



Iowa Ryan White Part B Client Experience Survey Results

November 2024

Acknowledgements

Thank you to the 463 Ryan White Part B (RWPB) clients who participated in the 2023 Client Experience Survey. Your collective responses offer insight into Iowa's HIV epidemic and guidance for improving RWPB services in Iowa. Thank you to International Translation Services for translating the survey, RWPB subrecipient agencies for distributing the surveys, and RDE Systems for developing the survey. Special thanks to Denise Montgomery for assisting clients to take the survey over the phone.

Lastly, thank you to RWPB subrecipient staff who provide services to Iowans living with HIV. The results of this survey show their outstanding work providing high quality services in a friendly, professional, and culturally competent way.

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Executive Summary

In 2023, the Ryan White Part B (RWPB) Program at the Iowa Department of Health and Human Services (Iowa HHS) conducted their second Client Experience Survey. The goal of the survey was to collect feedback from clients on the variety and availability of RWPB services offered at their case management agency, and the types of interactions they are having with agency staff. The results of the survey will be used to improve RWPB services in Iowa, the Stop HIV Iowa Plan and inform planning for the Ryan White Part B team.

There were 463 RWPB clients who completed the survey from nine agencies across the state of Iowa. Twenty-four percent (24%) of RWPB clients returned the survey—a 7% increase over the most recent survey done in 2022. In 2023, seventy-four percent (74%) of respondents identified as male, 25% as female, 1% as transgender, and 0.2% as gender non-binary. When asked about their race and ethnicity, 61% of respondents identified as White, 25% as Black, and 11% as Latino. The majority of respondents were aged 55-64 years (27%), followed by 45-54 (23%), 35-44 (19%), 65+ and 25-34 (15%), 18-24 (1%), and under 18 (0.2%).

The survey asked about case manager availability. Respondents were overwhelmingly satisfied with the availability and amount of contact they have with their case manager (93% very or somewhat satisfied). Eighty-nine percent (89%) of respondents reported that it was very or somewhat easy to get in contact with their case manager, and 93% said their case manager responds in a timely manner all or most of the time.

When asked about specific interactions with their case manager, almost all respondents reported having positive experiences (range of 91%-98% who strongly agreed or agreed with the statements in this section). Most notably, case managers shared information in an understandable way (98%) and respected and protected client confidentiality (97%).

The top five most important services to clients were HIV medical care (59%), case management (54%), help paying for medical bills (30%), help paying for housing costs (24%), and help paying for food or providing food and nutritional supplements (23%). There were 13% of clients who needed or wanted a service they weren't able to get, a five percent increase in comparison to the 2022 Client Experience Survey result. When evaluated for disparities, women were more likely to report wanting or needing a service that they weren't able to get compared to overall respondents (17% of women vs. 13% of all respondents wanted or needed a service that they weren't able to get). When asked about the quality of RWPB services received in the past 12 months, 95% of respondents reported they were very high or high quality.

All respondents were asked if they ever experienced discrimination or unfair treatment at their RWPB case management agency based on their race or ethnicity, gender, sexual orientation, culture or background, age, mental health, or substance use. Very few clients reported

experiencing discrimination (n=11) or two percent of respondents. Moreover, there was no statistical significance when evaluated by race and ethnicity.

All respondents were asked about a variety of positive experiences they may have had at their RWPB case management agency. The vast majority of respondents reported positive experiences with staff (87%–96% of respondents reported experiencing the positive experience statements often or always). There is no statistical significance in percentage differences between any race or ethnicity. This could indicate that overall, agencies are doing a superior job at treating all clients fairly.

Iowa Ryan White Part B Client Experience Survey Results

Introduction

In 2023, staff in the Ryan White Part B (RWPB) Program at the Iowa Department of Health and Human Services (Iowa HHS) conducted their second Client Experience Survey. The goal of the Client Experience Survey was to collect feedback from clients on the variety, availability, and quality of RWPB services offered at their case management agency. The results of the survey will be used to improve RWPB services in Iowa, support the goals of the Stop HIV Iowa Plan, and inform planning for the RWPB team.

Methods

SURVEY DEVELOPMENT

The 2023 Client Experience Survey (CES) was modeled after the 2022 CES, which was in turn based on a variety of national and jurisdictional resources. Overall, the survey was very similar to the 2022 CES to allow for comparison. The following sources were used to develop the survey questions:

1. Individual RWPB subrecipient satisfaction surveys from previous years
2. Other state's satisfaction and/or consumer needs surveys – Minnesota Consumer Survey, Kentucky Survey, and Utah's needs assessment survey
3. The Cultural Humility Scale developed by Hook, Davis, Owen, Worthington Jr., and Utsey (2013)
4. The 2019 Consumer Needs Assessment

The CES collected information about client demographics, case manager availability, case manager interactions, availability and quality of services, and discrimination and cultural humility. For both surveys, the Health Equity Coordinator in the Bureau of HIV, STI, and Hepatitis assisted with development of the Discrimination and Cultural Humility section, which in 2023 included a restructure. In 2022, respondents reported that the Cultural Humility and Discrimination section was confusing, and adjustments were made. In addition, discrimination questions were broken out into only negative statements or only positive statements to minimize confusion.

In addition, each of the nine RWPB subrecipient agencies were offered the opportunity to develop their own agency-specific section that only their clients would answer. Agency-specific sections were included for eight of the nine agencies.

The RWPB program contracted with a third party, RDE Systems, to program the survey online making it accessible on computers, tablets, and smartphones. The online survey was translated into Spanish and French. Computer generated audio was available in English, Spanish, and French. A paper version of the survey was available in English and Spanish. Respondents who elected to take the paper survey mailed their answers to the Ryan White Data Coordinator at Iowa HHS, who then entered their responses into the online tool. Lastly, respondents were also able to call the Ryan White Data Coordinator and the Ryan White Quality Coordinator at Iowa HHS to complete the survey over the phone.

Eligible respondents were provided the option of linking data from CAREWare (a Ryan White client-level data system) to their survey responses. To be offered this option, respondents had to be a current Iowa RWPB case management client and have the required CAREWare fields completed. When this option was selected, respondents could skip 8 questions within the survey. These included demographic data questions, including gender identity, HIV/AIDS status, Iowa residency, age, and race/ethnicity. If this option was not selected, or if the respondent was not eligible for this option, then they were asked to complete all questions within the survey.

SURVEY ADMINISTRATION AND RESPONSE RATES

Every RWPB case management client was mailed a survey letter containing a link to the survey and a unique access code. Throughout the survey period, fliers were posted in agencies and clinics, and RWPB subrecipient staff contacted their clients to encourage them to take the survey. The RWPB program staff at Iowa HHS and the RWPB subrecipient staff assisted respondents in completing the survey over the phone or in person if respondents were unable to access the internet. Respondents who completed the survey were eligible to receive an incentive (a gift card). Upon completing the online survey, respondents were prompted to select how they would like to receive their gift card (by mail, pick-up at their case management agency or email).

The survey was open for a period of 25 days, from October 14, 2023, to November 9, 2023. A total of 463 surveys were completed. Some survey questions incorporated skip-logic, so the number of respondents (n-value) is indicated throughout the report for questions answered by less than 463 respondents. Percentages of survey respondents may exceed 100% due to rounding or because some questions allowed for multiple answers.

Response rates were calculated by dividing the number of surveys completed by the number of surveys distributed, per agency. The overall survey response rate was 24%, a seven percent (7%) response rate increase in comparison to the 2022 CES. Individual agency response rates can be seen in Table 1, on the next page.

