

# Ryan White Part A 2022 Client Experience Survey Qualitative Results

Portland, OR Transitional Grant Area HIV Grant Administration and Planning

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## **EXECUTIVE SUMMARY:**

Ryan White (RW) client experience survey respondents provided close to 3,000 written responses to 13 open-ended questions that provide more context to quantitative survey results described in the 2022 HIV Client Experience Survey Report. This qualitative addendum to the initial report provides additional descriptions of service access, needs, gaps, and satisfaction by service category in clients' own words. Where applicable, differences in client qualitative responses by demographic group are described.

#### **Key Findings**

The number of open-ended responses across the 14 service categories ranged from 744 comments around food services to 19 comments describing employment/job support. The primary key take-aways by service category are ordered from most to least comments provided:

- Food: Food support gaps include better quality food, having too little assistance from
  or difficulty qualifying for food assistance programs (e.g. SNAP), needing
  transportation to food sources, and needing money for food. Top food supports noted
  were receiving cash for food; having access to food banks and pantries or meal
  assistance programs; respondents described eating healthier foods and having a
  healthier diet as a key health behavior.
- Medical: Respondents noted excellent care provision. Suggested facilitators to better
  access services include alternate locations to downtown, in-person and virtual service
  options, and flexible appointment scheduling options. Additional needs included
  expanded wraparound service and individualized care, improved follow-up and
  referrals, and more communications regarding HIV care plan/treatment standards.
  Routine medical care and medication adherence was a primary listed health behavior.
- Case Management (CM): Respondents wanted more contact with Medical Case Management (MCM) agency staff and more ongoing contact initiated by MCM staff. They also want providers to continue virtual CM services.
- Mental Health (MH): Expand MH services to include psychiatry, therapy, support groups, sex therapy, and walk-in MH services. Continue virtual MH services.
   Respondents noted that engaging in MH services helped them stay healthy.
- Psychosocial Support: Respondents described beneficial psychosocial service
  experiences, such as support groups and social support through staff, community and
  activities. Psychosocial support was also found through access to food/health nutrition
  services. Respondents noted how social isolation caused by the pandemic created
  barriers to receiving psychosocial/emotional support. The need for expanding services
  was cited, including having weekend and evening service hours, multi-generational
  groups, and more group and/or individual supports to address depression/anxiety,
  aging, sexual identity, living with HIV, addictions, service navigation, and issues
  related to involvement with the criminal justice system.

- Housing: Respondents cited the need for more housing, in general, and housing services including more communication and follow up with housing staff, help with accessing temporary housing, and assistance in dealing with an eviction.
- Dental Care: Most Dental Service patients had positive care experiences. Service
  improvement suggestions included: broader access to dental implants, emergency
  dental care, dental care caused by addictions, and nitrous oxide/sleep dentistry to help
  with dental anxiety; expanding the RW dental service coverage area; and faster dental
  appointment availability. The need for upgraded equipment and more comfortable
  offices was also suggested.
- Financial Assistance: Respondents cited the need for more information about financial assistance and services beyond those currently covered by RW. Also noted as barriers were that funds are too limited, that the eligibility criteria to qualify for financial assistance is too restrictive, and how inflation impacts the ability to access services and afford basic needs.
- HIV Medication/Pharmacy: Respondents noted how taking HIV medications regularly
  and improving their medication adherence contributed to their staying healthy. Service
  access issues noted included limited pharmacy hours, needing additional mail order
  pharmacy options, and the limited number of pharmacies that accepted CAREAssist.
- Information/Referral: A wide range of information and referral support networks are needed to access various services including medical, insurance, financial, housing, and legal and social services.
- Four additional service categories with under 50 responses focused on service access and gaps around services not traditionally funded by Ryan White in the Portland TGA.

The majority of open-ended responses without service category identification (n=1,045 of 2,998 comments) focused primarily on expressions of gratitude for RW services in general and to comment that there were no additional service, public emergency and/or COVID precaution gaps, along with descriptions of self-care health behavior.

#### INTRODUCTION:

During the fall and winter of 2021, the HIV Grant Administration and Planning (HGAP) program, which administers the Ryan White Part A federal grant, gathered consumer feedback in the form of a Client Experience Survey. This survey contained both closed-ended (quantitative) and open-ended (qualitative) questions.

These quantitative and qualitative survey data were analyzed and disseminated to each participating agency. Due to the amount of data collected from approximately 463 individuals, the Transitional Grant Area (TGA) level results were divided into two reports. The first report summarized the results of the quantitative analysis and was released on April 5th, 2022 (2022 HIV Client Experience Survey Report). The following report is the second of two and contains the qualitative analysis to be considered as an addendum to the first report released.

#### **METHODOLOGY:**

For a full summary of the development, dissemination, and analysis of the most recent client experience survey, please refer to pages 7-11 of the Ryan White (RW) Part A 2022 Client Experience Survey Results (2022 HIV Client Experience Survey Report). Similar to the CES survey, the total number of open-ended questions expanded substantially in 2021 in order to better capture the service experiences and needs of RW clients during the COVID-19 pandemic. A total of 13 open ended questions were asked of clients, including:

- experiences of people newly diagnosed with HIV accessing services after initial diagnosis
- experiences with addictions and recovery support services, as applicable
- food support gaps and facilitators
- general service availability/gaps and virtual service preferences
- primary health engagement activities during the COVID-19 pandemic
- factors contributing to service satisfaction, such as key improvement areas, what clients liked most about services, and thoughts on COVID-19 precautions
- any additional comments about the RW service system

In the previous iteration of the client survey administered in 2019, follow-up focus groups were conducted in 2020 to gather contextual information around specific client experiences with RW agencies and client recommendations on service and systems-level improvements to create a more responsive care system. Towards the end of February 2022, HGAP staff met with the BIPOC Data Review Committee (DRC) to discuss client information still needed to better understand the quantitative analysis and results.

In April and May of 2022, HGAP staff reviewed all comments provided by clients, developed a primary coding schema to code the qualitative data, and coded all client open-ended responses (see Appendix A for the list of codes used). The primary coding schema for each

open ended response is as follows: **Agency—Service Category—Main Theme—Sub-Theme**. Depending on the length and nature of the comment, a singular written response could have up to 2 main themes and 3 sub-themes associated with it to ensure the totality of each response was coded accordingly (see Appendix B for total number of written responses by main themes and sub-themes). All coded responses were imported into SPSS, with client population demographic characteristics associated with each response.

## **QUALITATIVE RESPONSE RATES AND DEMOGRAPHICS:**

A total of 2,998 written responses across 444 clients were provided, an average of 7 open ended comments per client. Only 19 CES respondents (4%) did not provide any responses to the open-ended questions. The table below displays the total number of responses per each open-ended question, and the response rate for each out of the total possible number of responses depending on how many agency's clients completed satisfaction surveys. Half or more respondents provided responses to the bolded question topics below.

