NATIONAL HEALTH CARE for the HOMELESS COUNCIL

Consumer Perspectives on Behavioral Health and Health Equity

April 2022

Introduction

The Consumer Participation Outreach (CPO) survey is a community-based research project coordinated by National Consumer Advisory Board (NCAB) and National Health Care for the Homeless (HCH) Council staff. In CPOs, NCAB develops the survey topic and tool, trains local consumers to interview other consumers at HCH sites and compiles the results and recommendations. The CPOs aims to engage HCH clients, learn more about their concerns and needs, and provide a platform to voice their thoughts and share their experiences.

COVID-19 has had significant impact on people's well-being and mental health, with folks enduring a variety of stress responses. At the same time, support systems and service provision were disrupted, and people had to find new ways to take care of themselves and their communities. Thus, NCAB decided to focus the CPO on understanding how COVID-19 impacted people's behavioral health and access to behavioral health services, the impact of systemic racism and other discrimination on well-being, and ways to improve access to behavioral health services during the pandemic and recovery. Results of this survey should improve current practices, identify policy changes, and inform training around behavioral health and health equity for health centers.

Background

The COVID-19 pandemic has been traumatic for many, also increasing depressive and anxiety symptoms[i]. Pandemics create disruption, uncertainty, distrust, fear, loss, grief, and increased stress that have short and long-term consequences[ii]. In this pandemic, we are seeing disproportionate impacts and outcomes for marginalized or vulnerable communities, such as people experiencing homelessness[iii]. Community support, economic well-being, and social service disruptions left people without homes unable to maintain their usual methods of survival (i.e., utilizing businesses to keep away from the elements and use the restroom, accessing internet and information at public libraries, or limited health care capacity or access). In addition to facing new barriers, groups that were already marginalized faced the pandemic with fewer resources and health that was already compromised. The pandemic exposed the importance of the social determinants of health and the systemic inequities that lead to inequitable outcomes among marginalized groups[iv]. Throughout the early course of the pandemic (this data reflects January to August 2020), the death rate for African Americans was more than double all other racialized groups, and when adjusted for age, African Americans had a 9x greater risk of death from COVID-19 compared to the white

population. There has also been an increase in depressive symptoms for many Asian individuals, as people have seen or experienced increased discrimination in response to the pandemic. Pre-existing inequities such as access to health care, social determinants of health, and health disparities are likely at the root of the disproportionate impact on minority groups in the US[v].

Being able to take precautionary measures (such as frequent hand-washing and decreased contact), time to rest, good social support, and the ability to maintain a healthy diet have been shown to prevent against negative mental health outcomes[iv]. However, many of these protective factors were not available or consistently available to people experiencing homelessness. Government interventions such as financial support, housing, and access to psychiatric first aid help to improve mental health. However, these provisions and programs were not widely used or maintained throughout the pandemic[vi].

During this time of increased mental health issues, the behavioral health system was overwhelmed by the demand and many providers had to change how they provided services, including increasing or solely providing telehealth services[vii]. Some providers were able to connect clients with cell phones for telehealth appointments, yet many individuals were not able to use telehealth due to lacking phones, phone capacity for multiple calls throughout the month, or other factors.

The Survey

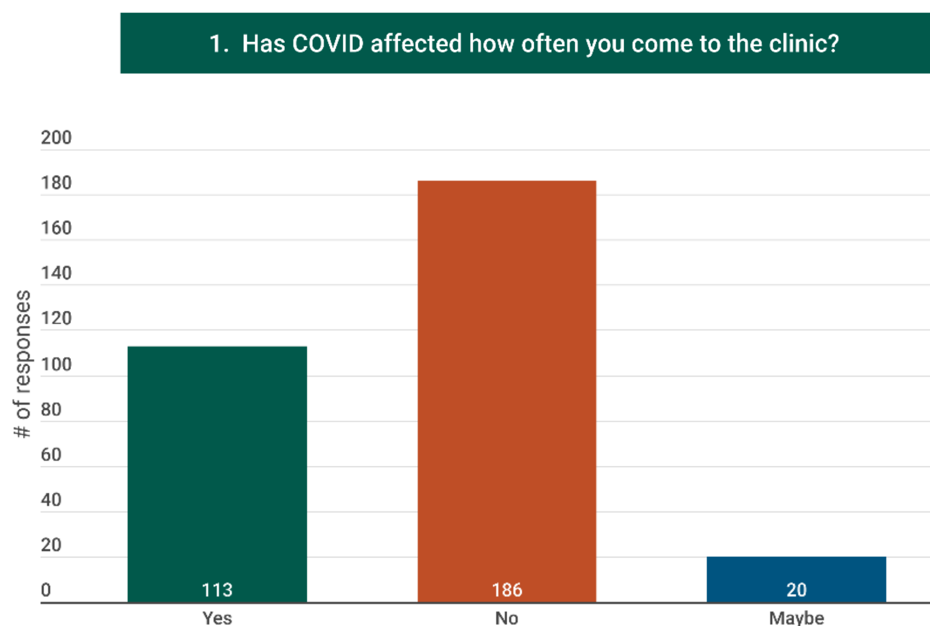
To examine the behavioral health needs and services during the pandemic, Council staff and NCAB researched the latest information about mental health, substance use, and stress in the pandemic. NCAB then worked with the Council's Implementation Research Team to create the questionnaire, which included 13 questions (Appendix A in this report). Health centers with Consumer Advisory Boards (CAB) were offered the option to participate, with three CABs signing on (many CABs had limited capacity during the pandemic to participate). NCAB members and participating consumers from the three cities received training on best practices in research, trauma-informed interviewing, and details about conducting this CPO.