Table 1. Survey response rate by RWPB subrecipient agency

Agency	# Survey Letters Distributed	# Surveys Completed	Response Rate
Cedar AIDS Support System	130	38	29%
Dubuque Visiting Nurses Association	56	34	61%
Linn County Community Services	203	74	37%
Nebraska AIDS Project	106	18	17%
North Iowa Community Action Organization	54	31	57%
Primary Health Care	679	115	17%
Siouxland Community Health Center	172	18	11%
The Project Quad Cities	192	52	27%
University of Iowa Hospitals and Clinics (including subcontracted agency River Hills Community Health Center)	306	83	27%
Totals	1,898	463	24%

CONFIDENTIALITY

Several precautions were taken to ensure respondent confidentiality. RDE Systems facilitated the data matching between CAREWare and the survey and assigned Survey IDs. The electronic survey did not require names or any other identifying information.

For the purposes of survey tracking and gift card dissemination, RDE Systems developed an *Incentive Module* to track the distribution of gift cards. This database was maintained in a secure environment, and approved users were provided a unique login.

After completing the survey, respondents were provided an incentive code. They could elect to receive their gift card by mail, pick-up at their case management agency, or email. "Name" was an optional field in the mailing address when requesting gift cards by mail. Identifying information tied to the gift cards was stored in a separate database from the survey responses.

Each agency received an appendix that detailed the number of clients who responded to each question by answer type. No identifying information was included in the dataset.

DATA ANALYSIS

Microsoft Excel 2016 was used to analyze the data. The data were stratified and analyzed in various ways. All question response options were analyzed for all respondents. Then, the answers were evaluated for disparities by sub-populations and compared to all respondents. These sub-populations included: age, gender, sexual orientation, and race. Individual agency results were also analyzed for their case management clients that responded to the survey. Once the aggregate data was stratified and analyzed by the Ryan White Data Coordinator, the RWPB team met to examine findings from the survey. The team discussed key

differences between the 2022 and 2023 CES and next steps to incorporate survey findings into quality improvement efforts. The Client Services Coordinator, Ryan White Quality Coordinator, and Ryan White Data Coordinator met to analyze survey results in more detail. Lastly, each subrecipient agency was asked to review their agency appendix and come prepared to monitoring calls with the Ryan White Client Services Coordinators to discuss their agency-specific findings.

LIMITATIONS

This section describes the limitations of the survey.

- ▶ Clients from the following agencies were underrepresented because their agencies' response rates were lower than the overall survey response rate of 24% (i.e. at a .05 margin of error the number of survey responses did not constitute a valid sample size; although Primary Health Care had a valid sample size with a .10 margin of error):
 - Siouxland Community Health Center (11%)
 - Nebraska AIDS Project (17%)
 - Primary Health Care (17%)
- ▶ The Discrimination and Cultural Humility section of the survey contained "other" as an option for three questions. Many clients indicated that they experienced "other" discrimination or a scenario, but when prompted to leave additional information, they stated they didn't have any or they "didn't mean to hit this button."

Results

DEMOGRAPHICS

There were approximately 1,898 RWPB clients who received a survey ID. Of those, 463 clients completed the survey, for a total response rate of 24%. This is a tremendous response rate considering only 320 clients needed to respond for the survey results to have a valid sample size, accounting for a .05 margin of error/95% confidence interval.

Furthermore, RWPB subrecipient agency response rates ranged from 11% to 61%. It is important to note that RWPB subrecipient agencies range in size. Samples were obtained from a total client population of 1,898, which ranged from 54 at the smallest agency to 679 at the largest agency.

The survey was offered in multiple languages. Ninety-four percent (94%) of respondents took the survey in English, 5% in Spanish and 0.2% in French. We saw a 2% increase in the percentage of Spanish surveys completed in comparison to the 2022 Client Experience Survey.

Gender

Figure 1, at right, shows the distribution of respondents by gender.

About three quarters of respondents identified as men, one quarter identified as women, and less than 2% identified as transgender or gender non-binary. This is very similar to the distribution of all RWPB clients.

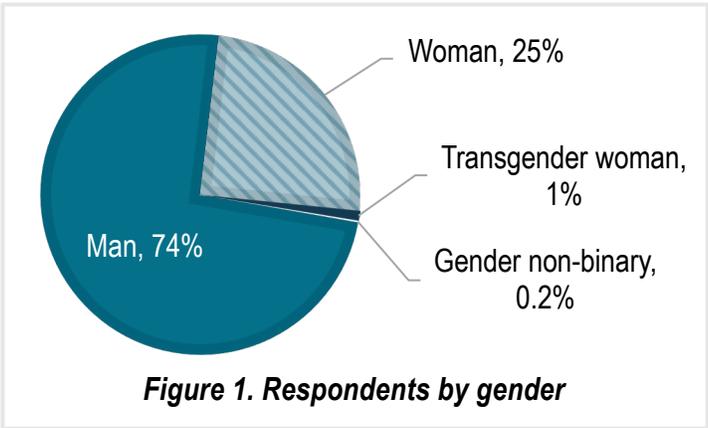


Figure 1. Respondents by gender

Age

When looking at respondents by age (Figure 2), most respondents were between the ages of 55-64 years (27%), followed by 45-54 (23%) and 35-44 (19%). The distribution of survey respondents varies somewhat from the distribution of all RWPB clients. Figure 2 compares the percentage of survey respondents by age group compared to all RWPB clients. Of interest, people 55 years and older are overrepresented in survey respondents compared to all RWPB clients. In contrast, people 25-44 years are underrepresented in survey respondents compared to all RWPB clients.