Table 1: Total Written Responses Provided By CES Question

Open Ended Question	n	% of total possible responses
Healthy Behaviors	386	83%
Like Most About Agency/Services/Staff	378	63%
Food Supports	305	66%
One Improvement	302	50%
Continued Services - Virtual/Online	266	57%
Service Gaps	266	57%
Food Gaps	251	54%
Ryan White Service System Comments	242	52%
Additional COVID Precautions	217	36%
Public Emergency/Information Gaps	208	45%

Additional Satisfaction Comments	143	24%
Addictions/Recovery Support Experiences	21	5%
Newly Diagnosed: Service Experiences After Diagnosis	12	3%

In order to provide comparable contextual results to the TGA quantitative results, where applicable, written responses were also examined by the same respondent demographics groups found in the initial report. The below table illustrates how many written responses were provided by respondent demographics.

Table 2: Total Written Responses by Respondent Demographics

	BIPOC	Clients w/Disabilities	>55+ years	LGB+	Gender Diverse/ Transgender	Clients Exp Homelessness
CES Total Respondents	164 (36%)	203 (46%)	180 (41%)	383 (88%)	23 (5%)	79 (17%)
CES Written Responses	1022 (34%)	1436 (49%)	1245 (43%)	2516 (87%)	184 (6%)	592 (20%)

A slightly higher percentage of written responses were provided by respondents with at least 1 disability and by clients experiencing homelessness in the past 2 years.

#### SERVICE CATEGORY QUALITATIVE RESULTS:

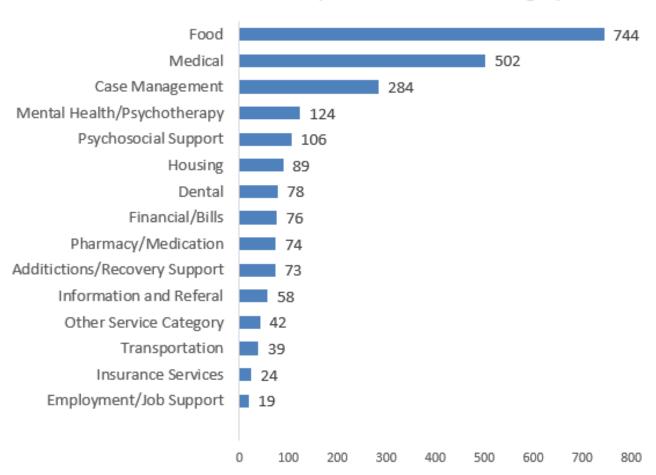
Open-ended question narratives were initially examined by the number of comments per question asked and by the main themes, sub-themes, and service categories associated with each comment. Upon further consultation with the BIPOC Data Review Committee, and reflecting on the primary responsibilities of HGAP and the Portland TGA Planning Council, the following qualitative results described focus on the two following areas:

- Narrative result descriptions by service category that provided either context to the quantitative survey results and/or actionable information for RW stakeholders for further programmatic priority setting, guidance and improvement efforts
- Contextual information on the needs of specific populations described in the quantitative results

A total of 1,971 open-ended respondent comments called out at least one of 15 distinct service categories that are included in the analysis below (66% of all written responses). Service categories with more than 100 written comments were examined by both main themes and subthemes, where applicable. Service categories with under 50 associated

responses resulted in overall descriptions of client comments. Analysis by service category is organized by total numbers of responses, while a summary of all remaining CES qualitative comments can be found by CES question in the following section. The following graph shows the number of qualitative responses associated with each service category.



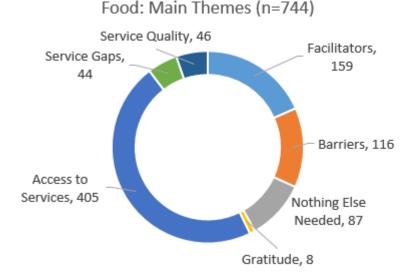


Written comments by service category and main themes were also examined by client demographics, with a focus on where there was a statistically higher number of responses by client demographic group (see table in Appendix C). Any substantive differences found in the written comments by client demographics are noted within each service category section. Service categories with less than 50 comments were excluded from this demographic analysis. Please note that the 2022 Client Experience Survey Report should be referenced to better understand client service access, needs, gaps, and satisfaction by demographic group. The results below are indicative of where there were substantive population differences expressed contextually within the written comments that complement this understanding.

**Food Services:** Food and food services represents the service category for which respondents wrote the highest number of comments (n=744 comments). Two specific

questions around RW client food gaps and food supports were specifically asked this year. The majority of responses regarding food/food services were in response to these two questions and the question asked on health behaviors. The majority of overall open-ended responses focused on:

- Access to services (n=405), including barriers, services gaps, and food supports used
- Food facilitators (n=159), including what supported food access, and food choices and/or diet as a health or self-care behavior described



Access to Services - Barriers and Gaps: 251 open-ended responses were provided to the CES question of what were the primary gaps seen with food support, as well as 24 additional responses where food service gaps/barriers were described. Primary themes around food access gaps included:

- Food types, quality or preparation issues including:
  - access to vitamins, fresh fruit and vegetables, dairy products, vegetarian options, diet restrictions/allergy free food, and more foods choices in general
  - expired and/or unhealthy food products at food pantries/banks
  - lack of appliances/resources to prepare food and/or store food
- Transportation: Several respondents described lack of transportation to get groceries
  or to food banks/pantries or inaccessible locations, couldn't bring food home physically
  or issues with mobility, and/or lack of assistance to transport food.
- Limited SNAP and other food assistance barriers: Several respondents wrote regarding SNAP benefits not being enough, having lower SNAP amounts due to employment, or being denied SNAP benefits. Respondents also described running out of food midway through the month due to low assistance amounts and the application process being overwhelming/not efficient. "Not enough food stamps to last month to month should be greatly increased for all." Some respondents described other food assistance barriers: not having a social security number, not having legal status in the United States, wait times at food pantries/banks, expanded meal center services and food delivery program needs, or being embarrassed to go to food pantries.
- Many respondents described money, having a low income, lack of employment and inflation/rising cost of food as their primary food barriers. Many respondents described food gaps as an issue with general accessibility/availability, lack of information, social distancing, supply chain, experiencing homelessness, injury, and a product of poor

policy writing and red tape. Lastly, around a quarter of respondents said that they did not have any food support gaps, hardly any, and/or none at this time.

Food Facilitators and Access to Food Services Support: Respondents described facilitators and access supports around food in two different ways - useful supports for accessing food and healthy diet/food as a health behavior.

