Community Catalyst

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Centering Perspectives of Dually Eligible Older Adults of Color

Piloting Co-Creation of Home and Community-Based Care Quality Measures

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Research bridging policy and practice

Introduction and Project Objective

Too frequently, health and social care quality measures are designed with provider or payer perspectives in mind, rather than the perspectives of the people receiving care.[1] Accordingly, decisions about funding, service provision, and policy may not reflect the needs and desires of the people they affect most, which can result in misallocations of resources. Medicaid's home and community-based services (HCBS) program provides personal assistance with daily tasks to help people stay in their own home as they get older, also known as aging in place, but this program's approaches to quality measurement are also highly variable,[2] which is particularly problematic. As many states move to support more people in their homes and communities rather than in institutional settings, designing person-centered approaches to HCBS quality monitoring is essential. Quality measurement issues are particularly important for older adults enrolled in both Medicaid and Medicare (dually eligible enrollees) whose complex health needs mean greater need for HCBS; this is especially true for people of color, who are disproportionately dually eligible for these programs.

To explore quality measurement issues, this project engaged a small group of dually eligible older adults of color to learn what they prioritize regarding the quality of HCBS. Specifically, we explored which aspects of access and quality of care they prioritize most, and which validated survey questions most reflect these priorities based on their lived experiences.

Broadly, this project aimed to counter the following concerns regarding HCBS quality monitoring:

1. The voices and priorities of the people who use HCBS are not often reflected or validated in measurements of HCBS quality;
2. Large-scale surveys are not typically designed to understand the specific needs of racial and ethnic minority groups and;
3. Cross-cultural validation and participatory approaches to survey development, testing, and execution for information reliability are limited, which raises questions about applicability to sub-groups in the population.

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[1] ATW Health Solution (2022). Theory of Change for an Equitable Patient Centered Measurement Ecosystem That Supports an Advanced healthcare System

[2] Harrison, J. Shih, R. and Sangeeta A. (2022). Understanding What Works: Measuring and Monitoring Quality in Medi-Cal's Home and Community-Based Services. Rand Corporation. January. https://www.chcf.org/wp-content/uploads2022/01MeasuringMonitoringQualityMediCalsHCBS.pdf

The project specifically focused on California, where 1.7 million people are dually eligible for Medicare and Medi-Cal (the state's Medicaid program),[3] 66% of whom are from communities of color. Recent analyses in California have pointed to concrete challenges obtaining reliable, valid, and disaggregated quality and access HCBS data for dually eligible from the state's communities of color.[4] National analyses also suggest that people of color are under-represented in patient experience surveys,[5] which could also be the case in California. At the time of this project, California is seeking substantial health care and social care transformation in Medi-Cal through the California Advancing and Innovating Medi-Cal (CalAIM) initiative. To achieve this transformation, the state's health and social care systems need to improve their understanding of what is most important to the people receiving care, which we feel made our project particularly timely, relevant, and well-suited to the context.

Community Catalyst and the LeadingAge LTSS Center @UMass Boston partnered with community organizations in California to engage dually eligible people of color in a pilot process of co-creating a set of HCBS quality measures. An integral part of this project was identifying, engaging, and establishing working relationships with community organizations in California led-by and serving this population. The community organizations included The Cambodian Family (Santa Ana), Curry Senior Center (San Francisco), and the Alliance for Leadership and Education (multi-county).

Components of The Co-Creation Process

Our pilot co-creation process centered on understanding what matters most to our priority population about the quality of HCBS. This meant identifying existing quality measures which prioritize care-recipient perspectives, exploring how these measures should best be used, and identifying gaps in quality measures that need to be addressed.