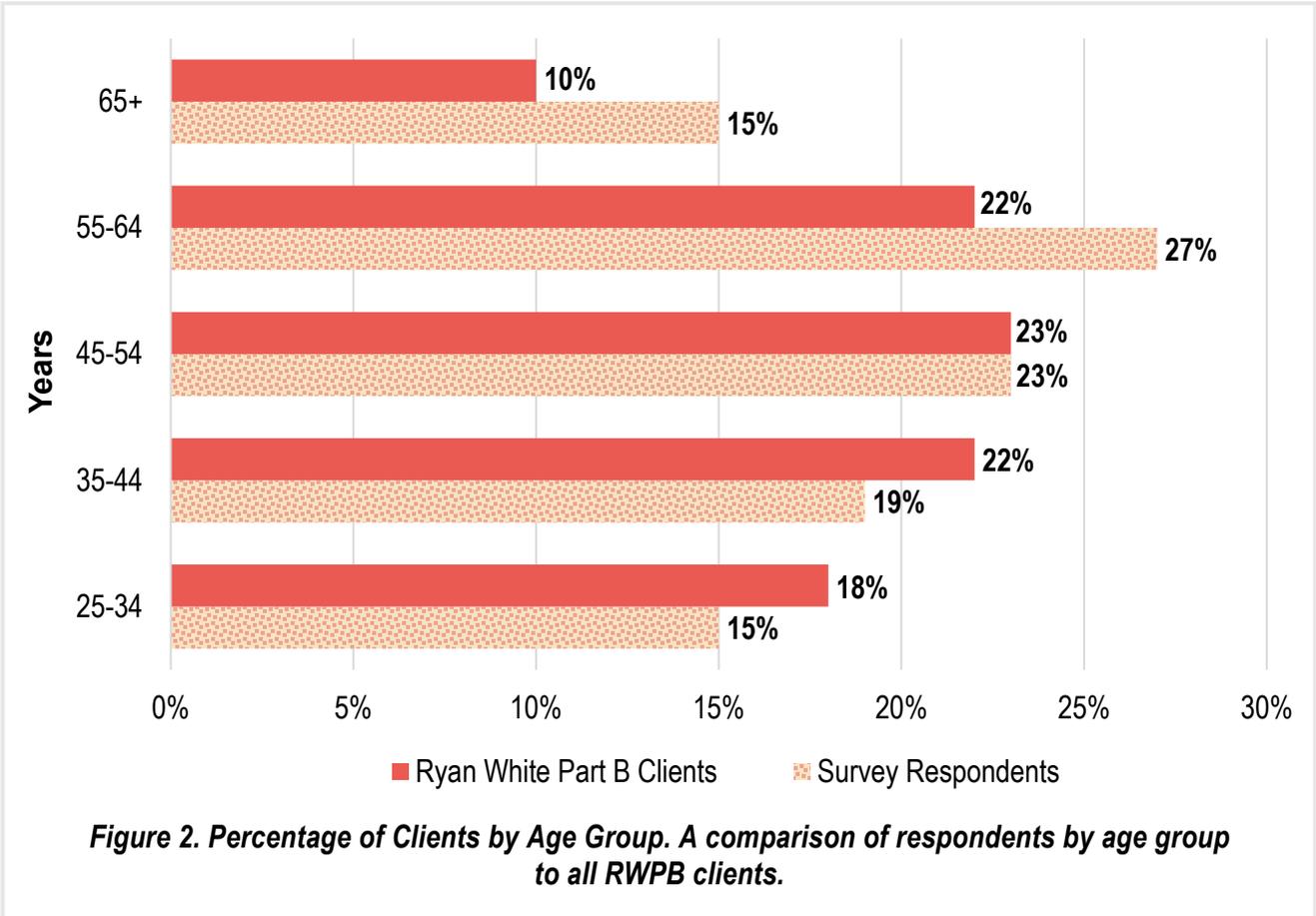
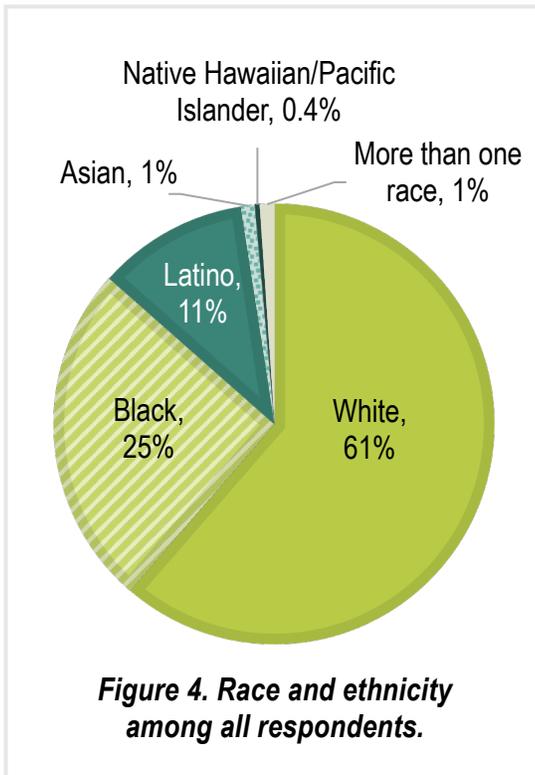
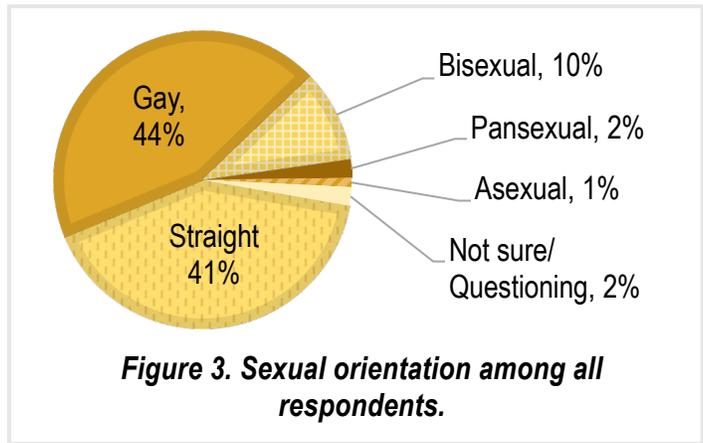


Figure 2. Percentage of Clients by Age Group. A comparison of respondents by age group to all RWPB clients.

Sexual Orientation

All respondents identified their sexual orientation, as shown in Figure 3.

Almost half of respondents identified as gay (44%), followed by straight (41%). Ten percent (10%) of respondents identified as bisexual, 2% were not sure or questioning, 2% identified as pansexual and 1% identified as asexual.



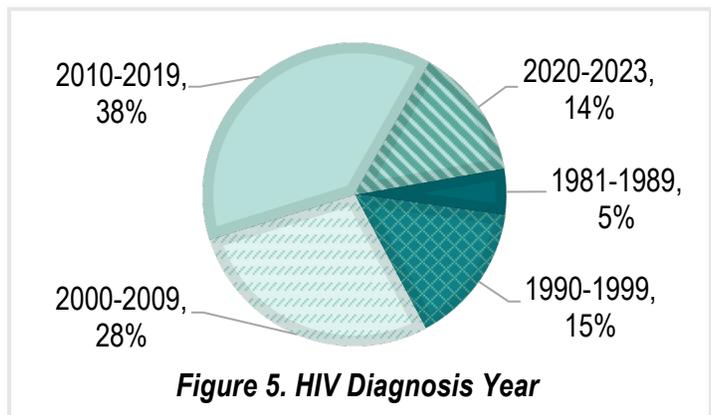
Race and Ethnicity

When looking at respondents by race and ethnicity (Figure 4), almost two-thirds identified as White (61%). One quarter identified as Black (25%), and 11% identified as Latino.

When compared to the race and ethnicity of all RWPB clients in 2023, White respondents were overrepresented (61% vs. 50% of all RWPB clients), and Black respondents were underrepresented (25% of respondents vs. 30% of all RWPB clients). This is a similar distribution compared to the HIV epidemic in Iowa. The only difference is that White clients were overrepresented (61% of respondents vs. 57% of all Iowans living with HIV). Lastly, in comparison to the 2022 CES, the 2023 CES saw a 2% response rate increase among Black clients and a 2% response rate decrease among White clients.

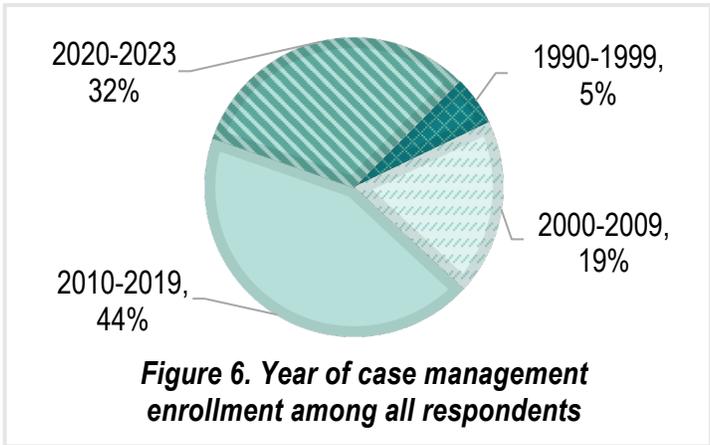
HIV Diagnosis Year

Figure 5 shows the distribution of all respondents by year of HIV diagnosis. Very few respondents were diagnosed between 1981 and 1989 (5%). Most respondents were diagnosed between 2010 and 2019 (38%).



