

Central Florida HIV
PLANNING
COUNCIL

SERVING

Orange | Osceola | Seminole | Lake | Brevard Counties

Client Needs Survey

Results from 2022-2023 HIV Care Needs Survey





Objectives

- **Describe the Consumer Needs Survey**
- **Review Respondent Characteristics**
- **Identify Most Important Services**
- **Review Top Inaccessible Services**
- **Review Top Barriers**



Technical Notes



- This presentation was created using the data acquired in the HIV Care Needs survey from 2022-2023.
- Provider agencies were asked to reach a target response goal of 10% of clients served.
- The Florida Comprehensive Planning Network (FCPN) elected to extend the survey deadline to March 31, 2023.
 - The last response that the OSA received was August 8, 2023.



Technical Notes

- **The HIV Care Needs Survey was available both online and via paper**
- **Copies of the survey were provided in English, Spanish, and Haitian Creole**
- **How the survey was distributed:**
 - **Ryan White HIV/AIDS Program (RWHAP) Providers**
 - **Planning Council events, meetings, and tabling opportunities**
 - **Social media and CFHPC newsletter**



What is the HIV Care Needs Survey?

- **Developed by the Florida Department of Health HIV/AIDS Section**
 - The CFHPC reviewed a draft of the survey and provided suggestions for improvement.
- **Gauges the needs of PWH**
- **Assessed every 3 years**

Note: the survey is not limited to RWHAP clients, all PWH are encouraged to complete the survey