Food supports included:

- Food banks/pantries, food boxes and food support programs: Over 250 responses described food assistance programs, such as:
  - SNAP (top response)
  - food banks and pantries, including Esther's and Martha's pantry
  - o food boxes, including home delivered food boxes and meals
  - food gift cards and vouchers
  - o community based meal programs, including group meals and church programs
  - o case worker assistance to either apply or obtain the above programs
- Respondents also described food support in terms of help from friends and families, healthier food options, and transportation to food resources
- Any possible support option/all of the above
- Less than 5 respondents described volunteering as a food access means, wanting assistance with budgeting, or not eating/fasting/food rationing

Healthy diet and food as healthy behaviors: Several respondents described food within the context of the top three things they did to stay healthy in the past year, including:

- Eating better/healthy/well, maintaining a healthy/balanced diet and/or eating/diet generally
- Specific dietary changes made (e.g. "eating more vegetables," "salad," "quit drinking soda," "ate less junk food," "keto," "eating less meat," "vitamins and supplements," "cutting back on sugar intake," "avoiding canned food," "organically grown foods")
- Cooking more often and cooking at home
- Monitoring diet for health, weight loss or diabetes control

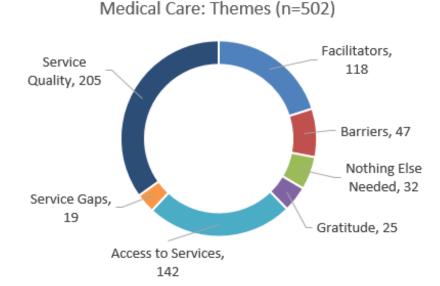
**Population Specific Comments:** A lower percentage of respondents with disabilities or experiencing homelessness described food facilitators, while a higher percentage of respondents with disabilities or experiencing homelessness and gender diverse/transgender clients described access to food services issues. Respondents with disabilities provided the majority of food transportation barrier comments (83%). Respondents experiencing homelessness in the past 2 years provided close to all of the comments on gaps in safe food storage and preparation. The majority of comments related to being denied SNAP/not being eligible (n=12) were from BIPOC respondents.

KEY FINDINGS: Food support gaps include better quality food, having too little assistance from or difficulty qualifying for food assistance programs (e.g. SNAP), needing transportation to food sources, and needing money for food. Top food supports noted were receiving cash for food, having access to food banks and pantries, or meal assistance programs. Respondents described eating healthier foods and having a healthier diet as a key health behavior.

**Medical Care Services:** Medical care services represents the service category for which respondents wrote the second highest number of comments (n=502 comments). Each of the primary themes were further examined by sub-themes within each thematic area. The majority of client comments related to medical care are described in the section below and focused on:

- Medical care experiences (183 comments)
- Physical environment (52 comments)
- Service network support (42 comments)
- Communications (33 comments)
- Self-care (32 comments)
- Negative care experiences (30 comments)
- Time and scheduling (28 comments)

Additional themes not described in the areas below focused on patient eligibility for specific preferred medical care providers due to insurance limitations.



Medical Care Experiences: Multiple CES respondents wrote about their medical care experiences in the Portland TGA, with the majority of comments expressing positive feedback (n=161) and some comments describing negative care experiences and potential areas for improvement (n=30). Positive characterization of medical care staff and the care provided can be found in the word cloud. Respondents descriptions of high quality medical care includes:

- Providers being experienced and knowledgeable of current HIV treatment protocols and other health practices, including Hepatitis C.
- The provision of wraparound services (mental health, MCM, pharmacy, housing, etc.) beyond medical care.

- Long standing relationships with providers that listen, care, advocate for their patients, and provide the "best level of medical care one can possibly get."
- Welcoming, compassionate services where patients "feel like providers are my friends" and are being "treated like family and like I matter."
- Service efficiency, including intakes and that medical concerns are handled quickly.



Negative care experiences were related to:

- Needing more information around COVID-19 vaccinations, testing options, or exposure.
- Experiences with medical care or medication prescription/treatment delays.
- Specific community needs, such as trauma informed care that focuses on patient trauma resulting from abuse/violence or homelessness. "You apply this one size fits all approach to everything you do. It's not working."
- Privacy concerns, such as at check-in and the front desk.
- Lack of contact or follow up by either case manager or medical staff. "No support no advocate. And I fall through the cracks. Struggling to stay alive."

Physical Environment: Respondents provided multiple descriptions about improving the physical environment in which they received medical care, including:

- Location: Several respondents did not like the downtown location where the primary RW medical clinic is located and that it affected care accessibility, including patient concerns around safety, fear of assault/confrontation, lack of appropriate syringe disposal, and people experiencing homelessness in the general area. Different location suggestions included SW Portland and unspecified locations "closer to" patients (e.g. "Move the location, downtown is scary," "Closer places for labs").
- Waiting Room Area: Respondents described wanting a warmer atmosphere; privacy concerns while checking-in; lack of seating, coffee, and hand sanitizer.

• Parking: Several respondents requested access to free parking downtown.

Service Network Support Needed: Respondents provided feedback on additional service and support needs that would facilitate medical care access and experiences, including:

- Additional on-site services needs, such as expanded mental health/psychiatric services; COVID testing and vaccination; housing assistance; and speciality medical care (e.g. orthopedics, vision care, etc; medical consultations; dental care, etc.).
- Having more medical information available (see Communications below).
- Provider relationship facilitators including: expanding provider diversity; long-term medical/patient partnerships; reducing staff turnover; etc. "Love my doctor. And the staff. Hate the high turnover rate."
- Improved referral processes to other needed medical care.

*Medical Care Communications:* CES respondents also described specific communication topics and preferences that would facilitate and improve access to medical care, including:

- Preference for both telehealth and in-person visits:
  - In-person: medical issues and when physical exams are needed. Respondents described missing personal connections to and seeing medical staff in-person, as well as telehealth barriers related to specific disabilities, such as hearing impairment. "It would just be nice to interact with everyone..face to face..person to person. I miss seeing you all."
  - Telehealth: routine medical lab result appointments and follow-up appointments. Respondents described the convenience of telehealth especially when working full time and for health precautionary reasons. "Follow up [virtual] appointments if no labs blood work or a physical examination is needed."
- Other communication facilitators include MyChart and ability to email/call case managers.
- Medical information needs include: specific information on HIV lab work, outcomes for COVID-19 for people living with HIV, guidance around COVID-19 boosters and where to get vaccinated, and overall HIV health/suggestions for care (e.g. "Info on the new once a month medication," "More info about what all the labs are.").

Specific communication barriers described by clients included not being sure who to contact for what services and knowing who is contactable online.

Self-Care Related to Medical Care: Close to 10% of all responses related to what clients did to stay healthy in the past year were related to medical care access and services, including routine medical appointments, seeking medical advice when needed, taking HIV medications every day, maintaining prolonged undetectable viral loads, emergency room visit use, and getting vaccinated. "Isolated, adhered to medication, Kept medical appointments."