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[3] ATI Advisory (2023). Profile of Older Californians: Medicare Beneficiaries near Income Eligibility for Medi-Cal. California Department of Health Care Services Office of Medicare Innovation and Integration Prepared by ATI Advisory. July. https://www.dhcs.ca.gov/services/Documents/OMII-Chartbook-3-Near-Medi-Cal-Income-Eligible.pdf

[4] Christ, A. and Huyenh-Cho, T. (2021). Using Data for Good: Toward More Equitable Home and Community-Based Care Services in Medi-Cal. December. https://www.chcf.org/wp-content/uploads/2021/11/UsingDataGoodHCBSMediCal.pdf

[5] George S, Duran N, Norris K. (2014). A Systematic Review of Barriers and Facilitators to Minority Research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American journal of public health*, *104*(2), e16–e31. https://doi.org/10.2105/AJPH.2013.301706

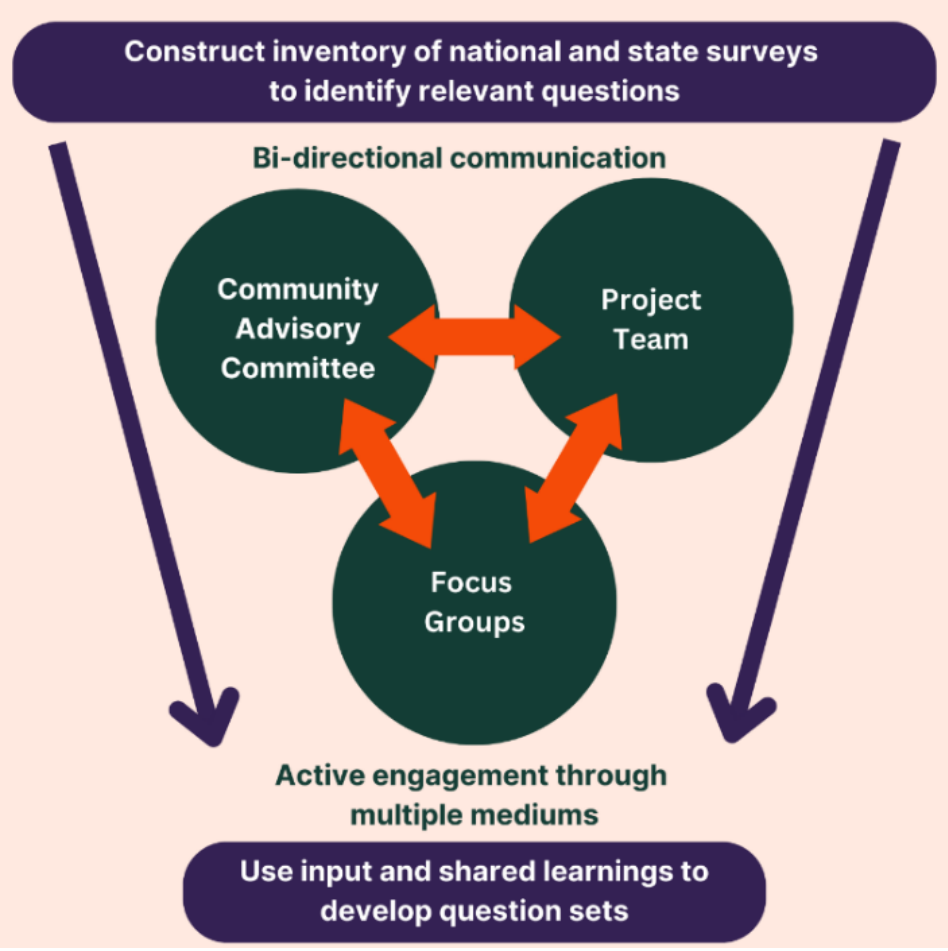
Our approach included three core elements:

- Developing an inventory of existing HCBS quality survey questions to serve as a foundation for working with stakeholders.

- Convening a Community Advisory Committee (CAC) to inform the project's approach, provide input into the prioritization process, and interpret findings.

- Conducting focus groups and interviews with HCBS recipients and their caregivers exploring what aspects of HCBS quality are most important and what survey questions capture those aspects best.