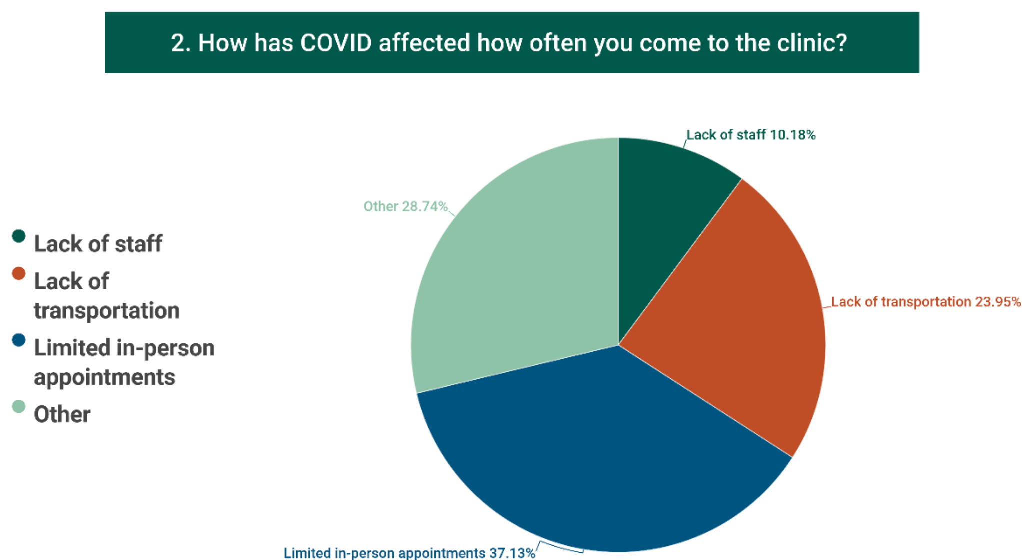
This survey was conducted amongst 323 participants between September and December 2021 in three cities: New York City, New York (105 participants); Houston, Texas (118 participants); and Louisville, Kentucky (100 participants). Most surveys were administered at HCH health centers or in the immediate vicinity of neighboring service providers. Individuals' privacy and confidentiality were guaranteed and respected. All interviewees were receiving services from an HCH program and were either currently or had previously experienced homelessness. Council staff analyzed the responses and prepared this report.

Methods: Where and when did the survey administration occur?

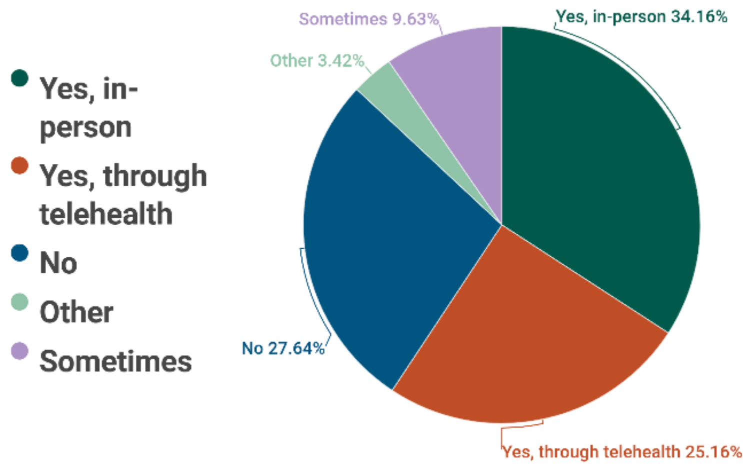
Respondents composed a convenience sample of self-reporting individuals, most of whom were still engaged in care from an HCH project. The sample likely excluded some individuals who may not have engaged with an HCH project during the pandemic due to several factors (i.e., discomfort with telehealth or leaving their shelter/hotel, conflicting information about the pandemic, increased distrust of medical system, etc.). Some respondents may have been struggling with trauma, mental illness, and stressful situations common for people experiencing homelessness that could affect their interpretations and feelings. These results are nonetheless notable, particularly for what they reveal about behavioral health and health equity during the COVID-19 pandemic.