*Time and Scheduling:* CES respondents described how improved scheduling and hours of operation would help facilitate and expand access to care, such as:

- Expanded medical care hours in the evening and on the weekends, including pharmacy services. "I work Monday to Friday 9-5pm, so I am unable to go see a doctor now as there are no alternative hours available."
- More time with providers during medical visits. "Longer visits with provider would be good."
- More flexibility with appointments, expanded drop-in hours and walk-in appointments.
   "MORE DROP IN HOURS FOR URGENT CARE...NO APPOINTMENT NECESSARY."
- Expanded onsite appointment availability for specific/speciality services, such as with mental health professionals, medical consultants and blood tests; routine appointment scheduling, such as with annual meetings with case manager; better understanding around laboratory services and routine HIV lab work scheduling. "...[C]larity of scheduling for regular tests and referrals."
- Reduced wait times during visits. "[R]educed waiting times. Beyond 20 mins the person should be in a room, no matter if a nurse is available or not."

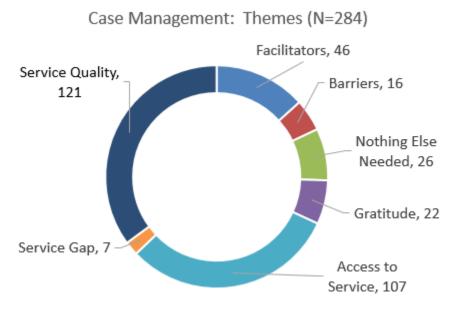
Respondents described additional time and scheduling medical care experiences that also acted as barriers to care, including sometimes feeling rushed at medical appointments and last minute staff cancellations.

Population Specific Comments: While respondents with disabilities, those less than 55 years of age, and respondents experiencing homelessness wrote more comments around barriers related to medical care, no substantive barrier description differences were found by age or disability. When examining barriers described by clients that had experienced homelessness in the past 2 years, respondents were more likely to describe experiences around mental health needs, being isolated, and poor care experiences with limited support. Comparatively, respondents not experiencing homelessness wrote more to location, safety, privacy, operation hours and physical environment as barriers. When examining additional contextual differences in responses, BIPOC respondents described information gaps around HIV treatment, while non-BIPOC respondents described needing more information around COVID testing and vaccination. Vision care/glasses was one of the most common responses for medical service gaps for respondents 55+ years of age in comparison to younger clients.

KEY FINDINGS: Respondents noted excellent care provision. Suggested facilitators to better access services include alternate locations to downtown, in-person and virtual service options and flexible appointment scheduling options. Additional needs included expanded wraparound service and individualized care, improved follow-up and referrals, and more communications regarding HIV care plan/treatment standards. Routine medical care and medication adherence was a primary listed health behavior.

**Case Management Services:** Medical case management represents the service category for which respondents wrote the third highest number of comments (n= 284 comments). These comments were divided into 7 themes. What follows is a summary of the content of the MCM comments across these themes. Not all themes are discussed. In some instances, sub-themes are also discussed.

Service Quality (n=121): Individual comments about Service Quality were further grouped into various sub-theme categories. The sub-themes most frequently cited were around both positive (n=91) and negative (n=22) service experiences. Most of the positive comments were around agency staff being helpful, friendly, knowledgeable and caring. The below WordCloud displays the adjectives used to describe the positive service experiences. The most commonly used adjectives were "Helpful" and "Friendly" as



evidenced by the size of the words in the image below.



Client respondent negative service experiences primarily revolved around a lack of communication; individuals would like to see more proactive communication and better follow through. Individuals also brought up frequent staffing changes that were challenging to weather and the preference for consistent and stable assistance.

"More proactive communication (newsletter?) rather than waiting for me to have a problem and get in contact. Everything, right now, seems to be crisis and problem solving mode. Otherwise, the only thing I ever get is my case manager has changed yet again to some unknown person."

Access to Service (n=107) & Facilitators (n=46): During the pandemic, service access points varied to include both in-person, virtual and online. When asked about the services individuals want to continue to receive virtually, case management was cited by 73 individuals. Most comments around access to services overlapped with the above section (Service Quality). Many individuals communicated that they wanted more contact with their case manager and were hopeful that case managers could check in even when there is no pressing issue at hand. "...[O]ccasional check-ins from case manager."

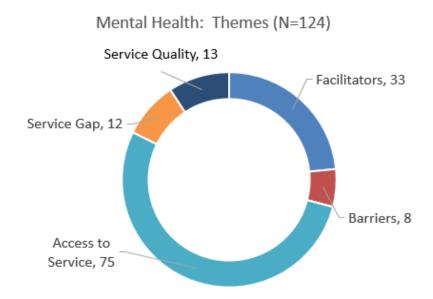
**Barriers & Service Gaps (n=23):** Most of the negative service experiences cited above also fit in the Barriers and Service Gaps themes. The various gaps and barriers cited include the location of services, lack of communication, lack of capacity to return calls, and the inability to choose staff with whom to work.

**Population-Specific Trends:** There were no noted substantive differences of the types of Addiction/Recovery comments provided by client respondents across various demographic categories (Disability/55+/BIPOC/LGB+/Gender Diverse).

KEY FINDINGS: Respondents wanted more contact with MCM agency staff and more ongoing contact initiated by MCM staff. They also want providers to continue virtual CM services.

Mental Health Services: Mental health (MH) represents the service category for which

respondents wrote the fourth highest number of comments (n=124 comments). These comments were divided into 5 primary themes. The chart displayed on the right contains the number of comments provided for each theme. The main themes that emerged from the comments around MH were Facilitators and Access to Service. For purposes of this summary, the themes with the most number of comments will be summarized.



**Access To Service (n=75):** The majority (n=52) of comments about service access involved the continued access to MH services virtually or via an online platform. The types of virtual MH services clients cited included counseling, support groups and group therapy. A few clients suggested having mental health providers on staff or mental health referrals available.

**Service Gaps (n=12) & Barriers (n=8):** Clients were also asked to cite needed services that were NOT available. A total of 18 clients pointed to MH services as a service they needed but could not access or barriers to these services. Examples of needed MH services included: psychiatry, therapy, support groups, psychotherapy, sex therapy, and walk-in MH services. "I have been looking for Mental health for months. No one is making recommendations and when I do get a name or referral, they won't take medicare. very frustrating."

**Facilitators/Healthy Behaviors:** Clients were asked to comment on the things they did during the pandemic to be healthy. A total of 22 clients reported accessing MH services as one of the things they did to stay healthy. MH service engagement cited included recovery meetings and therapy.

"Participation in the group meetings via zoom has been very helpful and helped me feel less isolated."

"The group facilitators have been insightful and encouraging. I hope that they can continue."

**Population-Specific Trends:** There were no noted substantive differences of the types of Addiction/Recovery comments provided by client respondents across various demographic categories (Disability/55+/BIPOC/LGB+/Gender Diverse).

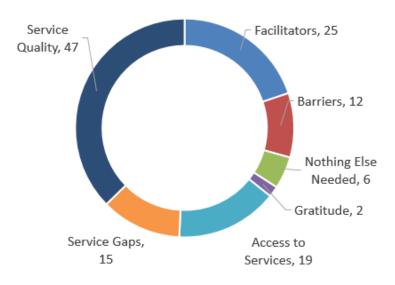
KEY FINDINGS: Expand MH services to include psychiatry, therapy, support groups, sex therapy, and walk-in MH services. Continue virtual MH services. Respondents noted that engaging in MH services helped them stay healthy.