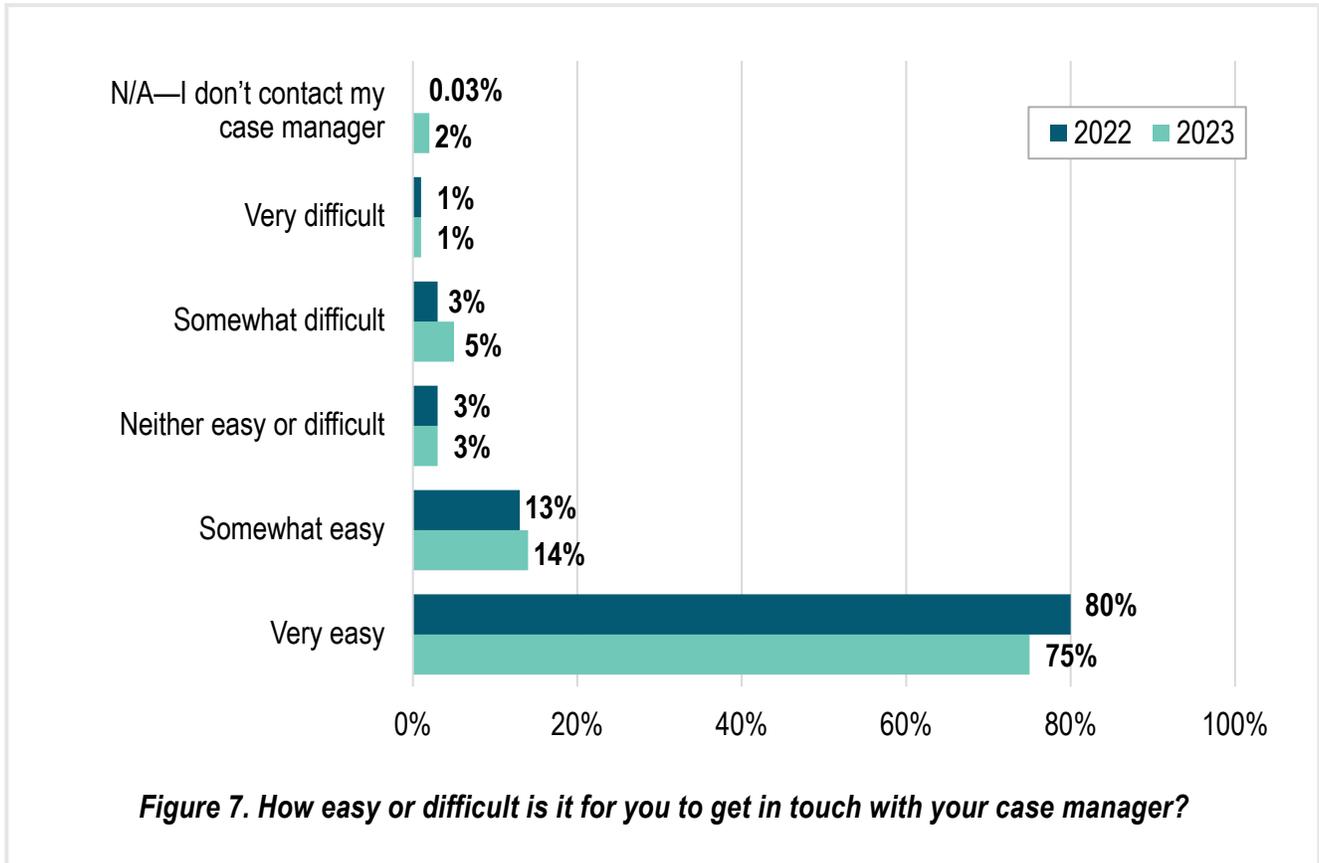
Year of Case Management Enrollment

Regarding the year respondents enrolled in case management (Figure 6), almost half enrolled between 2010 and 2019 and over one quarter enrolled between 2020 and 2023. Nineteen percent (19%) enrolled between 2000 and 2009 and 5% between 1990 and 1999.



CASE MANAGER AVAILABILITY

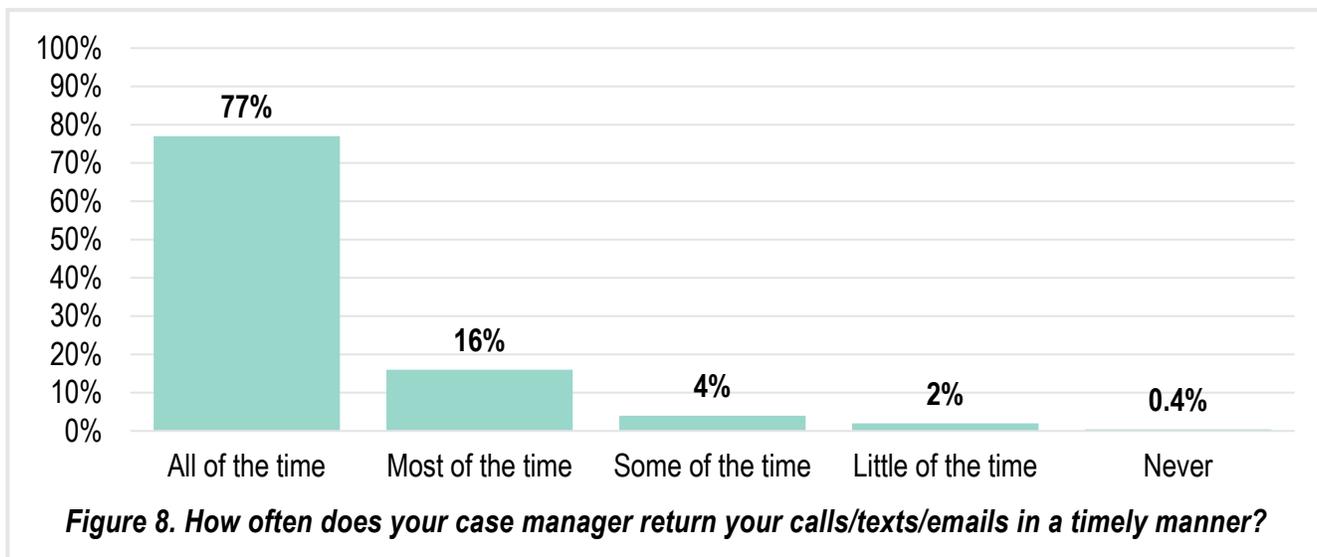
All respondents were asked a series of questions regarding the availability of their case manager. The 2023 CES found that eighty-nine percent (89%) of respondents reported that it was very easy or somewhat easy to contact their case manager (Figure 7). Though this is a commendable satisfaction rate, it is four percent (4%) lower satisfaction when it is compared to the 2022 CES and should be analyzed and monitored. Of note, when evaluated for disparities, there were no significant findings by race, gender, or age for this section of the survey.



Respondents who answered “Somewhat Difficult” or “Very Difficult” were asked to describe what makes it difficult to contact their case manager. The following summarizes their responses:

- ▶ “She won’t return my calls”
- ▶ “When you call the phone is answered by healthcare clerks at the front desk. If the clerk who is associated with our services is not there you are asked to call back or transferred to voicemail. You may not get a call back that day. That is why it is important to just show up and ask for help.”
- ▶ “Does not seem to respond very quickly if at all sometimes.”
- ▶ “She was busy a lot with others.”
- ▶ “Building renovations”
- ▶ “Case manager changed twice due to staffing. Not returning calls.”
- ▶ “Doesn’t get back to me. Sometimes it takes 2 or 3 tries before I get a response.”
- ▶ “Language barriers”
- ▶ “My case manager changes, I’ve had so many I’ve lost count.”