Behavioral Health and Services During COVID-19

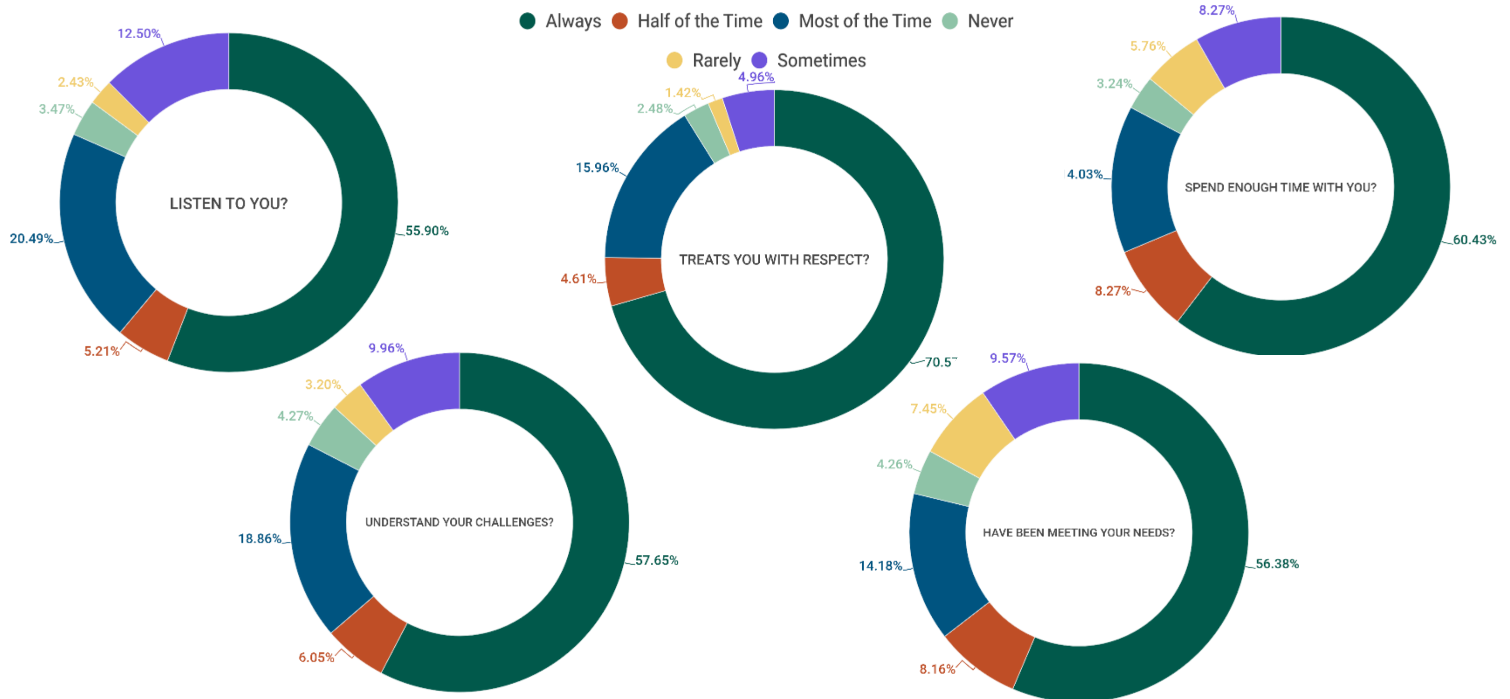




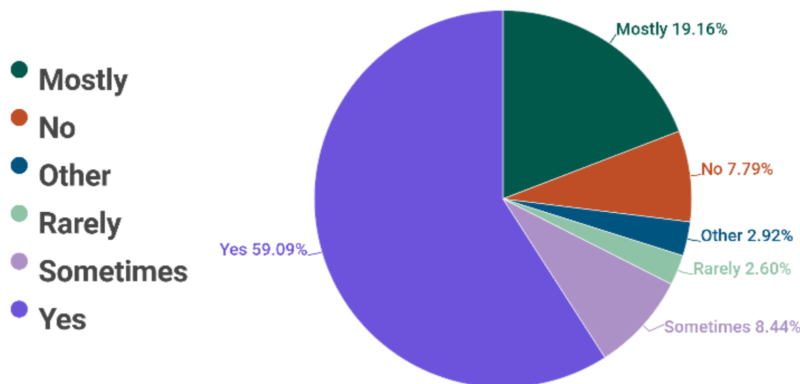
3. Did you have access to behavioral health services during the pandemic?



4. During the pandemic, do you feel like your behavioral health provider(s)...



5. Do you trust your behavioral health provider?



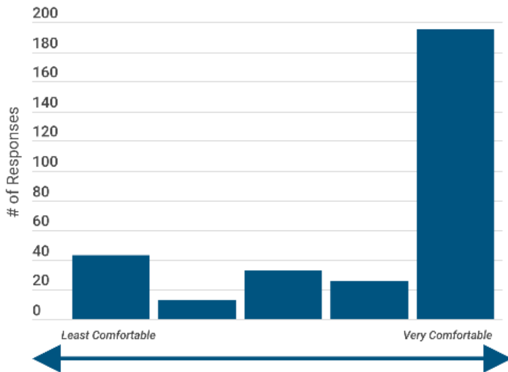
6. What is your access to electronic communication (check all that apply)?