### **Psychosocial Support Services:**

Psychosocial support (PS) represents the service category for which respondents wrote the fifth highest number of comments (n=106 comments). While clients primarily spoke to the main themes of psychosocial support service quality (n=47) and service access/facilitators to service access (n=19 and 25 respectively), specific sub-themes emerged around service access and quality which are described below. These included:

- Positive care and service experiences (32 comments)
- Social and social network support (23 comments)
- Service and service network support (13 comments)

Psychosocial Support: Themes (n=106)



Additional respondent comments not related to the described sections below include safety concerns at specific agencies (e.g. public drug use/drug distribution and general sanitation practices); better communications around agency/psychosocial support closures or cancellations; and advocacy for more client involvement in hiring practices and decision making around services.

Positive Care/Service Experiences: When respondents described the positive psychosocial support services provided, three primary areas of service provision emerged: the support groups available; social support that is provided through staff, community and activities; and access to food/health nutrition services. "The respect and attention to privacy and awesome support groups and outlets!" Multiple clients expressed gratitude for psychosocial support services remaining open and available during the pandemic. "They've bent over backwards to keep services going during covid."

Social and Social Network Support: Respondents provided suggestions for improved PS services and described social support networks facilitated health outcomes, including:

- Social networks as self-care: Several respondents described that one of the things
  they did to stay healthy during the pandemic was to reconnect/communicate with
  family and friends; attend support groups, including peer and long-term survivor
  groups; social activities; and connect with peers/mentoring with other PLWH. "Increase
  social activities."
- Expanded social support needs: more coordinated information on community support options available and increased social activities and outlets for PLWH. "Information connecting me to build community support and connection."

Social support barriers described were around client social isolation caused by bullying or pandemic and related safety concerns.

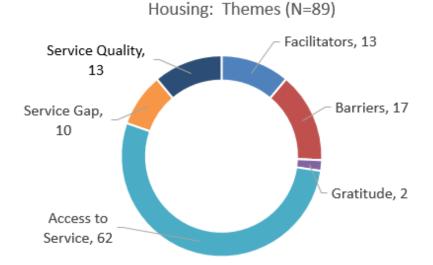
Service and Service Network Support: Client respondents had a range of different suggestions to facilitate access to psychosocial support services and what should be available at psychosocial support agencies, including:

- More psychosocial support services, including: expanded weekend and evening hours; checking in more often with clients unrelated to service needs but for general connection; and more one-on-one emotional support. "I wish we could get more one one support for emotional."
- Expanded group support, including: support groups for depression/anxiety, aging, addictions, service navigation, and living with HIV in general; as well as population specific support group needs, such as ones for those that have been/are criminal justice involved, multi-generational groups, sexual identity, etc. "Support services for former inmates." Respondents also mentioned really wanting in-person support group options.
- Additionally, expanded basic needs support services on-site including laundry, physical therapy, acupuncture/massage, language classes, and food/nutrition support.

**Population Specific Comments:** A higher percentage of respondents with at least one disability, those over 55 years of age, gender diverse/transgender respondents and those that had experienced homelessness in the past 2 years provided open-ended responses around psychosocial support services. However, there were no substantive differences that emerged by respondent demographic characteristics.

KEY FINDINGS: Respondents noted having positive psychosocial service experiences through support groups and social support through staff, community and activities. Psychosocial support was also found through access to food/health nutrition services. Respondents noted how social isolation caused by the pandemic created barriers to receiving psychosocial/emotional support. The need for expanding services was cited, including: having weekend and evening service hours; multi-generational groups; and more group and/or individual supports to address depression/anxiety, aging, sexual identity, living with HIV, addictions, service navigation, and issues related to involvement with the criminal justice system.

Housing Services: Housing services represents the service category for which respondents wrote the sixth highest number of comments (n=89). The theme that yielded the most comment was Access to Services. Barriers and Service Gaps were combined and grouped into one of the below sections. The other themes, shown in the graphic to the right, overlapped with these primary themes and, therefore, are not directly discussed.



#### Service Gaps (n=10) & Barriers (n=17):

Clients were asked to identify services they needed but could not access. A total of 38 reported Housing as a service gap. Specific housing services cited included: housing assistance, rent assistance, moving assistance, housing for veterans, eviction prevention, housing vouchers, affordable housing, subsidized housing, short-term housing and permanent housing.

"Please find funding for a overnight homeless shelter for HIV specific individuals that need that stability to remain adherent to medication. They get sick and suffer needless health complications so much faster on the street...life expectancy is shortened because chronic homelessness and lack of access to harm reduction policies ie housing first - safe using sights."

Barriers to accessing housing services were wide-ranging and included long wait lists for permanent housing, lack of follow up from housing staff, and access to temporary housing and advocacy after an eviction.

**Access to Services (n=62):** Most comments revolved around the challenges clients faced accessing Housing services. Specific challenges cited included needing more interaction with housing staff and not knowing how to get housing help. There were also a few clients who cited positive housing experiences that ended up being transformative.

"Get more interaction and help with housing."

"[Agency name] helped me alot. But the communication & clairity was dismal especially once the pandemic began. That was the biggest reason I moved out of my housing. I wanted to leave before I was in a position where I might lose my housing. It was very difficult to ask questions & get answers from my caseworker who oversaw my housing & financial stuff for said housing. So when the opportunity came to move into a less uncertain situation with family, I took it."

"Thanks to the Ryan White Care Act I didn't loose my apartment thanks to the rental assistance I have received thank you so much..."

**Population-Specific Trends:** There were no noted substantive differences of the types of Addiction/Recovery comments provided by client respondents across various demographic categories (Disability/55+/BIPOC/LGB+/Gender Diverse).

KEY FINDINGS: Respondents cited the need for more housing, in general, and housing services including more communication and follow up with housing staff, help with accessing temporary housing, and assistance in dealing with an eviction.

**Dental/Oral Health Services:** Dental/oral health services represents the service category for which respondents wrote the seventh highest number of comments (n=78 comments). The majority of dental/oral health services comments focused on service quality and access to dental services, including care facilitators. Dental care barriers and gaps are also incorporated into the dental services themes described below.

Dental Service Quality (n=33): Most dental service quality comments focused on positive descriptions of the dental care services, including the professional, caring and friendly RW dental care staff and that the services they provide are cost-prohibitive for many clients, yet critical for PLWH. "They provide services that are expensive and necessary to live in todays society with some modicum of self esteem."

Some dental service descriptions were negative (less than 10 comments), including having

Dental/Oral Health Services: Themes (n=78)

Facilitators, 15

Service
Quality, 33

Barriers, 4

Nothing Else
Needed, 2

Gratitude, 4

Service Gaps, 5

Access to Services,
32

unresolved dental issues after treatment, not being respectfully treated or listened to and/or not liking the involvement of dental students in the care received.