When asked about their case manager’s responsiveness, 93% of respondents reported their case manager returned their calls, text, and emails in a timely manner “All of the Time” or “Most of the Time” (Figure 8). This is a four percent (4%) reduction compared to the 2022 CES result of 97%. The clients who responded “Little of the Time” or “Never” were asked to describe how long it usually takes for their case manager to return their calls/text/emails. Clients reported that it can take 4-7 days, 1 week, 24-48 hours, or sometimes they don’t get a response at all.



On the next page, Figure 9 compares the results from the 2022 CES to the 2023 CES. Overall, in 2023 93% of clients were satisfied with the availability and amount of contact they have with their case manager. This is three percent (3%) lower than the 2022 survey result (96%).

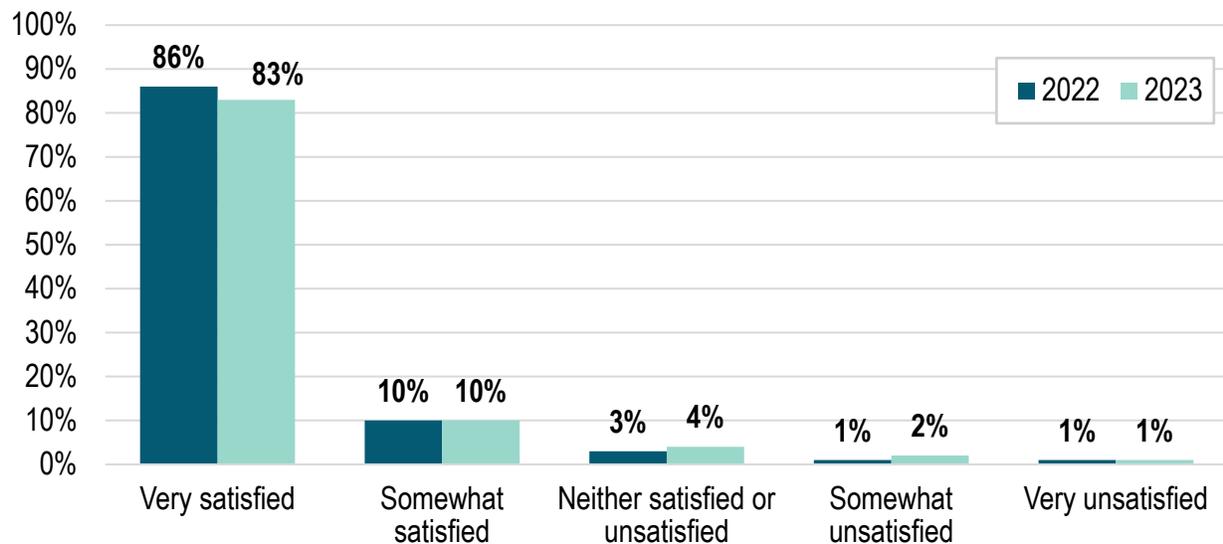


Figure 9. Overall, how satisfied are you with the availability and amount of contact that you have with your case manager?

Respondents who were “Somewhat Unsatisfied” or “Very Unsatisfied” were asked what would improve their satisfaction. The following were suggested:

- ▶ “Ridiculous to take two days sometimes longer before they get back with you. They should get back to you within 24 hours maximum”
- ▶ “I am usually contacted once a year to do annual, but I do attend monthly meetings for support group”
- ▶ “For her to be available”
- ▶ “To get a response back in a day to help decrease my stress level”
- ▶ “Would like answers to my questions provided promptly and knowledgeable”
- ▶ “Answering the phone”

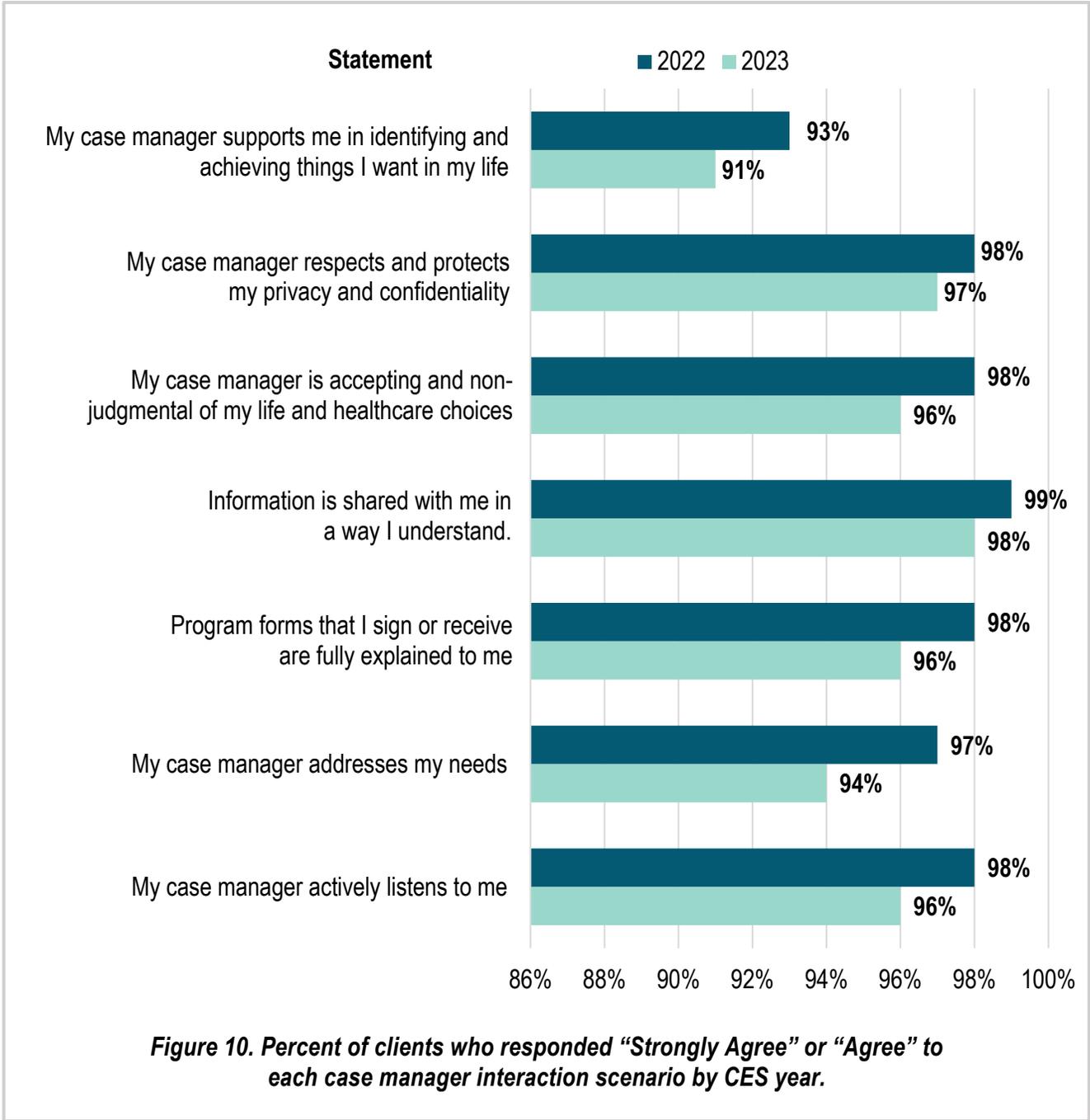
At the end of the Case Manager Availability section, clients were offered an opportunity to provide additional comments on the availability of their case manager. These responses will be sent to each agency privately. A sample of the additional comments are:

- ▶ “I have absolutely no complaints. She has been great.”
- ▶ “She’s wonderful. She’s very punctual. She reaches out to me most of the time. She checks on me.”
- ▶ “She means so much to me. She has helped me out so much. She’s really good at answering my questions. She’s fantastic.”
- ▶ “[REDACTED] is a delight to work with and advocates for me in every aspect of my life. She’s always available and listens to everything I say. I feel like she personally cares about my well-being.”