Responses



Total Responses: 551



Data as of: September 19, 2023

Submit

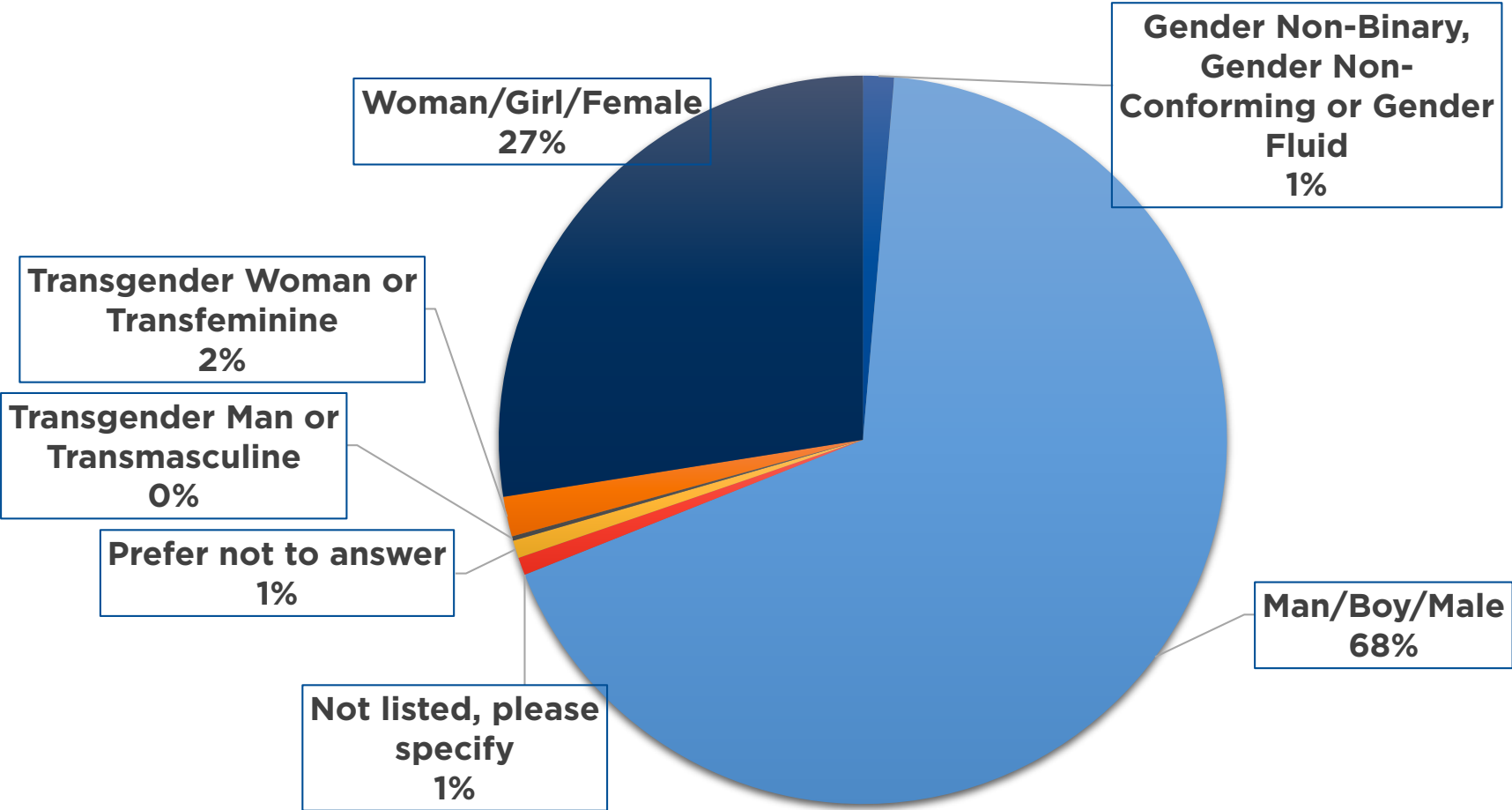


Characteristics of Respondents



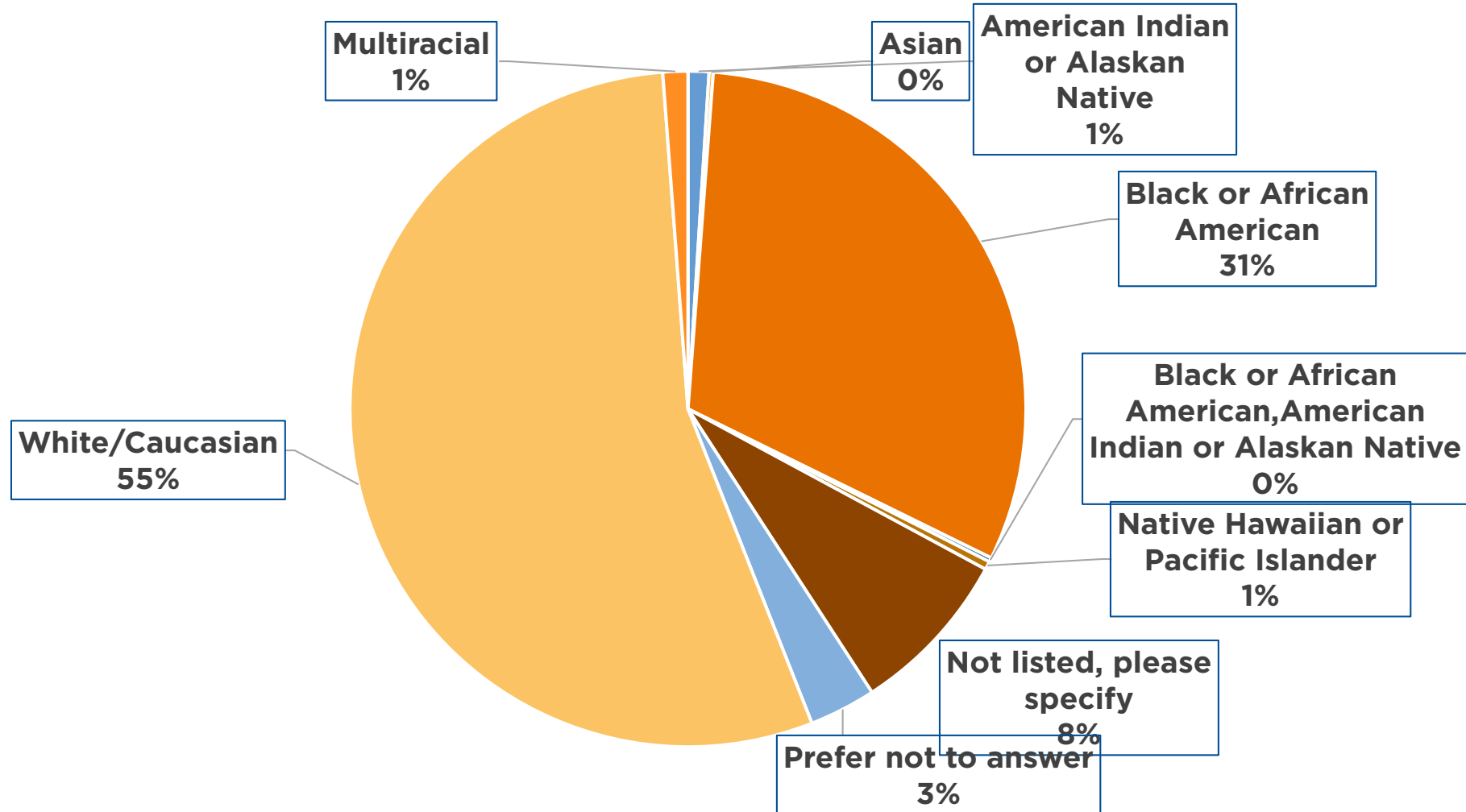
Gender

n=509



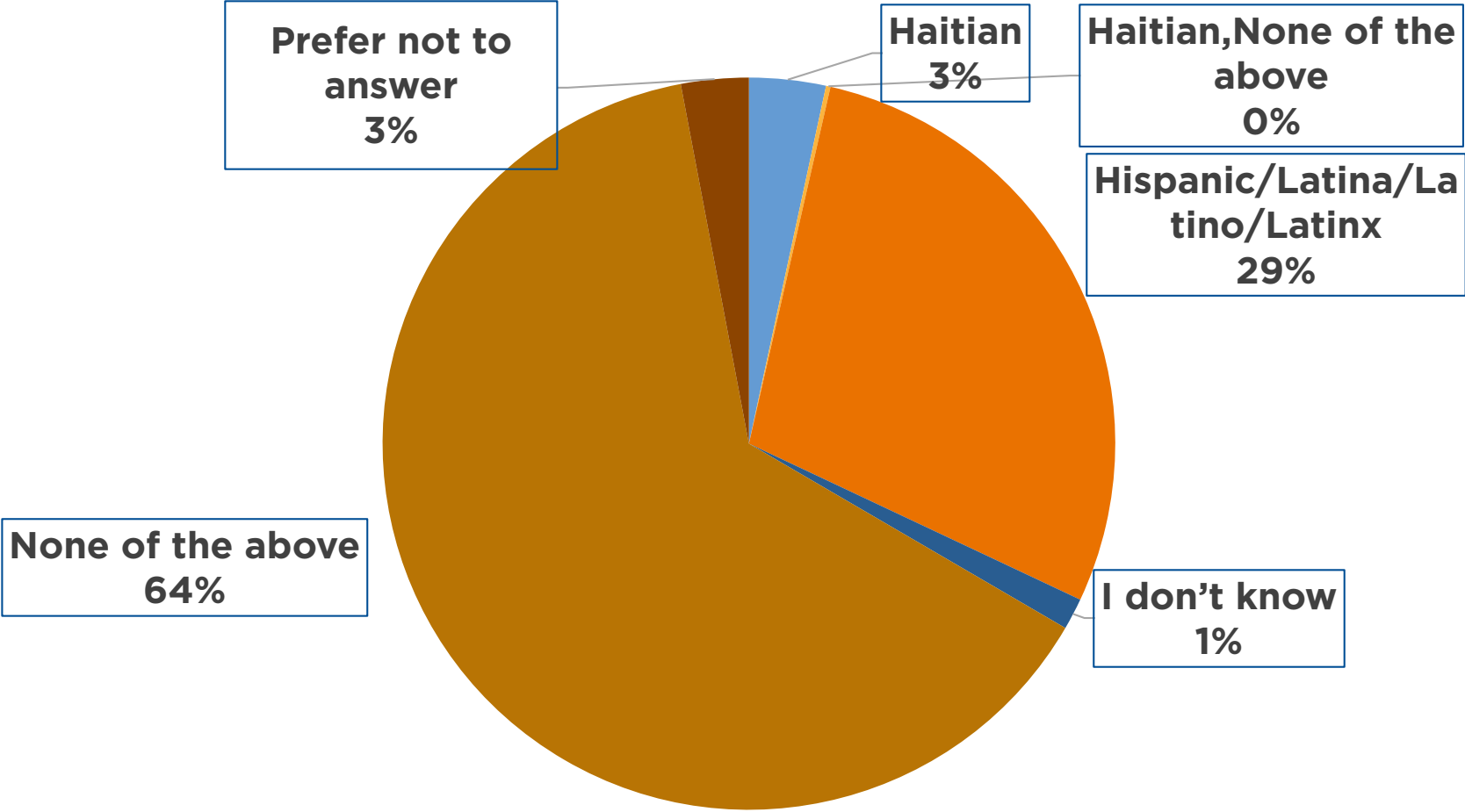
Race

n=502



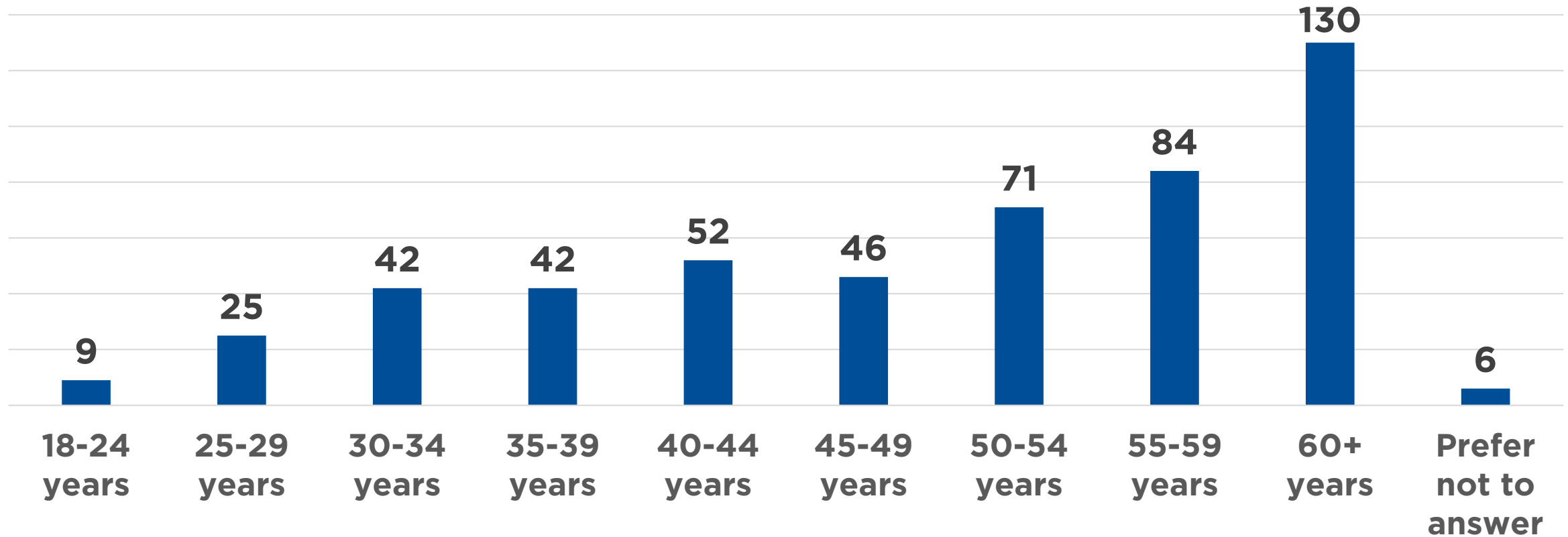
Ethnicity

n=503



Age

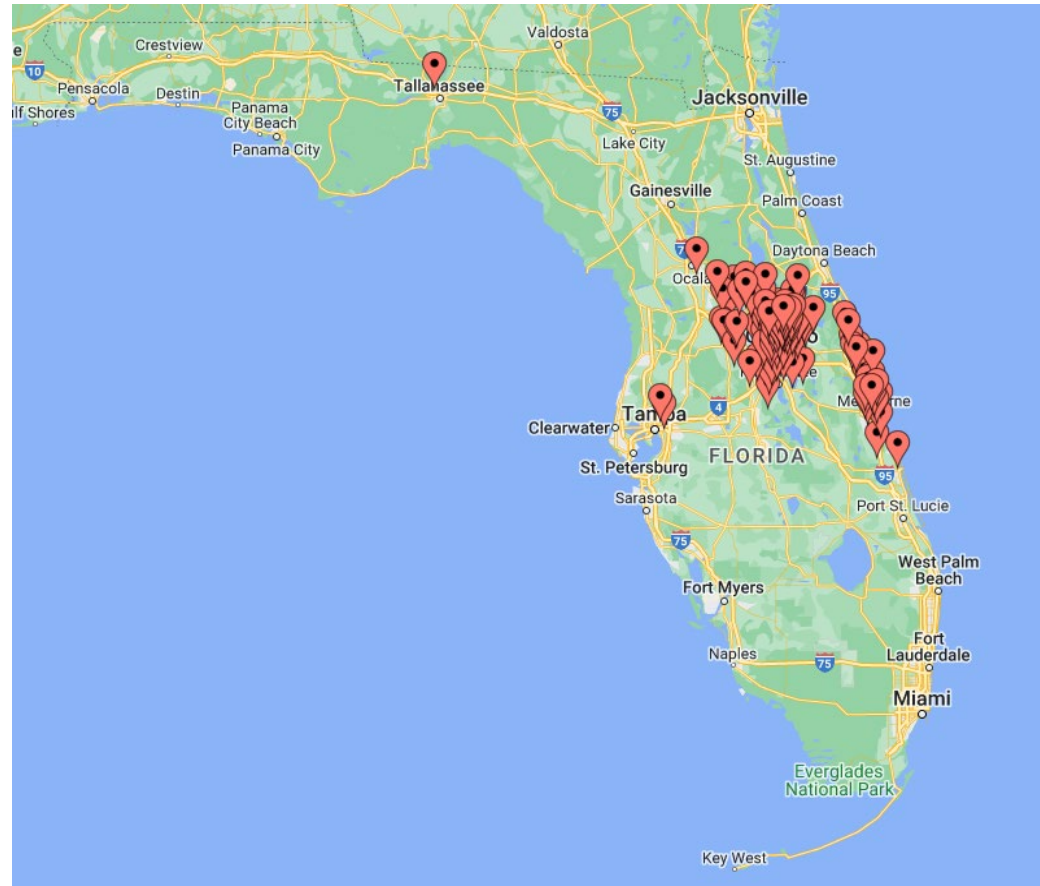
n=507



By Zip Code

