

**2023 North Carolina Home and
Community-Based Services (HCBS)
Consumer Assessment of Healthcare
Providers and Systems (CAHPS®)
Member Experience Report**

*North Carolina Department of Health and
Human Services Division of Health Benefits*

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Abbreviations

The following is a list of abbreviations and acronyms used throughout this report.

- **AHRQ**—Agency for Healthcare Research and Quality
- **CAHPS**[®]—Consumer Assessment of Healthcare Providers and Systems¹
- **CAP/C**—Community Alternatives Program for Children
- **CAP/DA**—Community Alternatives Program for Disabled Adults
- **CATI**—Computer Assisted Telephone Interviewing
- **CMS**—Centers for Medicare & Medicaid Services
- **DHB**—Division of Health Benefits
- **EQRO**—External Quality Review Organization
- **HCBS**—Home and Community-Based Services
- **HSAG**—Health Services Advisory Group, Inc.
- **LME**—Local Management Entity
- **LTSS**—Long-Term Services and Supports
- **MCO**—Managed Care Organization
- **NC**—North Carolina
- **NCOA**—National Change of Address
- **TEFT**—Testing Experience and Functional Tools

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ).

1. Executive Summary

Overview

The North Carolina (NC) Department of Health and Human Services Division of Health Benefits (DHB) contracts with Health Services Advisory Group, Inc. (HSAG), an external quality review organization (EQRO), to administer and report the results of the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS[®]) survey for members enrolled in NC Medicaid.² The goal of the HCBS CAHPS survey is to gather direct feedback from Medicaid members receiving HCBS about their experiences and the quality of the long-term services and supports (LTSS) they receive.

Survey Instrument

The survey instrument selected was the HCBS CAHPS survey without the Supplemental Employment module. The Centers for Medicare & Medicaid Services (CMS) developed the HCBS CAHPS survey for voluntary use by state Medicaid programs. As part of the Testing Experience and Functional Tools (TEFT) Demonstration, CMS funded the development and testing of the survey, which took place from 2010 through 2016. The survey was developed to be administered by an interviewer in person or by telephone.³ The HCBS CAHPS survey received the CAHPS trademark on June 22, 2016.⁴

The survey includes 96 core questions that yield 19 measures. The survey includes a set of measures that can be classified as:

1. Global ratings (ratings of member experience on a scale of 0 to 10).
2. Composite measures (groups of related questions that are combined to form a composite).
3. Recommendation measures (individual measures which ask how likely the member is to recommend a service).
4. Unmet need measures (individual measures that identify if needs were not being met because of a lack of help).
5. Physical safety measure (individual measure assessing the member's physical safety).

² CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ).

³ HSAG only administered the HCBS CAHPS survey by telephone.

⁴ Centers for Medicare & Medicaid Services. CAHPS Home and Community-Based Services Survey. *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*. July 2021. Available at: <https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbscahps-appk-data-analysis-guide.pdf>. Accessed on: June 3, 2024.

Survey Administration

Surveying was divided into two different administration periods: 1) members without a known legal guardian (i.e., standard population) and 2) members with a known legal guardian (i.e., legal guardian population). Members and/or their proxies (i.e., someone who could complete the survey on behalf of the member) completed the survey at two different times. The standard population completed the survey from August 7, 2023, to September 18, 2023, and the legal guardian population completed the survey from November 1, 2023, to December 27, 2023. Either the member or the member's proxy completed the survey. For members with a known legal guardian, the legal guardian was contacted to obtain permission to contact the member to complete the survey. Respondents provided feedback on their or the member's experience with HCBS services over the prior three months.

A pre-notification letter was sent to notify members or their guardians that they would be contacted to complete the survey. The survey administration process allowed members or their proxies to complete the survey via telephone. Up to six telephone calls via Computer Assisted Telephone Interviewing (CATI) were made to try to complete the survey.

Survey Population

HSAG administered the 2023 HCBS CAHPS survey to adult Medicaid members who were currently receiving services through the 1915(c) waiver (specifically, the North Carolina Innovations Waiver Program, Community Alternatives Program for Disabled Adults [CAP/DA] Waiver Program, or Community Alternatives Program for Children [CAP/C] Waiver Program) and received at least one qualifying HCBS service, including self-directed services (e.g., personal care service, behavioral health support, homemaker service, case management, or medical transportation). These services were provided by local management entity/managed care organizations (LME/MCOs). At the time of survey administration, there were six LME/MCOs providing HCBS in NC: Alliance Health, Eastpointe, Partners Health Management, Sandhills Center, Trillium Health Resources, and Vaya Health.⁵ A statewide-level sample of 10,127 adult members was selected. A total of 494 members responded to the survey, for a response rate of 4.95 percent.⁶ A total of 470 members from the standard HCBS population responded to the survey and a total of 24 members or legal guardians from the guardian population responded to the survey.⁷

⁵ Following survey administration, Sandhills Center was dissolved, and Eastpointe and Trillium Health Resources consolidated. The majority of Sandhills Center's counties were consolidated into Eastpointe/Trillium.

⁶ The response rate is defined as the total number of completed surveys divided by all eligible members of the sample.

⁷ Centers for Medicare & Medicaid Services. CAHPS Home and Community-Based Services Survey. *Technical Assistance Guide for Administration of the HCBS CAHPS Survey*. July 2021. Available at: <https://www.medicare.gov/medicaid/quality-of-care/downloads/hcbscahps-admin-ta-guide.pdf>. Accessed on: June 3, 2024.

Performance Highlights

HSAG calculated positive ratings for each measure. The positive scores represent the percentage of respondents with positive survey responses (i.e., rate their experience of care higher).⁸ The positive ratings include respondents who:⁹

- Provided a rating of 9 or 10 on the global ratings.
- Responded “Always,” “Yes,” or “All” on the composite measures.
- Responded “Definitely yes” for the recommendation measures.
- Responded “Yes” for the No Unmet Need in Toileting measure.
- Responded “No,” “Never,” or “Mostly no” to reverse coded questions.

These positive ratings are used to compare results to national benchmarks and by race and ethnicity.

National Comparisons

HSAG compared the NC HCBS Program’s positive ratings to the Agency for Healthcare Research and Quality’s (AHRQ’s) HCBS CAHPS database (i.e., CAHPS Database) benchmarks to determine whether positive ratings were statistically significantly higher or lower.^{10,11} For more detailed information regarding these comparisons, please refer to the Reader’s Guide beginning on page 17. For detailed results regarding these comparisons, please refer to the Results section beginning on page 24.

The following composite measure rates had a significantly *higher* positive rating in 2023 compared to the CAHPS database benchmark:

- *Transportation to Medical Appointments* (83.00%)
- *Personal Safety and Respect* (95.86%)
- *Planning Your Time and Activities* (62.52%)

⁸ Positive ratings combine responses from the standard population and legal guardian population.

⁹ Some questions in the HCBS CAHPS survey allowed respondents to complete an alternative question. Please reference the Reader’s Guide on page 14 for more information on alternative response options for the global ratings and some composite measures.

¹⁰ Agency for Healthcare Research and Quality. *The CAHPS® Home and Community-Based Services (HCBS) Survey Database 2023 Chartbook*. July 2023. Available at: <https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/cahps-database/2023-hcbs-chartbook.pdf>. Accessed on: June 3, 2024.

¹¹ HCBS CAHPS Database benchmarks were not available for 2023 at the time this report was prepared; therefore, 2021 data were used for this comparative analysis; therefore, caution should be exercised when comparing the 2021 HCBS CAHPS Database benchmarks to the 2023 results.

The following individual item measure rates had a significantly *higher* positive rating in 2023 compared to the CAHPS database benchmark:

- *Informed if staff cannot come* (87.71%)
- *Staff know kind of help you need* (97.69%)
- *Helped getting or fixing equipment* (93.88%)
- *Way to get to appointments* (91.21%)
- *Someone to talk to* (90.42%)
- *Staff do not take money or things* (99.06%)
- *Together with family* (50.84%)
- *Together with friends* (35.10%)
- *Community* (37.35%)
- *What to do with time* (91.02%)

The following individual item measures had a significantly *lower* positive rating in 2023 compared to the CAHPS database benchmark:

- *Staff work time supposed to* (83.38%)
- *Treated the way you want by staff* (84.12%)
- *Contact case manager* (89.21%)

Survey Results

HSAG evaluated the items (i.e., survey questions) that make up each composite measure to determine if there were any individual survey items that comprise the composite measure that had a lower positive rating (i.e., performed poorer) than the other composite items for the NC HCBS Program, as shown in Table 1-1. For detailed results regarding these comparisons, please refer to the Results section beginning on page 26.

Table 1-1—Composite Item Positive Ratings: NC HCBS Program

Composite Measure/Individual Item	Positive Rating
<i>Reliable and Helpful Staff Composite</i>	87.81%
Staff on time to work	81.44%
Staff work time supposed to	83.38%
Informed if staff cannot come	87.71%
<i>Staff Listen and Communicate Well Composite</i>	84.63%
Staff easy to understand	75.07%
Treated the way you want by staff	84.12%
Staff listen to you	84.14%

Composite Measure/Individual Item	Positive Rating
<i>Helpful Case Manager Composite</i>	90.44%
Contact case manager	89.21%
Helped getting other changes to services	88.24%*
<i>Choosing the Services that Matter to You Composite</i>	81.31%
Plan included important things	66.59%
<i>Transportation to Medical Appointments Composite</i>	83.00%
Timely pickup	70.94%
<i>Personal Safety and Respect Composite</i>	95.86%
Someone to talk to	90.42%
<i>Planning Your Time and Activities Composite</i>	62.52%
Together with family	50.84%
Together with friends	35.10%
Community	37.35%
* Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.	

Race and Ethnicity Comparisons

HSAG evaluated the positive ratings to determine if there were significant differences by self-reported race and ethnicity. Race is categorized as White, Black, and Other using the self-reported results. For this analysis, the Other race category includes: Multi-Racial, Asian, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native, and Other. The positive ratings for each race category were compared as follows: White respondents were compared to non-White respondents; Black respondents were compared to non-Black respondents; and Other respondents were compared to non-Other respondents. Ethnicity was categorized as Hispanic and Non-Hispanic using the self-reported results from the ethnicity question. The positive ratings for Hispanic respondents and Non-Hispanic respondents were compared to each other. For more detailed information regarding these comparisons, please refer to the Reader’s Guide beginning on page 17. For detailed results regarding these comparisons, please refer to the Results section beginning on page 42.

The following are the significant differences identify by race or ethnicity for the NC HCBS Program:

- A significantly *lower* percentage of Black (61.26 percent) respondents reported their mental or emotional health status as Excellent, Very Good, or Good when compared to Non-Black (73.63 percent) respondents.
- A significantly *higher* percentage of Hispanic (95.00 percent) respondents rated their personal assistance and behavioral health staff positively when compared to Non-Hispanic (81.23 percent) respondents.
- A significantly *lower* percentage of Hispanic (90.12 percent) respondents reported they had someone to talk to if someone hurt them or did something to them that they did not like, that staff did not take their money or things without asking them first, and staff did not yell, swear, or curse at them when compared to Non-Hispanic (96.39 percent) respondents.

- A significantly *higher* percentage of Black (100.00 percent) respondents reported they had no unmet need with toileting when compared to Non-Black (97.24 percent) respondents.

Conclusions

Overall, respondents reported positive experiences with receiving transportation to medical appointments, their personal safety and respect, and planning their time and activities as the positive ratings for these composite measures were higher in 2023 than their CAHPS database benchmark counterparts. Specifically, respondents felt that they had a way to get to appointments, which contributed to the higher rating for the *Transportation to Medical Appointments* composite measure. Respondents reported that they felt they had someone to talk to and that staff who help them do not take their money or things, which contributed to the higher rating for the *Personal Safety and Respect* composite measure. Lastly, respondents reported higher positive ratings for feeling like they could get together with their family and friends, had a sense of community, and knew what to do with their time, which contributed to the higher rating for the *Planning Your Time and Activities* composite measure.

The evaluation of the positive ratings by race and ethnicity suggests that some disparities exist in member-reported experiences with HCBS across a few HCBS CAHPS survey measures, although few consistent patterns of disparities were evident. Specifically, in evaluating the race and ethnicity findings, there were no consistent patterns of differences across the categories. A lower percentage of Black respondents reported their mental or emotional health status as Excellent, Very Good, or Good when compared to Non-Black respondents, but a higher percentage of Black respondents reported they had no unmet need with toileting when compared to Non-Black respondents. A higher percentage of Hispanic respondents rated their personal assistance and behavioral health staff positively when compared to Non-Hispanic respondents, but a lower percentage of Hispanic respondents reported they had someone to talk to if someone hurt them or did something to them that they did not like, that staff did not take their money or things without asking them first, and staff did not yell, swear, or curse at them when compared to Non-Hispanic respondents. DHB should consider efforts to engage Black and Hispanic members to determine possible barriers to care or opportunities for improvement that may result in increased satisfaction with their HCBS experiences.

2. Reader's Guide

This section provides a comprehensive overview of the HCBS CAHPS survey administration protocol and analytic methodology.

Survey Administration

Survey Overview

The HCBS CAHPS survey without the Supplemental Employment module is a standardized survey that assesses patient perspectives of care. The goal of the HCBS CAHPS survey is to gather direct feedback from Medicaid members receiving HCBS about their experiences and the quality of the LTSS they receive. The survey provides state Medicaid agencies with standard individual experience metrics for HCBS programs that are applicable to all populations served by these programs, including elderly and people with one or more disabilities (including physical disabilities, cognitive disabilities, intellectual impairments, or disabilities due to mental illness).

Performance Measures

The survey includes 96 core questions that yield 19 measures. These measures include three global ratings, seven composite measures, three recommendation measures, five unmet need measures, and one physical safety measure. Figure 2-1 lists the measures included in the survey.

Figure 2-1—HCBS CAHPS Measures

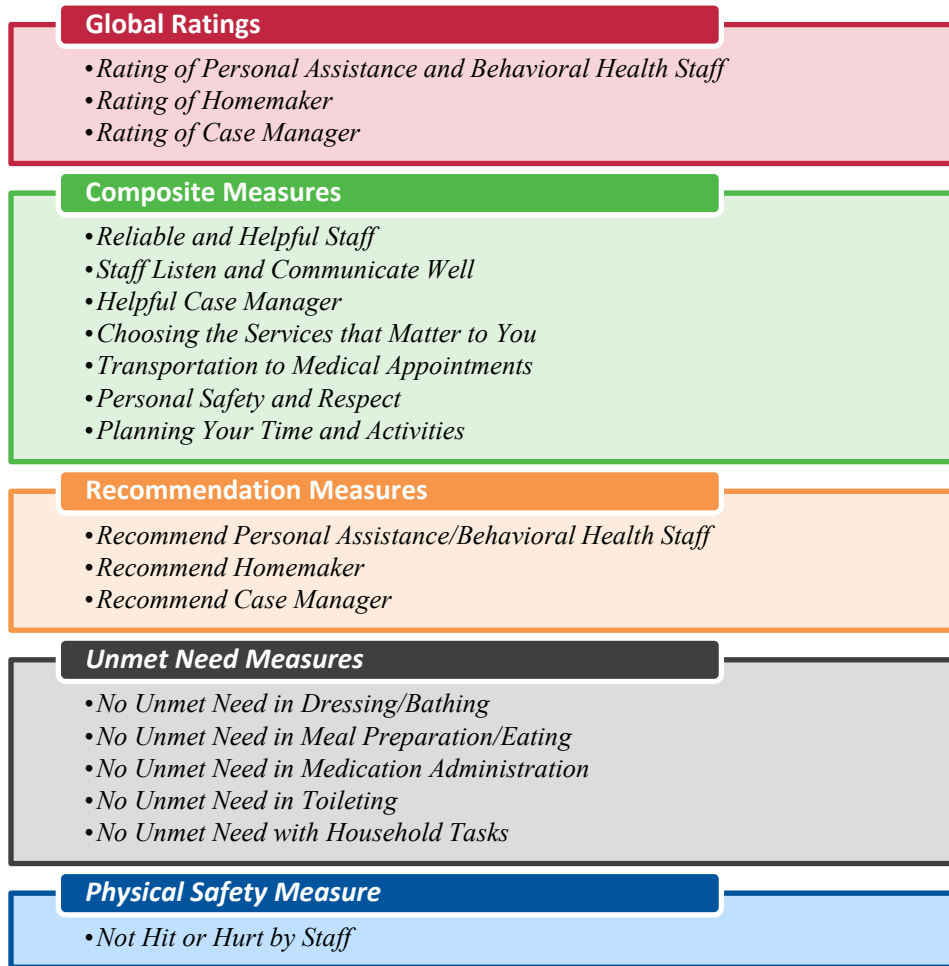


Table 2-1 presents the survey language and response options for each measure. The survey has two types of response options to increase accessibility for individuals with intellectual disabilities, categorized as standard response options and alternative response options. Respondents were first provided the standard response options; however, if a respondent finds these options challenging, the simpler alternative response options are used. The alternative response options were developed to enable more members to participate in the survey, regardless of cognitive acuity. Additionally, certain questions included the program-specific terms, indicated in brackets, that were provided by the respondent during the identification questions of the interview.