CASE MANAGER INTERACTIONS

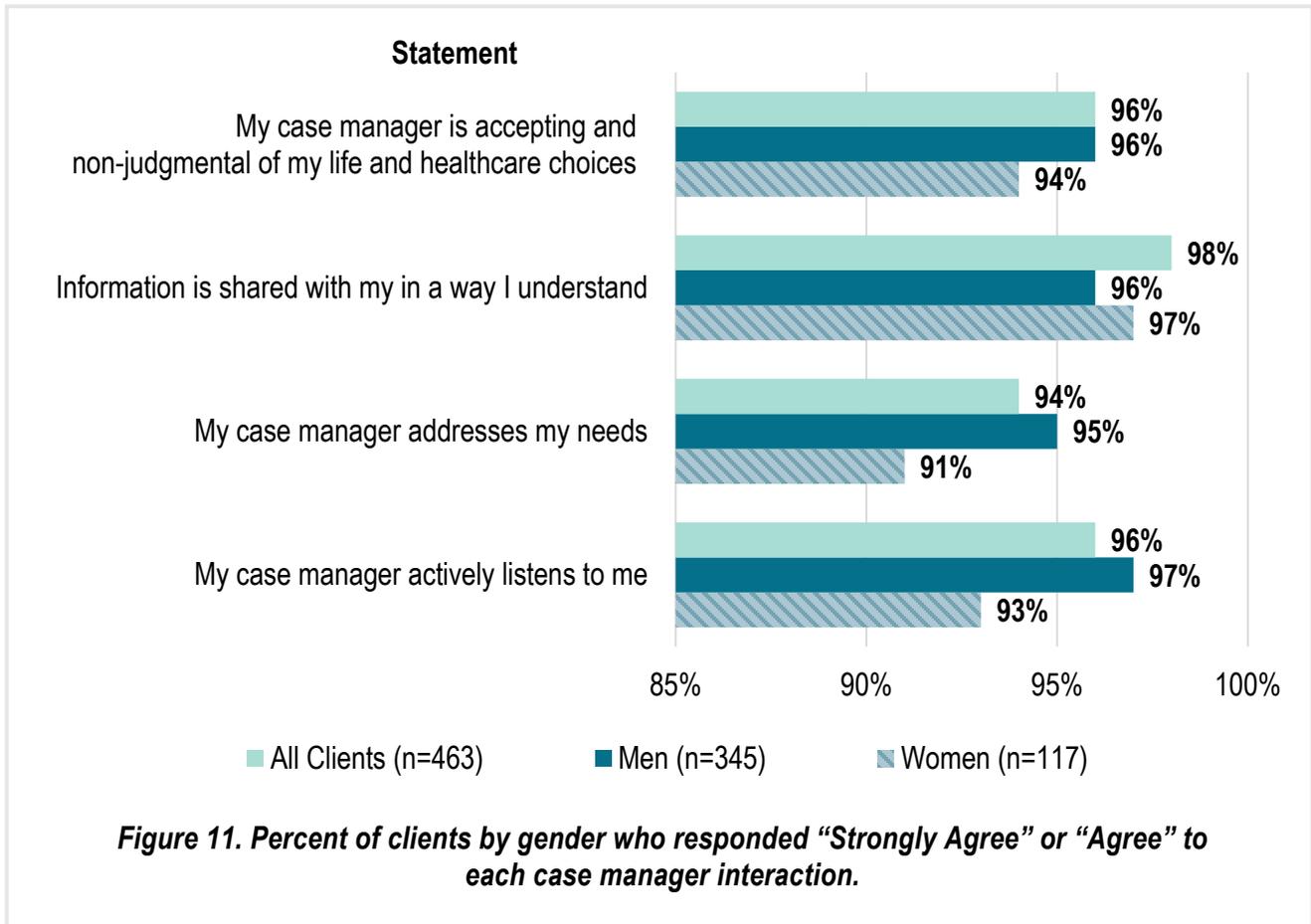
This section asked questions about interactions respondents had with their case manager over the past 12 months. Figure 10 presents the 2023 CES results in comparison to the 2022 results.

Clients responded overwhelmingly positive to the case manager interaction scenarios presented in the survey. Of note, the 2022 CES results ranged from 93%–99% while the 2023 CES results range from 91%–98%. The largest decrease can be seen in the scenario “My case manager addresses my needs,” which decreased by three percentage points.



There were some disparities when looking at positive experiences by gender (Figure 11). Women were less likely to experience the following case manager interactions:

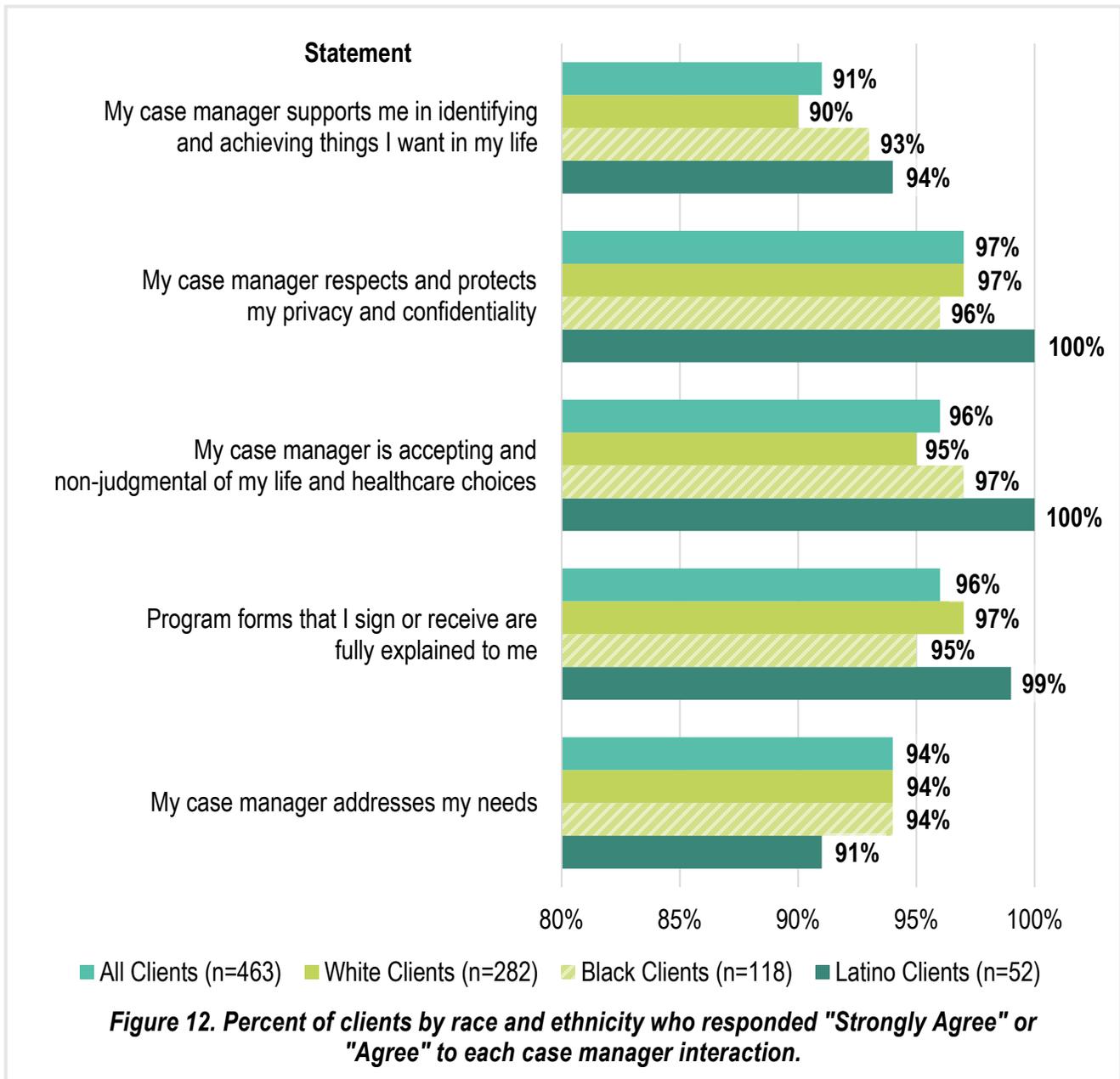
- ▶ My case manager is accepting and non-judgmental of my life and healthcare choices (94% of women vs. 96% of all clients).
- ▶ My case manager addresses my needs (91% of women vs. 94% of all clients).
- ▶ My case manager actively listens to me (93% of women vs. 96% of all clients).