n=491

Top 5 zip codes reported were 32839, 32808, 32806, 32811, 32792

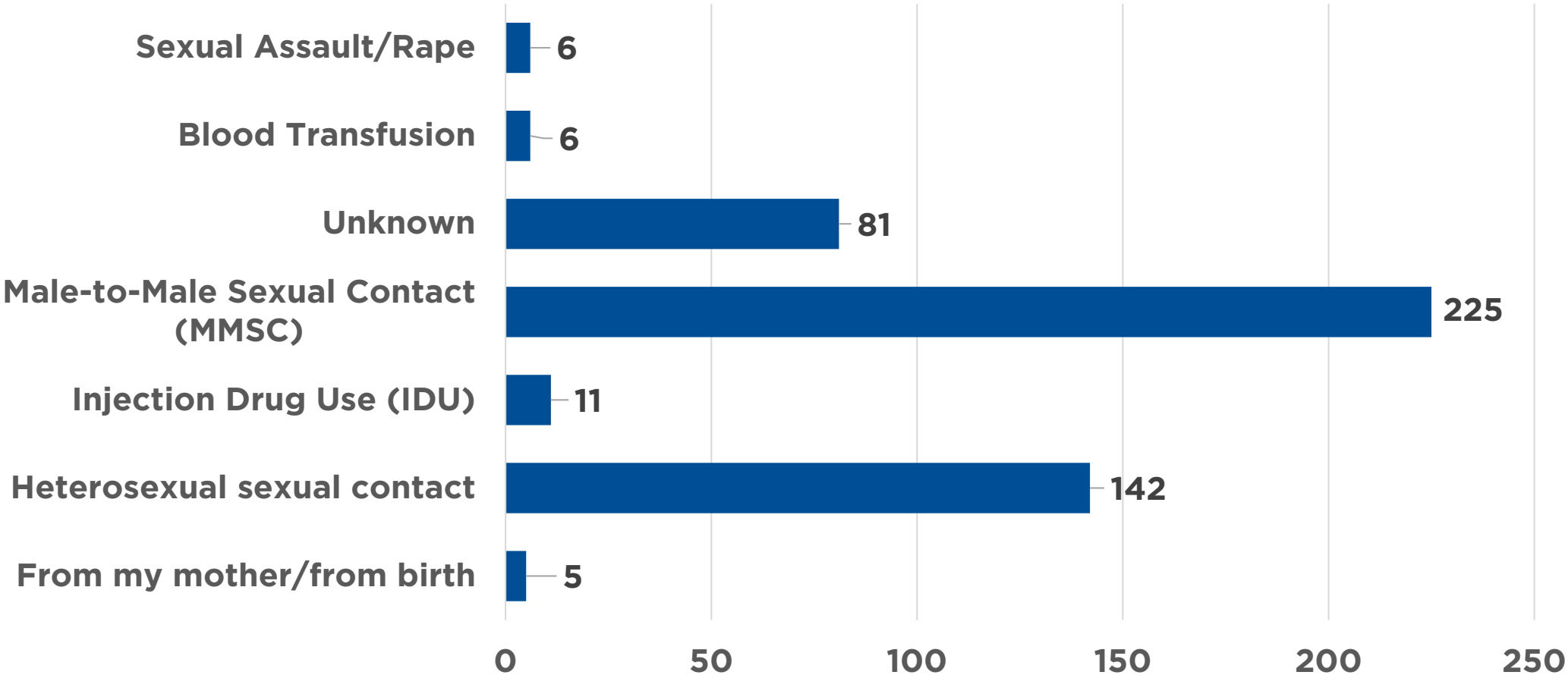


Zip Code Map



Mode of Exposure

n=498



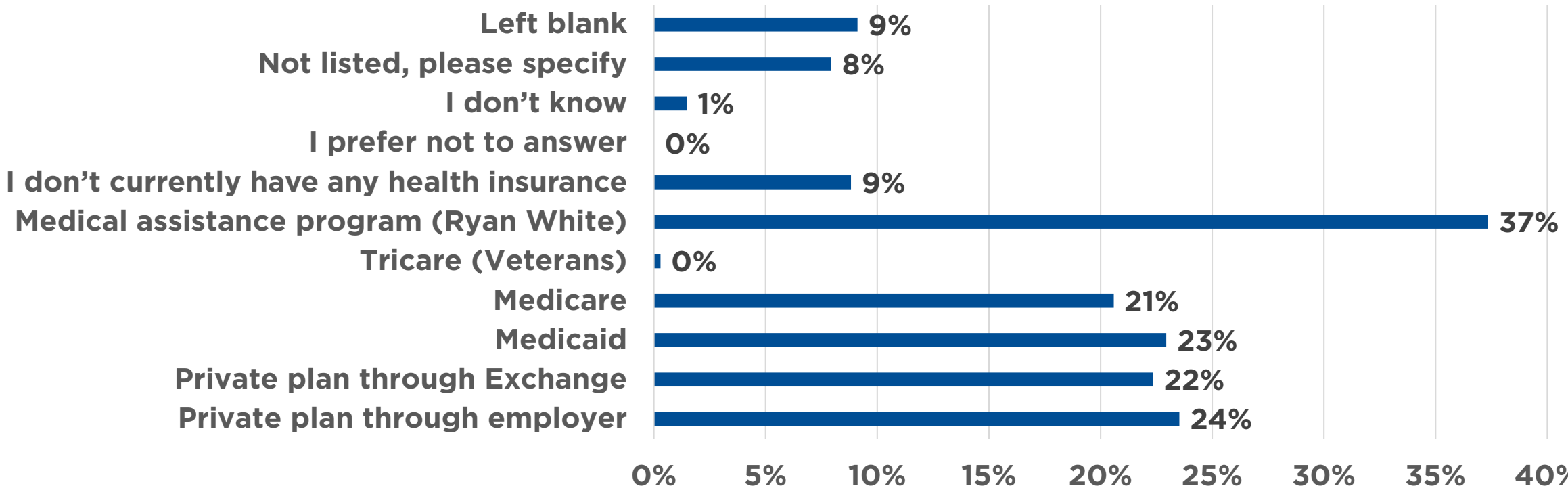
Mode of Exposure: Other Responses

- A female friend
- Abusive boyfriend
- Accident exposure
- An unfaithful spouse I was a victim unfortunately
- Biohazard blood cleanup in prison confinement