Table 2-1—Question Language and Response Options

Question Language	Response Options	
	Standard	Alternative
Global Ratings		
<i>Rating of Personal Assistance and Behavioral Health Staff</i>		
35. Using any number from 0 to 10, where 0 is the worst help from [personal assistance/behavioral health staff] possible and 10 is the best help from personal assistance/behavioral health staff possible, what number would you use to rate the help you get from [personal assistance/behavioral health staff]?	0–10 Scale	Excellent, Very good, Good, Fair, Poor
<i>Rating of Homemaker</i>		
46. Using any number from 0 to 10, where 0 is the worst help from homemakers possible and 10 is the best help from [homemakers] possible, what number would you use to rate the help you get from [homemakers]?	0–10 Scale	Excellent, Very good, Good, Fair, Poor
<i>Rating of Case Manager</i>		
54. Using any number from 0 to 10, where 0 is the worst help from case manager possible and 10 is the best help from [case manager] possible, what number would you use to rate the help you get from case manager?	0–10 Scale	Excellent, Very good, Good, Fair, Poor
Composite Measures and Composite Items		
<i>Reliable and Helpful Staff</i>		
13. In the last 3 months, how often did [personal assistance/behavioral health staff] come to work on time? (Staff on time to work)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
14. In the last 3 months, how often did [personal assistance/behavioral health staff] work as long as they were supposed to? (Staff work time supposed to)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
15. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that [personal assistance/behavioral health staff] could not come that day? (Informed if staff cannot come)	Yes, No	
19. In the last 3 months, how often did [personal assistance/behavioral health staff] make sure you had enough personal privacy when you dressed, took a shower, or bathed? (Privacy [dressing, showering, bathing])	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
37. In the last 3 months, how often did [homemakers] come to work on time? (Homemaker on time to work)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
38. In the last 3 months, how often did [homemakers] work as long as they were supposed to? (Homemaker work time supposed to)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
<i>Staff Listen and Communicate Well</i>		
28. In the last 3 months, how often did [personal assistance/behavioral health staff] treat you with courtesy and respect? (Staff courteous and respectful)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
29. In the last 3 months, how often were the explanations [personal assistance/behavioral health staff] gave you hard to understand because of an accent or the way [personal assistance/behavioral health staff] spoke English? (Staff easy to understand)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no

Question Language	Response Options	
	Standard	Alternative
30. In the last 3 months, how often did [personal assistance/behavioral health staff] treat you the way you wanted them to? (Treated the way you want by staff)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
31. In the last 3 months, how often did [personal assistance/behavioral health staff] explain things in a way that was easy to understand? (Staff explains things in an easy-to-understand way)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
32. In the last 3 months, how often did [personal assistance/behavioral health staff] listen carefully to you? (Staff listen to you)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
33. In the last 3 months, did you feel [personal assistance/behavioral health staff] knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community? (Staff know kind of help you need)	Yes, No	
41. In the last 3 months, how often did [homemakers] treat you with courtesy and respect? (Homemakers courteous and respectful)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
42. In the last 3 months, how often were the explanations [homemakers] gave you hard to understand because of an accent or the way the [homemakers] spoke English? (Homemakers easy to understand)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
43. In the last 3 months, how often did [homemakers] treat you the way you wanted them to? (Treated the way you want by homemakers)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
44. In the last 3 months, how often did [homemakers] listen carefully to you? (Homemakers listen)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
45. Do you feel [homemakers] know what kind of help you need? (Homemakers know kind of help you need)	Yes, No	
Helpful Case Manager		
49. In the last 3 months, could you contact this [case manager] when you needed to? (Contact case manager)	Yes, No	
51. In the last 3 months, did this [case manager] work with you when you asked for help with getting or fixing equipment? (Helped getting or fixing equipment)	Yes, No	
53. In the last 3 months, did this [case manager] work with you when you asked for help with getting other changes to your services? (Helped getting other changes to services)	Yes, No	
Choosing the Services that Matter to You		
56. In the last 3 months, did your [service plan] include none, some, most, or all of the things that are important to you? (Plan included important things)	None, Some, Most, All	
57. In the last 3 months, did you feel [personal assistance/behavioral health staff] knew what's on your service plan, including the things that are important to you? (Staff knows plan and important things)	Yes, No	
Transportation to Medical Appointments		
59. In the last 3 months, how often did you have a way to get to your medical appointments? (Way to get to appointments)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no

Question Language	Response Options	
	Standard	Alternative
61. In the last 3 months, were you able to get in and out of this ride easily? (In/out of ride easily)	Yes, No	
62. In the last 3 months, how often did this ride arrive on time to pick you up? (Timely pickup)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
Personal Safety and Respect		
64. In the last 3 months, was there a person you could talk to if someone hurt you or did something to you that you didn't like? (Someone to talk to)	Yes, No	
65. In the last 3 months, did any [personal assistance/behavioral health staff], [homemakers], or your [case managers] take your money or your things without asking you first? (Staff did not take any money or things)	Yes, No	
68. In the last 3 months, did any [staff] yell, swear, or curse at you? (Staff do not yell, swear, or curse)	Yes, No	
Planning Your Time and Activities		
75. In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby? (Together with family)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
77. In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby? (Together with friends)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
78. In the last 3 months, when you wanted to, how often could you do things in the community that you like? (Community)	Never, Sometimes, Usually, Always	Mostly yes, Mostly no
79. In the last 3 months, did you need more help than you get from [personal assistance/behavioral health staff] to do things in your community? (Help doing things in community)	Yes, No	
80. Do you take part in deciding what you do with your time each day? (What to do with time)	Yes, No	
81. Do you take part in deciding when you do things each day – for example, deciding when you get up, eat, or go to bed? (When to do things)	Yes, No	
Recommendation Measures		
Recommend Personal Assistance/Behavioral Health Staff		
36. Would you recommend the [personal assistance/behavioral health staff] who help you to your family and friends if they needed help with everyday activities?	Definitely no, Probably no, Probably yes, Definitely yes	
Recommend Homemaker		
47. Would you recommend the [homemakers] who help you to your family and friends if they needed [homemaker services]?	Definitely no, Probably no, Probably yes, Definitely yes	

Question Language	Response Options	
	Standard	Alternative
Recommend Case Manager		
55. Would you recommend the [case manager] who helps you to your family and friends if they needed [case management services]?	Definitely no, Probably no, Probably yes, Definitely yes	
Unmet Need Measures		
No Unmet Need in Dressing/Bathing		
18. In the last 3 months, was this [dressing/bathing need] because there were no [personal assistance/behavioral health staff] to help you?	Yes, No	
No Unmet Need in Meal Preparation/Eating		
22. In the last 3 months, was this [meal preparation/eating need] because there were no [personal assistance/behavioral health staff] to help you?	Yes, No	
No Unmet Need in Medication Administration		
25. In the last 3 months, was this [medication administration need] because there were no [personal assistance/behavioral health staff] to help you?	Yes, No	
No Unmet Need in Toileting		
27. In the last 3 months, did you get all the help you needed with toileting from [personal assistance/behavioral health staff] when you needed it?	Yes, No	
No Unmet Need with Household Tasks		
40. In the last 3 months, was this [household tasks need] because there were no [homemakers] to help you?	Yes, No	
Physical Safety Measure		
Not Hit or Hurt by Staff		
71. In the last 3 months, did any [staff] hit or hurt you?	Yes, No	

Sampling Procedures

Surveying was divided into two different administration periods: 1) members without a known legal guardian (i.e., standard population) and 2) members with a known legal guardian (i.e., legal guardian population). DHB provided HSAG with two sample frame files: 1) eligible adult members for the standard population and 2) eligible adult members for the legal guardian population. The sample frame file for the legal guardian population included contact information for both the member and their legal guardian. DHB and HSAG separately performed quality control of the file records to check for completeness and correctness of data. HSAG sampled adult members who met the following criteria:

- Standard population:
 - 18 years or older as of March 31, 2023.
 - NC HCBS waiver program members who were enrolled in the same plan or program during the measurement period (i.e., March 1, 2023, to May 31, 2023), with no gaps in enrollment.
- Legal guardian population:
 - 18 years or older as of August 31, 2023, and had a legal guardian.
 - NC HCBS waiver program members with a legal guardian who were enrolled in the same plan or program during the measurement period (i.e., June 1, 2023, to August 31, 2023), with no gaps in enrollment.
- Were enrolled in one of the following waivers:
 - North Carolina Innovations Waiver
 - CAP/DA
 - CAP/C
- Received at least one qualifying HCBS service, including self-directed services (e.g., personal care service, behavioral health support, homemaker service, case management, or medical transportation) during the measurement period.
- Were not institutionalized during the three months (i.e., 90 days) of the measurement period.

HSAG included all eligible members in the sample after ensuring all eligibility criteria had been met, invalid phone numbers were excluded, invalid legal guardian contact information was excluded (legal guardian population only), and deduplication for both phone number and address was performed. For groups of two or more members who shared an address or phone number, one member was selected at random to keep in the sample. The sample size was 10,000 members for the standard population and 127 for the legal guardian population, for a total sample size of 10,127.

HSAG processed sampled addresses through the United States Postal Service's National Change of Address (NCOA) system to obtain new addresses where possible.

Survey Protocol

Prior to survey administration, a pre-notification letter was sent to members and legal guardians alerting them to expect a telephone call to complete the survey and assured them that the survey was endorsed by DHB. The pre-notification letter was in English with a Spanish back side containing the same letter text. One week after the pre-notification letters were mailed out, CATI was conducted in either English or Spanish. For members in the standard population, outreach was made directly to the member, if available. For members with a legal guardian, outreach was first made to the legal guardian to obtain permission to contact the member to complete the survey.

While HSAG attempted to obtain responses to the survey directly from members, proxy respondents (including legal guardians, family members, and friends) were allowed to answer the questions on behalf of the member. Proxy respondents were allowed if the member was unable to participate in the survey and offered a specific individual to respond to the survey questions on his or her behalf. If a paid caregiver responded to the survey on behalf of the members, these completed surveys were excluded from the analysis.

Survey Administration Outcomes and Response Rates

The response rate is defined as the total number of completed surveys divided by all eligible members of the sample. A survey was assigned a disposition code of “completed” if at least one eligible question was answered, excluding the three cognitive screening questions that are administered at the beginning of the interview and the six interviewer questions used to determine survey eligibility.¹² Eligible members included the entire sample minus ineligible members. Ineligible members met at least one of the following criteria: they were deceased, were invalid (did not meet the criteria described on page 12), had a language barrier, or were mentally or physically incapacitated and did not have a proxy.¹³

$$\text{Response Rate} = \frac{\text{Number of Completed Surveys}}{\text{Sample Size} - \text{Ineligibles}}$$

Methodology

HSAG used the scoring approach recommended by CMS in the *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*.¹⁴ This section provides an overview of the analyses performed. In compliance with the CMS requirements, a minimum of 11 respondents in a cell is required for the results to be reported. Cells with fewer than 11 respondents in the numerator or denominator were suppressed and reported as “Insufficient Data.”

Scoring Calculations

Alternative Scale Transformation of Data

Some questions in the HCBS CAHPS survey allowed respondents to complete an alternative question:

¹² Eligible questions included any question in the survey between Question 4 and Question 99.

¹³ Invalid members of the sample do not meet the age or continuous enrollment criteria during the measurement period or did not receive at least one qualifying HCBS service during the measurement period.

¹⁴ Centers for Medicare & Medicaid Services. CAHPS Home and Community-Based Services Survey. *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*. July 2021. Available at: <https://www.medicare.gov/medicaid/quality-of-care/downloads/hcbscahps-appk-data-analysis-guide.pdf>. Accessed on: June 3, 2024.

1. “How Often” questions with response options of “Never,” “Sometimes,” “Usually,” or “Always” were provided an alternative question with a two-point “Mostly yes” or “Mostly no” response option. For example:
 - a. *Standard question:* “In the last 3 months, how often did [personal assistance/behavioral health staff] work as long as they were supposed to? Would you say, Never, Sometimes, Usually, or Always?”
 - b. *Alternative question:* “In the last 3 months, did [personal assistance/behavioral health staff] work as long as they were supposed to? Would you say, Mostly yes or Mostly no?”
2. Global rating questions that asked for ratings of 0–10 were provided an alternative five-point “Excellent,” “Very good,” “Good,” “Fair,” or “Poor” response option. For example:
 - a. *Standard question:* “Using any number from 0 to 10, where 0 is the worst help from [case manager] possible and 10 is the best help from [case manager] possible, what number would you use to rate the help you get from [case manager]?” Members provide a response on a 0 to 10 scale.
 - b. *Alternative question:* “How would you rate the help you get from the [case manager]? Would you say, Excellent, Very good, Good, Fair, or Poor?”
3. For age, respondents were allowed to complete an alternative question, as seen below:
 - a. *Standard question:* “What is your age?” Members provide a response based on an age category (e.g., 18 to 24 years, 25 to 34 years, etc.).
 - b. *Alternative question:* “In what year were you born?” Members respond with the year they were born.

In order to evaluate the standard and alternative response options, data were recoded into standardized response values for analysis. Table 2-2 presents the standard and alternative response options and the response values assigned.

Table 2-2—Response Options and Response Values

Standard Responses	Alternative Responses	Response Values
Composite Measures, Recommendations Measures, and Unmet Need and Physical Safety Measures		
Never	Mostly no	1 (Least positive option)
Sometimes		2 (Second least positive option)
Usually		3 (Third least positive option)
Always	Mostly yes	4 (Most positive option)
Global Ratings		
0–2	Poor	1 (Least positive option)
3–4	Fair	2 (Second least positive option)
5–6	Good	3 (Third least positive option)
7–8	Very Good	4 (Fourth least positive option)
9–10	Excellent	5 (Most positive option)
Age Demographic		
18 to 44 years	Years 1979–2005	18 to 44

Standard Responses	Alternative Responses	Response Values
45 to 54 years	Years 1969–1978	45 to 54
55 to 64 years	Years 1959–1968	55 to 64
65 to 74 years	Years 1949–1958	65 to 74
75 years or older	Years 1948 and below	75 or Older

Reverse Coding

HSAG reverse coded certain HCBS CAHPS Survey items to ensure that the most positive responses of each question were given the highest values according to the topic and wording. For example, Question 29 has the standard response options of Never, Sometimes, Usually, or Always. The most positive response to this question is Never, which indicates that the respondent never had a hard time understanding explanations from their personal care assistant because of an accent or the way they spoke English. The values of the responses to this question are reverse coded so that Never has the highest value of “4” rather than a value of “1” based on the original coding. Table 2-3 displays the response options to the questions that were reverse coded.

Table 2-3—Reverse Coded Response Options and Response Values

Question Numbers	Standard Responses	Alternative Responses	Response Values
29, 42	Always	Mostly yes	1 (Least positive option)
	Usually		2 (Second least positive option)
	Sometimes		3 (Third least positive option)
	Never	Mostly no	4 (Most positive option)
18, 22, 25, 40, 71	Yes		0 (Least positive option)
	No		1 (Most positive option)
65, 68, 79	Yes		1 (Least positive option)
	No		4 (Most positive option)

Positive Ratings

HSAG calculated positive ratings for each measure in accordance with CMS’ *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*.¹⁵ Positive ratings represent the percentage of

¹⁵ Centers for Medicare & Medicaid Services. CAHPS Home and Community-Based Services Survey. *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*. July 2021. Available at: <https://www.medicare.gov/medicaid/quality-of-care/downloads/hcbscahps-appk-data-analysis-guide.pdf>. Accessed on: June 3, 2024.

eligible respondents (from the standard and legal guardian populations) who answered with the most positive response. Positive ratings responses were defined as follows:¹⁶

- “9” or “10” for the standard Global Rating response or “Excellent” for the alternative response option.
- “Always,” “Yes,” or “All” for the standard Composite measure response, or “Mostly yes” for the alternative response option.
- “Definitely yes” for the standard Recommendation measure response.
- “Yes” for Question 27 in the No Unmet Need in Toileting measure.

For reverse coded response options, the positive rating responses were defined as follows:

- “No” for the Physical Safety measure, Unmet Need measures response, Question 65 and Question 68 in the Personal Safety and Respect composite measure, and Question 79 in the Planning Your Time and Activities composite measure.
- “Never” or “Mostly no” for Question 29 and Question 42 in the Staff Listen and Communicate Well composite measure.

National Comparisons

Positive ratings were compared to AHRQ’s 2021 CAHPS database benchmarks to see if the NC HCBS Program positive rating was statistically significantly higher or lower. A score was considered statistically significantly different from the CAHPS database benchmark if the p value < 0.05. Ninety-five percent confidence interval error bars were added to any result with statistically significant differences.

Race and Ethnicity Comparisons

Scores for the overall health demographics and measures were stratified by race and ethnicity. Stratifications were based on responses to the race and ethnicity questions (Question 89 and Question 87). Race was categorized as White, Black, and Other using self-reported results from the race question. The Other race category includes: Multi-Racial, Asian, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native, and Other. The positive ratings for each race category were compared as follows: White respondents were compared to non-White respondents; Black respondents were compared to non-Black respondents; and Other respondents were compared to non-Other respondents. Ethnicity was categorized as Hispanic and Non-Hispanic using the self-reported results from the ethnicity question. The positive ratings for Hispanic respondents and Non-Hispanic respondents were compared to each other. If race and ethnicity comparisons for a measure resulted in

¹⁶ Some questions in the HCBS CAHPS survey allowed respondents to complete an alternative question. Please reference the Reader’s Guide on page 14 for more information on alternative response options for the global ratings and some composite measures.

significant findings, these results appear on the following race and ethnicity categories: White, Black, Other, and Hispanic. If the race or ethnicity comparisons for a measure did not result in any significant findings or the majority of the results were suppressed, the race or ethnicity comparison figure was not included in the report.

A *t* test was performed to determine whether each rating of each category was statistically significantly different (i.e., *p* value < 0.05) from the other categories.

This analytic approach follows AHRQ's recommended methodology for identifying statistically significant performance differences. Ninety-five percent confidence interval error bars were added to any result with statistically significant differences.

Numerators and Denominators

HSAG presents the numerator and denominator in figures displaying measure rates, where appropriate. Numerators and denominators when calculated to percentages do not match for the composite measures, because these composite measure scores are determined by calculating the average score across all questions within the composite measure. Therefore, some figures may include numerators and denominators while others do not include this information. Numerator and denominator counts are provided within Appendix A for instances where the numerator and denominator, when calculated to a percentage, do not match the measure rate.

Limitations and Cautions

The findings presented in this report are subject to some limitations in the survey design, analysis, and interpretation. DHB should consider these limitations when interpreting or generalizing the findings.

Baseline Results

The 2023 HCBS CAHPS results are the first time HSAG evaluated the targeted population. The 2023 results presented in this report represent a baseline assessment of members' experiences specific to the NC Medicaid HCBS population.

Causal Inferences

Although this report examines whether members report differences with various aspects of their health care experiences, these differences may not be completely attributable to the overall performance of the HCBS waiver program. The survey by itself does not necessarily reveal the exact cause of these differences.

CAHPS Database Benchmarks

In 2022, a total of 17 programs voluntarily submitted data to the HCBS CAHPS Survey Database for adults receiving LTSS from State Medicaid programs, including both fee-for-service HCBS programs and managed LTSS programs with a combined total of 4,731 respondents.^{17,18} The respondents included HCBS beneficiaries and paid or unpaid proxy respondents who provided support to the respondent. Data collected through the HCBS CAHPS Database are based on responses to the versions of the HCBS CAHPS Survey with and without the optional Employment Module. Since 2023 HCBS CAHPS Database benchmarks, which will represent survey data collected from January 1 to December 31, 2021, were not available at the time this report was prepared, caution should be exercised when comparing the 2021 CAHPS Database benchmarks, which represent survey data collected from January 1 to December 31, 2019, to the NC Medicaid HCBS CAHPS 2023 results.

Low Number of Responses

The 2023 HCBS CAHPS survey administration yielded a low number of completed surveys. Known challenges with the survey instrument (e.g., length of the survey) and population surveyed may have contributed to a low number of responses. Please exercise caution when interpreting results due to the low number of completed surveys (n=494 completed surveys).

Disadvantages of Positive Rating Scoring

The positive rating score only looks at the percentage of positive results and does not use all the response options in calculating the results, which can lead to less accurate measure of experience.¹⁹

Supplemental Items

The supplemental items included in the survey instrument were developed by DHB and not field tested for the HCBS population.

¹⁷ Agency for Healthcare Research and Quality. The CAHPS Databases. *The CAHPS Home and Community Based Services (HCBS) Survey Database 2023 Chartbook*. Available at: <https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/cahps-database/2023-hcbs-chartbook.pdf>. Accessed on: June 3, 2024.

¹⁸ A limited number of programs or states choose to participate in the Database. Therefore, the HCBS CAHPS Database cannot be considered a statistically representative sample of HCBS programs.

¹⁹ Robert Wood Foundation. *How to Report Results of the CAHPS Clinician & Group Survey*. Available at: <https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/cg/cgkit/HowtoReportResultsofCGCAHPS080610FINAL.pdf>. Accessed on June 3, 2024.

Survey Bias

Non-Response Bias

The experiences of the survey respondent population may be different than that of non-respondents with respect to their health care services. In addition, caution should be exercised when extrapolating the HCBS CAHPS results to the entire population if the respondent population differs significantly from the actual population of the program. For further details, please refer to the Survey Respondent to Eligible Population Demographic Data Comparisons in Appendix A on page 52.

The incompleteness and inaccuracy of the contact information for sampled members may have resulted in lower-than-expected response rates. About 4 percent (448/10,127) of sampled members had undeliverable mail, and 48 percent (4,925/10,127) of sample members had wrong or bad telephone information. The inability to contact members could also result in non-response bias (e.g., a certain segment of the population may be more likely to have missing mail/phone information than other segments). DHB should consider that potential non-response bias may exist when interpreting CAHPS results.

Social Desirability Bias

Social desirability bias is a form of survey response bias that occurs when respondents answer more favorably to a question based on what they consider to be acceptable. Surveys completed via telephone are more prone to this type of bias.