Figure 1. The Co-Creation Process



Health104(2): e16-e31. February. https://pubmed.ncbi.nlm.nih.gov/24328648/

1. **Inventory of HCBS Quality Survey Questions.** As an initial step for the project, we compiled an inventory of existing quality-related survey questions for HCBS recipients to assess current approaches and create a set of relevant, validated questions as a foundation for our co-creation process. This inventory of 128 questions was pulled from the following surveys:
    - Home and Community-Based Consumer Assessment of Healthcare Providers and Systems survey (HCBS CAHPS);
    - National Core Indicators Aging and Disabilities survey (NCI-AD);
    - California Health Interview Survey (CHIS);
    - In-Home Supportive Services Consumer Satisfaction Survey (IHSS); and
    - Medicare Advantage Consumer Assessment of Healthcare Providers and Systems survey (MA CAHPS).

    To both provide a structure for co-creation and for interpreting results, we organized the inventory using the Donabedian framework for assessing quality in three areas:[6] (1) the **structure** of care; (2) the **process** of care provision; and (3) the **outcomes** of receiving care. The CAC provided input on which components of quality within the structure, process, and outcomes domains were most important and which questions best measured those components; this was explored further through focus groups and interviews (see below).- As discussed below, the CAC also reflected on findings from the focus groups and interviews. After an initial meeting to discuss project scope and process, a "starting point" question set was presented to the CAC as a basis for beginning the co-creation process. This baseline question set is shown in Appendix A.

2. **Community Advisory Committee (CAC).** To ensure broad input and perspectives, the 10-member CAC was comprised of representatives from our three partner community organizations including three older adults, an older adult caregiver, and an individual staff member from each of the three organizations. The CAC also included a recognized researcher with expertise in survey research and HCBS issues and two representatives from an integrated Medicare/Medi-Cal health plan.-This group helped guide all aspects of the project from start to finish. The CAC met five times to guide the project activities by: providing review and input on the project work plan, prioritization of aspects of HCBS quality and the questions that best capture what matters most to people, discussion guides and the interpretation of results from focus groups, and the compilation of findings from all project activities.

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[6] Donabedian, A. (1980). Explorations in quality assessment and monitoring Volume 1: The Definition of Quality and Approaches to its Assessment. Health Administration Press. https://psnet.ahrq.gov/issue/definition-quality-and-approaches-its-assessment-vol-1-explorations-quality-assessment-and

3. **Focus Groups and Interviews.** In addition to the discussions with community organizations and family caregivers within the CAC, we conducted two focus groups as well as individual interviews with HCBS recipients. Our partner community organizations were essential in helping us to engage directly with dually eligible HCBS recipients from communities of color. We conducted interviews in English with two HCBS recipients, as well as one focus group in Khmer (n=6), and another focus group in Spanish (n=6). For one of the focus groups and the individual interviews, we learned what mattered most (or least) to them regarding HCBS quality. For the other focus group, which was conducted in Spanish, we tested specific validated questions about quality to see if participants felt they were clear, easily understood, and measured the quality issue in the right way. The group also provided input on the format of answer categories for specific questions. The questions they examined are presented in Appendix B. This specific "trial question set" derived from the initial inventory and was most closely related to the quality issues deemed to be most important by the CAC, individual interviews, and the other focus group.

This process was iterative -- input informed the co-creation practice, while reflection and dialogue refined the co-creation strategy. For example, CAC input informed focus group design and recruitment, and focus group outcomes were used to inform further CAC discussion. It is important to note that input into this pilot study comes from a relatively modest number of 14 individuals, hence the findings are preliminary. Figure 1 illustrates the co-creation process, which is followed by a brief description of the survey inventory approach and the role and function of both the CAC and the focus groups in the co-creation process.

Results of the Co-Creation Process

Through multiple discussions with the CAC and through focus groups and interviews, we identified "what mattered most" to the study participants when it comes to HCBS quality. Key learnings are summarized below, and the specific prioritized issue areas and related survey questions designed to measure these issues are presented in Tables 1 and 2.