Continued, next page.

Lastly, there were some disparities found when evaluating by race and ethnicity (Figure 12). Latino clients were more likely to experience the following case manager interactions:

- ▶ My case manager supports me in identifying and achieving things I want in my life (94% of Latino vs. 91% of all clients)
- ▶ My case manager respects and protects my privacy and confidentiality (100% of Latino vs. 97% of all clients)
- ▶ My case manager is accepting and non-judgmental of my life and healthcare choices (100% of Latino vs. 96% of all clients)
- ▶ Program forms that I sign or receive are fully explained to me (99% of Latino vs. 96% of all clients)



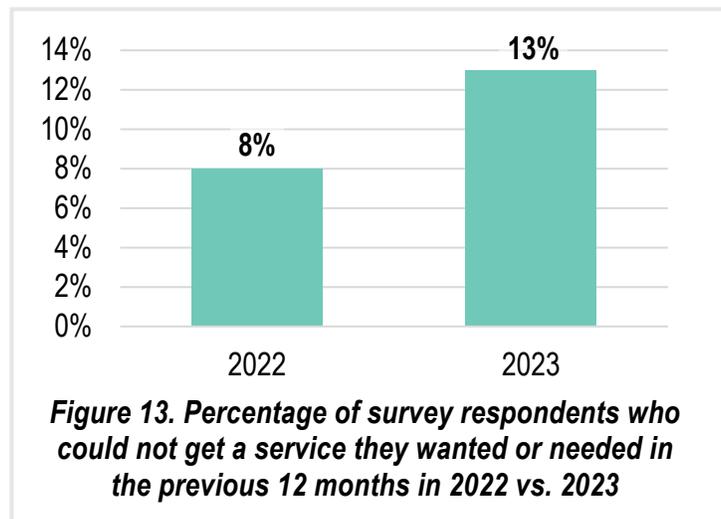
At the end of this section clients were offered an opportunity to provide additional comments on the interactions they've had with their case manager. The responses will be sent to each agency privately. A sample of the additional comments can be found below.

- ▶ “Every interaction I’ve had has been respectful and helpful and I feel like I can rely on every case manager I’ve had.”
- ▶ “She’s very friendly and interactive. She doesn’t just visit about anything she talks about business and explains things very well.”
- ▶ “Professional and personal allowing me to speak freely and without judgement.”
- ▶ “I can be myself with her. I always feel supported and I trust her.”

AVAILABILITY AND QUALITY OF SERVICES

This section asked questions about the availability of services, types of available services and the quality of services clients received.

Figure 13, at right, compares the percentage of CES respondents in 2022 and 2023 who could not get a service they wanted or needed in the previous 12 months. Notably, this number increased by five percent (5%) between surveys, from eight percent (8%) in 2022 to thirteen percent (13%) in 2023.

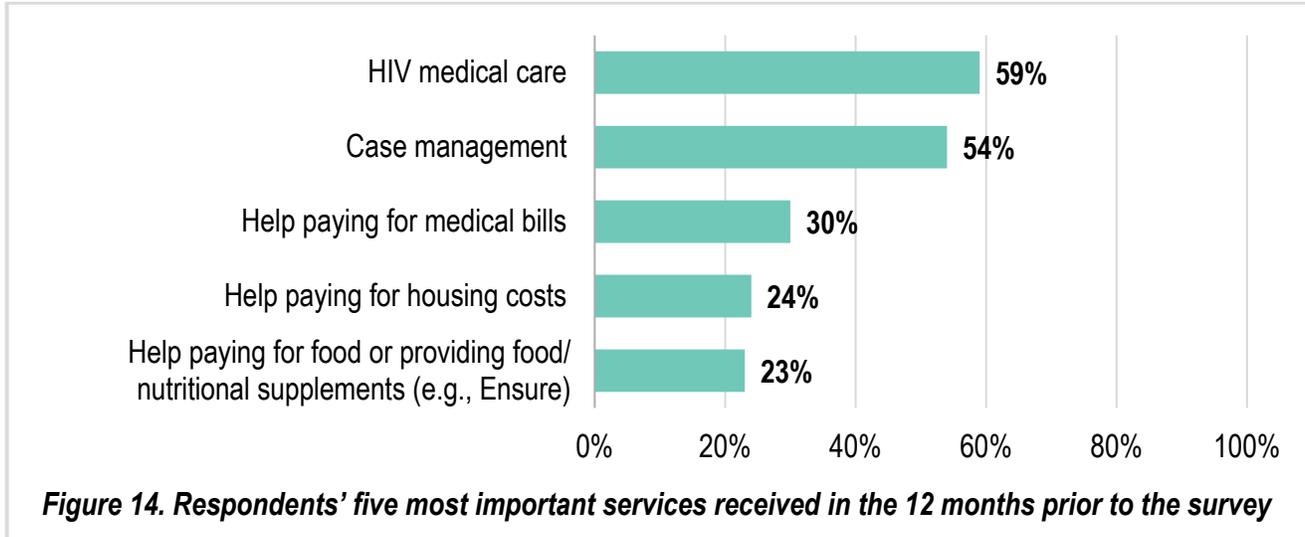


When examined by demographic group, women had the highest rate of reporting that they couldn't access a service they wanted or needed but could not access (17%), followed by respondents aged 25-44 years and Latino respondents (both at 15%). Black or African American survey participants also responded that there were services they wanted or needed but could not access at a rate slightly higher than average (14%).

The 13% of clients who weren't able to get all of the services they needed were asked to provide more information. The following summarizes their responses:

- ▶ Utilities, housing, and food, or that the help they did receive wasn't enough.
- ▶ Life insurance that is recommended for people living with HIV.
- ▶ Gym memberships, optometry, clothes, funding for school/work. (Unallowable for current funding sources to cover (i.e., Ryan White Part B)).
- ▶ Information on community events, information and resources for going back to school.
- ▶ Issues with insurance and paying certain medical bills.