Cognitive Screening Questions

The cognitive screening questions (questions 1 through 3) assess a respondent's cognitive ability to participate in the survey. Further investigation by the CAHPS Consortium showed that these questions hindered data collection (i.e., respondents were failing the cognitive screening since the questions do not apply to the respondent).²⁰ HSAG asked these three cognitive screening questions but did not stop the survey if the member failed the cognitive screening questions, to allow all sampled members an opportunity to complete the survey.

Survey Mode

During the development of the HCBS CAHPS survey, stakeholders recommended that the in-person mode be used for this survey; however, a telephone mode was also found to be acceptable.²¹ HSAG

²⁰ The CAHPS Consortium is overseen by AHRQ.

²¹ CAHPS survey development offers opportunities for stakeholder input and review through Technical Expert Panels and requests for comments in the *Federal Register*. More information about the process for developing a CAHPS survey can be accessed at the following site: <https://www.ahrq.gov/cahps/faq/index.html>.

used a telephone-only survey mode (with a pre-notification letter) for survey administration. The selected survey mode should be taken into consideration when evaluating results.

3. Results

HSAG surveyed a total of 10,127 members, and a total of 494 surveys were completed. The overall response rate was 4.95 percent.

In order to assess potential impact on the survey results, HSAG used data in the eligible population file, which uses Medicaid enrollment data, to compare the demographic characteristics of survey respondents to those in the eligible population. Compared to the eligible population:

- Significantly *fewer* NC HCBS Program respondents were Black.
- Significantly *more* NC HCBS Program respondents were 18 to 24 years of age and White.

DHB should exercise caution when extrapolating the CAHPS results to the entire population if the respondent population differs significantly from the actual population being evaluated. For additional details on the demographic information please see Appendix A. Supplemental Information which begins on page 49.

Survey Respondents

Table 3-1 shows the total number of members sampled, the number of eligible members, the number of respondents who failed the cognitive screening questions but completed the survey, the number of respondents (i.e., completed surveys), and the response rate for the NC HCBS Program.²² The survey response rate is the total number of completed surveys divided by all eligible members of the sample.²³

Table 3-1—Survey Administration Outcomes and Response Rates (2023)

Total Sample	Eligible Sample	Failed Cognitive Screening	Total Respondent	Response Rate
10,127	9,980	16	494	4.95%

²² Due to concerns identified by the CAHPS Consortium that the cognitive screening questions hindered data collection, these questions were asked but did not stop the survey if the member failed the cognitive screening questions.

²³ The response rate is defined as the total number of completed surveys (i.e., total respondent) divided by all eligible members of the sample (i.e., eligible sample [sample size minus ineligible]).

Table 3-2 shows the distribution of telephone non-response outcomes for the NC HCBS Program.

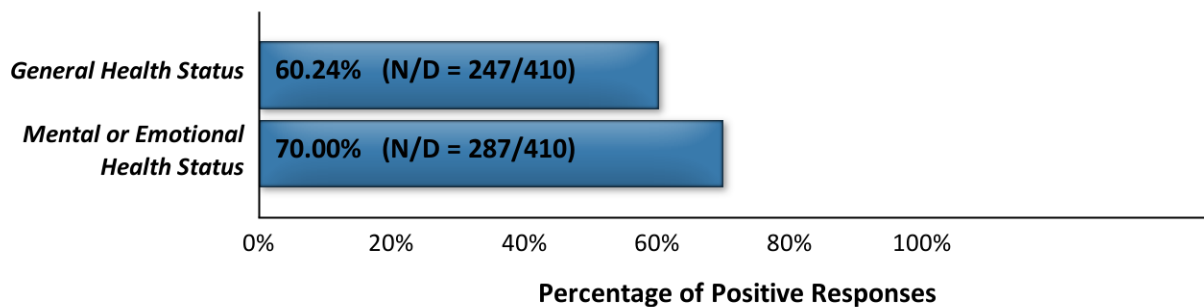
Table 3-2—Telephone Non-Response Outcomes (2023)

Wrong Number	Bad Number	No Answer	Refusal
494	4,431	2,269	521
<i>Wrong number encompasses the total number of cases where the phone number no longer belongs to the sampled member. Bad number encompasses the total number of cases where the phone number was non-working on dialing.</i>			

Overall Health Demographics

Figure 3-1 presents the respondent self-reported characteristics for general health status and mental or emotional health status. The scores represent the percentage of respondents who reported their general and mental or emotional health status as Excellent, Very Good, or Good.

Figure 3-1—Percentage of Respondents Who Rate Their General Health Status or Mental or Emotional Health Status as Either Excellent, Very Good, or Good



N/D Indicates the numerator and denominator of the score.

Positive Ratings and National Comparisons

HSAG calculated positive ratings for each measure in accordance with CMS' *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*.²⁴ Positive ratings represent the percentage of eligible respondents who answered with the most positive response. For more detailed information regarding positive ratings, please refer to the Reader's Guide beginning on page 16.

Additionally, the NC HCBS Program was compared to national data to determine if the results were significantly different. AHRQ's CAHPS database benchmarks were used for comparative purposes.²⁵ Ninety-five percent confidence interval error bars were added to the NC HCBS Program results when there was a statistically significant difference.

For purposes of reporting members' experience with care results, CMS requires a minimum of 11 respondents per measure (i.e., a minimum cell size of 11). If a cell size was less than 11, the measure's results were suppressed. Suppressed results are noted in the figures as "Insufficient Data." Scores with fewer than 100 respondents are denoted with a cross (+). Caution should be exercised when interpreting results for those measures with fewer than 100 respondents.

Global Ratings

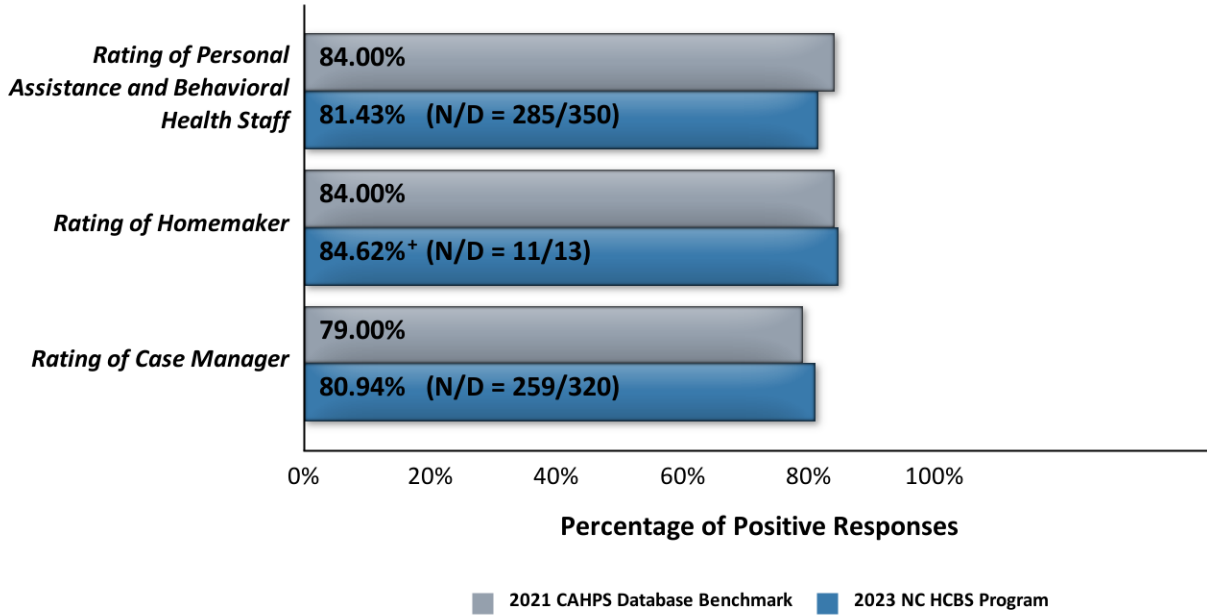
Respondents were asked to rate the help they received from personal assistance and behavioral health staff, homemakers, and their case manager on a scale of 0 to 10, with 0 being the "worst help received from homemakers; personal assistance and behavioral health staff; and case manager possible" and 10 being the "best help received from homemakers; personal assistance and behavioral health staff; and case manager possible." Ratings scoring a 9 or 10 are considered positive ratings.

Figure 3-2 shows the 2023 positive ratings for the three global ratings for the NC HCBS Program, with national comparisons. There were no significant differences for the global ratings when compared to the national average.

²⁴ Centers for Medicare & Medicaid Services. CAHPS Home and Community-Based Services Survey. *Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey*. July 2021. Available at: <https://www.medicare.gov/medicaid/quality-of-care/downloads/hcbscahps-appk-data-analysis-guide.pdf>. Accessed on: June 3, 2024.

²⁵ Agency for Healthcare Research and Quality. The CAHPS Databases. *The CAHPS Home and Community Based Services (HCBS) Survey Database 2023 Chartbook*. Available at: <https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/cahps-database/2023-hcbs-chartbook.pdf>. Accessed on: June 3, 2024.

Figure 3-2—Percentage of 2023 Respondents Who Rate the Help They Received from Personal Assistance and Behavioral Health Staff, Homemakers, and Their Case Manager Positively, with National Comparisons



+ Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
N/D Indicates the numerator and denominator of the score.

Composite Measures

Reliable and Helpful Staff

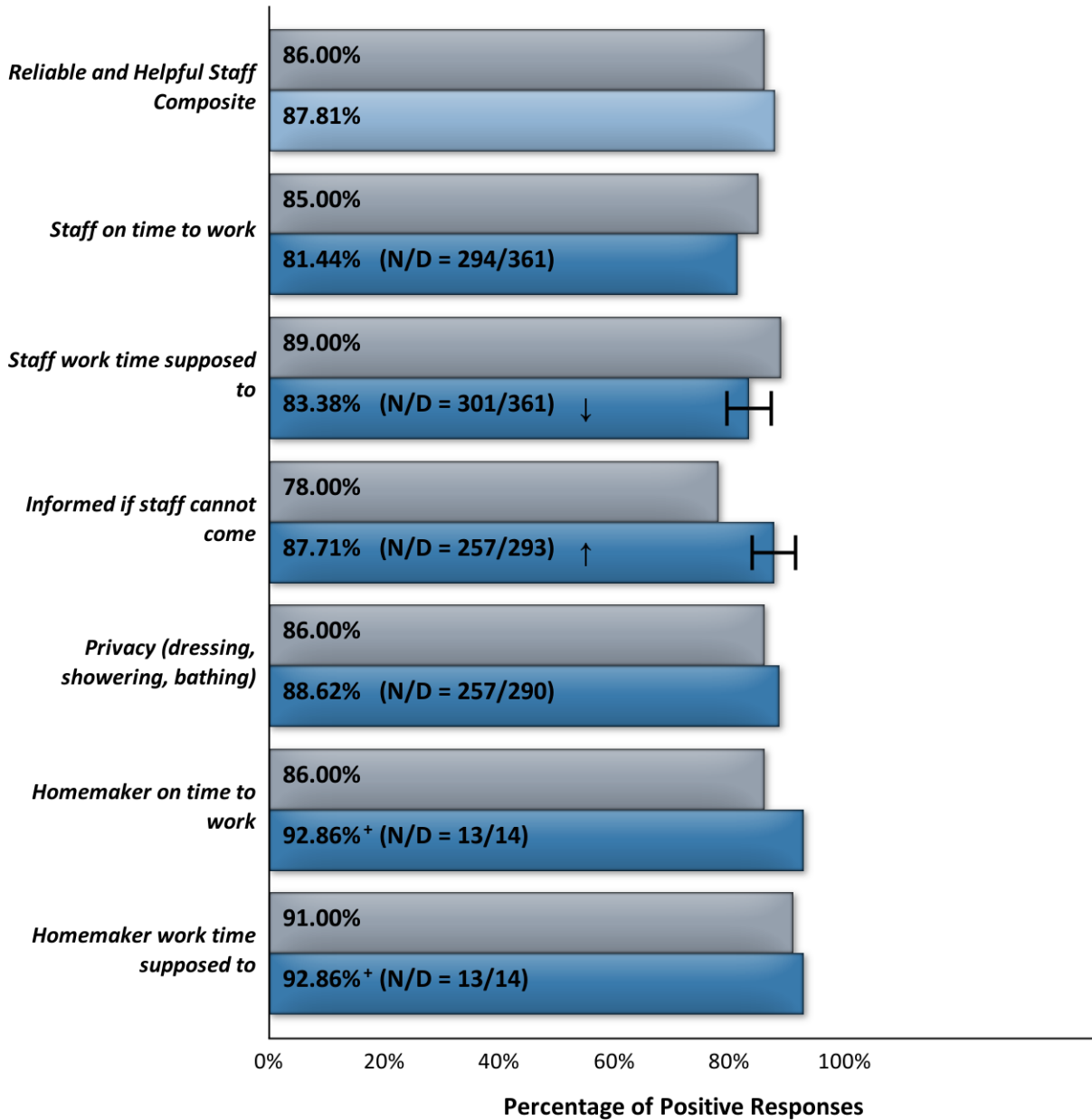
Six questions were asked to assess how reliable and helpful staff were for members:

- In the last 3 months, how often did [personal assistance/behavioral health staff] come to work on time? (Staff on time to work)
- In the last 3 months, how often did [personal assistance/behavioral health staff] work as long as they were supposed to? (Staff work time supposed to)
- In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that [personal assistance/behavioral health staff] could not come that day? (Informed if staff cannot come)
- In the last 3 months, how often did [personal assistance/behavioral health staff] make sure you had enough personal privacy when you dressed, took a shower, or bathed? (Privacy [dressing, showering, bathing])
- In the last 3 months, how often did [homemakers] come to work on time? (Homemaker on time to work)
- In the last 3 months, how often did [homemakers] work as long as they were supposed to? (Homemaker work time supposed to)

Responses of always or yes are considered positive ratings.

Figure 3-3 shows the *Reliable and Helpful Staff* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. The rate for *Staff work time supposed to* individual item was significantly *lower* than the national average, and the rate for *Informed if staff cannot come* individual item was significantly *higher* than the national average.

Figure 3-3—Percentage of 2023 Respondents Who Reported Having Reliable and Helpful Staff, with National Comparisons



■ 2021 CAHPS Database Benchmark ■ 2023 Composite Measure ■ 2023 Individual Question

↑ Indicates the score is significantly higher than the 2021 CAHPS database benchmark.
 ↓ Indicates the score is significantly lower than the 2021 CAHPS database benchmark.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 + Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

Staff Listen and Communicate Well

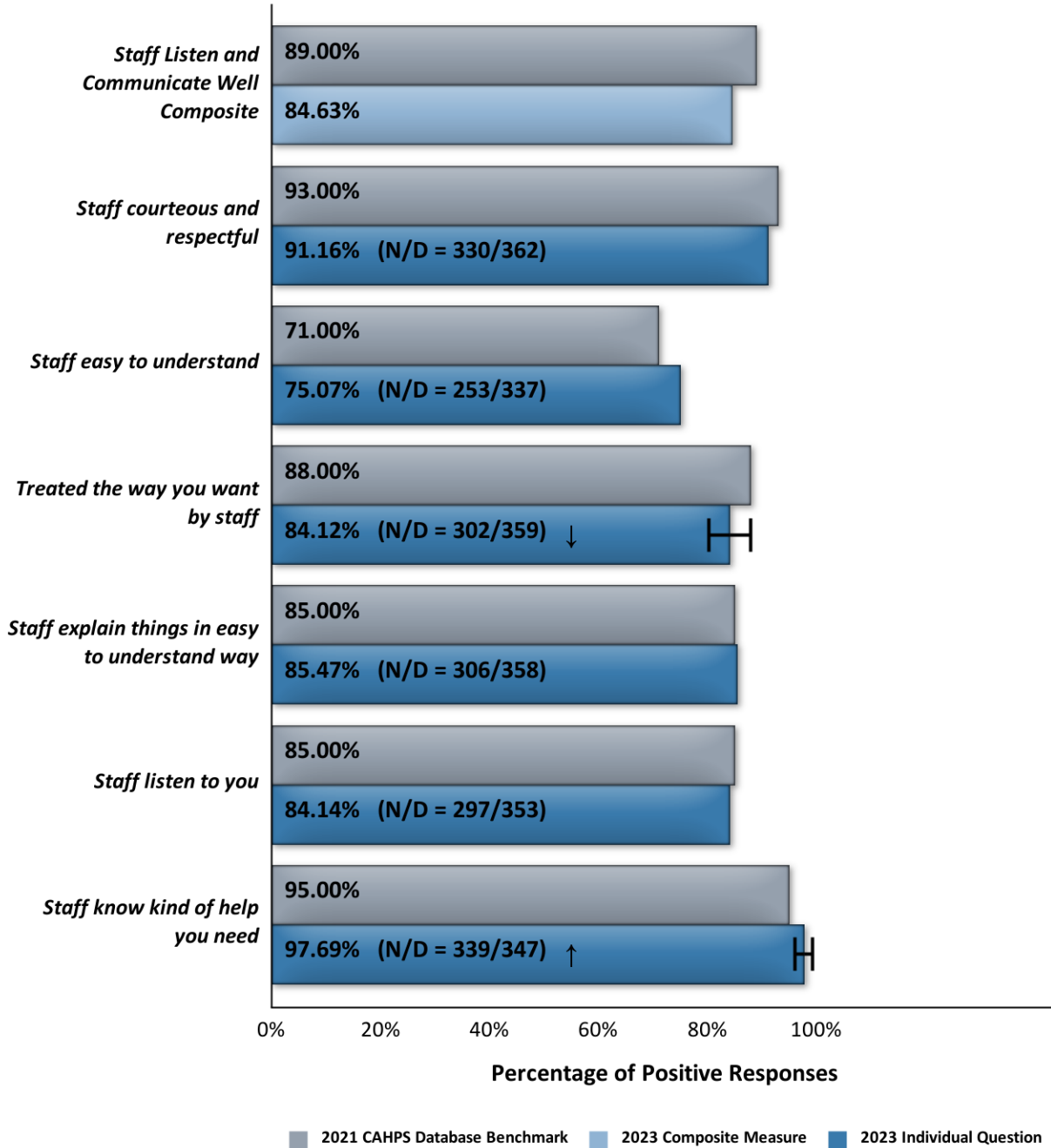
Eleven questions were asked to assess how often staff listened and communicated well with members:

- In the last 3 months, how often did [personal assistance/behavioral health staff] treat you with courtesy and respect? (Staff courteous and respectful)
- In the last 3 months, how often were the explanations [personal assistance/behavioral health staff] gave you hard to understand because of an accent or the way [personal assistance/behavioral health staff] spoke English? (Staff easy to understand)
- In the last 3 months, how often did [personal assistance/behavioral health staff] treat you the way you wanted them to? (Treated the way you want by staff)
- In the last 3 months, how often did [personal assistance/behavioral health staff] explain things in a way that was easy to understand? (Staff explains things in an easy-to-understand way)
- In the last 3 months, how often did [personal assistance/behavioral health staff] listen carefully to you? (Staff listen to you)
- In the last 3 months, did you feel [personal assistance/behavioral health staff] knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community? (Staff know kind of help you need)
- In the last 3 months, how often did [homemakers] treat you with courtesy and respect? (Homemakers courteous and respectful)
- In the last 3 months, how often were the explanations [homemakers] gave you hard to understand because of an accent or the way [homemakers] spoke English? (Homemakers easy to understand)
- In the last 3 months, how often did [homemakers] treat you the way you wanted them to? (Treated the way you want by homemakers)
- In the last 3 months, how often did [homemakers] listen carefully to you? (Homemakers listen)
- In the last 3 months, how often did [homemakers] know what kind of help you need? (Homemakers know kind of help you need)

Responses of always or yes are considered positive ratings for most individual questions. Responses of never or mostly no are considered positive ratings for *Staff easy to understand* and *Homemakers easy to understand*.