- Blood from fight/bite (2)
- Dirty needle stick from a patient
- Ex-wife
- Friend
- From my ex-partner
- From my guy friend
- From my husband
- MMSC and IDU
- Oral sex with man
- Sex or drugs



Health Insurance or Health Care Coverage

n= 499

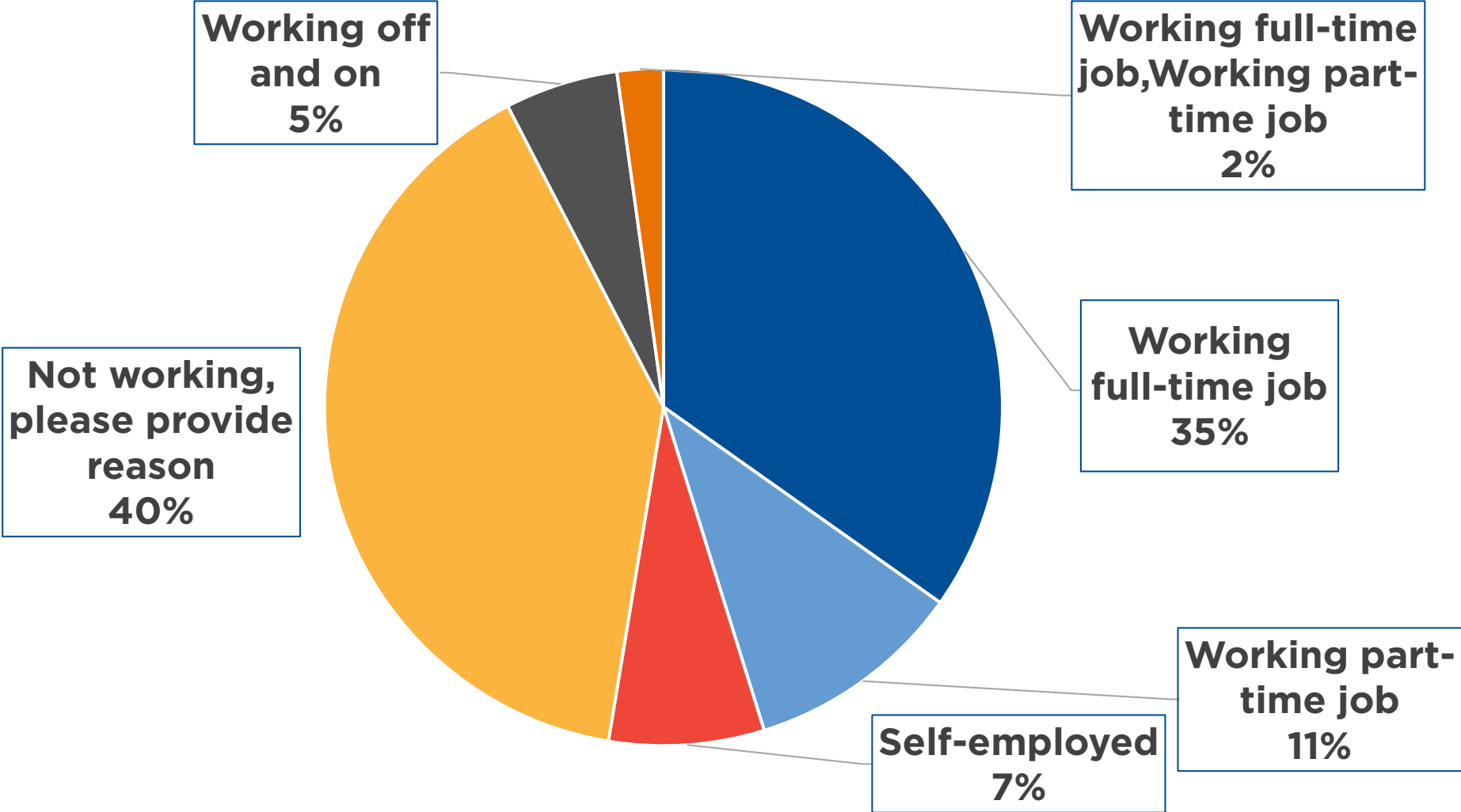


Some other health care plan includes:
Florida Blue, ADAP, Osceola, United Health, Disability