Access to services (and measures related to access) was the single most important issue for participants. All other quality-related issues were viewed as secondary, and our sample found it challenging to engage with other quality metrics such as staff consistency, transportation issues, complaint handling, and other concerns if access issues were not first addressed. For example, if services are not available consistently or

only available in a limited way, whether a provider is timely may be a secondary concern. However, when service accessibility is present, consistency and punctuality may become more important. The implication is that **quality metrics focusing on HCBS should begin with and always include access-related measures.**

Capturing post-acute care experience in quality measures – specifically, transitions from hospital to home settings - is very important. This has been the focus of much work and effort from providers, but it also consistently arose in discussions with participants as a very important quality measure to track and monitor. Several participants pointed to bad experiences during this transition process, which often require coordination of family and paid caregivers.

Other areas of high importance for HCBS quality measurement that emerged included:

- Whether there is coordination across the various care providers that may be providing specific part of an overall HCBS service package.
- The extent to which consumers have a clear understanding of where to go or who to call when problems with providers emerge.
- Whether there are instances of discrimination and documenting the nature of that discrimination during the caregiving process.

Empathy and compassion of care providers emerged as a clear area where quality measures are lacking, yet needed - no single question in our inventory related to this issue. During the co-creation process, several questions to measure this important element of quality were put forward by participants. These included:

- Did you feel that the HCBS caregivers cared about your well-being?
- Did your HCBS caregivers seem to enjoy what they were doing?
- Did your HCBS caregivers spend enough time with you?
- Did you feel that your needs and experiences were fully understood?

Certain validated questions were preferred over others. Participants were able to choose which questions they preferred for measuring aspects of HCBS quality and they did so based on ease of comprehension, relevance to quality concerns, and on the question's answer categories. We learned for example, that there was a **preference for a** "**yes/no" response category** to specific quality questions rather than scalar answer categories. Some participants did, however, find it acceptable for questions to be framed

in a way that allowed response categories to be hierarchical like “very,” “somewhat,” “not very,” and “not at all.” In such cases, the question would need to be modified to

accommodate this format.

Tables 1 and 2 represent the result of first and second order priorities that emerged after discussions with both the CAC and through the focus group and interview process. Specifically, Table 1 summarizes the quality domains, issue areas, and selected survey questions prioritized during the co-creation process. These consistently emerged as “what matters most” when it comes to HCBS quality. The questions associated with these prioritized issue areas were derived in two ways. They were either taken verbatim from the baseline inventory of existing HCBS quality survey questions or they were modified by the CAC to better address the specific quality issue. This is noted for each question.

Table 1: Priority Areas Identified by the Co-Creation Process and Preferred Questions from Inventory and CAC

Quality Dimensions	Prioritized Issue Areas	Specific Questions Preferred as Capturing Experience
Structure & Access	Finding Care	• Were you able to get the care you need? *(question from inventory)*
	Language & Cultural Competence	• Did you receive information in the language you prefer? *(question from inventory)* • How often did the individuals paid to provide you with personal care at home explain things in a way that was easy to understand? *(modified inventory question)*
	Navigation – Care Management & Coordination	• Did you have someone help you set up and coordinate care? *(question from inventory)* • Are your providers offering care working together on the care you need? *(question from inventory)*
Process	Person Centered Care	• How often did the individuals paid to provide personal care at home to you, listen carefully to you? (modified inventory question)
Outcomes	Problems with Care	• Did you know who to call if you had a complaint about the services you received from the individuals who are paid to provide personal care in your home? (modified inventory question)
	Problems with Discrimination When Receiving Care	• Are you ever treated poorly or unfairly by carers in your home because of your language, race, or culture? (question from inventory) • Do you ever avoid seeking care because you feel you will not be treated with respect? (question from inventory)
	Post-Acute Care	• Do you feel sufficiently supported for discharge back to home after a hospital or rehab stay? (question from inventory)

Because the discussions with participants became far ranging and often open-ended, other issues and priorities arose during the co-creation process that are also worth noting (Table 2). These issues, while not identified as top priority areas by participants, did relate directly to those covered in the initial question inventory. Again, CAC members felt that the dominant quality issues related to accessing care superseded all other quality issues, thus making it challenging for participants to focus on some of these other issues. We present these additional quality-related issues because, given the relatively small number of individuals participating in this co-creation pilot, it is very likely that an expanded group (or even one characterized by more rural participants) may have prioritized more highly

several of the issues and questions in Table 2. The CAC members confirmed this perspective.

