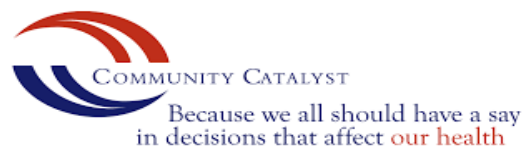


A Community Listening Session to Share and Validate Qualitative Findings

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ICH is a nonprofit consulting organization that provides participatory evaluation, applied research, assessment, planning, training, and technical assistance. ICH helps healthcare institutions, government agencies, and community-based organizations improve their services and maximize program impact.

Introduction

The Center for Consumer Engagement in Health Innovation at Community Catalyst examined Home and Community Based Services (HCBS) utilization among dually-eligible people of color age 50 and older. The three components of this project were a) a literature review and quantitative data analysis, b) interviews with content experts and other stakeholders and c) focus groups with dually-enrolled Medicare-Medicaid enrollees from communities of color across four regions of the U.S.. The focus groups component was led by researchers from the Institute for Community Health (ICH). After researchers conducted the focus groups and analyzed the findings, they then performed member checking¹ by conducting a listening session with the focus group participants. The objective of the listening session was to share back with the community and also to check for accuracy and resonance of the analysis with participants' experience. Member checking, also known as participant or respondent validation, is a qualitative analysis validation technique.

Following data collection, synthesis and reporting of focus group findings, the state partners which had initially assisted with recruitment for the focus groups (Alabama Arise, Arizona Caregiver Coalition, Michigan Elder Justice Initiative, Pennsylvania Health Action Network, and Tennessee Disability Coalition) were provided information on the listening session, after which participants from all 6 sessions were invited to attend the listening session. Of the 52 participants who received invitations, 21 expressed interest in attending the session and 17 attended. The 2-hour session was conducted virtually via Zoom, utilizing an adaptation of the World Cafe Methodology² for engaging the large group of participants.

Prior to Listening Session

In preparation for the listening session, a PowerPoint presentation was created to present findings from the 6 focus group sessions. Findings were focused on three themes: quality and decision making, family and professional care, and race and racism. Three breakout rooms and three moderator/note taker pairs were assigned to facilitate engagement with participants and each moderator/note taker pair was assigned a theme. The adaptation of the World Cafe method involved participants remaining in their assigned breakout rooms while each moderator-note taker pair moved from one breakout room to another, continuing to engage participants with their assigned theme. To ensure discussions from one breakout room were carried over to the other breakout rooms, where participants can build upon expressed views and opinions of other participants, researchers utilized Google Jamboards, which are virtual interactive whiteboards. Notetakers and moderators used the

¹ Birt L, Scott S, Cavers D, Campbell C, Walter F. *Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation?* Qualitative Health Research. 2016;26(13):1802-1811. doi:10.1177/1049732316654870

² *World Cafe Method*. The World Cafe. (2019, November 25). Retrieved March 27, 2023, from <https://theworldcafe.com/key-concepts-resources/world-cafe-method/>

Jamboards to: highlight findings from each theme; record participant feedback from each breakout room; and; exhibit/share feedback from one breakout room with the other breakout rooms.

During the Listening Session

A total of 17 participants attended the listening session. Sixteen participants identified as Black or African American while the remaining participant identified as Native American. All were 50 years or older, dually enrolled in Medicare and Medicaid, and had past or current experiences with HCBS. The session commenced with a moderator presentation summarizing the focus group findings, followed by an explanation of the World Cafe method and transitioning into breakout sessions. Each breakout room participated in a discussion with each of the three moderator/notetaker pairs on each of the topics. At the end of the session, all participants returned to the main room and moderators presented a brief summary of their discussions.

Multiple modes of communication were used during the session. Participants were able to both visually grasp and listen to the focus group findings and feedback sessions. Various participants participated via phone call, others used zoom. Participants provided input both by speaking and by typing in the chat. These techniques aided in engaging with participants with vision impairments. In addition, participants also utilized Zoom's chat feature to express their input. Some of the World Cafe principles³ adapted during the session included a) facilitating small group conversations with about 4-5 participants in each room, b) asking questions that matter to the participants and help attract collective energy and insight, c) encourage everyone's participation be it through chat or by unmuting and expressing their thoughts, d) sharing back with all participants the feedback harvested each room.

Family and professional care

Our original analysis identified three traits that participants prioritized in caregivers regardless of whether they preferred family or paid caregivers. These traits were: trustworthiness, caring relationships, and reliability. In our Listening Session discussion, participants added that mutual respect was a critical fourth component (Fig. 1). Mutual respect was particularly important to participants who felt that caregivers had a tendency to control their decisions, rather than support their decisions. These participants felt that it was important to be able to be themselves and to have as much independence as possible.