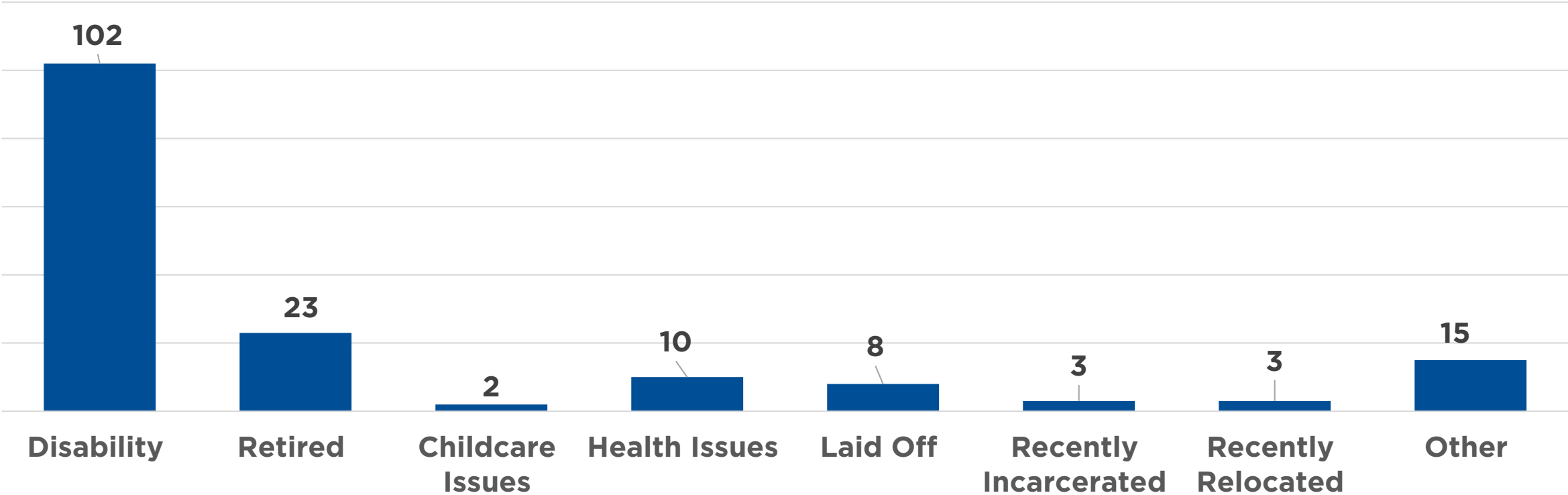
Employment Status

n=500



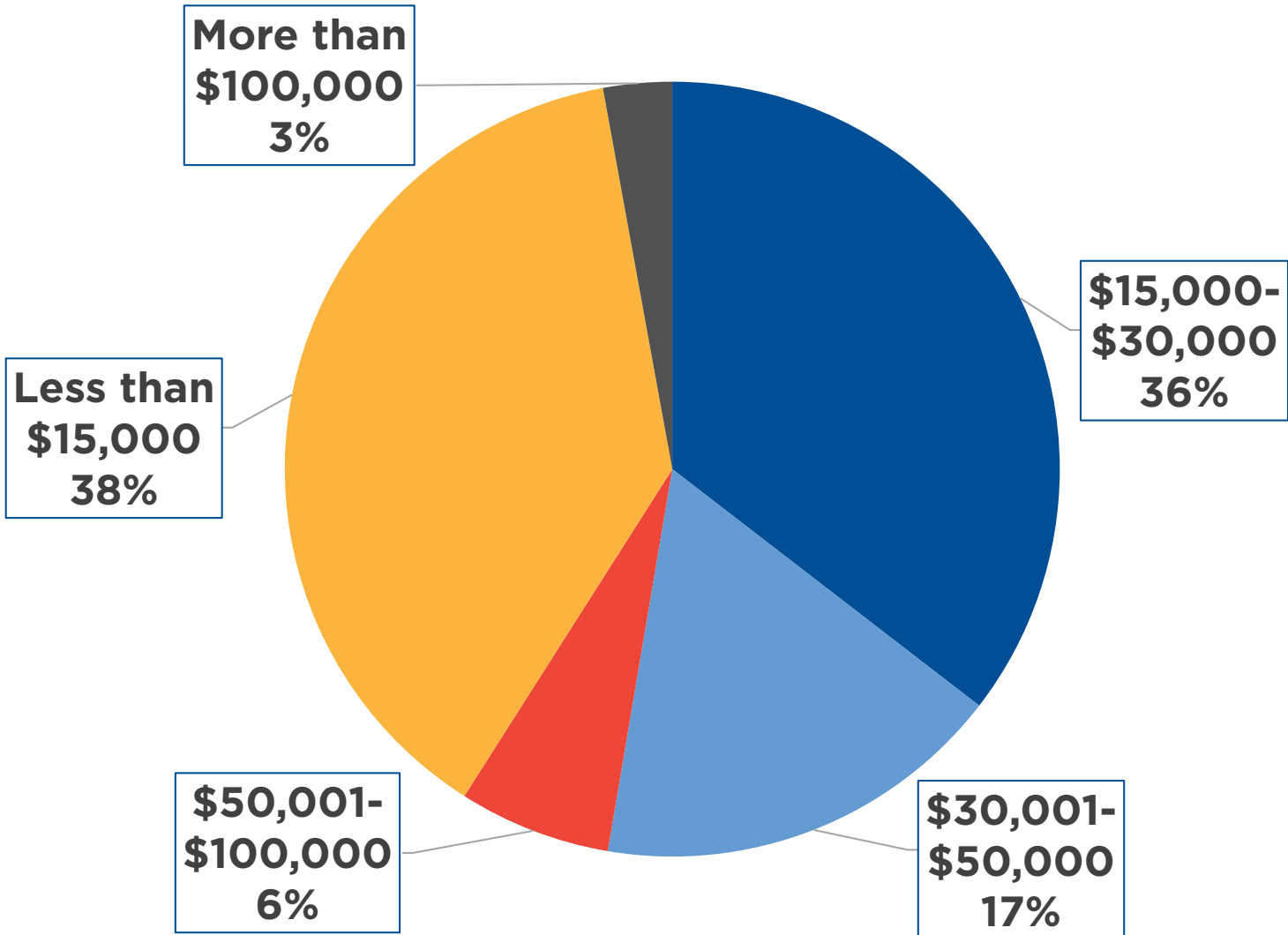
Employment: If not working, why?