69% 50% 29% 34% 17%

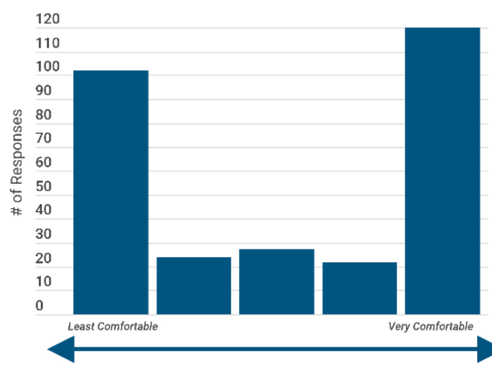
- Access to Phone
- Access to Email
- Access to a Computer
- Access to telehealth (i.e., cell phone call or computer visit)
- None

7. What is your comfort with...

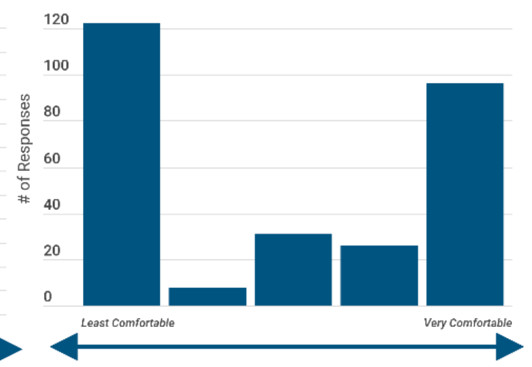
Phone Communication



Email Communication

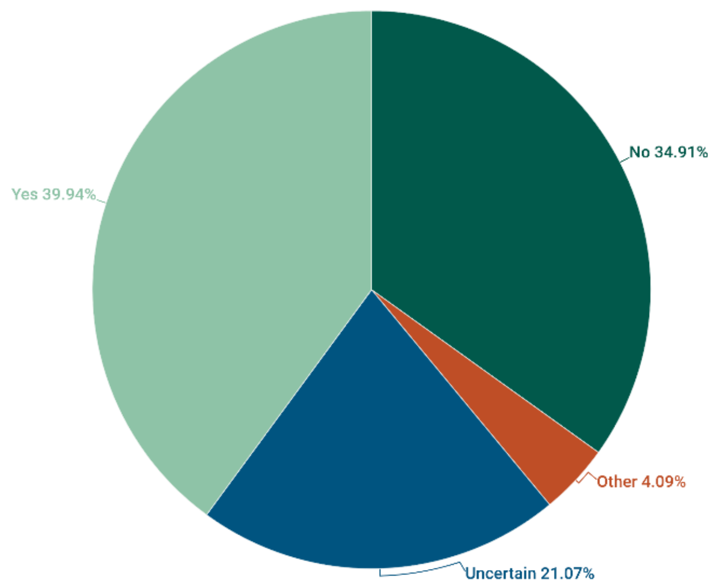


Telehealth



8. Do you feel that telehealth is an effective alternative to in-person behavioral health?

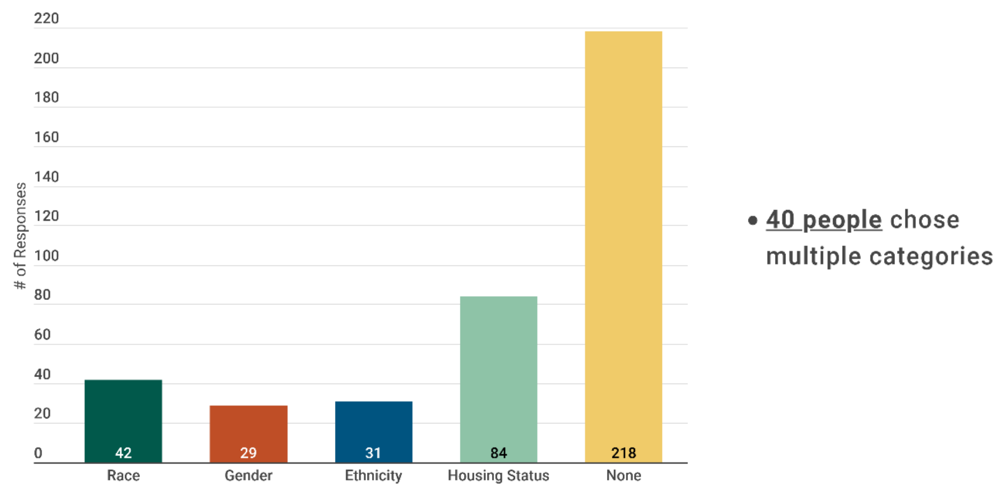
- No
- Other
- Uncertain
- Yes



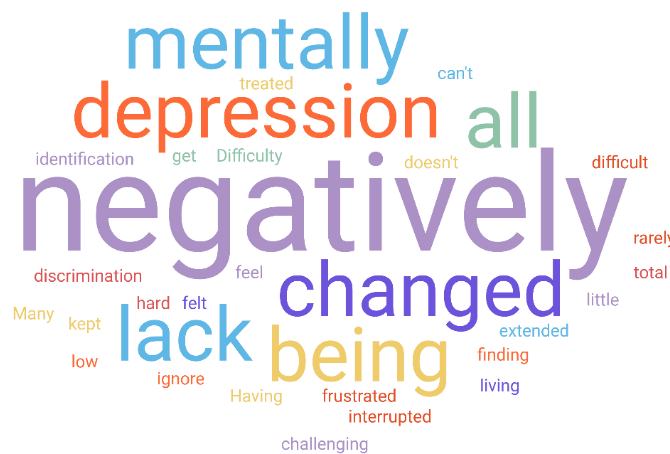
9. How has your access to resources (such as food, water, electricity, transportation, phones, medicine, etc.) and support been affected by the pandemic?