In addition to this new theme, participants reinforced the validity of our previous findings by describing the importance of being able to trust caregivers, feeling cared-for, having worries about being vulnerable to caregivers taking advantage of them. Participants also underlined the crucial importance of good communication between caregivers and patients.

³ *World Cafe Method*. The World Cafe. (2019, November 25). Retrieved March 27, 2023, from <https://theworldcafe.com/key-concepts-resources/world-cafe-method/>

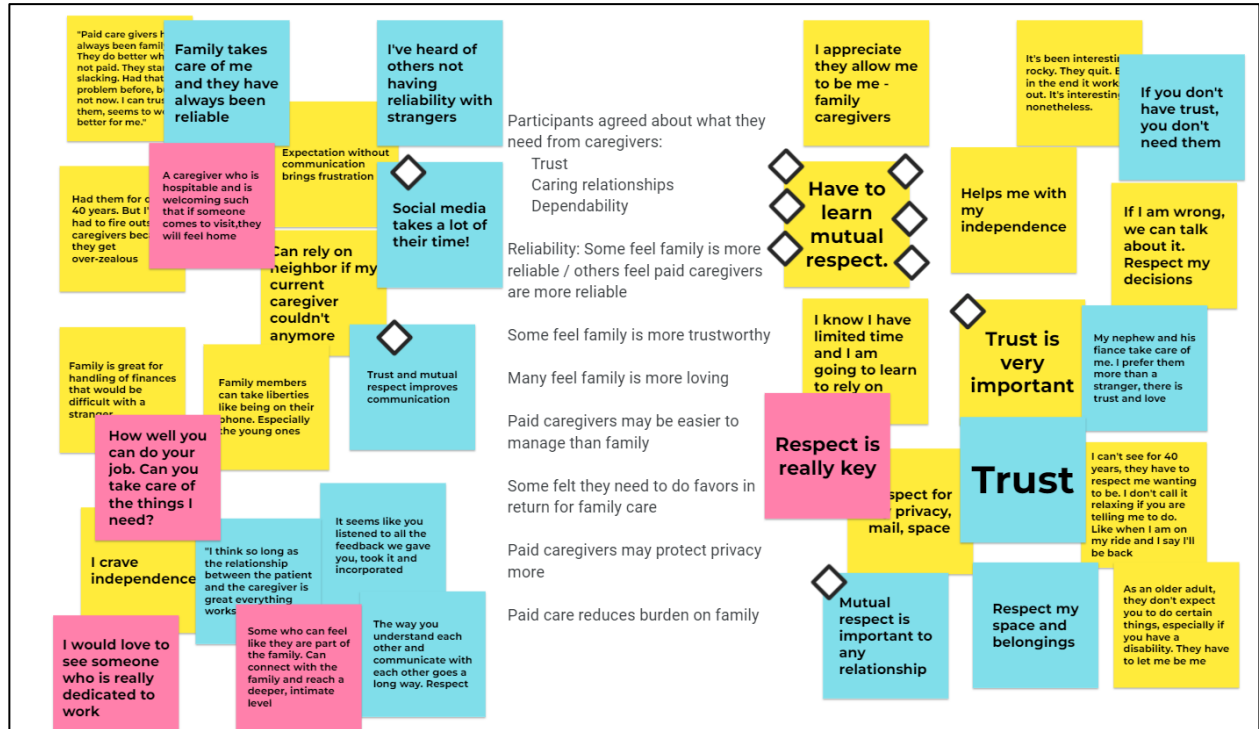


Figure 1: Jamboard used to theme 'Family and Professional Care'

Quality and decision making

Participants' source of information about HCBS

Our original analysis found that participants received information about HCBS from three main sources: a) family members who assisted in setting up services, b) social networks such as friends and colleagues and c) referrals, such as from medical providers. Participants in the listening session validated these findings, describing referrals from providers and recommendations from friends and family (Fig. 2).

Basis of selecting care provider

In our focus groups, participants described choosing providers on the basis of a) whether they could find willing and appropriate staff for their needs, b) personal recommendations; and c) eligibility requirements for enrolling with different HCBS care providers. Participants highlighted their difficulties with finding care providers who can anticipate their needs and who will respect them. Participants also validated our previous findings around concerns about the professionalism of caregivers and the need for a way for caregivers to be vetted and held accountable.



Figure 2: Jamboard used to theme 'Quality and Decision Making'

Perception of quality

Findings from focus group sessions highlighted dependability, relationship, trust and importance of care management as key factors of quality of care from caregivers. Of the four factors, trust seemed to be the most agreed upon and emphasized factor of quality. Participants provided examples of incidents that created distrust, such as identity theft, and continued to share recommendations such as improved and increased vetting process for caregivers including stricter regulations on hiring and background checks.

Race and racism

Experience of interpersonal racism

In our focus group discussions, people had mixed answers to the degree to which they had experienced interpersonal racism (Fig. 3). Some participants stated that they had not experienced racism or feel they were treated differently while others emphasized that they see race as an influencing factor when they have a negative experience with care providers.

