. The groups universally shared that the conversations were meaningful and a good use of their time. They shared comments such as,
 - “Thank you for coming to us rather than making us come you. It was nice that someone bothered to come out to the rural communities to have these conversations.”
 - “Thanks for asking about what matters to us and what makes a difference for us.”
 - “This discussion makes us feel like we matter and that we’re not in this alone.”
 - “I actually feel listened to, which doesn’t always happen in the medical system.”
- Focus group participants across all groups indicated that by far the best way to engage them to get their ideas and feedback was through these types of group discussions in their own communities. A few clarifications included:
 - “We want to talk to and with real people...this kind of dialogue really matters.”
 - “We want to talk to a human being, not to a computer.”
 - “We want to be a person and not a number or a dollar sign.”
- While in general most groups indicated that they prefer in-person opportunities to provide input, and some indicated “if we get phone calls or surveys, we ignore them,” further discussion indicated that “if they actually asked if this was a convenient time,” or “if we actually saw that our phone conversations or surveys actually changed something,” that they would be more likely to participate.
- Regarding preferred methods of communicating their opinions and ideas, they shared the following feedback:
 - That they want to know their time and input makes a difference—they want feedback on changes made in systems or impacts made in health.
 - They want “plain speak” communication on what things mean—“don’t dumb it down for me, but help me understand it in clear language,”
 - They want to make sure that their input is channeled up the chain to administration and decision-makers. Specifically, one attendee noted, “Often administration is so far removed from the real experience of the patient...the gap isn’t always bridged...there are too many policies that limit the doctors from providing good care, and they need to know this.”

- They suggested that somehow coordinating input through health coaches or the previously-referenced care coordination/information resource “hub” would help them better articulate what they were needing, and help them better understand what providers are asking. Thus indicating that care coordination, community health worker, or social service partner organizations could be tapped to be a conduit for meaningful engagement.
 - Tribal participants strongly advocated conversations with tribal elders, both because “they can’t come to groups like these” and because “they are the ones who will really talk.” They also suggested convening larger community conversations at the community center, school, or long houses on tribal land, noting, “it’s not too difficult to get a buzz going on the res, especially about something this important.”
 - Rural communities recommended both these smaller, conversational gatherings “where you can build trust and bounce ideas off others,” but also suggested that larger group discussions with more community members (and food!) could get more people involved and talking, “though you’d really need to promote it.” Like tribal members, rural community members specifically flagged the need to reach out to elders and to the disabled in other ways (e.g., in their homes), because “they can’t make it to events like these.”
 - Youth in foster care want to have meaningful, focused conversations like these, but to bring more people into the mix. And they suggested working with events like “Make it Happen” and organizations they trust (like the ones who referred them to this conversation to begin with) to secure input and voice.
- Regarding receiving information about health and health system changes, responses were varied:
- Many noted that they’d like to have access to a “central office to go to or call where they advocate for you, a resource center to give and get information and to get the help and support you need.” (These were suggested in conversations dealing with care coordination, health advocates/coaches, support “hubs” in the community).
 - Some indicated that they want to receive information from their physician or their provider team (though others indicated this would only be possible if you could actually get in to see them).
 - There were wildly varying reports regarding attendees’ desire to receive information from their insurance companies, with most participants indicating that “I can’t even get through to them to ask questions or get my cards, much less receive or share important information” and a few indicating, “I receive really valuable health reminders and resources from mine.”
 - Rural and tribal participants indicated preferences for receiving information and invitations via US Postal Service mail or through local newspapers and tribal publications. They again requested short, simple communications and “no big fat booklets” or “seven copies of the same thing, which always happens with my Medicaid coverage.”
 - Tribal attendees specifically requested that information be disseminated to “dispel misinformation that is constantly out there.”

- Urban and tribal participants suggested that electronic communications (social media, text, email, web) would be good avenues to share information because “everyone has a phone these days.” Rural attendees did not share this preference.