Feelings about Access to Resources	Specific Resources People Lacked
No impact (comfortable with my support system)	The shelter has no hot water and no personal items allowed including soap or toothpaste
Extremely difficult to obtain the necessary care that I need	No vaccine
Requiring appointments for service (no walk-ins) had a big impact	Access to fresh water (for drinking, cleaning, brushing teeth, etc.)
Delayed access	Lack of providing masks
Terrible, next to none, strained, hard to access	Food insecurity
Outreach and services stopped coming	Medicine disruption
Less help, less support	Financial disruption
Harder to get services	Transportation issues
Moving from hotel to hotel doesn't make me feel safe.	Lots of walking due to transportation issues
Need more and better communication	Housing
More fear associated with being in person	Limited emergency housing options for women
Difficult to navigate new rules	Phone access, no mailing or email address
More hoops to get resources	Trouble charging phone
Chaos	Electricity
Only certain supplies available	Access to toilets
It was harder at first, but now it is getting better	Feminine hygiene products
Stressful	Lost job
Harder to do most things over the phone	
I had access but COVID affected me mentally	

10. During the pandemic, have you been treated differently because of your race, gender, ethnicity or housing status? Check the boxes on which you have been treated differently.



11. How has that impacted you?



Feelings about the Impact	Specific Impacts
Angry, resentful, vengeful, frustrating,	It has made me not want to interact with others
Sad, humiliated, hopeless	More thoughts of suicide
Distrust	People judging you
Challenging, stressful, and wholly inequitable	Extended waits, delayed services
Made me feel worthless, less than	Lack of services and support, especially financial
Made me stronger	Impossible to get housing, lost housing
Depression	Feel like I have to prove everything
Anxiety	Hard to get feel stable, people want me to fail
Tried not to pay attention but it depressed me	Difficult to get important information or records
Felt ignored	Difficult to communicate and request help
I keep peace of mind regardless	Assumptions based on looks/presentation
Makes me feel like nobody cares	Sexual harassment
Low self-esteem	Makes me struggle with recovery
Felt less love and compassion from society	Cannot go in certain stores, bias in services
Made me more aware and cautious	I pray not to hate white people

12. What are the things (such as activities, relationships, communities, support) that helped you through the pandemic (physically and mentally)?

family friends none relationships my nothing church support activities community health talking exercise communication communities faith n/a working staying day partner mentally walking God reading speaking taking Goodwill services getting books stimulus mask videos psychiatrist wife relationship baby telehealth relations pray basketball drug yes sister keep outreach side pantry wheelchair meeting tribal following spent sleep AA art more the no not group watching self-will nobody being had vaccine daughter everything shelter spiritual isolation providers Going Praying medicine having some Doctor mental teleheath prayer haven't playing finding Love medication families provider worked hard prayers support/activities willingness myself LGBTQ donations humor nature food girlfriend strong all just people husband children arts studying walks work became boyfriend acquaintances

13. If you could share one improvement for your behavioral health service, what would it be?

Response	# of Responses
Better staff retention	63
More accessible hours	90
More harm reduction focus	36
Other	120

0 10 20 30 40 50 60 70 80 90 100 110 120

# of Responses

Other Responses		
More people with the experience in the field	More phone communication, including texting	Support for paperwork, should be electronic
Mental health identification	Give people more control	More intensive treatment
Transportation	Follow up missed appointments	Someone available at night
Trust, patience, compassion	More Spanish-speaking staff	Better customer service
Longer visits, more face to face	More staffing	Better housing options
Working on relationships	Open communication	Isolation support group
Housing access ASAP	Better attitude, less ridicule	Job training, access
Outreach/mobile clinics	Listen more, ask questions	Reduce delays
Exercise opportunities	Pay more attention to clients	Phone chargers

Discussion

Impact of COVID-19 on Behavioral Health

Many respondents shared that their limited access to resources or support during the pandemic caused several mental health impacts including depression, anxiety, and increased stress. The increased stress of COVID-19 included difficulty finding services or support, lacking provisions for basic needs, and a climate of fear and confusion.

Respondents shared numerous ways they chose to care for their behavioral health during COVID-19 including community (health center, church/faith community, support groups), relationships (family, friends, providers), activities (exercise, recovery meetings, reading, social media), and spirituality. A few people noted that they were not impacted by COVID-19 and instead carried forth regular daily activities. This demonstrates the internal strength that people can find when it is needed, while possibly feeling resistant to acknowledging systemic influences on life.