Table 2: Additional Quality–Related Issues and Questions for Further Exploration

Quality Dimensions	Prioritized Issue Areas	Questions for Further Exploration
Structure & Access	Control of Care	• Can you change the people who are paid to provide you with your personal care services if you wanted to? • Can you choose or change who provides your personal care services if you want? • If you want to make changes to the personal care services you receive, do you know whom to contact?
	Transportation	• Do you have transportation when you need to get to medical appointments? • Do your transportation options meet your current needs? • Were you easily able to get in and out of the service van or transportation vehicle service you used?
Process	Staff Consistency	• Do the individuals paid to provide personal care at home to you show up and leave when they are supposed to? • Do the paid individuals providing personal care in your home change too often? • Do you know who to contact if the individuals paid to provide personal care at home to you do not show up as scheduled and you have an immediate need for care?
	Service Plan Development	• Do the individuals paid to provide personal care at home to you do things the way you want them done? • Do you feel that the individuals paid to provide personal care at home to you know what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
Outcomes	Access to community	• Are you able to do things you enjoy outside of your home when and with whom you want to? • Has there a time that you wanted to leave the house to go somewhere but not been able to because of a personal care or health limitations?
	Overall rating	• Would you recommend the individuals who are paid to provide personal care in your home to your family and friends if they needed help with everyday activities? • Are you satisfied with the personal care services and supports you receive? • Do the personal care services and supports you receive meet your needs and goals?
	Problems with services – Elder Abuse	• Do you feel safe around the individuals who are paid to provide personal care in your home? • Do you ever feel worried about the security of your personal belongings when you have individuals who are paid to provide personal care in your home • Have you experienced neglect or abuse from the individuals who are paid to provide personal care in your home?

Lessons Learned from the Co-Creation Process

This project highlighted the importance of engaging people with lived experience to make a co-creation process meaningful and focused on the quality issues that matter most to people using services. The processes and learnings described here can therefore serve to support future co-design work. An important lesson is that **the nature of co-creation requires the flexibility to make course corrections** as needed. This requires investing the time and energy to **build trusted and collaborative relationships with community partners.** One of the ways to do this is to **concretely show that you value people's time** by providing compensation and making sure that the number of meetings throughout the process is manageable; for example, for this group, fewer meetings of longer duration was preferred to more meetings with shorter durations.
Other key lessons include:

- **Make communications concise, clear, and efficient.** Don't "over-communicate," as multiple emails can become more confusing than clarifying. Set expectations about communication frequency and methods at the outset of the process.

- **Leverage established community groups and spaces when possible.** Focus group attendance was improved when participants met at centralized locations, e.g., senior centers they already frequent. Additionally, having senior center staff available to coordinate and support the meeting allows participants to be fully engaged.

- **Engage people using varied methods.** We provided opportunities for written responses, polls, open-ended conversation, and individual meetings to ensure participation and create an inclusive space for all participants. This also helped improve participant attendance and retention rates over the course of the project.

- **Continuously** "**check the pulse" of how engagement and co-creation is going.** The project team should consistently check-in with community partners about the process and provide time during and after meetings for participants to provide anonymous feedback assessing the process.

- For a pilot process such as this one, **set expectations regarding project results**. For example, because this co-creation process was based on input from 24 individuals, not all of whom were HCBS users, results are preliminary and

suggestive at best. People engaging in the process should understand that while their contributions are essential to the research and the results are important, a pilot is just the first step in a broader improvement process.

Concluding Thoughts

This pilot process of co-creation was an effective start in helping us identify dimensions of quality that are particularly important to the group of HCBS users from communities of color participating in this study. We were able to generate an initial prioritization of quality issues and then begin to test specific validated questions to learn if these questions indeed measured what was most important to their lived experience. This represents a first step in what would need to be a broader-scale effort to validate these pilot findings and make them broadly useable. Such an effort would need to have a much larger number of participants with greater geographic dispersion, a well-defined process for validation of new questions such as those related to empathy and compassion, and a clear sense that investing in the effort would be worthwhile to the potential users of new questions sets, such as state agencies that oversee HCBS and Medi-Cal managed care plans that are increasingly responsible for delivering some HCBS.

California health and aging leaders have demonstrated interest in improving provision of and ability to monitor HCBS quality, and in improving health.[7] This project, with its focus on HCBS users of color, could be expanded beyond the pilot phase to build on initiatives already being undertaken by the state to better address quality concerns that are likely underrepresented in existing quality assessment efforts. Our learnings about issues and challenges of the co-creation process and ways to make it workable can inform similar future efforts, which is important for assuring that what matters most to people is what is ultimately measured.

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[7] These include the Gap Analysis and Multiyear Roadmap, Master Plan for Aging, and the CalAIM Long-Term Services and Supports Data Transparency Dashboard.

Appendix A:

INITIAL QUESTION SET PRESENTED TO THE COMMUNITY ADVISORY COUNCIL (CAC)

Quality Dimension	Specific Issues/Matters of Concern	Specific Questions
Structure and Access	Finding Care	• Were you able to get the personal care you need? • Were you able to get care as quickly as possible? • Were you able to find out about the care you need? • Did you have to delay getting the care you needed? • Did you face any "gatekeepers" such as prior-authorization that interfered with you getting care when and how you needed it?
	Language and Cultural Competence	• Did you need someone to help you understand your care providers? • Did you receive information in the language you prefer? • Did you have any difficulties understanding your care providers?
	Navigation – Care Management and Coordination	• Did you have someone help you set up and coordinate care? • Are your providers offering care working together on the care you need? • Did a care coordinator talk to you about how to meet your care needs?
	Control of Care	• Can you change the people who are paid to provide you with your personal care services if you want to? • Can you choose or change who provides your personal care services if you want? • If you want to make changes to the personal care services you receive, do you know whom to contact?
	Transportation	• Do you have transportation when you need to get to medical appointments? • Do your transportation options meet your current needs? • Where you easily able to get in and out of the service van or transportation vehicle service you used?
Process	Person Centered Care	• Do you feel "heard" and "understood" by care providers?" • Do you feel providers understand what is important to you? • Do you feel you are treated with courtesy and respect? • Are the home care providers ones that you find satisfactory?
	Staff Consistency	• Do the individuals paid to provide personal care at home to you show up and leave when they are supposed to? • Do the paid individuals providing personal care in your home change too often? • Do you know who to contact if the individuals paid to provide personal care at home to you do not show up as scheduled and you have an immediate need for care?

Appendix A Cont.

Quality Dimension	Specific Issues/Matters of Concern	Specific Questions
Process	Service Plan Development	• Do the individuals paid to provide personal care at home to you do things the way you want them done? • Do you feel that the individuals paid to provide personal care at home to you know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
Outcomes	Problems with Care	• Do you know how to find help to fix problems you experience with care you receive? • Do you know what to do if you have a complaint about care? • Are you ever treated badly by a provider of personal care in your home? • Do you have someone who can help you fix these problems?
	Problems with Discrimination When Receiving Care	• Are you ever treated poorly or unfairly by carers in your home because of your language, race, or culture? • Do you ever avoid seeking care because you feel you will not be treated with respect? • Do you ever avoid seeking care because you feel your needs will not be taken seriously?
	Post-Acute Care	• Do you feel sufficiently supported for discharge back to home after a hospital or rehab stay? • Do you feel you have adequate follow-up care after discharge? • Does anyone follow up after discharge to make sure you are doing what needs to be done? • Do you feel you have all the information and support you need to manage at home after discharge from a hospital or rehab stay?
	Access to community	• Are you able to do things you enjoy outside of your home when and with whom you want to? • Has there been a time that you wanted to leave the house to go somewhere but not been able to because of a personal care of health limitation?
	Problems with services – Elder Abuse	• Do you feel safe around the individuals who are paid to provide personal care in your home? • Do you ever feel worried about the security of your personal belongings when you have individuals who are paid to provide personal care in your home? • Have you experienced neglect or abuse from the individuals who are paid to provide personal care in your home?
	Overall rating	• Would you recommend the individuals who are paid to provide personal care in your home to your family and friends if they needed help with everyday activities? • Are you satisfied with the personal care services and supports you receive? • Do the personal care services and supports you receive meet your needs and goals?

Appendix B: Sample Questions Presented to Spanish Focus Group for Input

Q1. Were you able to get the personal care you needed?

A. Always
B. Sometimes
C. Rarely
D. Never

Q2. Did you delay getting or not get any personal care you felt you needed?

A. Yes
B. No

Q3. Were you able to find out about the personal care you needed?

A. Yes
B. No

Q4. When you needed personal care at home or in the community, how often did you get care as quickly as you needed it?

A. A lot
B. A little bit
C. Not much
D. Not at all

Q5. How often did the individuals paid to provide you with personal care at home explain things in a way that was easy to understand?

A. Never
B. Sometimes
C. Usually
D. Always

Q6. Did you receive information about the personal care needs you had and the services you received in the language you prefer?

A. Yes, all information
B. Some information
C. No

Q7. Were services and supports delivered in a way that was respectful of your culture? This can be things like respecting your religion, your beliefs, the food you prefer, or the holidays you celebrate.

A. Yes
B. Sometimes or some services
C. No

Q8. Did you have a case manager or care coordinator – someone whose job it was to work with you to help set up and coordinate the personal care services you needed and wanted?

A. Yes
B. No

Q9. Did service providers work together to provide support? For example, did the agency providing transportation work together with the agency providing in-home support, if necessary?

A. Yes, all service providers
B. Sometimes, or some service providers
C. No

Q10. How often did the individuals paid to provide personal care at home to you listen carefully to you?

A. Never
B. Sometimes
C. Usually
D. Always

Q11. How often did the individuals paid to provide personal care at home to you do things the way you wanted them done?

A. Always
B. Sometimes
C. Rarely
D. Never

Q12. How often did the individuals paid to provide you with personal care at home treat you with courtesy and respect?

A. Never
B. Sometimes
C. Usually
D. Always

Q13. Did you feel respected by the individuals who are paid to provide personal care in your home?

A. Yes
B. No

Q14. Did you know who to call if you had a complaint about the services you received from the individuals who are paid to provide personal care in your home?

A. Yes
B. Maybe
C. Not sure
D. Don't know

Q15. If you had a problem with the individuals who were paid to provide personal care in your home, did someone work with you to fix this problem? Please choose all that apply.

A. Yes, Family member or friend
B. Yes, Case manager
C. Yes, Agency
D. Yes, someone else, please specify _____
E. No

Q16. Have you ever been treated poorly by the individuals who are paid to provide personal care in your home because of your race/ethnicity?

A. Yes
B. No

Q17. Was there ever a time when you feel you would have gotten better care if you had belonged to a different race or ethnic group?

A. Yes
B. No

Q18. Have you ever avoided personal care services because you felt you would not be treated fairly or with respect?

A. Yes
B. No

Q19. When leaving the hospital or rehab/nursing facility, did you feel comfortable and supported enough to go home/back where you live?

A. Yes
B. In-between
C. No

Q20. After leaving the hospital or rehab/nursing facility, did anyone follow-up with you to make sure you had the services and supports you needed? This could be a doctor, a case manager, a social worker, or someone else.

A. Yes
B. No

Q21. Do you feel that the individuals providing you with personal care at home truly care about your wellbeing?

A. Yes
B. No