n=166



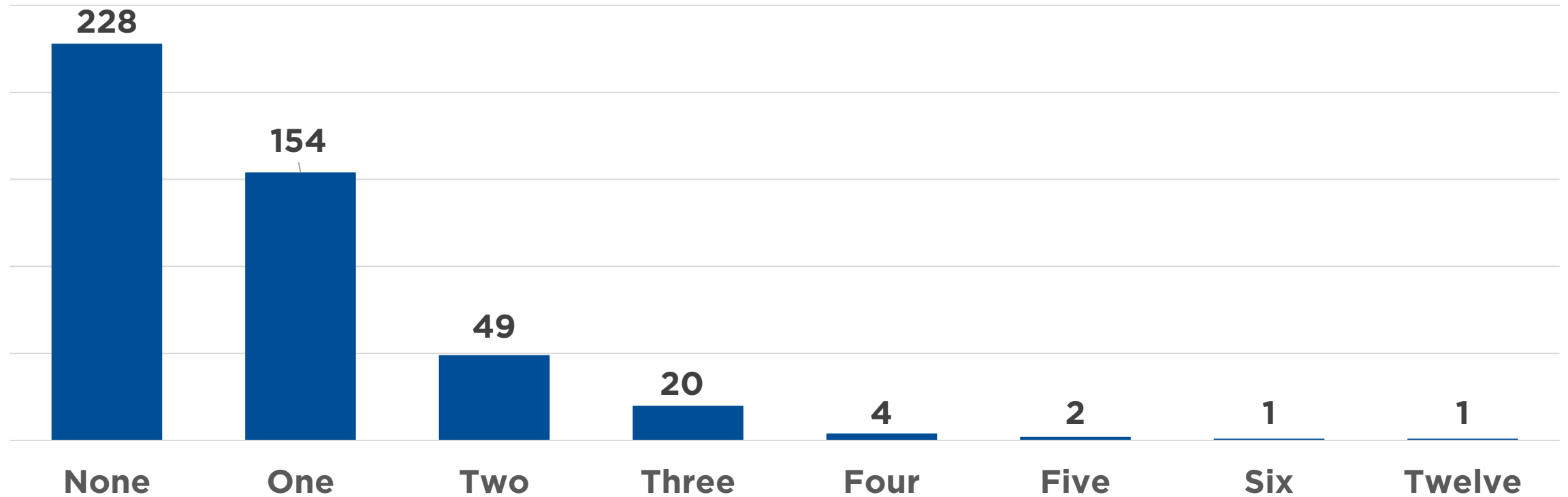
Household Income

n=488



Number of Dependents

n=459



Incarceration

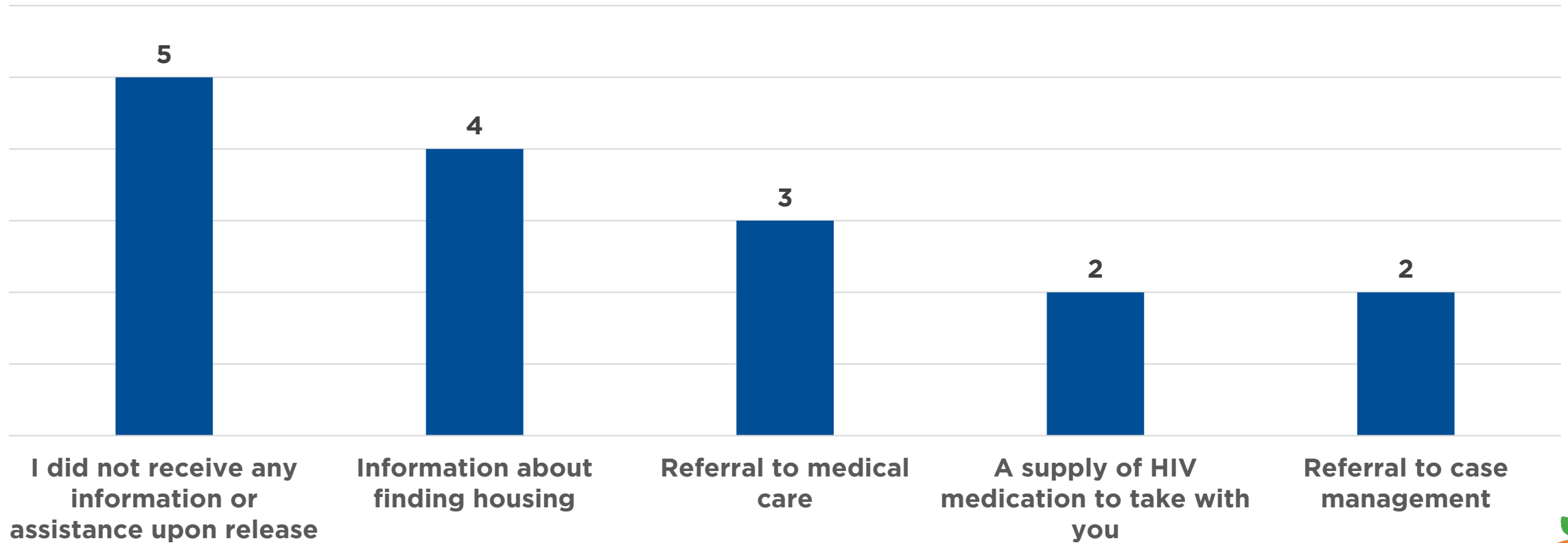
Question	Number of Respondents	Yes	No
Incarcerated during the past twelve months?	455	3%	97%
Did jail/prison staff know you had HIV?	13	77%	23%
Did you receive HIV-related medical care while incarcerated?	13	54%	46%

Reasons care was not received:

- Denied service (1)
- Was diagnosed after release (1)
- Was not offered services (1)
- Was not offered and was not available (1)



When you were released from jail/prison, which of the following did you receive? n=12



Incarceration, continued

n=12

- Reasons preventing formerly incarcerated PWH from taking care of their health:
 - Lack of money to pay rent
 - Lack of stable housing
 - Lack of a bed to sleep in
 - Not enough food to eat

42% of respondents are not currently experiencing any barriers to taking care of their health



Frequency of Care



Frequency of Medical Care

n=486

49%

- Received medical care at least three times in the past year

34%

- Received medical care at least twice in the past year

8%

- Received medical care once in the past 12 months

9%

- Did not receive medical care in the past 12 months



Reasons for receiving care less than 2 times per year

n=61

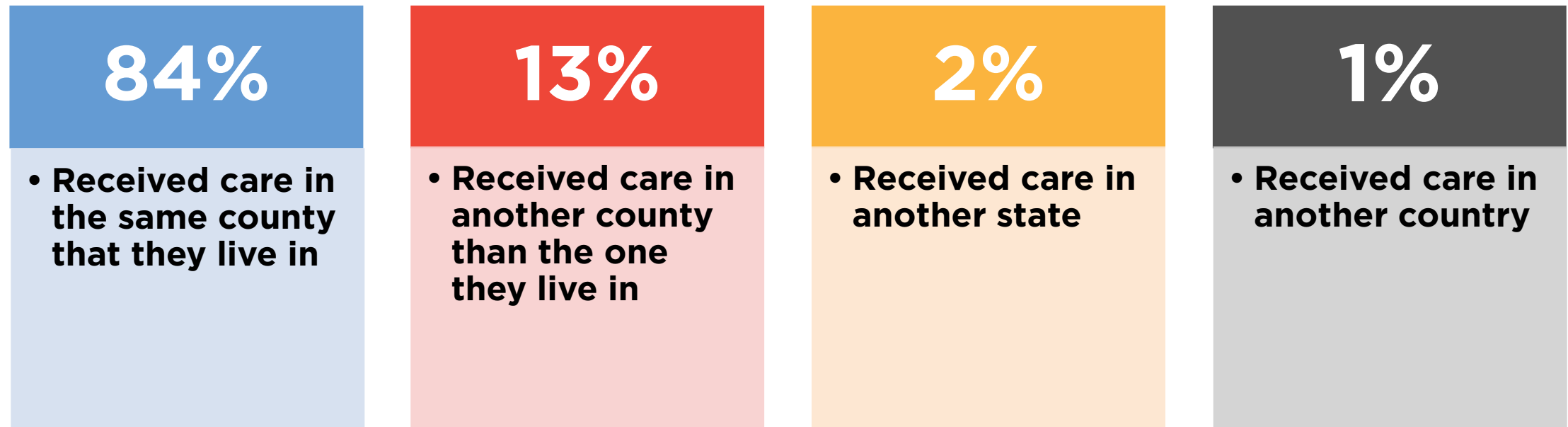
Reason	%
Not listed, please specify and Other	34%
Provider decision	15%
I did not feel sick	13%
I could not get transportation there	7%
I did not know where to go	7%
I did not want people to know I have HIV	3%
I was not ready to deal with having HIV	5%
There are not enough doctors in my area	5%
I was depressed	7%
I missed my appointment(s)	3%
I was too busy taking care of a family member/partner	3%
I could not get time off work	5%