Impact of Systemic Racism and Other Discriminations

Most people (218 respondents) said that they had not been treated differently during the pandemic due to their race, gender, sexual orientation, or housing status. On the other hand, 84 people said they were treated differently because of their housing status, while 40 people were impacted by multiple categories of discrimination. Respondents noted numerous ways that being treated differently affected them. The word cloud for question 11 provides a visual of the negative impact, while the written comments provide insight about the numerous ways that it impacted people including their worldview, thoughts about self and community, and their relationships with others.

Impact of COVID-19 on Behavioral Health Services and Support

The largest share of respondents said that COVID-19 did not affect how often they came to the clinic (186 out of 323). Of those impacted, the majority were affected by systemic factors (limited in-person appointments or lack of transportation), with several people writing in other factors such as fear, lack of information, difficulty communicating or setting up appointments, and quarantine.

More than half of the respondents received behavioral health services during the pandemic (110 in-person and 81 through telehealth). The responses for how that care looked during COVID-19 (did your provider listen to you, do you trust them, etc.) trended positive but did vary slightly for each question. The question about providers treating respondents with respect provided the most positive responses, with 199 respondents saying always and 45 saying most of the time.

Most people had access to a phone (69%), with fewer having access to a computer (29%) or telehealth (34%), while 17% of respondents did not have access to any of these resources. There was a lower level of respondents who stated they had access to telehealth (34%) versus those who had access to a phone (69%); which is interesting to note as many telehealth appointments are taking place with audio only, and likely available through the phone. This may point to a lack of education from the health center to the consumers on how to access telehealth. When it comes to comfort using various communication methods, there were varying trends. The largest portion were very comfortable using the phone, with a split amongst those who are comfortable with email or telehealth, but trending towards not comfortable for telehealth. At the same time, a large portion of respondents felt that telehealth was an effective alternative for behavioral health (39%), but a slightly lower number of people felt that it was not (34%). Several people also noted that they were not aware of what telehealth services were or had never been offered telehealth.

Ways to Improve Behavioral Health Services During COVID-19 and the Recovery

The largest share of respondents wrote in their own ideas for how to improve behavioral health including having more people with the lived experience of homelessness working in health centers, easier ways to communicate with staff, and a transition to electronic paperwork and applications. However, of the options given, more accessible hours (90) and better staff retention (63) were important to respondents.

Limitations of the Survey and the Data

Due to COVID-19, we were only able to complete the survey at three cities, which limits our data and may have impacted some of our demographics. Of our respondents, 176 were Black (52%) and 72 were White (21%), which is significantly different than the general health center population, which is 29% Black and 49% White (2021 UDS Data).

Some of the responses appear to be inconsistent (i.e., answering they trust their provider while also responding 'never' for the specific questions about their behavioral health provider, or saying they did not have a behavioral health provider but still responding specifically to the questions about their behavioral health provider). It is hard to understand some of the responses without further information from the respondents.

Our information about telehealth was limited in that the survey did not ask about preferences and attitudes toward different types of telehealth (i.e., phone-only vs. video chat). We also asked respondents about comfort and access to telehealth, but not how they were currently connecting to telehealth.

The multiple phases of the ongoing pandemic have impacted mental health in different ways; including the omicron wave that primarily occurred after CPO data collection was complete. Some respondents may have been answering about their experience at the time, whereas others were speaking holistically about the pandemic. Constantly evolving modes of care, comfort with technology, care delivery changes, and changing social landscapes are all factors in the responses collected.

Recommendations

The results of the CPO provide valuable insight into how the Covid-19 pandemic has affected consumers of health centers. The resulting consumer perspectives on behavioral health and health equity can be translated into actionable recommendations for health centers to improve the effectiveness, safety, and equitable access of their services. The CPO recommendations can be leveraged and built upon by local CABs to guide the priorities of health centers through the Covid-19 pandemic and beyond. The recommendations include:

- Expanding behavioral health services during the pandemic and other prolonged periods of isolation
- Offering both telehealth and in-person appointments as options for consumers engaging in behavioral health services
- Facilitating safe, trauma-informed opportunities for social connection
- Increasing holistic health opportunities and offering access to resources alongside behavioral health services
- Creating policies for consumer governance and feedback specific to Covid-19 response

Expanding Behavioral Health Services

More than a third of consumers reported that the Covid-19 pandemic affected their utilization of health center clinics, due to a variety of factors (e.g., limited in-person appointments and limited transportation). This decrease in clinic utilization has happened at a time when so many experience social isolation and need extra social support. During the Covid-19 pandemic, it is more important than ever to improve the reach of behavioral health services at health centers. Health centers can improve their reach by offering appointments outside of the clinic setting or by offering in-clinic appointments in areas conducive to social distancing. Health centers can utilize staff like case managers or Community Health Workers to provide outreach outdoors, in shelters, or in homes to provide in-person follow up to telehealth appointments with behavioral health clinicians.

Offering Telehealth and In-Person Options

Of all the CPO questions, the items on telehealth garnered the most divided results. Almost 40% of consumers reported feeling that telehealth is an effective alternative to in-person behavioral health, while 35% reported feeling the opposite. This feedback provides support that both types of appointment approaches are important to consumers. It is important for health centers to remain flexible, especially in the pandemic when the need to social distance and the need to receive social support can feel like competing priorities.