Provider Input Regarding Long-term Meaningful Consumer Engagement Strategy

Overview

In addition to consumer focus groups, representatives of 14 organizations were interviewed to gather their ideas for establishing a long-term meaningful consumer engagement strategy to inform the MTD and the broader activities of the ACH. These organizations demonstrated the following diversity:

- Geography (rural, urban, tribal)
- Race and ethnicity
- Health system size and model (large, small, independent, university-affiliated, community non-profit)
- Type of practitioner/provider (medical, behavioral, substance abuse, oral health, public health)
- Social determinants organizations (housing, food security, social services)
- Professional associations
- Managed Care Organizations
- Associations
- Community-based Initiatives

Names of interviewees are included in Appendix A.

Ideas for Consumer Engagement

When asked their ideas on “which engagement strategies would be most effective in reaching consumers for their input and ideas into the MDT and the long-term goals of the ACH?”, the following themes emerged:

- The top recommendation was to **reach out to consumers through the conduit of trusted providers, advocates, and organizations** with whom consumers already have trusting relationships.
 - “If BHT is reaching out to consumers, do so through the trusted organizations or consumers might get confused and frustrated.”
 - “Meet them where they are through their core connections.”

- “Work through Navigators and CHW initiatives, because they really have their pulse on the consumer needs and the trust of their clients.”
 - “Reach out through rural coalitions and health champions, who really know their people.”
 - “Build on existing events and fairs that MCOs take part in—partner with them as they connect with consumers. MCOs could be ambassadors for specific engaging questions/actions in their interface with consumers.”
 - “Outreach through Health Homes care coordinators or other care coordination programs, or interview clients in waiting rooms at FQHCs, Native Clinic, or the Teaching Health Clinic. Getting one-on-one input in these settings would richly inform our work.”
 - “Host outreach events such as mini town halls in various communities, with invitations coming from trusted partners.”
 - “Don’t just say, we’re here to help you. Break break with people. Build relationships. Invite them to partner.”
 - “Dovetail consumer engagement activities with other established organization meetings or events (e.g., homeless coalition, rural coalitions, health fairs)”
- Respondents indicated that the result of that outreach through trusted organizations and advocates should yield the following **formal, structured, long-term engagement opportunities**:
 - ***Implement an Advisory Committee*** that informs staff, board, and leadership council regularly
 - People selected based on their representation, expertise, and willingness to provide voice over time
 - People connected to other advisory boards or trusted organizations so you are channeling a much broader audience voice
 - “It takes a lot of expertise, time, and energy to manage these types of groups to really get what you need from it” and another respondent said, “it’s not just about meeting OUR needs, it’s about making sure the participants’ time and expertise are honored”
 - Learn from other entities that do this well and replicate how they have made it effective, with one example as Providence Saint Peter in Olympia
 - Capitalizing on existing consumer panels and advisory boards with the caveat that, “these are the people who have been showing up for 20 years...we need to hear from new voices.”
 - ***Integrate Consumers into the Leadership Council*** meetings and have supportive people there to help them use their voice...call them out as consumer representatives (not professionals serving an organization) and pay them for their time just as everyone else in the room is paid to be there. E.g., perhaps have organization representatives bring a consumer representative to help support them.

- Hear consumer stories monthly at Leadership Council and board meetings. From the consumers directly.
 - “Having consumers randomly attend meetings isn’t effective. There needs to be a specific structure and supports to make them comfortable and to make their attendance count.”
 - We need more advisory or Leadership Council representation from front-line providers working directly with clients.
- ***Ensure consumer voice on the board (like FQHCs have)***
 - One interviewee offered “an important caveat; one consumer cannot represent all consumers. One consumer’s experience is exactly that...one consumer’s experience.”
 - “Changing board and Leadership Council composition may take a long time, so we need to start now.”
 - One respondent suggested, “ensure the board and Leadership Council are truly diverse because that will help make all of the activities of the ACH more diverse.”
- Respondents suggested that the most appropriate **short-term strategies for securing input into project planning** and specific implementation activities could include:
 - ***Focus groups with particular populations***, hosted by/recruited by organizations they know and trust, be sure to compensate/incentivize participation
 - Early method of getting meaningful input now while you are setting the stage for a more comprehensive plan long-term
 - Option for specific focus areas, e.g., exploring bidirectional integration of care, opioids, etc. with a specific population weighing in on a specific topic
 - ***Carefully designed surveys***, particularly for those less comfortable in group settings or with limitations in mobility, transportation, etc.
 - One interviewee stated, “laser in on key issues that meet consumers where they are at so they don’t get lost in the global parts of system design but have a voice in the things that really matter to them”
 - Another suggested a tiered survey process similar
 - One suggested using a platform such as Thought Exchange, which is used in some school system settings
 - Several noted that it would be important to provide incentives for survey participation to get better response rates
- Regarding the above-listed options for engaging consumers, respondents were very clear about the considerations that would make consumers more likely to participate:
 - Structure meetings and events with the following considerations
 - Schedule at “nontraditional times”
 - Provide food and childcare
 - Provide financial stipends and transportation