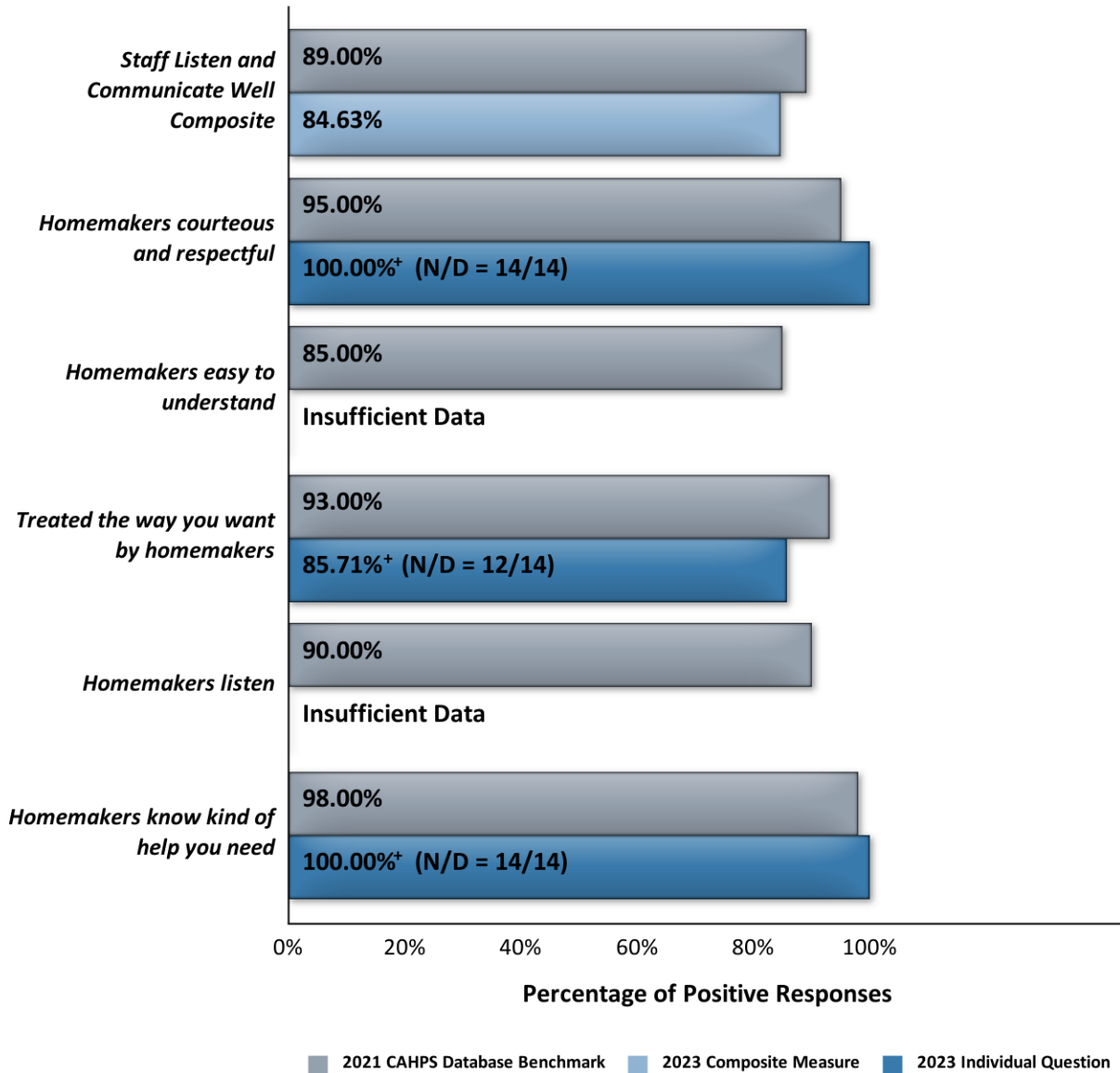
Figure 3-4 and Figure 3-5 show the *Staff Listen and Communicate Well* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. The rate for *Treated the way you want by staff* individual item was significantly *lower* than the national average, and the rate for *Staff know kind of help you need* individual item was significantly *higher* than the national average. The positive ratings for the *Homemakers easy to understand* and *Homemakers listen* individual items were suppressed due to an insufficient number of responses.

Figure 3-4—Percentage of 2023 Respondents Who Reported Staff Listened and Communicated Well, with National Comparisons



↑ Indicates the score is significantly higher than the 2021 CAHPS database benchmark.
 ↓ Indicates the score is significantly lower than the 2021 CAHPS database benchmark.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 N/D Indicates the numerator and denominator of the score.
 [-] Indicates the 95% confidence interval of the score.

Figure 3-5—Percentage of 2023 Respondents Who Reported Staff Listened and Communicated Well, with National Comparisons, Continued



+ Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results. Results based on fewer than 11 respondents were suppressed and noted as “Insufficient Data.” N/D Indicates the numerator and denominator of the score.

Helpful Case Manager

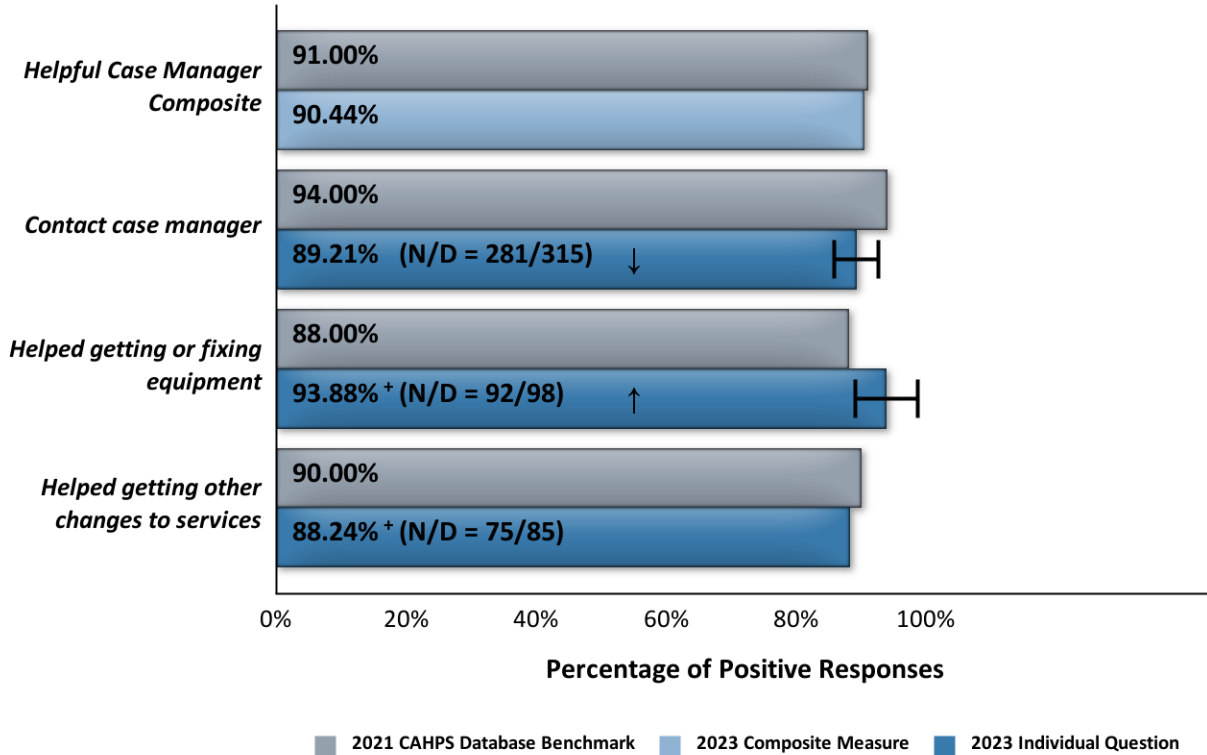
Three questions were asked to assess how helpful members' case managers were:

- In the last 3 months, could you contact this [case manager] when you needed to? (Contact case manager)
- In the last 3 months, did this [case manager] work with you when you asked for help with getting or fixing equipment? (Helped getting or fixing equipment)
- In the last 3 months, did this [case manager] work with you when you asked for help with getting other changes to your services? (Helped getting other changes to services)

Responses of yes are considered positive ratings.

Figure 3-6 shows the *Helpful Case Manager* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. The rate for *Contact case manager* individual item was significantly *lower* than the national average, and the rate for *Helped getting or fixing equipment* individual item was significantly *higher* than the national average.

Figure 3-6—Percentage of 2023 Respondents Who Reporting Having a Helpful Case Manager, with National Comparisons



↑ Indicates the score is significantly higher than the 2021 CAHPS database benchmark.
 ↓ Indicates the score is significantly lower than the 2021 CAHPS database benchmark.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 + Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

Choosing the Services that Matter to You

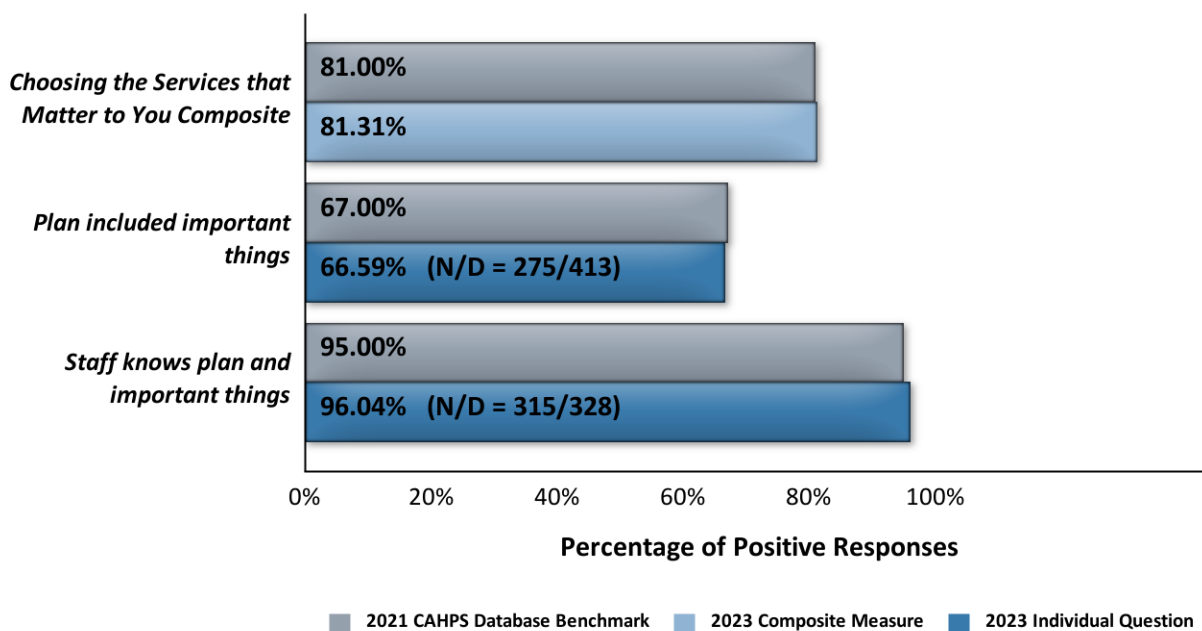
Two questions were asked to assess if a member’s service plan included things that were important to them and if the member’s personal assistance/behavioral health staff know what was on the service plan, including the things that were important to the member:

- In the last 3 months, did your [service plan] include none, some, most, or all of the things that are important to you? (Plan included important things)
- In the last 3 months, did you feel [personal assistance/behavioral health staff] knew what’s on your service plan, including the things that are important to you? (Staff knows plan and important things)

Responses of all or yes are considered positive ratings.

Figure 3-7 shows the *Choosing the Services that Matter to You* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. There were no significant differences for the composite measure or individual items when compared to the national averages.

Figure 3-7—Percentage of 2023 Respondents Whose Service Plan Included Things that Matter to the Member, with National Comparisons



N/D Indicates the numerator and denominator of the score.

Transportation to Medical Appointments

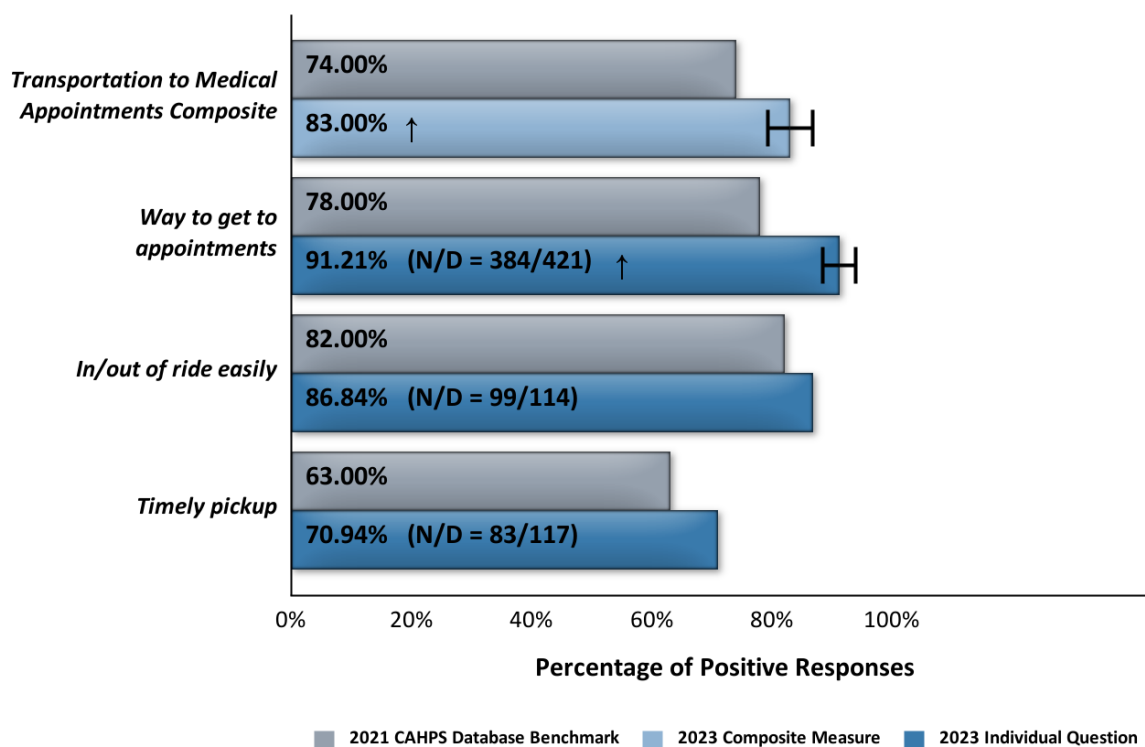
Three questions were asked to assess how often members were able to get transportation to their medical appointments:

- In the last 3 months, how often did you have a way to get to your medical appointments? (Way to get to appointments)
- In the last 3 months, were you able to get in and out of this ride easily? (In/out of ride easily)
- In the last 3 months, how often did this ride arrive on time to pick you up? (Timely pickup)

Responses of always or yes are considered positive ratings.

Figure 3-8 shows the *Transportation to Medical Appointments* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. The rates for the *Transportation to Medical Appointments* composite measure and *Way to get to appointments* individual item were significantly *higher* than the national average.

Figure 3-8—Percentage of 2023 Respondents Who Reported Receiving Transportation to Their Medical Appointments, with National Comparisons



↑ Indicates the score is significantly higher than the 2021 CAHPS database benchmark.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

Personal Safety and Respect

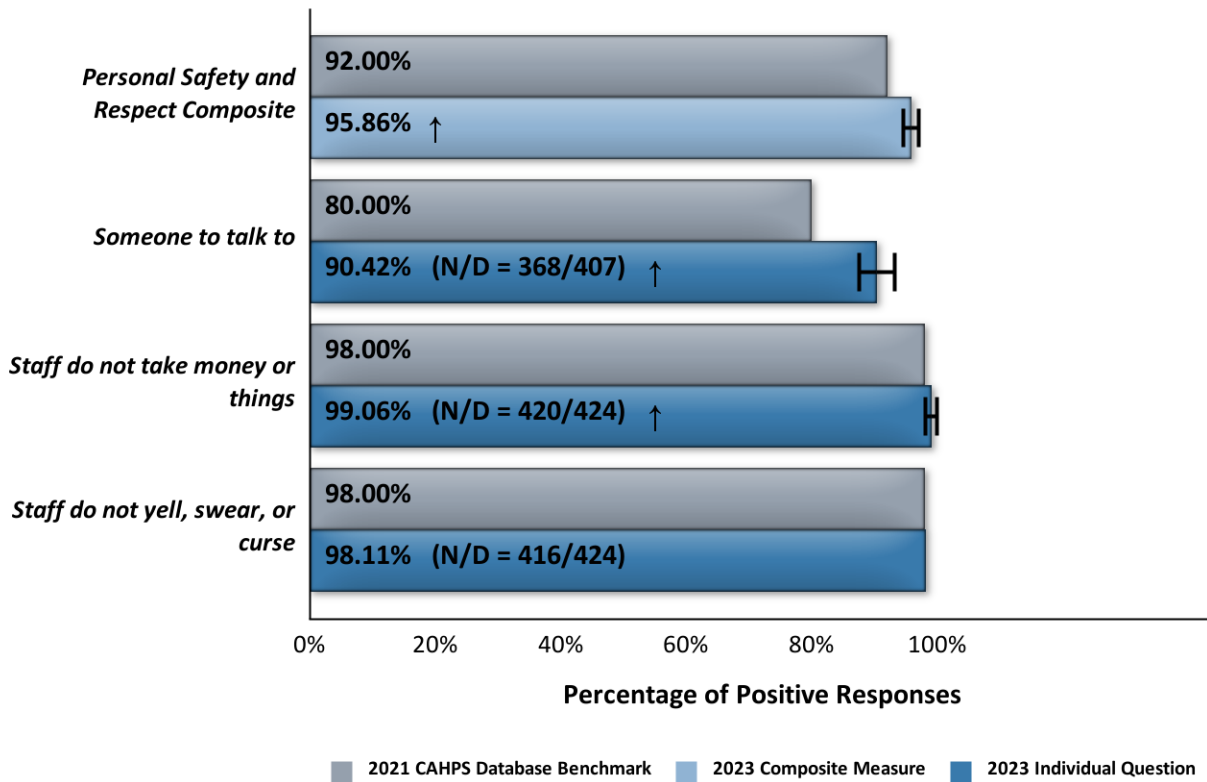
Three questions were asked to assess members' perspectives of their personal safety and if their personal assistance/behavioral health staff treated them with respect:

- In the last 3 months, was there a person you could talk to if someone hurt you or did something to you that you didn't like? (Someone to talk to)
- In the last 3 months, did **any** [personal assistance/behavioral health staff] or your [case managers] take money or your things without asking you first? (Staff did not take any money or things)
- In the last 3 months, did any [staff] yell, swear, or curse at you? (Staff do not yell, swear, or curse)

Responses of yes are considered positive ratings for *Someone to talk to*. Responses of no are considered positive ratings for *Staff did not take any money or things* and *Staff do not yell, swear, or curse*.

Figure 3-9 shows the *Personal Safety and Respect* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. The rates for the *Personal Safety and Respect* composite measure, and *Someone to talk to* and *Staff do not take money or things* individual items were significantly *higher* than the national average.