#### Access to Dental Services (n=32) focused on:

- Dental services expansion, including being accessible to patients residing outside of the Portland TGA and wanting additional RW dental service provider options beyond the single funded TGA provider.
- Additional dental services needed, including dental implants; emergency dental care; extensive dental care caused by addictions; use of nitrous oxide/sleep dentistry to help with dental anxiety; and expanded, more rapid dental appointment availability in

general and specifically with dental pain management and periodontal appointments. *"I need a new partial and can't get one."* 

 Additional dental care facilitators, such as co-located dental services with medical care and more "comfortable, spacious" dental offices and upgraded equipment.

Some respondents also described that one of the things they did to stay healthy during the pandemic was to start receiving dental care services again.

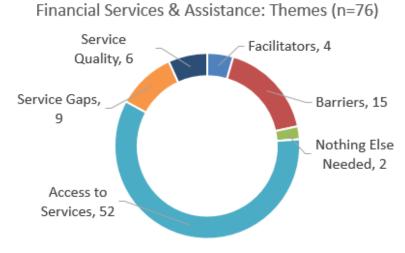
**Population Specific Comments:** A higher percentage of written comments were provided by respondents over 55 years of age around dental care. When examining dental service access comments by age, clients 55 years of age and older indicated that getting implants, dentures, and partial dentures were current service gaps. Clients less than 55 years of age indicated emergency dental services were needed, as well as information on how to access dental services, in general.

KEY FINDINGS: Most Dental Service patients had positive care experiences. Suggestions to improve these services included expanding dental services beyond the TGA coverage area and improving access to dental implants, emergency dental care, dental care caused by addictions, use of nitrous oxide/sleep dentistry to help with dental anxiety, and faster dental appointment availability. The need for upgraded equipment and more comfortable offices was also suggested.

**Financial Assistance Services:** Financial assistance services/bill assistance represents the service category for which respondents wrote the eighth highest number of comments (n=76 comments). The primary themes related to financial assistance services focused on access to these services (n=52) and service barriers (n=15). The questions in which financial assistance was most frequently mentioned pertained to where there were services and/or information that were not currently available or in relation to main gaps in food support.

Access to Services (n=52): Several respondents described areas in which access to more financial services and financial assistance was needed and/or information around what financial assistance existed outside of RW services, including:

 Financial mentoring/planning, budgeting, career path and other economic development opportunities



- More food financial support related to current low assistance amounts and rising cost of food
- Housing, rent and moving assistance
- Bills, utilities, and phone assistance
- Student loans, scholarships, and tuition assistance
- Transportation assistance, including gas money, Trimet/HOP cards, etc.
- Assistance with debt reduction, medical debt reduction, taxes, fraud, etc.
- Money and income, in general and related to COVID-19

**Service Barriers, Gaps and Quality** (n=40): The primary barrier to financial assistance that respondents described was having a source of income that was too much to qualify for needed assistance, but too low to be able to cover basic needs, such as food, housing, bills, transportation assistance, etc., as well as the rising costs due to inflation. Respondents also described assistance needs related to the complexity of medical/medication coverage and that associated bills cannot be paid when there is inadequate insurance coverage. Some respondents described their frustration with answering a needs assessment survey versus RW funds being used for direct financial assistance.

"Electrical Assistance (got from [agency name]), holiday meals"

"I'll take care of myself for the Covid 19. Help me pay my bills."

While clients described a number of barriers and service gaps related to financial assistance, there are currently limitations to RW funding resources. Currently, Ryan White fundable emergency financial assistance is limited to "one-time or short-term payments to assist clients with an urgent need for essential items or services necessary to improve health outcomes, including utilities, housing, food (including groceries and food vouchers), transportation, medication not covered by an ADAP or LPAP, or another Ryan White HIV/AIDS Program (RWHAP)-allowable cost" and cannot be used for long-term financial assistance or mentoring services.

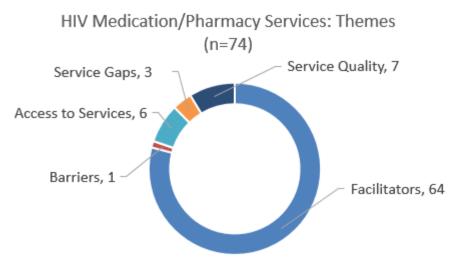
**Population Specific Comments:** A higher percentage of written responses around financial assistance were provided by BIPOC respondents and respondents experiencing homelessness. BIPOC respondents provided the majority of responses regarding assistance need with financial mentoring and student loan/tuition assistance.

KEY FINDINGS: Respondents cited the need for more information about financial assistance and services beyond those currently covered by RW. Also noted as barriers were that funds are too limited, that the eligibility criteria to qualify for financial assistance is too restrictive, and inflation impacts the ability to access services and afford basic needs.

**HIV Medication/Pharmacy Services:** HIV medication assistance and pharmacy services represents the service category for which respondents wrote the ninth highest

number of comments (n=74 comments). The majority of comments related to HIV medication and/or pharmacy services were descriptors of care and health facilitators (n=64) and related to the question of what clients did to remain healthy in the last 12 months.

**Facilitators** (n=64): Out of the 386 written responses provided by clients on the 3 main things they did to stay healthy, taking HIV medications regularly or improving medication



adherence was described by approximately 1 in 6 clients (n=60). Other key facilitators to care and/or health outcomes include financial assistance with medications and medical case management (MCM) partnerships around medication management. "It has been and will to continue to be a vital service that I need to financially afford my HIV medication."

Other respondent comments primarily described some of the access issues, barriers and improvement suggestions within the RW system regarding HIV medications and/or pharmacy services, including:

- After hours/weekend pharmacy hours
- Additional mail order pharmacy options (e.g. "Options for mail order pharmacies other than CVS and Credena")
- Additional CAREAssist (CA) cooperating pharmacies options for easier medication filling coordination or reimbursement options for non-CA pharmacies

Other individual comments expressed gratitude for the medication assistance received or concern with ability to access ongoing HIV medications.

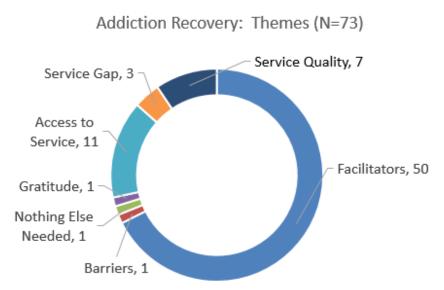
**Population Specific Comments:** A lower percentage of respondents with disabilities provided open-ended responses around HIV medications/pharmacy services. Respondents 55 years of age or older described the majority of access issues and improvement suggestions, while respondents that have experienced homelessness and those that are gender diverse described HIV medication/pharmacy services only in terms of self-care and what they did to stay healthy.

KEY FINDINGS: Respondents noted how taking HIV medications regularly and improving their medication adherence contributed to their staying healthy. Service access issues noted included limited pharmacy hours, needing additional mail order pharmacy options and the limited number of pharmacies that accepted CAREAssist.