CPO survey respondents also provided useful feedback on their comfort level with specific types of telehealth delivery. Participants were the most comfortable with phone communication, while comfort with emails and telehealth software were more mixed. Considering these results, health centers should remain as flexible as possible when providing behavioral health services via telehealth. Health centers should ask consumers what form of communication they are comfortable with and provide education about how to access different platforms the health center uses (i.e., heath portals, telehealth, and social service application websites). Everyone has differing levels of comfort with these modes of technology. By prioritizing options for phone communication and offering alternatives for those that are comfortable, health centers can provide more accessible services that are driven by consumer-preference.

Facilitating Opportunities for Social Connection

The CPO results emphasize the social isolation experienced by consumers during the Covid-19 pandemic. A striking number of respondents reported that they had no supports to help them through the pandemic. Many also reported isolation from discrimination based on housing status, race, ethnicity, and gender. Considering the connection and trust they have with many consumers; health centers are poised to facilitate opportunities for social connection during the pandemic. By offering events informed by public health and trauma-informed principles, health centers can host safe opportunities for community members to support one another socially and emotionally. Health centers can consider the feasibility of hosting events with options to socially distance or join virtually, especially for those that are under Covid-19 lockdown.

Working to Increase Holistic Health Opportunities and Access to Resources

A significant number of CPO participants indicated that their access to resources has been severely impacted by the Covid-19 pandemic. Challenges in accessing basic resources like food, transportation, and shelter impacts one's ability to attend to their own health and well-being. It is important to note that some people, even those from

the same cities, responded that they had no trouble accessing resources. This suggests that even when resources are offered within a community, there are unknown factors regarding who is aware of them, who is accessing them, and whether they are equitably distributed. Health centers can engage with their community partners to increase the range of resources available during the pandemic (i.e., relationship/community cultivation, healthy food options, public hygiene services, phone charging stations, transportation) and ensure that consumers are aware of how to access them.

Creating or Expanding Policies for Consumer Governance

The CPO results exemplify the value of consumer input in guiding the operations and policies of health centers. Without formal avenues for asking consumers their preferences and needs for services, health centers will not be able to adequately respond to, or mitigate the harm of, the pandemic. Health centers should work to expand their policies around consumer leadership and prioritize consumer input when guiding and leading their Covid-19 programming.

Conclusion

COVID-19 has had a widespread impact on behavioral health, but those who were marginalized or vulnerable, like those experiencing homelessness, endured further stress and trauma. Health centers did incredible work continuing to provide high-quality care and setting up new service delivery methods like telehealth. However, people without homes need more systemic solutions to provide access to things they need to survive, particularly during a pandemic. Health centers should consider expanding behavioral health services during the pandemic and other prolonged periods of isolation, offering both telehealth and in-person appointments as options for consumers engaging in behavioral health services. Health centers should also facilitate safe and trauma-informed opportunities for social connection, increase holistic health opportunities and access to resources alongside behavioral health services. Thus, creating policies for consumer governance and feedback specific to Covid-19 response.

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Appendix A: Survey

Age: ____________

Ethnicity (check all that apply): ◯ African American/Black ◯ White ◯ Asian/Pacific Islander ◯ Hispanic/Latino ◯ Native American ◯ Other ___________________________________

1.) Has COVID affected how often you come to the clinic? (If no, go to question #3)

- Yes
- No
- Maybe

2.) How has COVID affected how often you come to the clinic?

- Limited in-person appointments
- Lack of transportation
- Lack of staff
- Other (please write-in)____

3.) Did you have access to behavioral health services during the pandemic?

- Yes, in-person
- Yes, through telehealth
- Sometimes
- No
- Other (please write-in)____

4.) During the pandemic, do you feel like your behavioral health providers..

	Always	Most of the Time	Half of the Time	Sometimes	Rarely	Never
Listen to you?						
Treats you with respect?						
Spend enough time with you?						
Understand your challenges?						
Have been meeting your needs?						

5.) Do you trust your behavioral health provider?

- Yes
- Mostly
- Sometimes
- Rarely
- No
- Other (Please write-in)

6.) What is your access to electronic communication (check all that apply)?

- Access to email
- Access to a phone
- Access to a computer
- Access to telehealth (i.e., cell phone call or computer visit)
- None

7.) What is your comfort with… (1 is least comfortable, 5 means very comfortable)

	1	2	3	4	5
Phone communication					
Email communication					
Telehealth					

8.) Do you feel that telehealth is an effective alternative to in-person behavioral health?

- Yes
- No
- Uncertain
- Other (please write-in)

9.) How has your access to resources (such as food, water, electricity, transportation, phones, medicine, etc.) and support been affected by the pandemic?

____

____

10.) During the pandemic, have you been treated differently because of your race, gender, ethnicity, or housing status? *Check the boxes on which you have been treated differently.* (If no, go to question #12)

- Race
- Gender
- Ethnicity
- Housing Status
- None

11.) How has that impacted you?

____

____

12.) What are the things (such as activities, relationships, communities, support) that helped you through the pandemic (physically and mentally)?