Figure 3-9—Percentage of 2023 Respondents Who Felt Safe and Respected, with National Comparisons



↑ Indicates the score is significantly higher than the 2021 CAHPS database benchmark.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

Planning Your Time and Activities

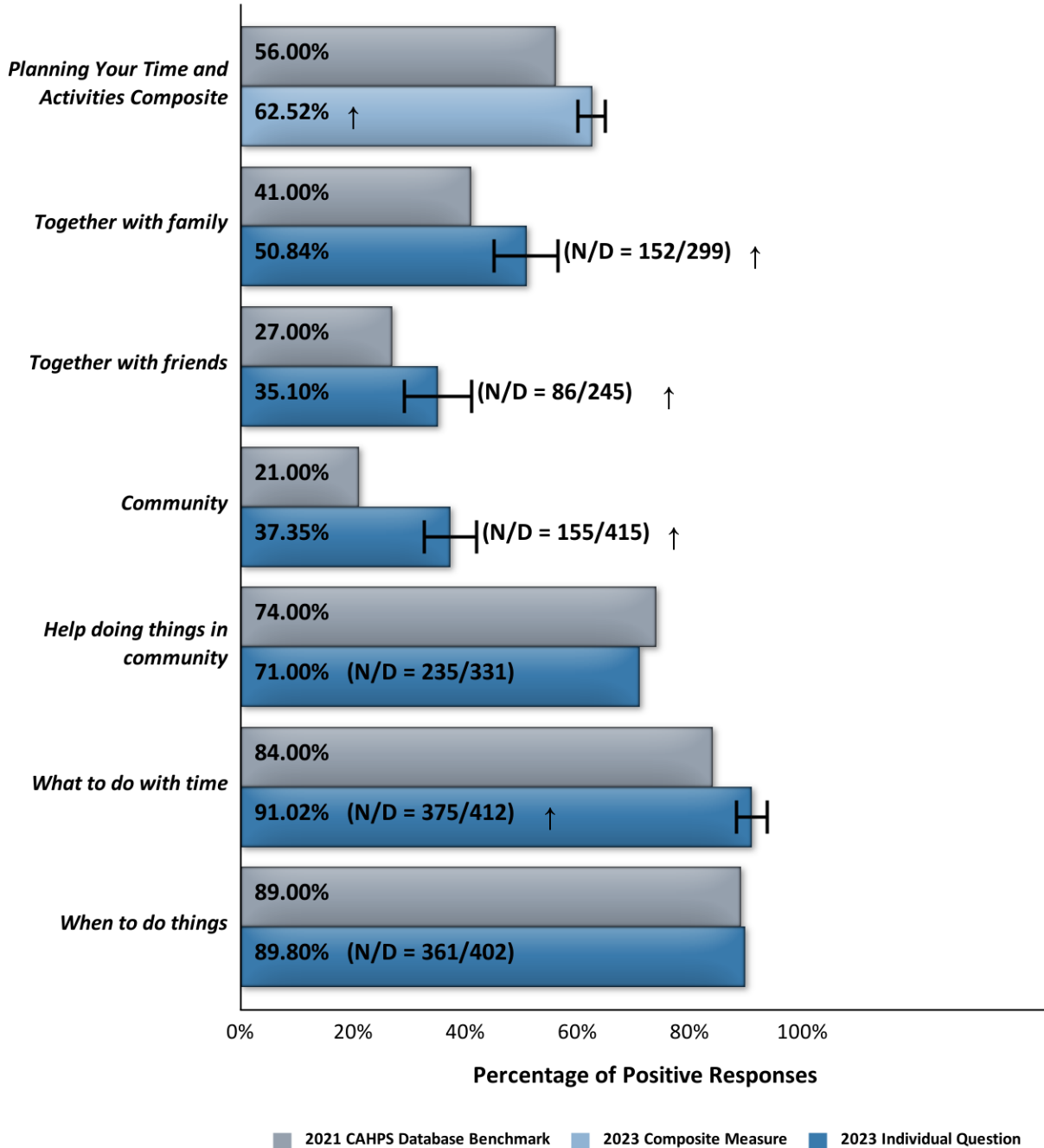
Six questions were asked to assess how often members could plan their time and activities:

- In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby? (Together with family)
- In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby? (Together with friends)
- In the last 3 months, when you wanted to, how often could you do things in the community that you like? (Community)
- In the last 3 months, did you need more help that you get from [personal assistance/behavioral health staff] to do things in your community? (Help doing things in community)
- Do you take part in deciding **what** you do with your time each day? (What to do with time)
- Do you take part in deciding **when** you do things each day – for example, deciding when you get up, eat, or go to bed? (When to do things)

Responses of always or yes are considered positive ratings for all individual questions except *Help doing things in community*, where responses of no are considered positive ratings.

Figure 3-10 shows the *Planning Your Time and Activities* positive rating results for the NC HCBS Program, with national comparisons, and the individual items within the composite measure. The rates for the *Planning Your Time and Activities* composite measure and *Together with family*, *Together with friends*, *Community*, and *What do to with time* individual items were significantly *higher* than the national average.

Figure 3-10—Percentage of 2023 Respondents Who Reported They Could Plan Their Time and Activities with Family and Friends, with National Comparisons



↑ Indicates the score is significantly higher than the 2021 CAHPS database benchmark.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

Recommendation Measures

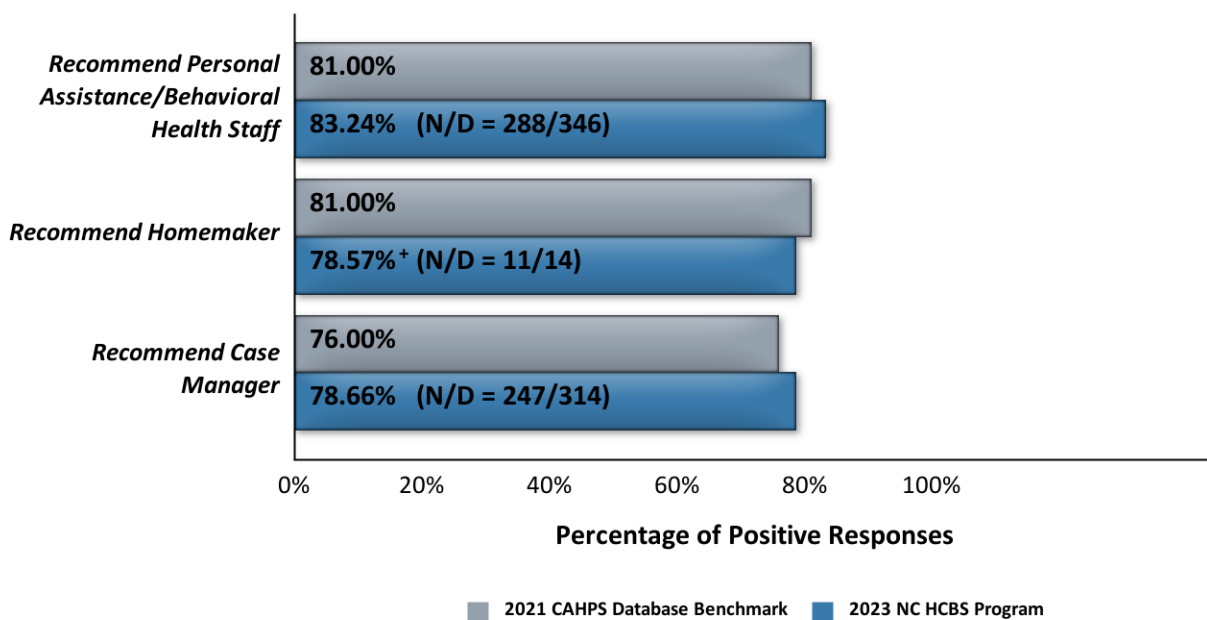
Respondents were asked if they would recommend the following individuals to their family and friends:

- **Personal Assistance/Behavioral Health Staff**—the personal assistance/behavioral health staff who helped them if they needed help with everyday activities.
- **Homemaker**—the homemaker who helped them if they needed homemaker services.
- **Case Manager**—the case manager who helped them if they needed care coordination services.

Responses of definitely yes are considered positive ratings.

Figure 3-11 shows the 2023 positive ratings for the three recommendation measures for the NC HCBS Program, with national comparisons. There were no significant differences for the recommendation measures when compared to the national averages.

Figure 3-11—Percentage of 2023 Respondents Who Would Definitely Recommend Their Personal Assistance/Behavioral Health Staff, Homemaker, or Case Manager, with National Comparisons



+ Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 N/D Indicates the numerator and denominator of the score.

Unmet Need and Physical Safety Measures

The unmet need measures evaluate whether the needs listed below were not being met because of a lack of help. Respondents were asked if they needed help from personal assistance/behavioral health staff with the following needs:

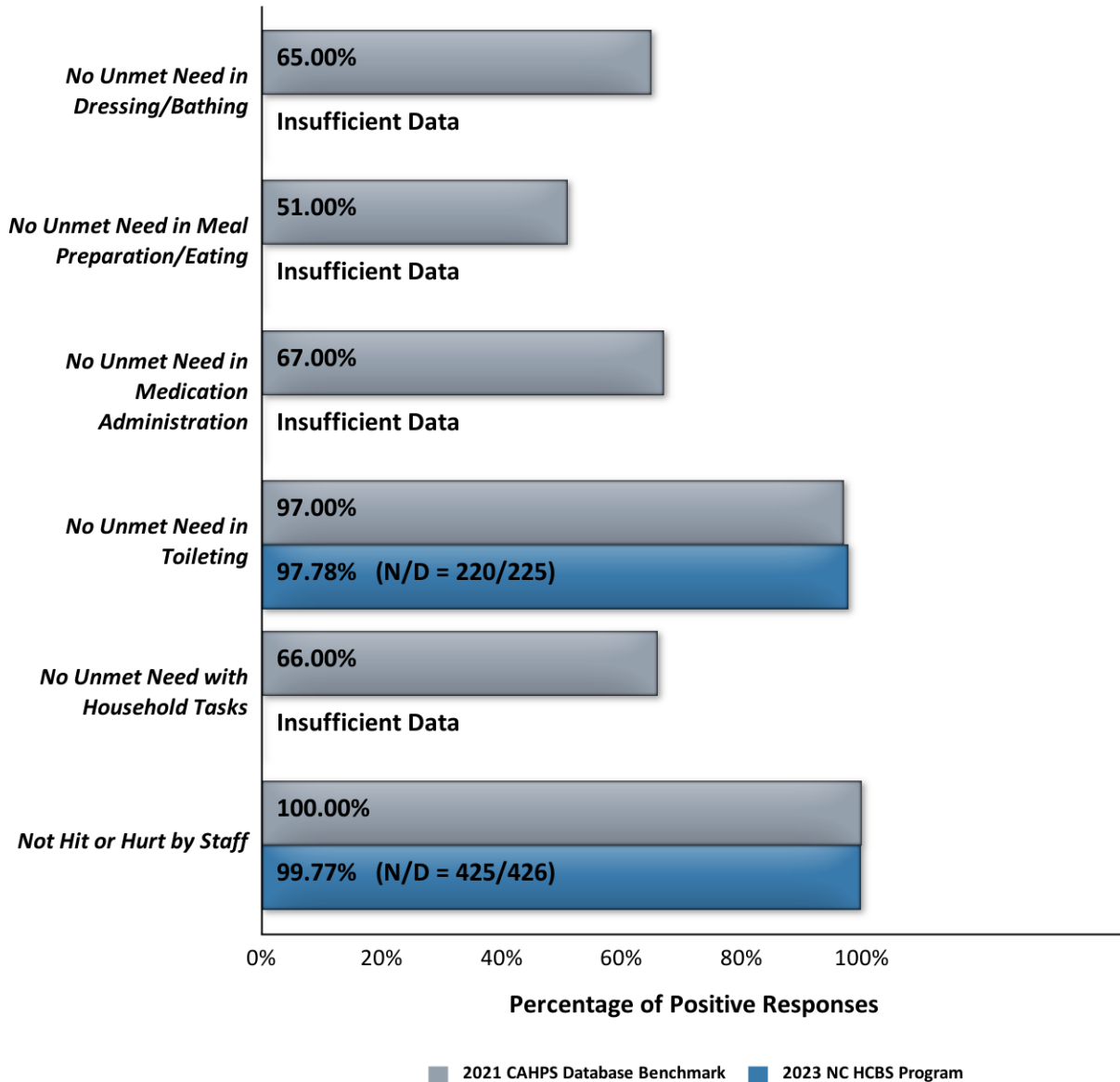
- **Dressing/Bathing**—getting dressed, taking a shower, or bathing.
- **Meal Preparation/Eating**—preparing their meals, such as help making or cooking meals, or help eating.
- **Medication Administration**—taking their medicines when they were supposed to.
- **Toileting**—with toileting.
- **Household Tasks**—completing household tasks, like cleaning and laundry.

In addition, members were asked if any staff hit or hurt them.²⁶ Responses of no are considered positive ratings, except for *No Unmet Need in Toileting*, where responses of yes are considered positive ratings. These measures were scored so that higher values indicate better care; therefore, a higher positive rating indicates a positive response (e.g., no unmet need), and a lower positive rating indicates a negative response.

Figure 3-12 shows the 2023 positive ratings for the five unmet need measures and one physical safety measure, *Not Hit or Hurt by Staff*. The positive ratings for the *No Unmet Need in Dressing/Bathing*, *No Unmet Need in Meal Preparation/Eating*, *No Unmet Need in Medication Administration*, and *No Unmet Need with Household Tasks* measures were suppressed due to an insufficient number of responses. There were no significant differences for the unmet need measures and physical safety measure when compared to the national averages.

²⁶ Staff members could be personal assistance staff, behavioral health staff, homemakers, or case managers.

Figure 3-12—Percentage of 2023 Respondents Who Did Not Have an Unmet Need or Were Not Hit or Hurt by Staff, with National Comparisons



Results based on fewer than 11 respondents were suppressed and noted as “Insufficient Data.”
 N/D Indicates the numerator and denominator of the score.

Race and Ethnicity Comparisons

HSAG stratified the NC HCBS Program positive ratings by self-reported race and ethnicity. Race is categorized as White (217), Black (112), and Other (81). For this analysis, the Other race category includes: Multi-Racial, Asian, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native, and Other. The positive ratings for each race category were compared as follows: White respondents were compared to non-White respondents; Black respondents were compared to non-Black respondents; and Other respondents were compared to non-Other respondents. Ethnicity is categorized as Hispanic (28) and Non-Hispanic (384). The positive ratings for Hispanic respondents and Non-Hispanic respondents were compared to each other. For more detailed information regarding these comparisons, please refer to the Reader's Guide beginning on page 17.

Figure 3-13 through Figure 3-16 show the race and ethnicity stratifications and comparisons. Ninety-five percent confidence interval error bars were added to the results. Of note, overlapping confidence intervals does not indicate the results are not significantly different.²⁷

Overall Health Demographics

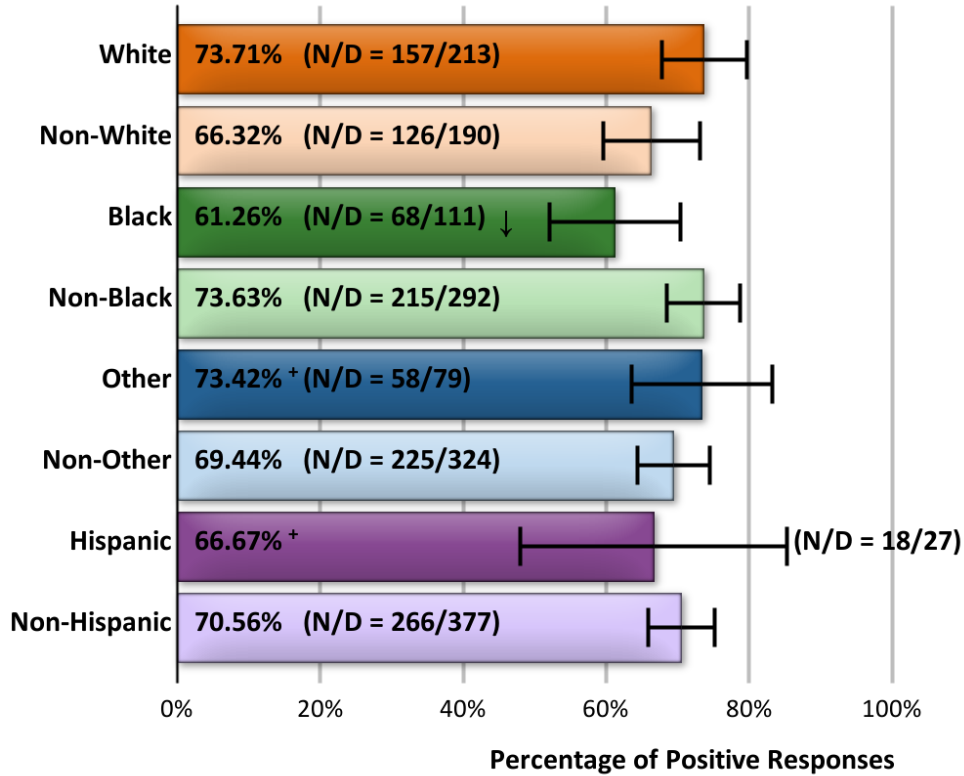
There were no significant differences identified by race or ethnicity for *General Health Status*.

Mental or Emotional Health Status

Figure 3-13 shows the *Mental or Emotional Health Status* positive rating results of respondents for the NC HCBS Program by race and ethnicity. A significantly *lower* percentage of Black respondents reported their mental or emotional health status as Excellent, Very Good, or Good when compared to Non-Black respondents for the NC HCBS Program. There were no significant differences identified by ethnicity.

²⁷ Cornell Statistical Consulting Unit. *Overlapping Confidence Intervals and Statistical Significance*. Available at: <https://cscu.cornell.edu/wp-content/uploads/ci.pdf>. Accessed on: June 3, 2024.

Figure 3-13—Percentage of 2023 Respondents Who Rate Their Mental or Emotional Health Status as Excellent, Very Good, or Good, by Race and Ethnicity



↓ Indicates the demographic category’s score is statistically significantly lower than the comparison group’s score. If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 + Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

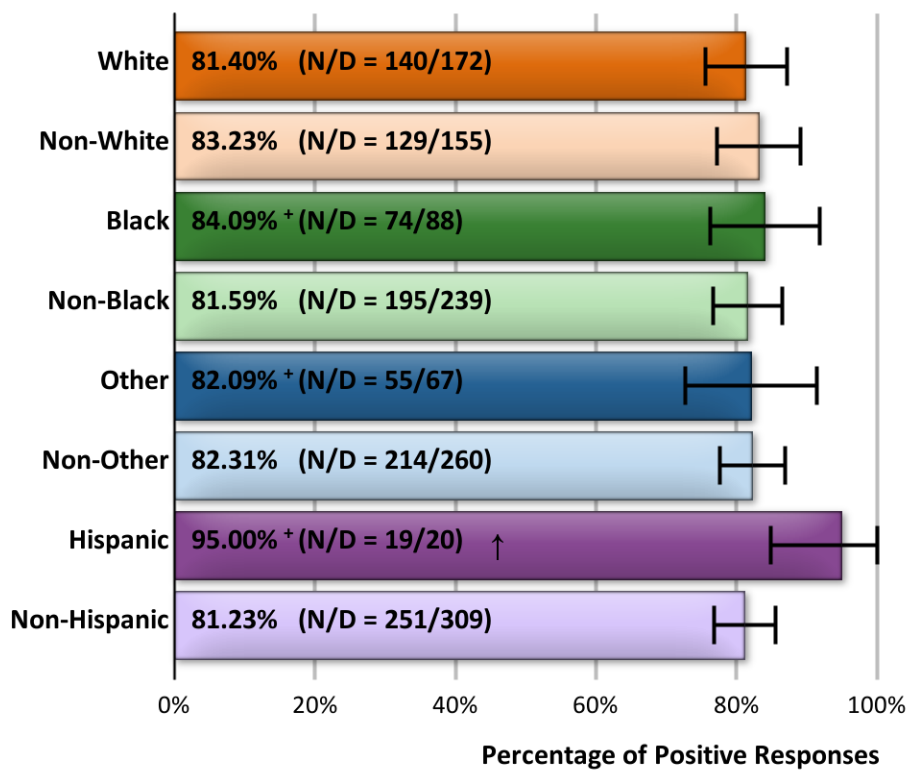
Global Ratings

There were no significant differences identified by race or ethnicity for the *Rating of Homemaker* and *Rating of Case Manager* measures.