**Addiction/Recovery Services:** Addiction and Recovery Support services represents the service category for which respondents wrote the tenth highest number of comments (n=73). Because a smaller number of survey respondents' comments were categorized as related to Addiction/Recovery, a breakdown of all of the emergent themes will not be provided. However, the primary themes of Facilitators/Healthy Behaviors and Access to Services are explored below.

Facilitators/Healthy Behaviors

(n=50): Clients were asked to comment on the healthy activities they engaged in during the pandemic. A total of 44 clients reported accessing Addiction/Recovery services and/or or harm reduction actions related to alcohol, drugs, and/or cigarettes as one of the things they did to stay healthy. Examples of recovery behaviors included involvement with 12 step meetings, recovery support



services, staying sober, cutting back on methamphetamine use, drinking less alcohol, and stopping shooting up. "I'm really trying to eat healthier. I'm constantly seeking mental health support, and I've stayed clean."

Access to Services (n=11): Clients who received Substance Use Disorder (SUD) services were asked about their service experience. A total of 19 clients wrote a variety of comments ranging from a report about length of sobriety to general comments about the services received (e.g. "good experiences...", "Poor!"). There were also clients who reported they needed these services but could not access them. A few suggested sober mentors or others to help connect to these services. "Yes I wish I could have somebody help me get into drug and alcohol treatment..." Finally, some clients also cited wanting to continue addiction recovery services virtually or online.

**Population-Specific Trends:** There were no noted substantive differences of the types of Addiction/Recovery comments provided by client respondents across various demographic categories (Disability/55+/BIPOC/LGB+/Gender Diverse).

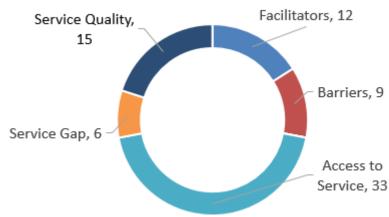
KEY FINDINGS: Participating in addiction/recovery services and/or engaging in harm reduction actions related to alcohol, drugs and/or cigarettes were cited as behaviors respondents did to stay healthy. The need for more peer services or navigation support connecting to addiction/recovery services was indicated. Respondents also want to continue virtual access to addiction/recovery services.

# Information and Referral Services: Information/Referral services represents the

service category for which respondents wrote the eleventh highest number of comments (n=58). Information and referral services are often not services in and of themselves. These services are often part of the structure of the Ryan White service system, where all service providers provide information and referrals to various resources in the community.

Access to Services (n=33): Client respondents cited many services for which they needed additional

Info/Referral: Themes (N=58)



information and referral to access. These needs were wide-ranging and included the following: chiropractic care, computer assistance, services for former inmates, financial mentoring, insurance assistance, domestic violence help, affordable meal planning, legal Social Security Disability (SSD) help, HIV medication options (once per month), dental, more information on housing options, how to change providers, COVID information, better communication both within agencies and between them, and information about the Ryan White system.

"I've tried, without success, to find organizations that seek to provide support and navigation for former inmates needing help (resources, socialization, etc.)...[Agency Name] Community Corrections discerns a need, as recidivism has skyrocketed during COVID, but they have no resources..."

In terms of how best to convey updates, several client respondents had the following ideas:

"Having a good quarterly newsletter that included HIV information - or links to such information and announcements of upcoming events."

"Do [not] just limit information to [those] who are there. There should be a 411 to everyone"

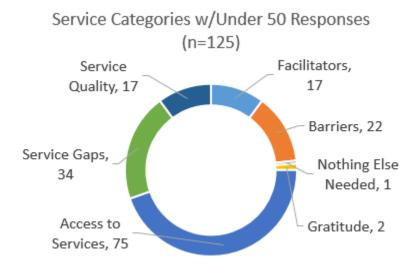
**Population-Specific Trends:** There were no noted substantive differences of the types of Addiction/Recovery comments provided by client respondents across various demographic categories (Disability/55+/BIPOC/LGB+/Gender Diverse).

KEY FINDINGS: A wide range of information and referral support networks are needed to access various services including medical, insurance, financial, housing, legal and social services.

**Service Categories with 50 or Fewer Comments:** There were four remaining service category areas in which there were fewer than 50 open-ended responses provided. The main themes found across the remaining service category responses can be found to

the right. The majority of client comments focused on access to services and service gaps, which are described below with other primary themes identified accordingly.

Other Service Categories: There were 42 comments that addressed the service category of Other Services. The majority of comments fell into the two themes of Service Gaps and Access to Services. Many Service Gaps responses cited the need for legal services. There were also a few comments about needing



in-home care services. Access to Services responses also mentioned the need for in-home care services and needing emotional and mental health support. "At-home nursing support & at-home physical/occupational therapy & massage therapy & chiropractor."

**Transportation:** Comments that discussed the service category of Transportation (n=39) fell primarily into the theme of Access to Services (n=35). Many of these comments noted the need for transportation to get food including transportation to grocery stores and food pantries (e.g. "Limited access within walking distance, need rides to stores," "Far from food banks"). There were also a few comments about needing transportation to medical services. Some respondents stated that they needed assistance to buy gas.

**Insurance:** There were a total of 32 responses that described insurance services. The majority of these fell into the themes of Service Quality (n=10) and Access to Services (n=9). In terms of Service Quality, the comments focused on appreciating the help received to get insurance to pay for medical services and care: "helping me navigate my medical insurance needs during life/job transitions." Responses that discussed Access to Services discussed how they received help to enroll in medical insurance but expressed some frustration with accessing mental health services with Medicare: "I have been looking for Mental health for months. No one is making recommendations and when I do get a name or referral, they won't take medicare. very frustrating."

**Employment/Job Support:** There were 22 responses about Employment/Job Support. Of these, 13 responses discussed the theme of Access to Services especially around the need for career development and finding a job: "Financial mentoring. Career path development and grants." Respondents also described needing assistance with navigating the unemployment system.

#### **ALL OTHER QUALITATIVE RESULTS:**

Around one-third of written respondent comments (n=1,045) did not have a distinct service category associated with the response. The table below described the number of responses by question asked for which there were no specific service categories mentioned.

Table 5. Responses with No Associated Service category by CES Question

Open Ended Question	n	% of total comments
Ryan White Service System Comments	201	83%
Additional COVID precautions	156	72%
Public Emergency/Information Gaps	139	67%
Healthy Behaviors	120	31%
Service Gaps	117	44%
Like Most About Agency/Services/Staff	92	24%
Continued Services - Virtual/Online	78	29%
One Improvement	62	21%
Additional Satisfaction Comments	32	22%
Newly Diagnosed Service Comments	8	67%
Addictions/Recovery Support Experiences	2	10%

Examination of the responses for which there were no service categories mentioned revealed the following:

**RW Service System Comments:** The majority of the 201 non-service specific comments about RW services were positive in general (84%), with many different expressions of gratitude:

"I have used Ryan White services since their beginning, I'm alive today because of them! I know many others in the same situation"

"Excellent in my case, always protected, well served and grateful"

Over half of the remaining comments either indicated that respondents did not have additional comments, while 12 comments provided additional comments around general RW service improvements needed:

"Get rid of red tape archaic process that prevent people like me from getting services... we are dying in the waiting line."