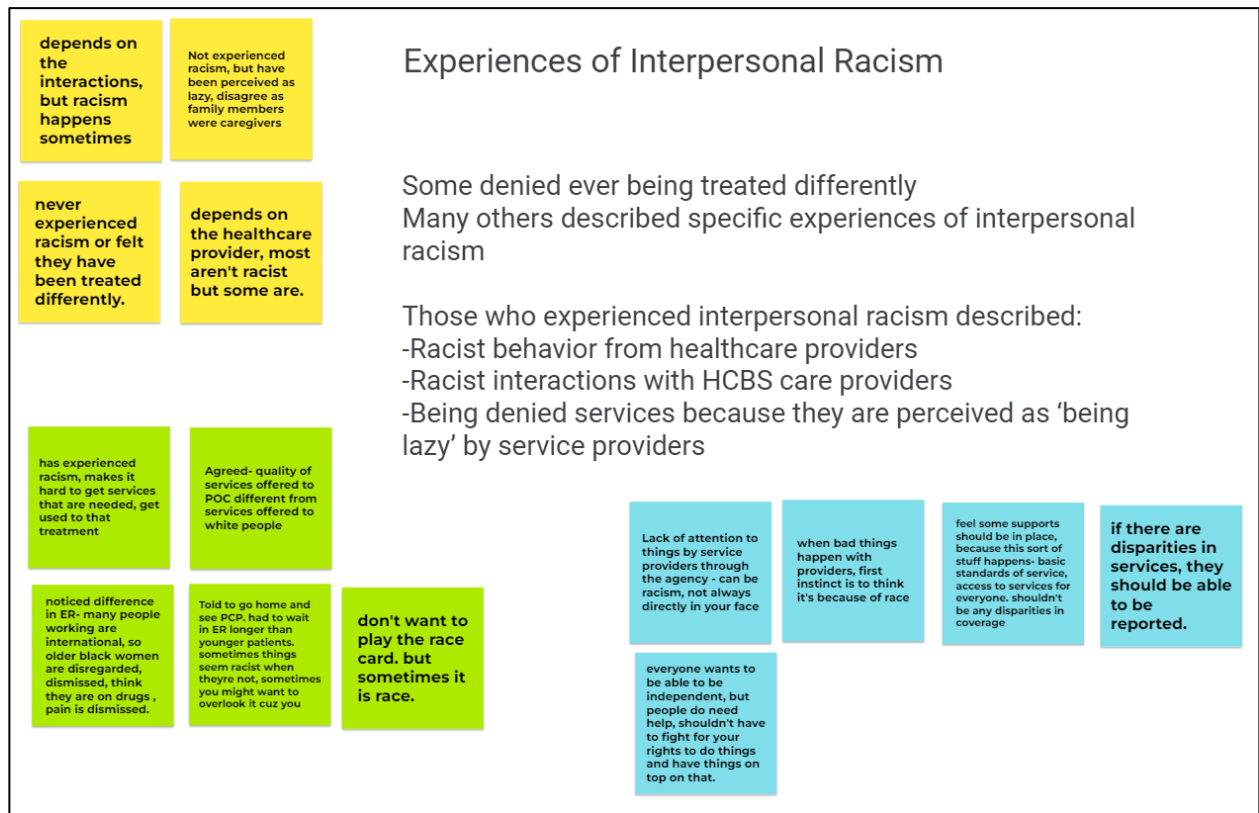


Figure 3: Jamboard used to theme 'Race and Racism'

Structural racism

Participants agreed that people of care are often disadvantaged due to environmental factors such as their neighborhoods. It was highlighted that while regions with higher percentages of Black populations such as North Philadelphia and Detroit have poor transportation systems, other regions of the states have better transportation and customer service.

HCBS disparities

Due to time restraints, very little feedback was given on this theme. One participant mentioned that they did not experience disparities around accessing HCBS information, but also shared this may not be the case for everyone and suggested the need for more information with how to access HCBS services.

Learnings

We recommend researchers conducting future listening sessions for member-checking consider the following factors.

Limitations of virtual platforms: Although virtual platforms have been helpful in engaging with people in different geographical regions, in-person sessions are likely to produce better rapport building.

Budget enough time for accommodations: Visual communication techniques such as screensharing a Jamboard can be engaging for visual learners, but must be backed up through reading out loud in order to accommodate the needs of participants with visual disabilities and those participating using an audio-only phone call. This accommodation is time-consuming, and future sessions should plan for this extra time in order for enough time to remain for reflection and providing feedback.

The Listening Session worked: Overall, the virtual listening session was an effective way to validate the focus group findings. Participants agreed with the summary of findings that was presented; none of the themes we extracted from the original sounded new or foreign. The discussions were an effective opportunity to refine and elaborate on our themes.