Rating of Personal Assistance and Behavioral Health Staff

Figure 3-14 shows the *Rating of Personal Assistance and Behavioral Health Staff* positive rating results of respondents for the NC HCBS Program by race and ethnicity. A significantly *higher* percentage of Hispanic respondents rated their personal assistance and behavioral health staff positively when compared to Non-Hispanic respondents for the NC HCBS Program. There were no significant differences identified by race.

Figure 3-14—Percentage of 2023 Respondents Who Rate Their Personal Assistance and Behavioral Health Staff Positively, by Race and Ethnicity



↑ Indicates the demographic category’s score is statistically significantly higher than the comparison group’s score. If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 + Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

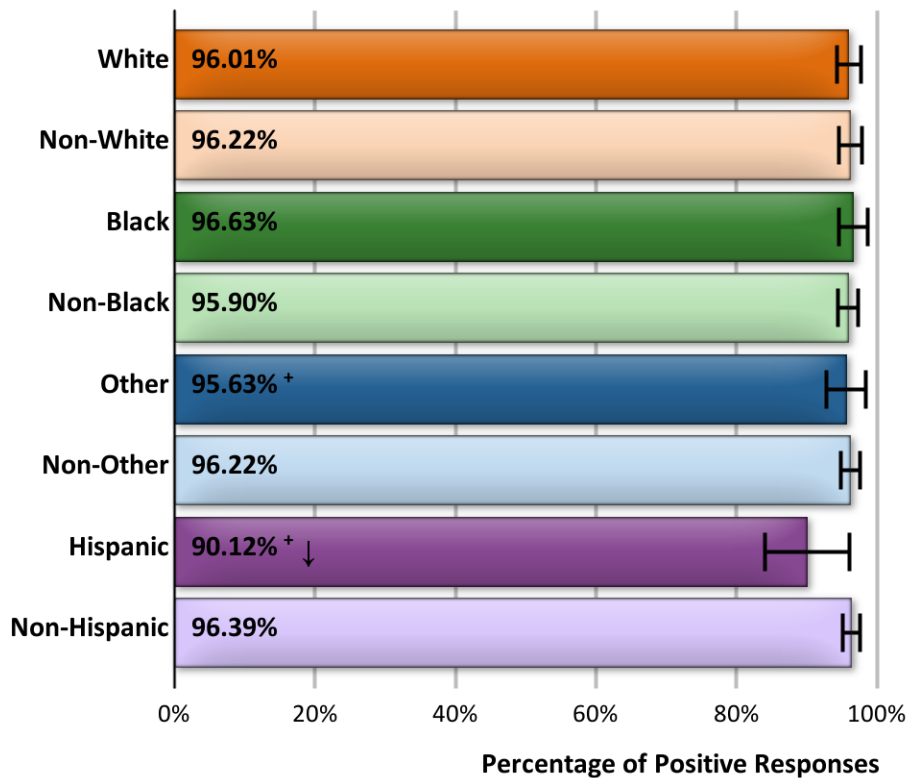
Composite Measures

There were no significant differences identified by race or ethnicity for the *Reliable and Helpful Staff*, *Staff Listen and Communicate Well*, *Helpful Case Manager*, *Choosing the Services that Matter to You*, *Transportation to Medical Appointments*, and *Planning Your Time for Activities* measures.

Personal Safety and Respect

Figure 3-15 shows the *Personal Safety and Respect* positive rating results of respondents for the NC HCBS Program by race and ethnicity. A significantly lower percentage of Hispanic respondents reported they felt safe and respected when compared to Non-Hispanic respondents for the NC HCBS Program. There were no significant differences identified by race.

Figure 3-15—Percentage of 2023 Respondents Who Felt Safe and Respected, by Race and Ethnicity



↓ Indicates the demographic category’s score is statistically significantly lower than the comparison group’s score.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 + Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 |—| Indicates the 95% confidence interval of the score.

Recommendation Measures

There were no significant differences identified by race or ethnicity for the *Recommend Personal Assistance/Behavioral Health Staff*, *Recommend Homemaker*, and *Recommend Case Manager* measures.

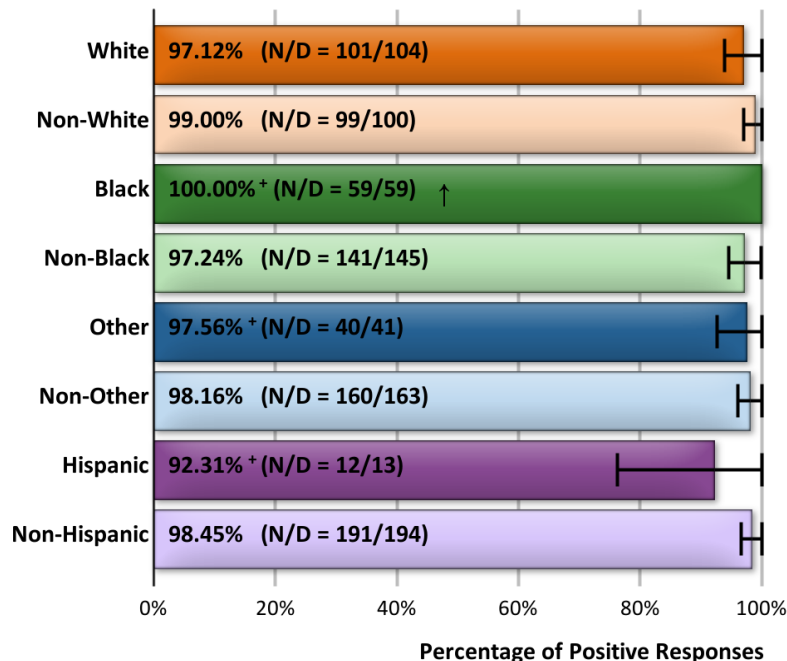
Unmet Need Measures

There were no significant differences identified by race or ethnicity for the *No Unmet Need in Dressing/Bathing*, *No Unmet Need in Meal Preparation/Eating*, *No Unmet Need in Medication Administration*, and *No Unmet Need in Household Tasks* measures.

No Unmet Need in Toileting

Figure 3-16 shows the *No Unmet Need in Toileting* positive rating results of respondents for the NC HCBS Program by race and ethnicity. A significantly *higher* percentage of Black respondents reported they had no unmet need with toileting when compared to Non-Black respondents for the NC HCBS Program. There were no significant differences identified by ethnicity.

Figure 3-16—Percentage of 2023 Respondents Who Did Not Have an Unmet Need in Toileting, by Race and Ethnicity



↑ Indicates the demographic category’s score is statistically significantly higher than the comparison group’s score.
 If no statistically significant differences were found, no indicators (↑ or ↓) appear on the figure.
 + Indicates fewer than 100 respondents. Caution should be exercised when evaluating these results.
 N/D Indicates the numerator and denominator of the score.
 |-| Indicates the 95% confidence interval of the score.

Physical Safety Measure

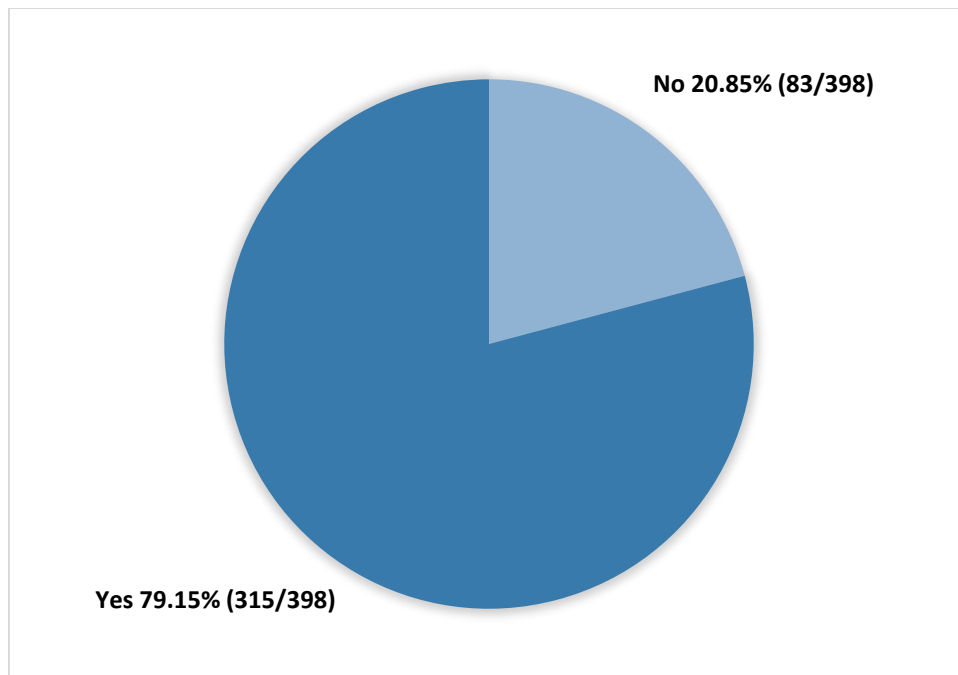
There were no significant differences identified by race or ethnicity for the *Not Hit or Hurt by Staff* measure.

Supplemental Items

Informed on What to do if Hurt or Mistreated

DHB added three supplemental questions to the survey instrument regarding health equity. The supplemental items included in the survey instrument were developed by DHB and not field tested for the HCBS population. Figure 3-17 presents the percentage of respondents who reported they received information on or had someone talk with them about what to do if they or someone they know is hurt or mistreated. The majority of respondents reported receiving information or had someone talk with them about what to do if they or someone they know is hurt or mistreated.

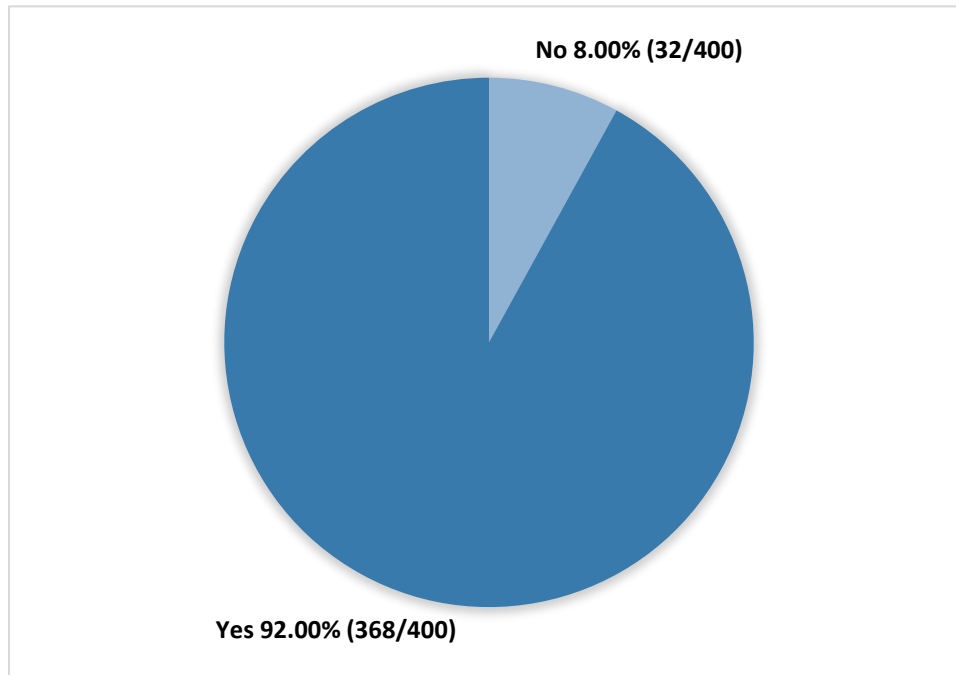
Figure 3-17—Percentage of 2023 Respondents Who Received Information on What to do if They or Someone They Know is Hurt or Mistreated



Coordination of Care from Care Manager

Figure 3-18 presents the percentage of respondents whose care manager seemed informed and up-to-date about the health care they received from their personal doctor and specialty doctors. The majority of respondents reported their care manager was up to date about the health care they received from their personal doctor and specialty doctors.

Figure 3-18—Percentage of 2023 Respondents Whose Care Manager Seemed Informed and Up To Date



Treated Unfairly or Insensitively

Respondents were asked if someone who was paid to help them treated them in an unfair or insensitive way (i.e., due to a health condition, disability, their age, culture or religion, language or accent, race or ethnicity, sexual orientation, and income). The results for this supplemental item were suppressed due to having less than 11 respondents for all response options.

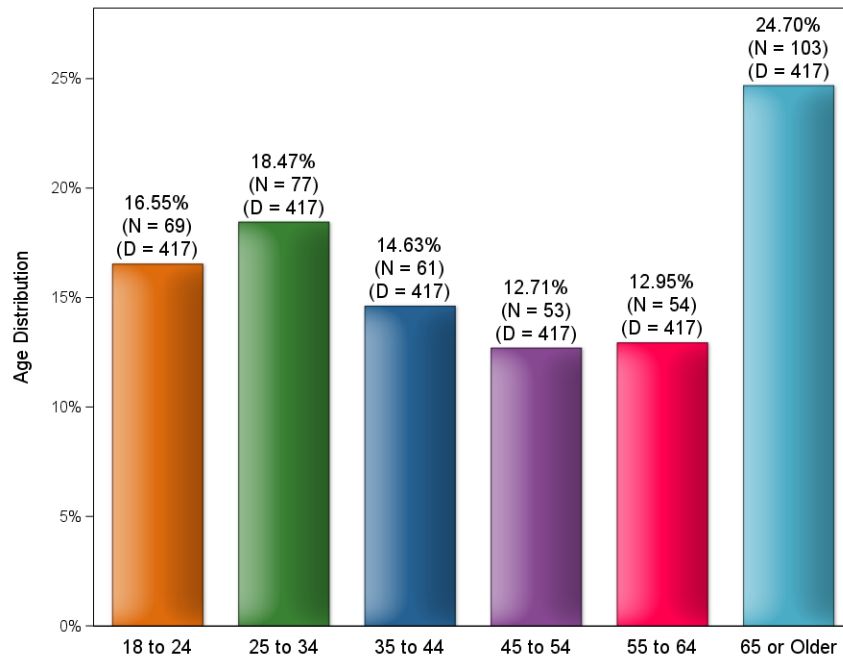
Appendix A. Supplemental Information

Respondent Demographics

The demographics include the *self-reported* demographic information reported by respondents in the HCBS CAHPS survey. Figure A-1 through Figure A-5 present the respondent self-reported demographic characteristics (i.e., demographic information reported on the survey) for age, sex, race, ethnicity, and education level, respectively.

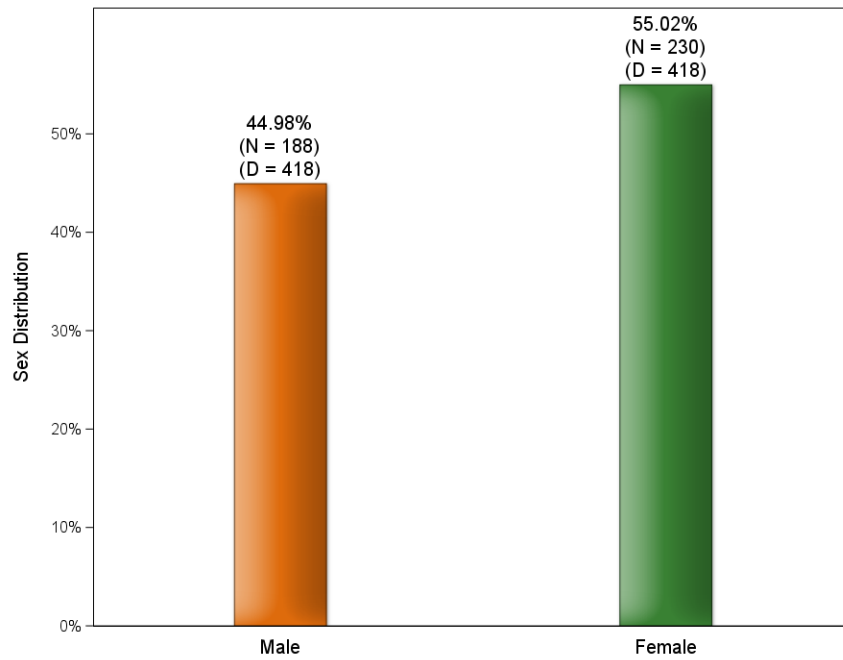
Overall, the majority of respondents were female (55.02 percent), White (52.93 percent), and Non-Hispanic, Latino, or Spanish (93.20 percent). The plurality of respondents were 65 years of age or older (24.70 percent) and reported an education level of high school graduate or General Education Development (GED) (48.46 percent).

Figure A-1—Percentage of 2023 Respondents Who Reported Their Age



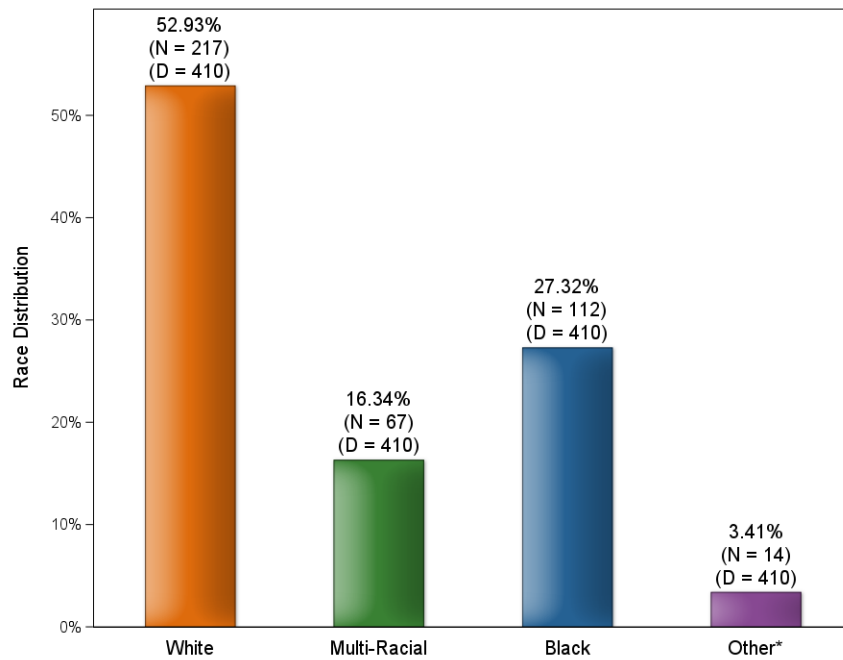
*Please note, some percentages may not total 100 percent due to rounding.
 N Indicates the numerator of the demographic category.
 D Indicates the denominator of the demographic category.*

Figure A-2—Percentage of 2023 Respondents Who Reported Their Sex



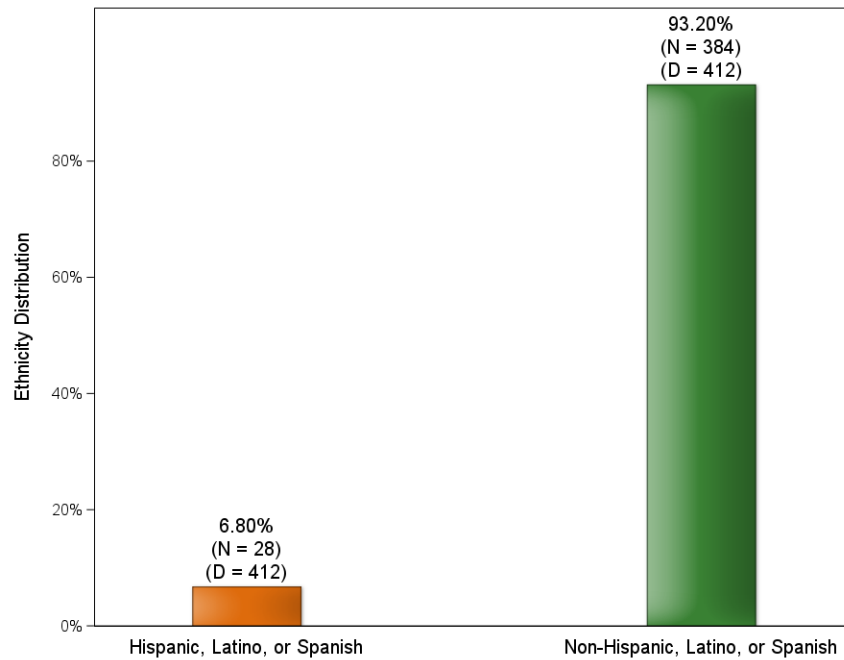
Please note, some percentages may not total 100 percent due to rounding.
N Indicates the numerator of the demographic category.
D Indicates the denominator of the demographic category.