Specified reasons include: COVID-19, Fear of bloodwork, Worried about getting my next fix, I didn't know I had HIV, New diagnosis, No Response, Relocated, Recently diagnosed



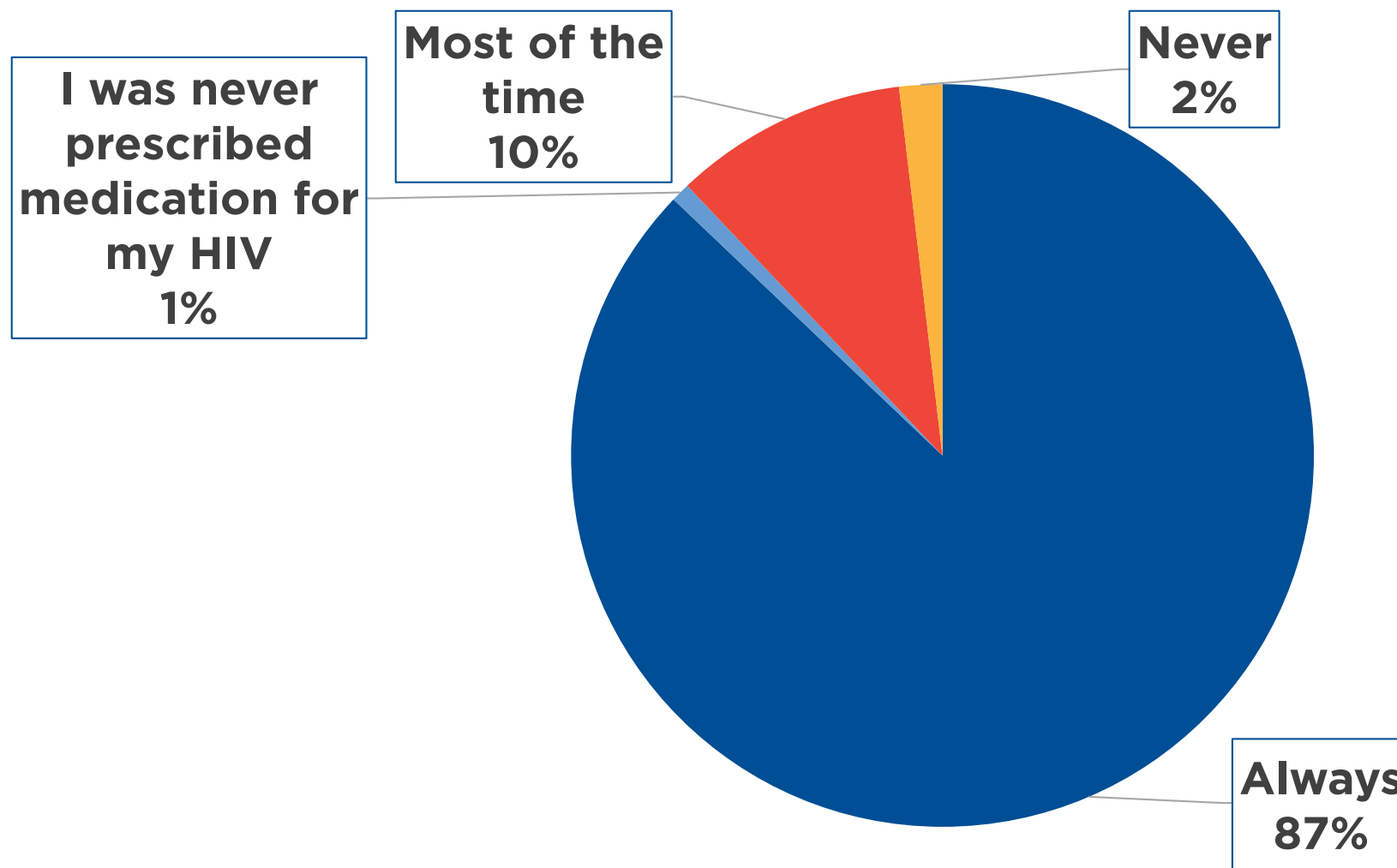
Care Site/County of Residence

n=459



How often do you take your HIV medications?

n=481



Reasons for missing HIV medications

n=53



Reasons for missing HIV medications: Other

- Incarcerated and out of state
- Not available in care
- Depression
- Delivery
- I have to get labs for more meds
- Missed my appointment
- Never had meds
- New diagnosis
- Sometimes ran out
- Trying to be normal



Services



Top 5 Services Most Often Received

	All Respondents
HIV Medication	91%
HIV Medical Care	89%
Case Management	82%
Oral health	62%
Non-Medical Case Management (Eligibility)	50%



Least Needed Services – All Respondents

Hospice Care	89%
Substance Use treatment - Residential	89%
Interpretation and translation services	86%
Home health care	85%
Psychosocial support (Group or individual support and counseling by PWH, including bereavement and pastoral counseling)	83%
Counseling for substance use/misuse	83%
Outreach to find people with HIV not in care and help them to visit their doctor and get services	80%
Physical therapy, occupational therapy, speech therapy, low vision training, etc.	79%
Legal services to help with HIV-related legal issues (will, living will, SSDI, etc.)	78%



Top Inaccessible Services – All Respondents

Oral Health	17%
Food Assistance/Nutritional Supplements	16%
Transitional, short-term or emergency housing assistance to prevent homelessness	13%
Mental Health Counseling	12%
Legal Services	11%



Top 5 Most Important Services n=451

1. Case Management
2. Medications
3. Health Insurance
4. Dental/Oral Health
5. Housing



Top 5 Most Important Services were the same for the EIIHA Populations



Knowledge of PrEP

	Number of Responses	No	Yes	Does Not Apply
Are you aware of HIV prevention medications (i.e., PrEP)?	448	10%	90%	
If you were diagnosed with HIV after 2011, were you taking Truvada® or Descovy® for PrEP at the time of diagnoses?	452	41%	12%	47%



HIV-Related Stigma/Attitudes

“In many areas of my life, no one knows I have HIV.”

- 35% of PWH strongly disagreed or disagreed with this statement.
 - 65% of PWH strongly agreed or agreed with this statement.

“People’s attitudes about HIV make me feel worse about myself.”

- 59% of PWH strongly disagreed or disagreed with this statement.
 - 41% of PWH strongly agreed or agreed with this statement.