____

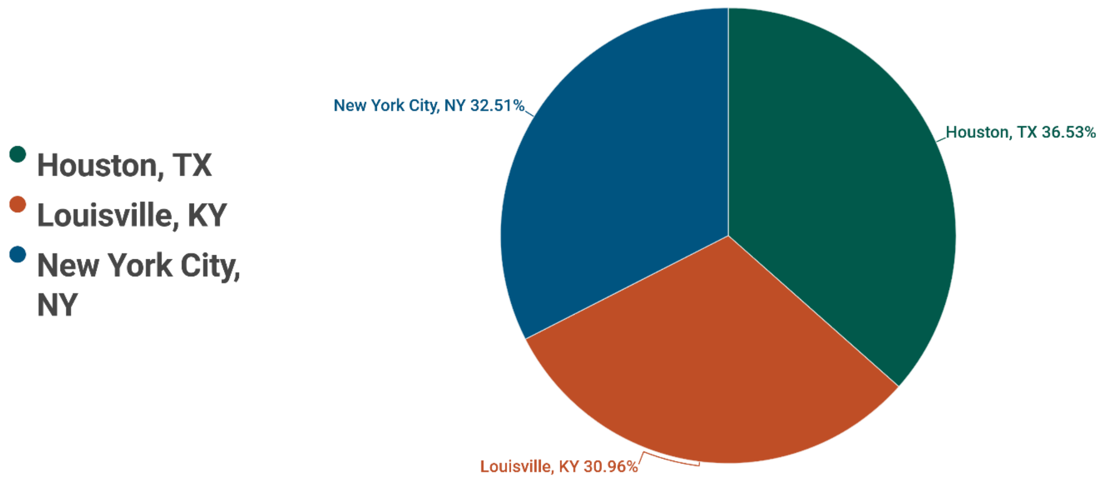
____

13.) If you could share one improvement for your behavioral health service, what would it be?

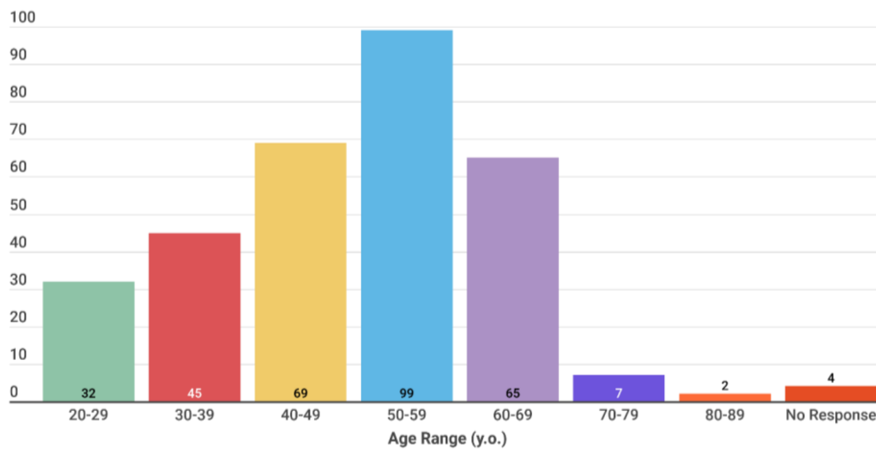
- More accessible hours
- Better staff retention
- More harm reduction focus
- Other (please write-in)____

Appendix B: Demographic Information

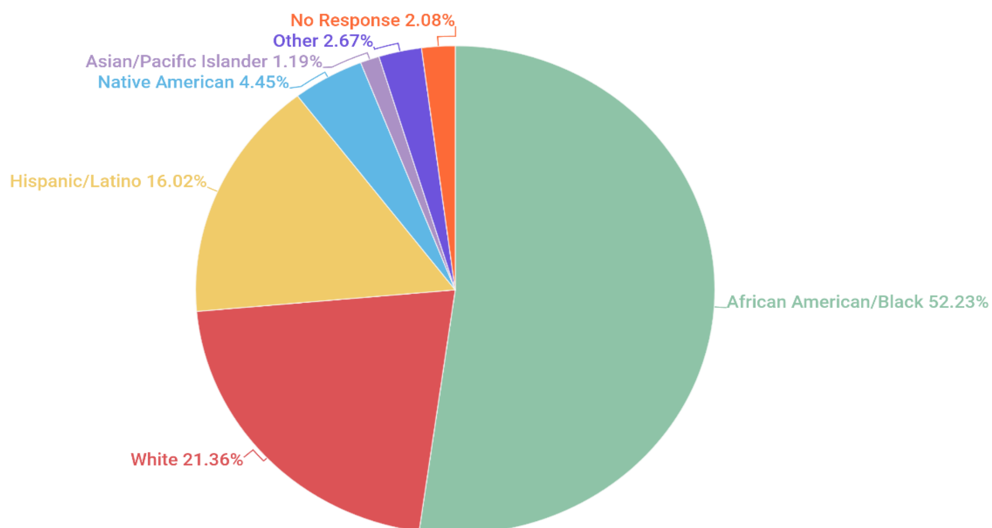
Which states did the responses come from?



How old were the respondents?



What race & ethnicity were the respondents?



Appendix C: Resources

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