- Engage support and coaching from trusted advocates to help them feel more comfortable
 - One respondent noted, “Everyone else gets paid for their contribution to this planning effort. Consumers should be similarly compensated because arguably their voice is the most important.”
- Other suggestions included:
 - Social media. “Get the younger voice and engagement through social media.”
 - Earned media and local publications (tribal, rural, Inlander). “People rely on these resources and they can be a good door opener.”
 - Continue asking, “who else should be at the table...or whose voice should we secure from elsewhere to bring to the table? If we keep asking this question it will identify where the gaps are in our strategy.”
 - Reduce Medicaid stigma to invite more open input. “Do a community campaign that destigmatizes Medicaid—it is some of the best coverage you can get. Help providers and consumers understand it is a good thing and how to maximize health with it. Treat consumers like they have an insurance plan—which they do—it’s not welfare. They will be more likely to share their ideas.”
 - Look at the certification requirements for Patient Centered Care and model consumer engagement strategies after that.
 - Pull the actual billing codes for Medicaid and look at who is using those services the most...start there and ask them for their input on how to shape the patient experience and outcomes.
 - “Engage the people who have effectively transitioned off Medicaid, those who have successfully bettered their life, to learn more about what helped them do that. Allow that to inform how we provide supports now.”
 - Learn from other states who have gone through MTD activities...what did they find worked (and didn’t work)?
- Only two respondents indicated that comprehensive consumer engagement might not be desirable at this point, indicating,
 - “Unless there are going to be targeted/focused changes that will impact them, it’s a waste of time/energy/money and will only create more confusion. They want to know...’do I still have benefits, will I still be able to see my provider?’ This individual noted that the better approach would be to have these conversations with the advocates who work with consumers “day in and day out, as they know their struggles and needs and would be able to speak on behalf of the broader population without confusing or frustrating them.” This respondent feared that asking consumers for input on social determinants issues (transportation, housing, etc.) would only confuse and irritate them because “Medicaid clients are here and now...trying to meet their needs today...if we bring up things that won’t change for 4-5 years (if then) we’ll make them mad.”

- “If we put too much out there right now without answers and specific changes, it will create fear. Change is hard for this population. Many are living day to day.”
- One other respondent provided the following recommendation: “Ask consumers and providers questions about things we can actually DO something about, otherwise it’s a recipe for frustration.”

How Success Will Be Measured

When asked, “how will you know that BHT had been successful in meaningfully engaging consumers?” the following themes emerged:

- “I will see them and hear them at meetings and events, and their voice will be included in minutes and in plans. They will be at the table and their voice truly informs what we do.”
- I will see long-term attendance and engagement at the Leadership Council, more diversity, more legislative and elected officials attending focusing on policy for their constituents because their constituents are asking for it
- “You would see it in the stories that people are sharing—their stories inform change and their new stories reflect change”
- “We are seeing the evolution of projects and solutions based on feedback from the people impacted by them”
- “The prescriptiveness of the MTD Toolkit will be customized by the voice of the people it is intended to serve”
- “Consumer health has improved.”
- “Consumer satisfaction with their care, their health, and their voice in health system transformation has appreciably increased.”
- “Consumers would know who BHT is and trust them and indicate that they are a trusted organization to go to for advocacy, help, partnership.”

Which Consumer Populations Should Be Informing the Work of the ACH?