Clients were asked to identify the most important services they received in the past 12 months. Figure 14, below, displays the top five services among all respondents. These results are similar to the 2022 CES results. The main difference is that in 2023, help paying for housing ranked as the fourth most-important service and food ranked as fifth—swapping places from the 2022 survey, wherein food ranked as fourth most-important and housing as fifth.



When asked about the quality of RWPB services received in the past 12 months, 95% of clients reported they were “Very High” or “High” quality. This result is very similar to the 2022 CES result of ninety-six percent (96%).

At the end of this section, clients were offered an opportunity to provide additional comments on the availability and quality of services they received. These responses will be sent to agencies privately; however, a few examples are highlighted below.

- ▶ “I’ve been with the Ryan White program for many years and the quality of care has always been excellent!!”
- ▶ “I am eternally grateful for the support.”
- ▶ “So many wonderful services that are offered.”

DISCRIMINATION AND CULTURAL HUMILITY

Clients were asked a series of questions regarding any discrimination they’ve experienced and the cultural humility skills displayed by staff at their RWPB agency.

All clients were asked questions related to experiencing discrimination or being treated unfairly. In total, 11 clients responded that they experienced discrimination at their case management agency, accounting for 2% of survey participants overall, a low percentage. Of these 11 clients, four identified as White, four identified as Black, and two identified as Latino. There was no statistical significance between race and ethnicity of the 11 clients that reported discrimination.

All clients were asked about positive experience scenarios with all staff at their RWPB case management agency. Figure 15 shows the percentage of clients by race who indicated positive experiences with RWPB staff. There is no statistical significance in percentage differences between any race or ethnicity. This could indicate that overall, agencies are doing a superior job at treating all clients fairly.

Thinking about the core aspects of my personal identity, staff at my case management agency...

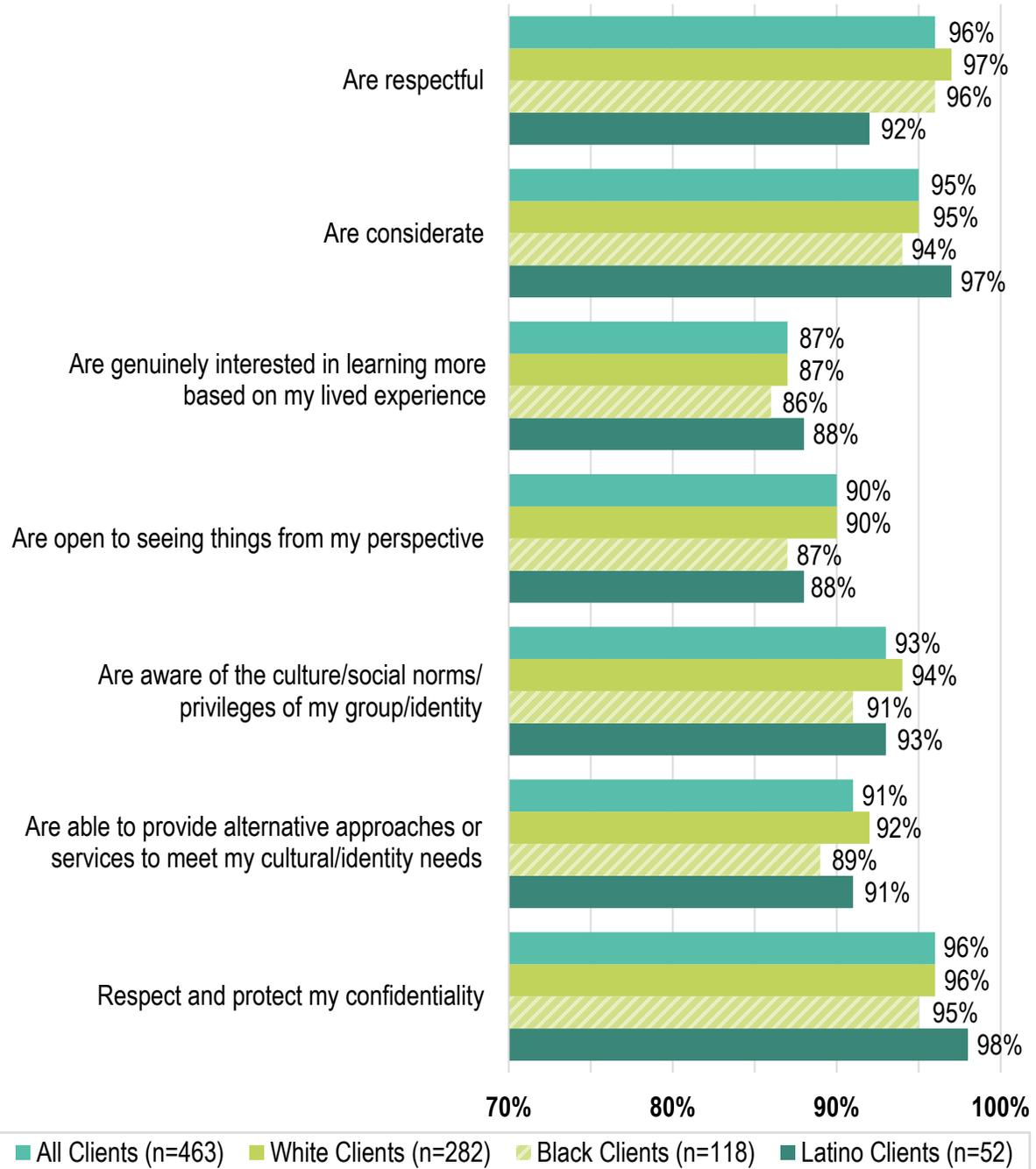


Figure 15. Positive experiences with RWPB staff by race and ethnicity. Clients that responded “Often” or “Always” were considered to have had a positive experience.

At the end of this section, clients were offered an opportunity to provide additional comments on their experiences with discrimination and cultural humility at their RWPB case management agency. These responses will be sent to each agency privately and a few examples can be seen below.

- ▶ “I’ve felt listened to and never have felt discriminated against.”
- ▶ “I’ve never seen or felt any discrimination at case management. They are always very supportive.”
- ▶ “I’ve never been discriminated against or disrespected! Love all of the staff!”
- ▶ “I always feel comfortable and safe.”

CONCLUSION

The 2023 Client Experience Survey results provided valuable feedback to the Ryan White Part B team at Iowa HHS as well as to the subrecipient agencies who serve Iowans living with HIV.

Key takeaways:

- ▶ The CES response rate increased from 17% in 2022 to 23% in 2023. The higher response rate means that the 2023 CES provided a more accurate representation of the experiences of Iowa’s Ryan White Part B clients.
- ▶ While Iowa continues to see high satisfaction rates overall, satisfaction rates in some areas decreased from the 2022 CES to the 2023 CES.
 - Several subrecipient agencies struggled with high staff turnover in 2023; this may be a factor in the drop in respondent satisfaction.
- ▶ The percentage of clients that wanted or needed a service that they didn’t receive increased from 8% in 2022 to 13% in 2023.
 - Many clients indicated that they needed help with food and/or housing, services that Ryan White currently provides. It’s unclear if the respondents never have received the assistance or if the assistance is insufficient due to rising inflation or programmatic caps.

Next steps will include reviewing the results with a wide variety of stakeholders (e.g., staff at Iowa HHS, all RWPB subrecipients, HIV and Hepatitis Community Planning Group, Positive Iowans Taking Charge (PITCH) etc.). In addition, the results will be analyzed in tandem with the results of the 2024 HIV Care Needs Assessment. Many activities are currently either underway or being planned as part of Iowa’s Comprehensive Integrated Plan (2022-2026)/Stop HIV Iowa Plan that will maintain the strong system of care and support as well as seek to address disparities.