Comments



Positive Comments

- **All good.**
- **Every question I've had, I've asked. Thanks so much.**
- **I am glad that in the healthcare sector, physicians are more "comfortable" dealing with patients.**
- **I am happy to say that I am blessed living with HIV so many years.**
- **I am very grateful for the kindness and attention shown.**
- **I am very happy with myself cause this medication is working for me and I'm so happy thank you so much and I'm not scared for anyone to know that I'm HIV. I'm blessed God bless you all.**
- **I feel very fortunate to have the best possible doctor and access to the best medication. Due to my 30+ years of living with HIV/AIDS I am disabled and live on social security. I am thankful that I can occasionally access assistance as a low income person.**
- **I have been diagnosed now for 35 years. i am so glad all these wonderful tools, like places such as Hope & Help are now available for people that need them. When I started I was told, that day, I had 6 months to live but fortunately for me I am an RN and could find education and treatment options even back then. And have gone from vomiting almost every day for years on AZT. To now a beautiful 1 pill a day.. My t-cells have always been good > 400. so please keep these places going. ... we need them**



Positive Comments

- **I thank God everyday for people like you all that are there to help.**
- **It's a difficult life to live and turns your entire universe upside down. The financial and medical support does make it more feasible to get by in an already complicated situation.**
- **I've been learning how to deal with having HIV, its hard because some people are out here to judge you. But I continue to do what I need to do to live my life and not care about what others think.**
- **Ryan white and the services they provide for are why I am able to remain healthy without these services, I believe I would not be alive today. I am so grateful!**
- **Thank you for all you do for so many.**
- **Thank you for all you do!**
- **Thank you for doing this. It's not for us if it doesn't include us.**
- **Undetected. Yay. Thanks**
- **What you are doing is already wonderful! Thank you!**
- **With medical attention, I feel happy and I know that by taking care of myself, I'll live many more years without having to receive an AIDS diagnosis.**
- **I'm ok with my own skin I grew to love me & I can actually say I'm stronger then ever!**
- **I was diagnosed in 1998. I have been coming here since 98. I think the services have become better and more streamlined over time.**



Other Comments

- **I have been HIV positive for over 30 years. And hope and help has been with me the entire time. At times it's embarrassing to still be going to them. But I have no choice because I do not have insurance. My prior employer did not offer insurance. And now I'm a self-employed artist and still do not make enough money to purchase my own insurance.**
- **I have been one of the lucky ones. I have watched multiple friends die since I was diagnosed in 1992. This July will mark 30 years that I have been living with this disease. I wished I was able to share my status with others but my last job I was not allowed to come back after the pandemic. I know that this was due to my HIV status. My upper management made comments “ you just need to take care of your health” I never received a bad review in my close to 12 years working for Landry's. This was a move to stop having to pay for my insurance.**
- **I have diagnosed + for HIV going on 37 years. I have never been diagnosed with AIDS or ARC for over 30 years my CD4 count has been anywhere from 700-1100. My viral load is always undetectable. What would happen if I stop taking HIV medication?**
- **More information on Medication to stay Healthy**
- **My confidentiality!**
- **Need eyes checked**
- **There needs to be more services for the aging HIV population. Seriously.**
- **Hard to get help we need. Case managers are overwhelmed. Lots of loopholes. We just want medicine to live. Healthcare and support services**
- **I wish there was help with vision care**
- **HIV support groups are very helpful.**



Other Comments

- **No thank you**
- **Normal**
- **People are still confused regarding REAL knowledge of HIV (contracting and living with same). This includes those actually diagnosed with HIV. Improper knowledge of HIV leads to FEAR. Correct knowledge and understanding leads to better management of the all person's involved.**
- **Relieve the stigma that HIV makes you "DIRTY". HIV and AIDS are NOT interchangeable terms**
- **To find a cure.**
- **recommendations for longevity**
- **Care at VA except dental**
- **Many services unobtainable due to agency staff mismanagement and unwillingness to help**
- **The facilities that provide healthcare need to be more attentive to patient privacy. Crowded waiting rooms and staff turnover creates a concern with privacy.**
- **I think help with housing is important for someone living with hiv to have that stability where he or she can take care and do all the things needed to be healthy with hiv. Employers still have questioners asking if you have hiv listed u set disabilities... so I think we get discriminated against and it's hard to maintain good jobs where we can pay rent. That's why I think a better housing assistance plan should be in affect with less strict criteria and with case workers that actually want to help you and are understanding of your needs and no judging you for needing help.**



Other Comments

- **Facilities that offer healthcare should be more discreet with patients and information**
- **Rent is very high and assistance definitely welcome. Cost of food is getting very expensive. Physical activity assistance is needed with gym. Need an advocate to help with meal preps. Healthy lifestyle advocate.**
- **Just difficult to get scheduled to see a doctor or get a referral to see a doctor.**
- **Had to wait many many many months to get help from a mental health counselor after the case manager requested help. I think I had to wait 4 to 6 months.**
- **I think a lot of people think that HIV is done, is not a threat, or don't care. The commercials shown on TV are wonderful as they do help remind people HIV is still present and new drugs that keep it from spreading as in the past**
- **We (HIV patients) should be able to get inexpensive life insurance as people who are smokers, diabetic , etc.**
- **Have better access to housing doctors when you are 1st diagnosed**



Agency Kudos

- Excellent service provided by all at Project Response. Thank you.
- I am serviced with Project Response. They are good. They have explained and have a STD/STI center which is great for the community but I wish they offered activities for a chance to socialize with others who have HIV.
- I have been diagnosed now for 35 years. i am so glad all these wonderful tools, like places such as Hope & Help are now available for people that need them. When I started I was told, that day, I had 6 months to live but fortunately for me I am an RN and could find education and treatment options even back then.
- Pleased with staff at Comprehensive Health Care
- Thank you C.H.C
- You guys and gals nurses, dr., etc. are doing a great job and I really appreciate everything. (FDOH Orange)



Agency Kudos, Continued

- **I would like to thank Hope and Help, Ryan White and ADAP for everything that is made possible for me to continue living in a healthy matter. My case worker Norm is very helpful. The staff at Hope and Help are always caring and professional. Many blessing to the future years to come.**
- **I would no be alive today is not for Ryan White ADAP services. Diagnosed 1996.**
- **The case worker Annai Centola is a model employee and a life saver for my father.**
- **When I moved to Orlando I had the fortunate luck of getting Norm Gentry as my case manager. He is beyond excellent and don't know what I would have done or would do without him. He is a great asset to Hope and Health and for people living with HIV.**
- **I thank God for Hope and Help and staff in the office and Case Manager Norman. The staff are always pleasant to talk to on the phone and in person. Dr. Robert Rowe is an awesome doctor and takes his time and gives his concern to what ever health issue is needed. Thank you Hope and Help for being there for so many of us in need.**



Agency Kudos, continued

- **Norman Gentry with Hope and Help in Orlando is a true asset to our community. He is amazing. He is always happy and cherrie even hen I am down. He is very resourceful in that he does whatever he can do to assist his clients. Both my partner and myself have Norm. Norm is ALWAYS available and if he can't anger the phone he calls you back as soon as possible. I have no problems talking to Norm about anything. He is very receptive Ms does not judge at all. Norm has gone out f his way to help me and I truly appreciate all he has don for me all these years. Norm is truly an asset to the community upon which he serves. Thank you Norm from my heart for all that you have done for me!**
- **I love you all at comprehensive health care**