Respondents are seeking new voices:

- “Specifically we do NOT need to be reaching the average consumer who often has a voice (defined as a person in a professional capacity advising on these issues). These are not the consumers we want to hear from.”
- “We tend to have a small group of vocal people who may or may not be representative of the larger group. That can end up yielding token consumer input.”
- “We tend to get the highest functioning and most vocal people who have been providing input for a long time. We need new voices.”
- “We as service providers are designing programs for people who aren’t in the room. This has to stop. We need to hear directly from the people we are serving.”

Respondents suggested that BHT should outreach to vulnerable populations who haven't had a say in the past, such as:

- Behavioral health, substance abuse, and dual diagnosis clients (we need this voice but want to make sure we are engaging them in the right way)
- Those with chronic conditions and multiple complex health issues
- Individuals across the age range, particularly calling out seniors
- Disabled
- Rural and urban residents
 - "Rurals get forgotten and we are not reached out to because most of the providers (and all of the big ones) are in Spokane."
 - "People don't come to us...they expect us to come to them."
- Foster youth and those aging out of foster care
- Homeless or insufficiently housed
- Medicaid clients and the uninsured, those "stuck in the middle" between Medicaid and insurance (they make too much for Medicaid but not enough to purchase their own and don't have access to commercial insurance)
- Those with the highest Medicaid/healthcare costs
- Low income
- Children/parents of children
- Communities of color and diverse cultural groups (African American, Native American/Alaska Native, Immigrants, Refugees), especially women of color
- Populations with specific disparities (look at the SRHD data on disparities and seek out these populations)
- Specific geographic areas of the region who have very low income, high risk, significant health issues

Which Organizations Might Help Engage the Consumer Voice Effectively?

Specific suggestions included:

- National Association of Mentally Ill
- BHO Consumer Panel
- FQHC Consumer Panels
- Homeless Coalition
- Community Action Networks
- Washington State Community Action Partnership
- Spokane Alliance
- In Person Assister Network
- World Relief
- Health Plans
- VOA
- MCOs
- Catholic Charities
- SNAP

In What Other Ways Can BHT Continue to Improve Consumer Engagement Over Time?

- Almost universally respondents indicated that BHT could improve its meaningful consumer engagement process by creating a formal, structured, consistent meaningful engagement policy and/or strategy.
 - While many respondents indicated that BHT had done a great job bringing partners and professionals into the room and creating strong momentum around this platform, most indicated that the “true, authentic, in-person consumer voice had not been effectively solicited” until this process began.
 - Respondents reported being pleased that BHT is taking such a comprehensive approach to planning its meaningful engagement strategy.
- The most common suggestion offered to help improve engagement was a communication strategy that provides more regular, clear, specific, “plain-speak” communication that is “not just on a by-request basis.”
 - “Don’t use waiver-speak!”
 - “Help consumers understand how all of this impacts them and benefits them, and they will be more likely to want to engage.”
 - “Communication needs to be improved for both providers and consumers. Providers don’t understand what it all means, so how can they help consumers understand?”
 - “There isn’t enough dissemination of the information down through organizations, either. There’s a bottleneck where administrators know the information and the mid-level and front-line staff don’t get the details, but they are the ones interacting with the consumers. Providers are the coaches, so if you want good community engagement, educate them well.”
- Specific communication requests included:
 - Transparency about “here’s what we know, here’s what we don’t know.”
 - Clear, concise mapping of the process.
 - Push notifications (to alert of changes).
 - Dynamic and concise web content (to clearly outline the process and progress). Make sure website is updated and that it’s navigable and focused on what people most need to know. Basic, clear information that is separated based on audience (consumers, providers, policymakers), clearly articulating the value proposition and action items for each. “We don’t have a place to direct consumers or providers where they can learn more and find what they need easily.”
 - Close the communication loop...make sure people know that their voice made a difference. Inform and show that change has been made.
 - Consumers and providers alike need to see these projects as “relevant and accessible to them,” so the communication and outreach has to convey this. Provide “predictably frequent communications—consistent and sustained, forums, and other ways to reach people and engage them.”

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