"there needs to be more funding for hiv services.."

**Additional COVID Precautions:** 149 out of 217 written comments (69%) indicated that no additional covid precautions were needed or that respondents did not know or could not think of any additional actions RW services could take. The remaining 7 comments not associated with a service category were mainly client indications that they did not believe COVID-19 existed.

**Public Emergency/Information Gaps**: 138 out of the 208 responses (68%) for this question indicated that no additional information on public emergencies or otherwise were needed.

Healthy Behaviors: 120 out of the 386 comments (31%) provided were not directly related to a specific service category. Around half of these responses (46%) pertained to individual exercise (e.g. walking, hiking, biking, working out, exercise, etc.). Of the remaining responses, 1 in 5 comments were related to general COVID safety precautions (e.g. wearing a mask, washing hands, staying home/isolating, etc.), while the majority of remaining comments focused on some aspects of personalized self-care (e.g. more sleep, meditation/mindfulness, volunteering, movies, art, etc.).

**Service Gaps:** 101 out of the 117 comments (86%; 38% of total service gap responses) suggested no service gaps existed (e.g "no", "none", etc.) or none that could be thought of at the time of the survey (e.g. "not at this time," "can't think right now," etc.). The remaining 16 responses indicated that there were service gaps, but did not indicate what they specifically

were (e.g. "yes," "I don't know all of the services entirely...", etc.) or listed services not usually related to RW and/or federally funded services (e.g. "my faith community...", etc.).

**Continued Services - Virtual/Online:** Over 40% of the 78 continued virtual/online service comments that did not mention a specific service category primarily addressed:

- the type of virtual service contact preferred (e.g. "zoom," "phone calls," "online scheduling," etc.)
- That services should remain virtual in general (e.g. "continue virtually," "anything that would save driving time," etc.)

Close to 50% of the remaining comments said that no services should remain virtual, a preference for in-person services, or that a mix of virtual and in-person services were preferred, but without naming a service category.

All Other Comments: The majority of the responses for the remaining questions focused on satisfaction with services where respondents did not name a specific service category nor could a service category be inferred through staff names mentioned. Around 4 out of 5 of the remaining comments were generally positive in nature (e.g. "the staff is awesome," "they know their job," "it is open and welcoming," etc.) or stated that no improvements were needed. The remaining comments described service experiences, environments, and/or improvements that could not be attributed to a specific service category, but are in alignment with other thematic descriptors found in the Service Category Qualitative Results section above. All RW agencies received their specific anonymous client satisfaction responses, regardless of service categories mentioned, to inform their service improvement efforts.

#### **NEXT STEPS:**

These qualitative findings will be disseminated to the Portland TGA Planning Council and other community partners, as applicable, for use and incorporation into service guidance, resource prioritization and program planning efforts. HGAP and the Portland TGA Planning Council will determine additional quantitative and qualitative result dissemination efforts, as needed, to further develop actionable service improvement priorities and alignment with the upcoming 2022-2027 Oregon and Washington Integrated Comprehensive Plans.

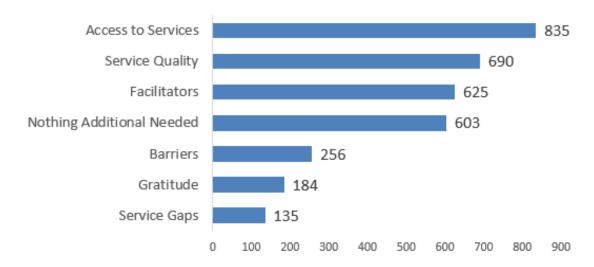
# **APPENDIX A:** List of Primary Qualitative Codes

Table 1 List of Primary Codes

Agency	Service Category	Primary Themes	Sub-Themes
PP Quest CAP SW CAP PDX HSC EMO Russell CareAssist Other Non-RW Agency	<ul> <li>Dental</li> <li>Employment/Job Support</li> <li>Medical</li> <li>Pharmacy/Medication</li> <li>Housing</li> <li>Financial/Bills</li> <li>Food</li> <li>Mental Health/ Psychotherapy</li> <li>Addictions/Recovery Support</li> <li>Psychosocial Support</li> <li>Case Management</li> <li>Insurance Services</li> <li>Transportation</li> <li>Information and Referral</li> <li>Other Service Category</li> </ul>	<ul> <li>Access to Services</li> <li>Service Gaps</li> <li>Service Quality</li> <li>Barriers</li> <li>Facilitators</li> <li>Gratitude</li> <li>Nothing Additional Needed</li> </ul>	<ul> <li>Positive Service/Care Experience</li> <li>Negative Service/Care Experience</li> <li>Positive Built Environment</li> <li>Negative Built Environment</li> <li>Negative Built Environment</li> <li>Communication Modes &amp; Preferences</li> <li>Eligibility &amp; Affordability</li> <li>Service &amp; Service Network Support</li> <li>Availability:Time, Hours, Scheduling</li> <li>Advocacy</li> <li>Social &amp; Social Network Support</li> <li>Covid-Related Items</li> <li>Self Care</li> <li>Healthy Diet/Healthy Foods</li> <li>Harm Reduction</li> <li>Safety Related</li> <li>Stigma and Discrimination</li> <li>Population Specific Needs</li> </ul>

APPENDIX B: The Total Number of Written Responses by Main Themes and Sub-Themes

# CES Written Responses by Main Themes



# CES Written Responses by Sub-Themes



**APPENDIX C:** Statistical Differences in the Number of Service Category and Main Theme Comments by Respondent Demographics

	BIPOC	Client w/Disabilities	55+	LGB+	Gender Diverse/ Transgender	Homelessness
Service Categories						
Addictions/Recovery Support			lower %			higher %
Case Management		lower %				lower %
Dental			higher %			
Employment/Job Support			lower %			
Financial/Bills	higher %					higher %
Food	higher %	higher %				higher %
Housing		higher %	lower %		higher %	higher %
Information and Referral	higher %					higher %
Insurance Services						
Medical	lower %					lower %

Mental Health/Psychotherapy	lower %	higher %			higher %	
Other Service Category		higher %	lower %			
Pharmacy/Medication		lower %				
Psychosocial Support		higher %	higher %		higher %	higher %
Transportation		higher %				higher %
Main Themes						
Access to Services		higher %			higher %	higher %
Barriers		higher %	lower %	higher %	higher %	higher %
Facilitators						
Gratitude						
Nothing Additional Needed		lower %	higher %	lower %	lower %	lower %
Service Gap		higher %				higher %
Service Quality						