Figure A-3—Percentage of 2023 Respondents Who Reported Their Race



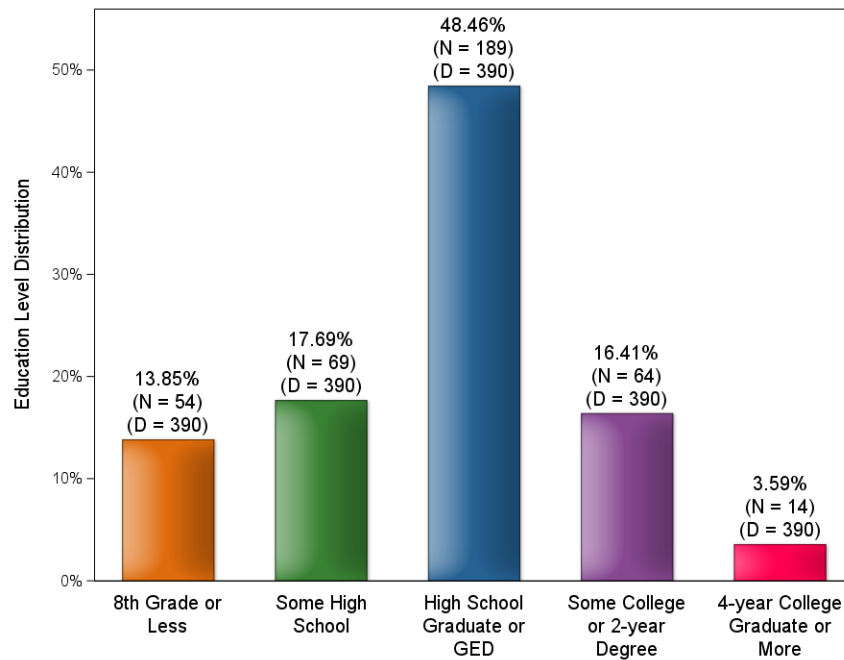
Please note, some percentages may not total 100 percent due to rounding.
N Indicates the numerator of the demographic category.
D Indicates the denominator of the demographic category.

Figure A-4—Percentage of 2023 Respondents Who Reported Their Ethnicity



Please note, some percentages may not total 100 percent due to rounding.
N Indicates the numerator of the demographic category.
D Indicates the denominator of the demographic category.

Figure A-5—Percentage of 2023 Respondents Who Reported Their Education Level



Please note, some percentages may not total 100 percent due to rounding.
N Indicates the numerator of the demographic category.
D Indicates the denominator of the demographic category.

Survey Respondent to Eligible Population Demographic Data Comparisons

HSAG used the sample frame (i.e., eligible population) data, which was pulled from Medicaid enrollment data, to compare the demographic characteristics of those who responded to the survey (i.e., survey respondents) to the total eligible population. The demographic characteristics evaluated as part of the respondent analysis included age, sex, race, and ethnicity. HSAG performed a *t* test to determine whether the demographic characteristics of survey respondents were significantly different from the demographic characteristics of all members in the eligible population. A difference was considered significant if the two-sided *p* value of the *t* test was less than 0.05. If the respondent population differs significantly from the actual population, then caution should be exercised when extrapolating the survey results to the entire population.

Please note that variables from the sample frame were used as the data source for this analysis; therefore, these results will differ from those presented in the demographics subsection, which uses responses from the survey as the data source. Table A-1 presents the results of the comparisons of the demographic characteristics of the survey respondents to the eligible population, using the Medicaid enrollment data, for the NC HCBS Program.

Table A-1—Survey Respondent to Eligible Population Demographic Comparisons Using Medicaid Enrollment Data (2023)

	Demographics of Survey Respondents from Medicaid Enrollment Data % (N/D)	Demographics of Eligible Population from Medicaid Enrollment Data % (N/D)
Age		
18 to 24	16.80% [†] (83/494)	12.49% (2,424/19,404)
25 to 34	18.22% (90/494)	21.05% (4,085/19,404)
35 to 44	14.78% (73/494)	14.92% (2,895/19,404)
45 to 54	12.35% (61/494)	10.56% (2,050/19,404)
55 to 64	12.96% (64/494)	13.13% (2,547/19,404)
65 or Older	24.90% (123/494)	27.84% (5,403/19,404)
Sex		
Male	44.53% (220/494)	47.23% (9,164/19,404)
Female	55.47% (274/494)	52.77% (10,240/19,404)

	Demographics of Survey Respondents from Medicaid Enrollment Data % (N/D)	Demographics of Eligible Population from Medicaid Enrollment Data % (N/D)
Race		
White	60.12% [↑] (297/494)	52.79% (10,243/19,404)
Multi-Racial	2.43% (12/494)	2.23% (433/19,404)
Black	33.40% [↓] (165/494)	40.37% (7,834/19,404)
Other	4.05% (20/494)	4.61% (894/19,404)
Ethnicity		
Hispanic	4.61% (22/477)	3.30% (615/18,624)
Non-Hispanic	95.39% (455/477)	96.70% (18,009/18,624)
<p>N/D Indicates numerator and denominator. Blue shading indicates the respondent percentage is significantly different than the eligible population percentage. ↑ indicates the respondent percentage is significantly higher than the eligible population percentage and ↓ indicates the respondent percentage is significantly lower than the eligible population percentage. Respondent percentages that are not significantly different than the eligible population percentages are not noted with arrows.</p>		

Numerator and Denominator Breakouts

The tables in this section include the numerators and denominators for rates in the respective subsections of the Results section.

Positive Ratings: Composite Measures

Table A-2 presents the numerators and denominators for the positive ratings for the composite measures for the NC HCBS Program.

Table A-2—Numerators and Denominators for 2023 Respondents Who Gave Positive Ratings for NC HCBS Program

Measures	NC HCBS Program (N/D)
Composite Measures	
<i>Reliable and Helpful Staff</i>	189/222
<i>Staff Listen and Communicate Well</i>	171/198

Measures	NC HCBS Program (N/D)
<i>Helpful Case Manager</i>	149/166
<i>Choosing the Services that Matter to You</i>	295/370
<i>Transportation to Medical Appointments</i>	188/217
<i>Personal Safety and Respect</i>	401/418
<i>Planning Your Time and Activities</i>	227/350
<p>N/D Indicates the numerator and denominator of the score. Numerators and denominators when calculated to percentages do not match the corresponding rates in Figure 3-3 through Figure 3-10 for the NC HCBS Program because final composite measure scores are determined by calculating the average score across all questions within the composite measure. For further details, please refer to the Methodology section within the Reader's Guide beginning on page 14.</p>	

Race and Ethnicity Comparisons: Composite Measures

Table A-3 presents the numerators and denominators for the composite measures for the NC HCBS Program by race and ethnicity.

Table A-3—Numerators and Denominators for 2023 Respondents Who Gave Positive Ratings for the Composite Measures for NC HCBS Program, by Race and Ethnicity

Measures	Race						Ethnicity	
	White (N/D)	Non-White (N/D)	Black (N/D)	Non-Black (N/D)	Other (N/D)	Non-Other (N/D)	Hispanic (N/D)	Non-Hispanic (N/D)
<i>Personal Safety and Respect</i>	205/213	181/188	106/110	279/291	74/78	311/323	25/27	362/376
<p>N/D Indicates the numerator and denominator of the score. Numerators and denominators when calculated to percentages do not match the corresponding rates in Figure 3-15 because final composite measure scores are determined by calculating the average score across all questions within the composite measure. For further details, please refer to the Methodology section within the Reader's Guide beginning on page 14.</p>								

Appendix B. Survey Instrument

The survey instrument administered was the HCBS CAHPS survey. This section provides a copy of the survey instrument without the supplemental questions. Since the HCBS CAHPS survey is CATI-only, the supplemental questions are programmed directly into the CATI system and do not appear on any paper version of the survey instrument.

CAHPS[®] Home- and Community-Based Services Survey

Version: 1.0

Population: Adult

Language: English



File name: CAHPSHcbs01192017SurvEng508
Last updated: January 19, 2017

Instructions for Vendor

- The interview is intended as an interviewer-administered survey; thus all text that appears in initial uppercase and lowercase letters should be read aloud. Text that appears in **bold, lowercase letters** should be emphasized.
- Text in *{italics and in braces}* will be provided by the HCBS program’s administrative data. However, if the interviewee provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.
- For response options of “never,” “sometimes,” “usually,” and “always,” if the respondent cannot use that scale, the alternate version of the survey with response options of “mostly yes” and “mostly no” should be used. These alternate response options are reserved for respondents who find the “never,” “sometimes,” “usually,” “always” response scale cognitively challenging.
- For response options of 0 to 10, if the respondent cannot use that scale, the alternate version of the survey with response options of “excellent,” “very good,” “good,” “fair,” or “poor” should be used. These alternate response options are reserved for respondents who find the numeric scale cognitively challenging.
- All questions include a “REFUSED” response option. In this case, “refused” means the respondent did not provide any answer to the question.
 - All questions include a “DON’T KNOW” response option. This is used when the respondent indicates that he or she does not know the answer and cannot provide a response to the question.
 - All questions include an “UNCLEAR” response option. This should be used when a respondent answers, but the interviewer cannot clarify the meaning of the response even after minor probing or the response is completely unrelated to the question, (e.g., the response to “In the last 3 months, how often did your homemakers listen carefully to what you say?” is “I like to sit by Mary”).
 - Some responses have skip patterns, which are expressed as “→ GO TO Q#.” The interviewer should be advanced to the next appropriate item to ask the respondent.
 - Not all respondents receive all home and community-based services asked about in this instrument. Items Q4 through Q12 help to confirm which services a respondent receives. The table after it summarizes the logic of which items should be used.
 - Survey users may add questions to this survey before the “About You” section. A separate supplemental employment module can be added.
- Use singular/plural as needed. In most cases, questions are written assuming there is more than one staff person supporting a respondent or it is written without an indication of whether there is more than one staff person. Based on information

collected from Q4 through Q12, it is possible to modify questions to be singular or plural as they relate to staff.

- Use program-specific terms. Where appropriate, add in the program-specific terms for staff (e.g., [*program-specific term for these types of staff*]) but allow the interviewer to modify the term based on the respondent's choice of the word. It will be necessary to obtain information for program-specific terms. State administrative data should include the following information:
 - Agency name(s)
 - Titles of staff who provide care
 - Names of staff who provide care
 - Activities that each staff member provides (this will help with identifying appropriate skip logic)
 - Hours of staff who come to the home

COGNITIVE SCREENING QUESTIONS

People might be paid to help you get ready in the morning, with housework, go places, or get mental health services. This survey is about the people who are paid to help you in your home and community with everyday activities. It also asks about the services you get.

1. Does someone come into your home to help you?

- ¹ YES
- ² NO → END SURVEY
- ⁻¹ DON'T KNOW → END SURVEY
- ⁻² REFUSED → END SURVEY
- ⁻³ UNCLEAR RESPONSE → END SURVEY

2. How do they help you?

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

- HELPS ME GET READY EVERY DAY
 - CLEANS MY HOME
 - WORKS WITH ME AT MY JOB
 - HELPS ME DO THINGS
 - DRIVES ME AROUND
- ⁻¹ DON'T KNOW → END SURVEY
 - ⁻² REFUSED → END SURVEY
 - ⁻³ UNCLEAR RESPONSE → END SURVEY

3. What do you call them?

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

- MY WORKER
 - MY ASSISTANT
 - NAMES OF STAFF (JO, DAWN, ETC.)
- ⁻¹ DON'T KNOW → END SURVEY
 - ⁻² REFUSED → END SURVEY
 - ⁻³ UNCLEAR RESPONSE → END SURVEY

CSQPASS.

[IF ALL 3 QUESTIONS WERE ANSWERED CORRECTLY, ENTER 1 TO CONTINUE.]

1 PASS - ALL 3 QUESTIONS WERE ANSWERED CORRECTLY → GO TO Q4

2 FAIL - AT LEAST 1 QUESTION WAS NOT ANSWERED CORRECTLY → GO TO SURVEND

SURVEND.

Thank you for your time. Those are all the questions we have.

Have a nice day/evening. [ENTER 1 TO EXIT SURVEY]

IDENTIFICATION QUESTIONS

Now I would like to ask you some more questions about the types of people who come to your home.

4. In the last 3 months, did you get *{program specific term for personal assistance}* at home?

¹ YES

² NO → GO TO Q6

⁻¹ DON'T KNOW → GO TO Q6

⁻² REFUSED → GO TO Q6

⁻³ UNCLEAR RESPONSE → GO TO Q6

5. What do you call the person or people who gave you *{program-specific term for personal assistance}*? For example, do you call them *{program-specific term for personal assistance}*, staff, personal care attendants, PCAs, workers, or something else?

[ADD RESPONSE WHEREVER IT SAYS "*personal assistance/behavioral health staff*"]

6. In the last 3 months, did you get *{program specific term for behavioral health specialist services}* at home?

¹ YES

² NO → GO TO Q8

⁻¹ DON'T KNOW → GO TO Q8

⁻² REFUSED → GO TO Q8

⁻³ UNCLEAR RESPONSE → GO TO Q8

7. What do you call the person or people who gave you *{program specific term for behavioral health specialist services}*? For example, do you call them *{program-specific term for behavioral health specialists}*, counselors, peer supports, recovery assistants, or something else?

[ADD RESPONSE WHEREVER IT SAYS “*personal assistance/behavioral health staff.*” IF Q4 ALSO = YES, LIST BOTH TITLES]

8. In the last 3 months, did you get {*program specific term for homemaker services*} at home?

- ¹ YES
- ² NO → GO TO Q11
- ⁻¹ DON'T KNOW → GO TO Q11
- ⁻² REFUSED → GO TO Q11
- ⁻³ UNCLEAR RESPONSE → GO TO Q11

9. What do you call the person or people who gave you {*program specific term for homemaker services*}? For example, do you call them {*program-specific term for homemaker*}, aides, homemakers, chore workers, or something else?

[ADD RESPONSE WHEREVER IT SAYS “*homemaker*”]

10. [IF (Q4 OR Q6) AND Q8 = YES, ASK] In the last 3 months, did the same people who help you with everyday activities also help you clean your home?

- ¹ YES
- ² NO
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

11. In the last 3 months, did you get help from {*program specific term for case manager services*} to help make sure that you had all the services you needed?

- ¹ YES
- ² NO
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

12. What do you call the person who gave you {*program specific term for case manager services*}? For example, do you call the person a {*program-specific term for case manager*}, case manager, care manager, service coordinator, supports coordinator, social worker, or something else?

[ADD RESPONSE WHEREVER IT SAYS “*case manager*”]

BELOW ARE INSTRUCTIONS FOR WHICH QUESTIONS TO ASK FOR EACH RESPONSE ABOVE.

ITEM AND RESPONSE—FOLLOW ALL ROWS THAT APPLY	ACTION
IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES), AND Q8 = NO, DON'T KNOW, REFUSE, UNCLEAR (HOMEMAKER SERVICES)	ASK Q13–Q36, AND Q48 ONWARD
IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES), AND Q8 = YES (HOMEMAKER SERVICES)	ASK Q13 ONWARD
IF Q4 AND Q6 = NO (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES)	SKIP Q13–36, Q57 AND Q79
IF Q8 = YES (HOMEMAKER SERVICES)	ASK Q37 ONWARD
IF Q10 = YES (HOMEMAKER AND PERSONAL ASSISTANCE STAFF SAME)	ASK Q13–Q36, Q39, Q40, AND Q48 ONWARD
IF Q11 = ANY RESPONSE (CASE MANAGER)	ASK Q48 ONWARD

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

13. First I would like to talk about the {*personal assistance/behavioral health staff*} who are paid to help you with everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. In the last 3 months, how often did {*personal assistance/behavioral health staff*} come to work on time? Would you say . . .

¹ Never,

- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: First I would like to talk about the *{personal assistance/behavioral health staff}* who are paid to help you with everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. In the last 3 months, did *{personal assistance/behavioral health staff}* come to work on time? Would you say. . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

14. In the last 3 months, how often did *{personal assistance/behavioral health staff}* work as long as they were supposed to? Would you say. . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did *{personal assistance/behavioral health staff}* work as long as they were supposed to? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

15. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that *{personal assistance/behavioral health staff}* could not come that day?

- 1 YES

- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

16. In the last 3 months, did you need help from {*personal assistance/behavioral health staff*} to get dressed, take a shower, or bathe?

- 1 YES
- 2 NO → GO TO Q20
- 1 DON'T KNOW → GO TO Q20
- 2 REFUSED → GO TO Q20
- 3 UNCLEAR RESPONSE → GO TO Q20

17. In the last 3 months, did you **always** get dressed, take a shower, or bathe when you needed to?

- 1 YES → GO TO Q19
- 2 NO
- 1 DON'T KNOW → GO TO Q19
- 2 REFUSED → GO TO Q19
- 3 UNCLEAR RESPONSE → GO TO Q19

18. In the last 3 months, was this because there were no {*personal assistance/behavioral health staff*} to help you?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

19. In the last 3 months, how often did {*personal assistance/behavioral health staff*} make sure you had enough personal privacy when you dressed, took a shower, or bathed? Would you say. . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did *{personal assistance/behavioral health staff}* make sure you had enough personal privacy when you dressed, took a shower, or bathed? Would you say. . .

- ¹ Mostly yes or
- ² Mostly no?
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

20. In the last 3 months, did you need help from *{personal assistance/behavioral health staff}* with your meals, such as help making or cooking meals or help eating?

- ¹ YES
- ² NO → GO TO Q23
- ⁻¹ DON'T KNOW → GO TO Q23
- ⁻² REFUSED → GO TO Q23
- ⁻³ UNCLEAR RESPONSE → GO TO Q23

21. In the last 3 months, were you **always** able to get something to eat when you were hungry?

- ¹ YES → GO TO Q23
- ² NO
- ⁻¹ DON'T KNOW → GO TO Q23
- ⁻² REFUSED → GO TO Q23
- ⁻³ UNCLEAR RESPONSE → GO TO Q23

22. In the last 3 months, was this because there were no *{personal assistance/behavioral health staff}* to help you?

- ¹ YES
- ² NO
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

23. Sometimes people need help taking their medicines, such as reminders to take a medicine, help pouring them, or setting up their pills. In the last 3 months, did you need help from *{personal assistance/behavioral health staff}* to take your medicines?

- ¹ YES
- ² NO → GO TO Q26
- ⁻¹ DON'T KNOW → GO TO Q26
- ⁻² REFUSED → GO TO Q26

⁻³ UNCLEAR RESPONSE → GO TO Q26

24. In the last 3 months, did you **always** take your medicine when you were supposed to?

¹ YES → GO TO Q26

² NO

⁻¹ DON'T KNOW → GO TO Q26

⁻² REFUSED → GO TO Q26

⁻³ UNCLEAR RESPONSE → GO TO Q26

25. In the last 3 months, was this because there were no *{personal assistance/behavioral health staff}* to help you?

¹ YES

² NO

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

26. Help with toileting includes helping someone get on and off the toilet or help changing disposable briefs or pads. In the last 3 months, did you need help from *{personal assistance/behavioral health staff}* with toileting?

¹ YES

² NO → GO TO Q28

⁻¹ DON'T KNOW → GO TO Q28

⁻² REFUSED → GO TO Q28

⁻³ UNCLEAR RESPONSE → GO TO Q28

27. In the last 3 months, did you get all the help you needed with toileting from *{personal assistance/behavioral health staff}* when you needed it?

¹ YES

² NO

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

HOW WELL PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF COMMUNICATE WITH AND TREAT YOU

The next several questions ask about how *{personal assistance/behavioral health staff}* treat you.

28. In the last 3 months, how often did *{personal assistance/behavioral health staff}* treat you with courtesy and respect? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did *{personal assistance/behavioral health staff}* treat you with courtesy and respect? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

29. In the last 3 months, how often were the explanations *{personal assistance/behavioral health staff}* gave you hard to understand because of an accent or the way *{personal assistance/behavioral health staff}* spoke English? Would you say ...

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, were the explanations *{personal assistance/behavioral health staff}* gave you hard to understand because of an accent or the way *{personal assistance/behavioral health staff}* spoke English? Would you say. . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

30. In the last 3 months, how often did *{personal assistance/behavioral health staff}* treat you the way you wanted them to? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did *{personal assistance/behavioral health staff}* treat you the way you wanted them to? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

31. In the last 3 months, how often did *{personal assistance/behavioral health staff}* explain things in a way that was easy to understand? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did *{personal assistance/behavioral health staff}* explain things in a way that was easy to understand? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

32. In the last 3 months, how often did *{personal assistance/behavioral health staff}* listen carefully to you? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?

- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did *{personal assistance/behavioral health staff}* listen carefully to you?
Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

33. In the last 3 months, did you feel *{personal assistance/behavioral health staff}* knew what kind of help **you** needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

34. In the last 3 months, did *{personal assistance/behavioral health staff}* encourage you to do things for yourself if you could?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

35. Using any number from 0 to 10, where 0 is the worst help from *{personal assistance/behavioral health staff}* possible and 10 is the best help from *{personal assistance/behavioral health staff}* possible, what number would you use to rate the help you get from *{personal assistance/behavioral health staff}*?

- __ 0 TO 10
- 1 DON'T KNOW
 - 2 REFUSED
 - 3 UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from *{personal assistance/behavioral health staff}*? Would you say . . .

- 1 Excellent,
- 2 Very good,
- 3 Good,
- 4 Fair, or
- 5 Poor?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

36. Would you recommend the {*personal assistance/behavioral health staff*} who help you to your family and friends if they needed help with everyday activities? Would you say you would recommend the {*personal assistance/behavioral health staff*} . . .

- 1 Definitely no,
- 2 Probably no,
- 3 Probably yes, or
- 4 Definitely yes?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

GETTING NEEDED SERVICES FROM HOME MAKERS

The next several questions are about the {*homemakers*}, the staff who are paid to help you do tasks around the home—such as cleaning, grocery shopping, or doing laundry.

37. In the last 3 months, how often did {*homemakers*} come to work on time? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {*homemakers*} come to work on time? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW

- 2 REFUSED
- 3 UNCLEAR RESPONSE

38. In the last 3 months, how often did {homemakers} work as long as they were supposed to? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} work as long as they were supposed to? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

39. In the last 3 months, did your household tasks, like cleaning and laundry, **always** get done when you needed them to? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]

- 1 YES → GO TO Q41
- 2 NO
- 1 DON'T KNOW → GO TO Q41
- 2 REFUSED → GO TO Q41
- 3 UNCLEAR RESPONSE → GO TO Q41

40. In the last 3 months, was this because there were no {homemakers} to help you? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

HOW WELL HOMEMAKERS COMMUNICATE WITH AND TREAT YOU

The next several questions ask about how {homemakers} treat you.

41. In the last 3 months, how often did {homemakers} treat you with courtesy and respect? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} treat you with courtesy and respect? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

42. In the last 3 months, how often were the explanations {homemakers} gave you hard to understand because of an accent or the way the {homemakers} spoke English? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, were the explanations {homemakers} gave you hard to understand because of an accent or the way {homemakers} spoke English? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

43. In the last 3 months, how often did {homemakers} treat you the way you wanted them to? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} treat you the way you wanted them to? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

44. In the last 3 months, how often did {homemakers} listen carefully to you? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} listen carefully to you? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

45. In the last 3 months, did you feel {homemakers} knew what kind of help you needed?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

46. Using any number from 0 to 10, where 0 is the worst help from {homemakers} possible and 10 is the best help from {homemakers} possible, what number would you use to rate the help you get from {homemakers}?

- __ 0 TO 10
-1 DON'T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from {homemakers}?
Would you say . . .

- 1 Excellent,
2 Very good,
3 Good,
4 Fair, or
5 Poor?
-1 DON'T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

47. Would you recommend the {homemakers} who help you to your family and friends if they needed {program-specific term for homemaker services}? Would you say you would recommend the {homemakers} . . .

- 1 Definitely no,
2 Probably no,
3 Probably yes, or
4 Definitely yes?
-1 DON'T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

YOUR CASE MANAGER

Now I would like to talk to you about your {case manager}, the person who helps make sure you have the services you need.

48. Do you know who your {case manager} is?

- 1 YES
2 NO → GO TO Q56
-1 DON'T KNOW → GO TO Q56
-2 REFUSED → GO TO Q56

-3 UNCLEAR RESPONSE → GO TO Q56

49. In the last 3 months, could you contact this {*case manager*} when you needed to?

1 YES

2 NO

-1 DON'T KNOW

-2 REFUSED

-3 UNCLEAR RESPONSE

50. Some people need to get equipment to help them, like wheelchairs or walkers, and other people need their equipment replaced or fixed. In the last 3 months, did you ask this {*case manager*} for help with getting or fixing equipment?

1 YES

2 NO → GO TO Q52

3 DON'T NEED → GO TO Q52

-1 DON'T KNOW → GO TO Q52

-2 REFUSED → GO TO Q52

-3 UNCLEAR RESPONSE → GO TO Q52

51. In the last 3 months, did this {*case manager*} work with you when you asked for help with getting or fixing equipment?

1 YES

2 NO

-1 DON'T KNOW

-2 REFUSED

-3 UNCLEAR RESPONSE

52. In the last 3 months, did you ask this {*case manager*} for help in getting any changes to your services, such as more help from {*personal assistance/behavioral health staff and/or homemakers if applicable*}, or for help with getting places or finding a job?

1 YES

2 NO → GO TO 54

3 DON'T NEED → GO TO Q54

-1 DON'T KNOW → GO TO Q54

-2 REFUSED → GO TO Q54

-3 UNCLEAR RESPONSE → GO TO Q54

53. In the last 3 months, did this {*case manager*} work with you when you asked for help with getting other changes to your services?

1 YES

- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

54. Using any number from 0 to 10, where 0 is the worst help from {*case manager*} possible and 10 is the best help from {*case manager*} possible, what number would you use to rate the help you get from {*case manager*}?

__ 0 TO 10

- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from the {*case manager*}? Would you say . . .

- 1 Excellent,
- 2 Very good,
- 3 Good,
- 4 Fair, or
- 5 Poor?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

55. Would you recommend the {*case manager*} who helps you to your family and friends if they needed {*program-specific term for case-management services*}? Would you say you would recommend the {*case manager*} . . .

- 1 Definitely no,
- 2 Probably no,
- 3 Probably yes, or
- 4 Definitely yes?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

CHOOSING YOUR SERVICES

56. In the last 3 months, did your [*program-specific term for "service plan"*] include . . .

- 1 **None** of the things that are important to you,
- 2 **Some** of the things that are important to you,

- 3 **Most** of the things that are important to you, or
- 4 **All** of the things that are important to you?
- 1 DON'T KNOW → GO TO Q58
- 2 REFUSED → GO TO Q58
- 3 UNCLEAR RESPONSE → GO TO Q58

57. In the last 3 months, did you feel {*personal assistance/behavioral health staff*} knew what's on your [*program-specific term for "service plan"*], including the things that are important to you?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

58. In the last 3 months, who would you have talked to if you wanted to change your [*program-specific term for "service plan"*]? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

- 1 CASE MANAGER
- 2 OTHER STAFF
- 3 FAMILY/FRIENDS
- 4 SOMEONE ELSE, PLEASE SPECIFY _____
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

TRANSPORTATION

The next questions ask about how you get to places in your community.

59. Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, how often did you have a way to get to your medical appointments? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, did you have a way to get to your medical appointments? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

60. In the last 3 months, did you use a van or some other transportation service? Do not include a van you own.

- 1 YES
- 2 NO → GO TO Q63
- 1 DON'T KNOW → GO TO Q63
- 2 REFUSED → GO TO Q63
- 3 UNCLEAR RESPONSE → GO TO Q63

61. In the last 3 months, were you able to get in and out of this ride easily?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

62. In the last 3 months, how often did this ride arrive on time to pick you up? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did this ride arrive on time to pick you up? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED

⁻³ UNCLEAR RESPONSE

PERSONAL SAFETY

The next few questions ask about your personal safety.

63. Who would you contact in case of an emergency? [INTERVIEWER MARKS ALL THAT APPLY]

- ¹ FAMILY MEMBER OR FRIEND
- ² CASE MANAGER
- ³ AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
- ⁴ PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
- ⁵ 9–1–1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)
- ⁶ SOMEONE ELSE, PLEASE SPECIFY _____
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

64. In the last 3 months, was there a person you could talk to if someone hurt you or did something to you that you didn't like?

- ¹ YES
- ² NO
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

The next few questions ask if anyone paid to help you treated you badly in the last 3 months. This includes {*personal assistance/behavioral health staff, homemakers, or your case manager*}. We are asking everyone the next questions—not just you. [ADD STATE-SPECIFIC LANGUAGE HERE REGARDING MANDATED REPORTING, IF APPROPRIATE—“I want to remind you that, although your answers are confidential, I have a legal responsibility to tell {STATE} if I hear something that makes me think you are being hurt or are in danger.”]

65. In the last 3 months, did **any** {*personal assistance/behavioral health staff, homemakers, or your case managers*} take your money or your things without asking you first?

- ¹ YES
- ² NO → GO TO Q68
- ⁻¹ DON'T KNOW → GO TO Q68
- ⁻² REFUSED → GO TO Q68
- ⁻³ UNCLEAR RESPONSE → GO TO Q68

66. In the last 3 months, did someone work with you to fix this problem?

- 1 YES
- 2 NO → GO TO Q68
- 1 DON'T KNOW → GO TO Q68
- 2 REFUSED → GO TO Q68
- 3 UNCLEAR RESPONSE → GO TO Q68

67. In the last 3 months, who has been working with you to fix this problem? Anyone else?
[INTERVIEWER MARKS ALL THAT APPLY]

- 1 FAMILY MEMBER OR FRIEND
- 2 CASE MANAGER
- 3 AGENCY
- 4 SOMEONE ELSE, PLEASE SPECIFY _____
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

68. In the last 3 months, did any {staff} yell, swear, or curse at you?

- 1 YES
- 2 NO → GO TO Q71
- 1 DON'T KNOW → GO TO Q71
- 2 REFUSED → GO TO Q71
- 3 UNCLEAR RESPONSE → GO TO Q71

69. In the last 3 months, did someone work with you to fix this problem?

- 1 YES
- 2 NO → GO TO Q71
- 1 DON'T KNOW → GO TO Q71
- 2 REFUSED → GO TO Q71
- 3 UNCLEAR RESPONSE → GO TO Q71

70. In the last 3 months, who has been working with you to fix this problem? Anyone else?
[INTERVIEWER MARKS ALL THAT APPLY]

- 1 FAMILY MEMBER OR FRIEND
- 2 CASE MANAGER
- 3 AGENCY
- 4 SOMEONE ELSE, PLEASE SPECIFY _____
- 1 DON'T KNOW
- 2 REFUSED

-3 UNCLEAR RESPONSE

71. In the last 3 months, did any {staff} hit you or hurt you?

1 YES

2 NO → GO TO Q74

-1 DON'T KNOW → GO TO Q74

-2 REFUSED → GO TO Q74

-3 UNCLEAR RESPONSE → GO TO Q74

72. In the last 3 months, did someone work with you to fix this problem?

1 YES

2 NO → GO TO Q74

-1 DON'T KNOW → GO TO Q74

-2 REFUSED → GO TO Q74

-3 UNCLEAR RESPONSE → GO TO Q74

73. In the last 3 months, who has been working with you to fix this problem? Anyone else?
[INTERVIEWER MARKS ALL THAT APPLY]

1 FAMILY MEMBER OR FRIEND

2 CASE MANAGER

3 AGENCY

4 SOMEONE ELSE, PLEASE SPECIFY _____

-1 DON'T KNOW

-2 REFUSED

-3 UNCLEAR RESPONSE

COMMUNITY INCLUSION AND EMPOWERMENT

Now I'd like to ask you about the things you do in your community.

74. Do you have any **family** members who live nearby? Do not include family members you live with.

1 YES

2 NO → GO TO Q76

-1 DON'T KNOW → GO TO Q76

-2 REFUSED → GO TO Q76

-3 UNCLEAR RESPONSE → GO TO Q76

75. In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these family members who live nearby? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

76. Do you have any **friends** who live nearby?

- 1 YES
- 2 NO → GO TO Q78
- 1 DON'T KNOW → GO TO Q78
- 2 REFUSED → GO TO Q78
- 3 UNCLEAR RESPONSE → GO TO Q78

77. In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these friends who live nearby? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

78. In the last 3 months, when you wanted to, how often could you do things in the community that you like? Would you say . . .

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you do things in the community that you like? Would you say . . .

- 1 Mostly yes or
- 2 Mostly no?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

79. In the last 3 months, did you need more help than you get from {*personal assistance/behavioral health staff*} to do things in your community?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

80. In the last 3 months, did you take part in deciding **what** you do with your time each day?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

81. In the last 3 months, did you take part in deciding **when** you do things each day—for example, deciding when you get up, eat, or go to bed?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ABOUT YOU

Now I just have a few more questions about you.

82. In general, how would you rate your overall health? Would you say . . .

- 1 Excellent,
- 2 Very good,
- 3 Good,
- 4 Fair, or
- 5 Poor?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

83. In general, how would you rate your overall mental or emotional health? Would you say . . .

- 1 Excellent,
- 2 Very good,
- 3 Good,
- 4 Fair, or
- 5 Poor?
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

84. What is your age?

- 1 18 TO 24 YEARS
- 2 25 TO 34 YEARS
- 3 35 TO 44 YEARS
- 4 45 TO 54 YEARS
- 5 55 TO 64 YEARS
- 6 65 TO 74 YEARS
- 7 75 YEARS OR OLDER
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In what year were you born?

_____ (YEAR)

- 1 DON'T KNOW
- 2 REFUSED

-3 UNCLEAR RESPONSE

85. [IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE] Are you male or female?

1 MALE

2 FEMALE

-1 DON'T KNOW

-2 REFUSED

-3 UNCLEAR RESPONSE

86. What is the highest grade or level of school that you have completed?

1 8th grade or less

2 Some high school, but did not graduate

3 High school graduate or GED

4 Some college or 2-year degree

5 4-year college graduate

6 More than 4-year college degree

-1 DON'T KNOW

-2 REFUSED

-3 UNCLEAR RESPONSE

87. Are you of Hispanic, Latino, or Spanish origin?

1 YES, HISPANIC, LATINO, OR SPANISH

2 NO, NOT HISPANIC, LATINO, OR SPANISH → GO TO Q89

-1 DON'T KNOW → GO TO Q89

-2 REFUSED → GO TO Q89

-3 UNCLEAR RESPONSE → GO TO Q89

88. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

1 Mexican, Mexican American, Chicano, Chicana

2 Puerto Rican

3 Cuban

4 Another Hispanic, Latino, or Spanish origin

-1 DON'T KNOW

-2 REFUSED

-3 UNCLEAR RESPONSE

89. What is your race? You may choose one or more of the following. Would you say you are. . .

1 White → GO TO Q92

2 Black or African-American → GO TO Q92

- 3 Asian → GO TO Q90
- 4 Native Hawaiian or other Pacific Islander → GO TO Q91
- 5 American Indian or Alaska Native → GO TO Q92
- 6 OTHER → GO TO Q92
- 1 DON'T KNOW → GO TO Q92
- 2 REFUSED → GO TO Q92
- 3 UNCLEAR RESPONSE → GO TO Q92

90. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

- 1 Asian Indian → GO TO Q92
- 2 Chinese → GO TO Q92
- 3 Filipino → GO TO Q92
- 4 Japanese → GO TO Q92
- 5 Korean → GO TO Q92
- 6 Vietnamese → GO TO Q92
- 7 Other Asian → GO TO Q92
- 1 DON'T KNOW → GO TO Q92
- 2 REFUSED → GO TO Q92
- 3 UNCLEAR RESPONSE → GO TO Q92

91. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

- 1 Native Hawaiian
- 2 Guamanian or Chamorro
- 3 Samoan
- 4 Other Pacific Islander
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

92. Do you speak a language other than English at home?

- 1 YES
- 2 NO → GO TO Q94
- 1 DON'T KNOW → GO TO Q94
- 2 REFUSED → GO TO Q94
- 3 UNCLEAR RESPONSE → GO TO Q94

93. What is the language you speak at home?

- 1 Spanish,
- 2 Some other language → Which one? _____
- 1 DON'T KNOW

- 2 REFUSED
- 3 UNCLEAR RESPONSE

94. [IF NECESSARY, ASK] How many adults live at your home, including you?

- 1 1 [JUST THE RESPONDENT] → END SURVEY
- 2 2 TO 3
- 3 4 OR MORE
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

95. [IF NECESSARY, ASK] Do you live with any family members?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

96. [IF NECESSARY, ASK] Do you live with people who are not family or are not related to you?

- 1 YES
- 2 NO
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

INTERVIEWER QUESTIONS

THE FOLLOWING QUESTIONS SHOULD BE ANSWERED AFTER THE INTERVIEW IS CONDUCTED.

97. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

- 1 YES
- 2 NO

98. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- 1 YES
- 2 NO → END SURVEY

99. WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)

- ¹ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- ² STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

100. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

- ¹ YES
- ² NO → END SURVEY

101. HOW DID THAT PERSON HELP? [MARK ALL THAT APPLY.]

- ¹ ANSWERED **ALL** THE QUESTIONS FOR RESPONDENT
- ² ANSWERED **SOME** OF THE QUESTIONS FOR THE RESPONDENT
- ³ RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/PROMPTED THE RESPONDENT
- ⁴ TRANSLATED THE QUESTIONS OR ANSWERS INTO THE RESPONDENT'S LANGUAGE
- ⁵ HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS
- ⁶ HELPED THE RESPONDENT IN ANOTHER WAY,
SPECIFY _____

102. WHO HELPED THE RESPONDENT? (MARK ALL THAT APPLY.)

- ¹ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- ² STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT