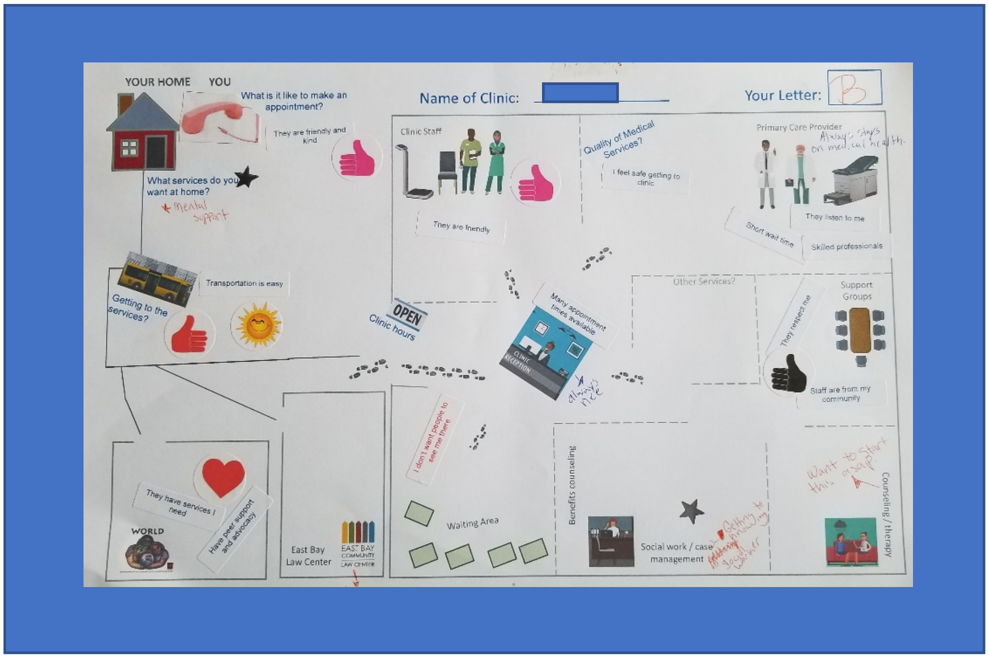
FAMILY CARE NETWORK NEEDS ASSESSMENT

FINAL REPORT

DESCRIPTION

The Family Care Network (FCN) is funded by Ryan White Part D to provide primary care and support services to women, infants, children, and youth (WICY) living with HIV in Alameda and Contra Costa counties. This needs assessment focuses on better understanding how best to meet the needs of WICY, including trans women and trans youth, who use FCN services.

Report prepared by Facente Consulting
September 2019



Needs assessment participant's picture representing their experience with FCN services

ACKNOWLEDGMENTS

We would like to thank the Family Care Network staff who took time out of their busy schedules to help guide the needs assessment, distribute and collect the client surveys, and share their knowledge about the clients and communities they serve. We would also like to express our gratitude to the clients living with HIV who participated in focus groups and interviews. Their insights were invaluable to understanding the client needs presented in this report.

FAMILY CARE NETWORK

Alameda Health System (AHS) Adult Immunology Clinic

East Bay AIDS Center at Alta Bates Summit Medical Center

East Bay AIDS Center Downtown Youth Clinic

East Bay Community Law Center (EBCLC)

La Clinica de la Raza

UCSF Benioff Children’s Hospital, Oakland Pediatric AIDS/HIV Program

Women Organized to Respond to Life-threatening Diseases (W.O.R.L.D.)

Report prepared by:

FACENTE CONSULTING
UNDERSTAND • IMPLEMENT • TELL YOUR STORY

EVALUATION, RESEARCH AND TRAINING
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TABLE OF CONTENTS

I. BACKGROUND AND PURPOSE

The Family Care Network (FCN) is a Ryan White Part D-funded collaboration that provides services for women, infants, children, and youth in Alameda and Contra Costa counties. The FCN partner agencies are: Alameda Health System (AHS) Adult Immunology Clinic; East Bay AIDS Center (EBAC) at Alta Bates Summit Medical Center; EBAC Downtown Youth Clinic; East Bay Community Law Center (EBCLC); La Clinica de la Raza; UCSF Benioff Children's Hospital, Oakland Pediatric AIDS/HIV Program; and Women Organized to Respond to Life- threatening Diseases (W.O.R.L.D.)

In 2019, the FCN contracted with Facente Consulting, in collaboration with Evaluation Research and Training, to conduct a needs assessment in order to get input from clients and service providers. The purpose of this needs assessment was to document client needs (met and unmet), using a whole-health (not just HIV-focused) approach. Generally, published literature suggests that individuals with fewer unmet needs are more likely to consistently engage in primary care. Therefore, the more service providers understand client life experiences, barriers to care, and needs, the better equipped they will be to design programs and to provide the support that clients need to stay engaged in care.

This report describes the findings from surveys, interviews, and focus groups conducted with FCN clients, service providers, and partners. The report also includes recommendations that can inform FCN's clinical quality management (CQM) efforts and can be incorporated into the FCN Quality Management Plan. The ultimate aim is to improve the quality of services to better meet client needs, allowing them to achieve and maintain viral suppression and experience the best possible health and quality of life.

II. METHODS

This needs assessment was conducted using a mixed methods approach, using both qualitative and quantitative methods to examine the areas of focus.

Data Collection and Analysis

Quantitative Client Survey

A 4-page, primarily quantitative client survey was developed and pilot-tested in collaboration with FCN partners. The partners distributed the survey to a convenience sample of their clients, using various approaches depending on what agency staff thought was likely to maximize response rate (e.g., in person at appointments, via mail). A $2 bill was included as a thank you. The survey is provided in Appendix A. Attempts were made to disseminate the survey at venues outside the FCN provider network to get a broader community perspective, but the three agencies contacted did not participate.

Qualitative Methods

Exhibit 1 summarizes the qualitative data collected. The following methods were used:

- **Group discussions.** A range of focused discussions were held with both clients and FCN providers, using qualitative semi-structured protocols in most cases. Despite multiple attempts, it was not possible to arrange a focus group specifically with Spanish speakers, so all group discussions were conducted in English.

- **Individual interviews.** Individual semi-structured qualitative interviews were held with both providers and clients/members of the communities addressed by the needs assessment. The purpose of the client interviews was to delve deeper into client experiences in a confidential non-group setting. Individual provider interviews were held when needed to fill in data gaps.

All participants gave consent to participate. Focus groups and most interviews were recorded and transcribed; hand-written notes were taken at the Community Advisory Board (CAB) member recruitment events and other discussions and interviews.

Analysis

Quantitative data were analyzed with SPSS software using standard descriptive statistical analysis procedures. Qualitative data were analyzed using Dedoose software with an *a priori* coding structure. The coding structure was informed by a review of qualitative research literature on needs of women (cis and trans) with HIV and the goals of this needs assessment. The coding was refined as needed during the process.

Although most questions were quantitative, the survey contained four open-ended questions. The data from these questions is integrated with the group discussion and interview qualitative data in this report.

Exhibit 1: Qualitative Data Collection Methods				
Clients/Community Members			**Providers**	
Trans women	**Cis Women**	**Youth**	**FCN Providers**	**Non-FCN Providers**
One focus group with discussion and "My Clinic Map" exercise One semi-structured discussion at a Community Advisory Board (CAB) recruitment event Two individual interviews	Two focus groups with discussion and "My Clinic Map" exercise One semi-structured discussion at a CAB recruitment event	One interview with a parent of a teenager with perinatally acquired HIV One interview with the teenager with perinatally acquired HIV	One semi-structured discussion at an FCN provider bi-monthly meeting One group interview with FCN providers serving youth with perinatally acquired HIV Informal discussions with agency staff during the course of needs assessment implementation Interview with medical case manager at Highland Hospital	One semi-structured interview with the Alameda County Public Health Department (ACPHD) Disease Intervention Specialist

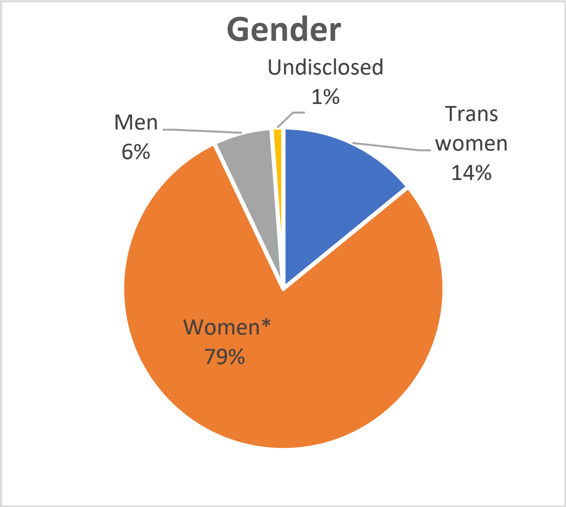
Reporting on Gender Identity in the Findings

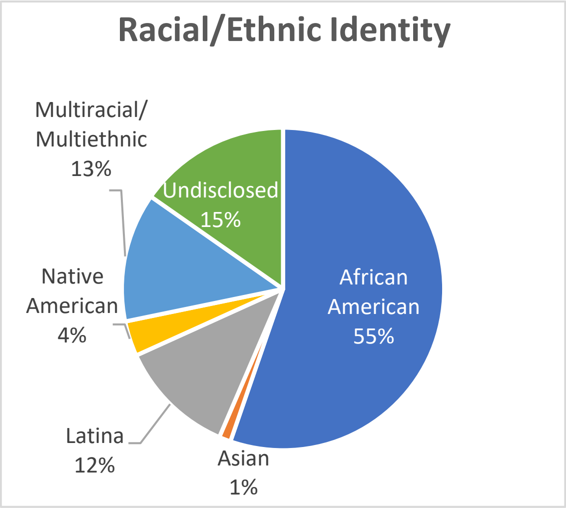
Throughout this report, "trans women" is used in reporting on data where the participant(s) explicitly self-identified as trans women and/or were speaking about the specific needs of trans women. Likewise, "cis women" is used when the participant(s) self-identified as cis-gendered and/or were speaking about cis women's specific needs. When "women" is used, it is inclusive of trans and cis-gendered women either because both were represented in the data being reported, or because the participant(s) did not self-identify as cis or trans.

Client Characteristics

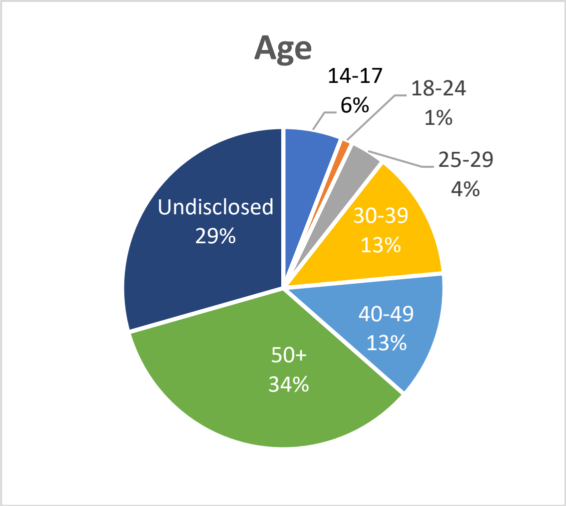
Overall, approximately 85 clients and 25 providers participated in the needs assessment. Demographics and other key characteristics of the clients participating in the needs assessment are presented in Exhibit 2. Group discussion participants were invited to complete the survey; to the extent possible, these individuals are counted only once (unduplicated) in the description of client characteristics.

Exhibit 2: Client Demographics





**Inclusive of cis women as well as a few trans women who did not self-identify as trans.*



Limitations

Because this needs assessment used convenience sampling, the findings may not be representative of all trans women, women, and youth living with HIV in Alameda and Contra Costa counties. Caution should be exercised when interpreting the findings. The data describes the needs of clients who are engaged in care much more than of those who are not engaged in care. The interview with the ACPHD HIV Disease Intervention Specialist, who works with persons living with HIV who are out of care, was conducted in an effort to understand the issues of this population.

In addition, the sample size was relatively small, and therefore the findings may not be generalizable to all FCN clients or communities.

III. FINDINGS

Introduction

Overall, needs assessment client participants described not only their HIV-related needs, but also needs and desires that go beyond the boundaries of what is traditionally considered HIV care. Many clients spoke of their plans for the future, emotional growth, and the ways they are contributing back to their communities – a sign that the message has been widely embraced that HIV is no longer a "death sentence." Participants spoke of life goals, such as losing weight or getting fit. One participant said that his slight speech impairment bothers him more day-to-day than does his HIV. He is currently making plans to attend college. A woman in her 30s said her goal was to study to become a medical assistant. These are the aspirations and hopes of people with HIV in the era of extremely effective antiretroviral therapy. As further evidence of how HIV treatment has improved quality of life for people with HIV, of the 48 survey participants who answered the question on how often they cope well with their HIV, 92% responded they cope well "almost always" or "most of the time."

The findings also show the very real challenges that people living with HIV still face. From stigma and discrimination, to homelessness, to depression and isolation, there are still many hurdles for people with HIV. Those who did not participate in the needs assessment are likely those least engaged in care, and therefore have more dire and urgent needs than those whose perspectives are represented. At nearly every needs assessment meeting with an agency, a provider or staff person mentioned having a client who had died recently. This is evidence that not all people with HIV in Alameda and Contra Costa counties are being reached or served effectively. Although this needs assessment, like services, did not for the most part reach these extremely vulnerable and marginalized people with HIV, where possible, their voices are represented by the participating service providers who care for them.

Quantitative Survey Findings

Fifty-six participants completed the survey, with clients of all the FCN agencies represented; 43 were completed in English and 13 in Spanish. Of the 56 surveys, 4 were completed by parents of children with HIV. The survey asked questions about four categories of services: Medical, Emotional Support, Financial/Legal, and Practical Support. Respondents were asked whether they received the service and if they did, whether they continued to need the service. If they had not received the service, they were asked if they do not need the service, need it somewhat, or need it a lot. **Exhibit 3** shows the percent who received each type of service, the percent of respondents who need the services (total need), and the percent of respondents who need the services but haven't received them (unmet need). The table ranks the services from highest to lowest unmet need.

Exhibit 3: Services Received and Needed, Ranked by Level of Unmet Need

Service Type	Service	% Unmet Need*	% Total Need†	% Received service‡
Basic	Transportation Vouchers	24%	60%	41%
Medical	Nutrition Counseling	23%	57%	46%
Personal	Work / School / Skills Development**	21%	46%	27%
Emotional	Spiritual Support	20%	63%	47%
Medical	Dental	18%	75%	66%
Basic	Food Bank/ Food Pantry	18%	63%	50%
Emotional	Group Social or Recreational Outings	18%	59%	43%
Personal	Support for Safety Concerns	18%	32%	14%
Medical	Pain Management	16%	37%	25%
Emotional	Peer Support / Peer Advocacy	15%	53%	43%
Medical	Eye Care	14%	77%	73%
Emotional	Counseling / Therapy	14%	64%	52%
Emotional	Support Groups	14%	68%	58%
Legal	Legal Services	12%	37%	32%
Basic	Housing (Finding or Keeping)	11%	57%	57%
Personal	Home Help for Personal Care	9%	25%	20%
Emotional	Substance or Alcohol Use—outpatient	7%	16%	27%
Medical	Gender-affirming Care	6%	15%	20%
Basic	Benefits Assistance	5%	55%	63%
Emotional	Psychiatrist (adjust medications)	4%	28%	27%
Emotional	Substance or Alcohol Use--inpatient	4%	9%	22%
Personal	Disability Adaptive Equipment	4%	15%	13%
Personal	Childcare	4%	6%	7%

*Unmet need is the percent of participants who reported they have not ever received the service but they need it.

†Total need is the sum of unmet need plus the percent of participants who have received the service and continue to need it (unmet need + ongoing need)

‡Received service is the percent of respondents who reported they had ever received the service.

** Finding work, finishing school, classes for new skills like computers, music, crafts, etc.

Key findings are as follows:

Total Need

- Most respondents need Eye Care and Dental Care (77% and 75%, respectively), and most have received these routine medical services.
- After dental and eye care, the greatest needs were for Support Groups (68%) and Counseling/Therapy (64%).
- The greatest need in the basic needs category, and ranked fourth overall, was Food Bank/Food Pantry (63%).

Unmet Need

- Transportation vouchers had the highest level of unmet need (24%), followed by Nutrition Counseling (23%), Work/School/Skills Development (21%), and Spiritual Support (20%).
- Nutrition Counseling had the highest level of unmet need of all the medical services.
- Spiritual Support had the highest level of unmet need of the social / emotional /behavioral services.
- More survey respondents have received Support Groups and Counseling/Therapy than any other emotional/support service listed, yet these is still moderate unmet need for these services (14%).
- More than one-third of respondents need Pain Management services (37%), and more than half of these respondents report unmet needs in this area.

Qualitative Findings

The following description of findings integrates the qualitative data on client needs from the survey, as well as provider and client group discussions and interviews. The data can be summarized as eight key needs, grouped by theme (in no particular order).

BASIC NEEDS	1. Housing, mental health, and substance health
	2. Foundational stability and financial well-being
PERSONAL AND SOCIAL NEEDS	3. Personal and spiritual well-being
	4. Social connectedness
DIGNITY	5. An end to stigma and discrimination
	6. Respect
QUALITY SERVICES	7. Accessible services
	8. Skilled and culturally humble providers

The following sections describe each of these needs in detail, and the related recommendations from clients for addressing those needs and improving FCN services.

NEED 1: HOUSING, MENTAL HEALTH, AND SUBSTANCE HEALTH

The trifecta of homelessness, mental health disorders, and substance use are widely understood as significant barriers to care engagement, although participants did not highlight these needs as much as others. The interview with the HIV Disease Investigation Specialist at the Alameda County Public Health Department shed some light on a likely explanation for the relative dearth of client comments about homelessness, mental illness, and substance use. She estimates three-quarters to four-fifths of clients she works with who are out of care or only intermittently engaged experience methamphetamine addiction, mental illness, homelessness, or some combination. These populations by and large did not participate in the needs assessment, since participants were recruited via service providers. What participants did say about their needs in these areas is discussed below.

Housing Services

Participants described how the lack of stable housing can get in the way of accessing services: "*Housing problems makes it hard to call*," noted one trans woman. Stable housing is not enough, however, according to participants; the housing also needs to be safe: "*A lot of people don't have housing. I was homeless for a while. I finally got my place now. And then the place is a dangerous neighborhood. You can't move. You just have to stay where you are. Cause if you ain't got no money to pay straight up rent, it's hard*."

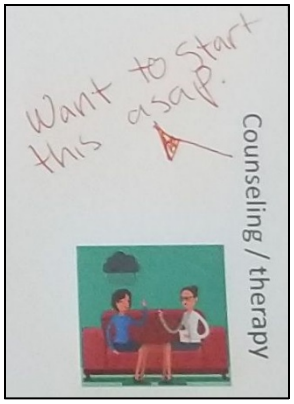
Clients noted housing as an area needing expanded services, and not just services to address homelessness. Client suggestions for service improvements included: "*Homeless support*," "*More housing resources*," "*Safe, affordable housing*," "*Housing and mental health*," and "*Reduction in homelessness for mentally ill persons*." Although Latinas made up 12% of clients participating in the needs assessment, it is noteworthy that in focused discussions and survey write-in responses they represented 42% of those who said they need housing services.

> **"I want to move to a peaceful, quiet place."**
>
> —Native American cis woman
>
> **"I don't ask you to put me in a condo where I can see the Bay Bridge. I want something nice, clean, comfortable, and safe."**
>
> ---African American trans woman

FCN providers also acknowledged the impact of the Bay Area housing crisis and indicated a willingness to find ways to increase coordination of resources for finding available housing, information about housing strategies, and advocacy efforts.

In addition to comments on basic housing needs, 25% of clients and several FCN providers commented on the need for better housing or amenities. African American participants were much more likely than Latina participants to want better housing or amenities, 71% compared to 19%. Desires included more space, home ownership, home and cleaner, safer, more comfortable living situations.

Mental Health Services



Focused discussions with both clients and providers indicated a need for increased focus on mental health services. Although the term "trauma" was not often used, the experiences they described fall into that category. A youth-serving provider pointed out that many of their clients have lived in environments where *"it's very challenging for them because the parents are struggling still. Many of them live in a single-parent home. Many of them are in abusive or neglectful environments*." A trans woman in her 50s described her childhood. "*My mother was a country girl with no support. She didn't know what to do. …it was atrocity after atrocity after that; she had no idea…Anyway, I have come to honoring myself and my life today and addressing this [childhood trauma]."* One woman spoke of the depression she experienced when first diagnosed: "*I used to work like all the time. Then, it's like I kind of got in this little depression-mode type thing. So, I didn't want to work anymore. I was kind of giving up."*

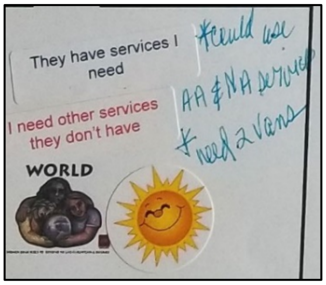
FCN providers also recommended more mental health (and substance use) services, beyond support groups. One provider noted there is especially a dearth of Spanish-speaking therapists. Children and youth have specific needs, including neuropsychological testing to assess the effects of HIV on their development. An FCN provider recommended "*support for internationally adoptive children/families: mental health, effects of institutionalization, attachment issues, cognitive concerns*."

Providers emphasized the challenges around access to appropriate mental health care. One provider explained, "*You have to see a therapist before a psychologist, and the therapists are backed up.*" Another indicated, "*The FCN needs psychiatrists in the mix. I have some homebound people too mentally ill to take meds. Some have anger problems and have been kicked out of the clinic. We need mental health practitioners with prescribing privileges*."

> **"I feel like the services are already strained for mental health. Prior to that we would refer people to somewhere and there would be a three-month wait before they could get in and that's not appropriate for somebody that is having a mental health crisis."**
>
> --FCN service provider

Substance Use Services

A handful of clients recommended AA and NA materials, such as daily meditations, be widely available at clinics.



A youth-serving provider noted the need to be able to quickly place clients who are ready for substance use treatment. "*I've had a number of youth who are ready to quit on Tuesday…when that window opens you need something available on that Tuesday. Because there's a very small window of opportunity."* Another HIV provider noted that, "*We need board and care facilities that can do for HIV what DOT [Directly Observed Therapy] does for TB, ensuring medical compliance*." Finally, another noted the need for more dual diagnosis (substance use and HIV) beds.

Recommendations

1.1 Expand housing services, both to address homelessness and to help clients find and keep safe, affordable housing.

1.2 Increase collaboration across FCN partners to share information about housing opportunities.

1.3 Expand residential care beds for people with HIV who have complex medical, mental health, and substance use disorders.

1.4 Improve access to appropriate mental health care by adding psychiatric services within FCN.

1.5 Streamline the pathways within the FCN mental health continuum of care, to ensure timely access to appropriate care, such as addressing referral processes.

1.6 Make mental health services, including psychiatric services, available in Spanish and other languages to the degree possible (e.g., consider medical interpreters if needed).

1.7 Make substance use education and support materials more available, including Alcoholics Anonymous and Narcotics Anonymous information.

1.8 Work to expand access to substance use treatment on demand, so that when clients are ready for treatment they have a place to go that same day

1.9 Participate in policy change/advocacy efforts related to expand affordable housing opportunities, expanded mental health access, and substance use treatment on demand with same-day availability.

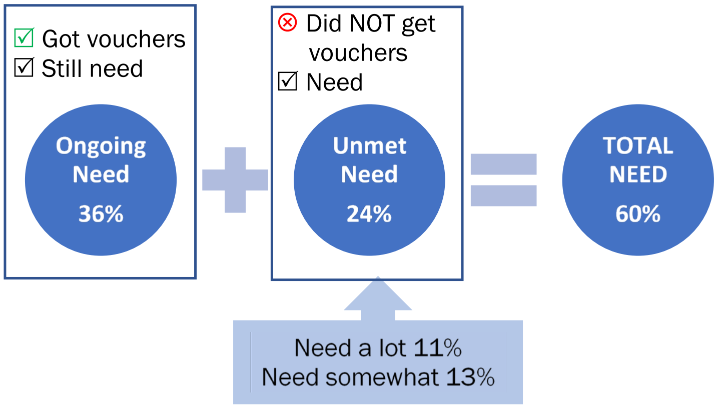
NEED 2: FOUNDATIONAL STABILITY AND FINANCIAL WELL-BEING

“Foundational” refers to the idea that meeting these needs establishes a foundation on which to build engagement in care and improved health. For example, without transportation, people cannot get to appointments. Without money, they cannot readily survive. If they are concerned about legal troubles, or are in chronic pain, taking HIV medication might be low on the priority list.

Transportation

Transportation assistance emerged as a clear need among participants. A total of 60% of survey respondents reported that they need transportation vouchers, and of those, nearly half have not received them.

Transportation Voucher Needs



In addition, four FCN providers and 15 clients made explicit recommendations about transportation to FCN services, including providing transportation to and from services, vouchers or passes for BART, and paratransit. One client noted, “*It’s easier for me to get on BART than bus. We need BART vouchers.*” Another suggested, “*They need to work on getting a medical van. Because we only have one medical ride to pick people up. And have it running every day during the week, not two or three out of the week because people need to get somewhere every day.*”

> **”People need to get somewhere every day.”**
>
> --Participant

Income and Money

Nearly 30% of all clients participating in focus groups, interviews, or the survey commented on income and money issues. Several expressed a goal to have enough money just to pay the rent and buy food. Several participants said they want employment opportunities because they are looking for income beyond any public sector income supports. Seven others want to improve their current income situation with a better job or owning a flourishing business.

Several FCN providers also suggested that clients need improved income or finances. The providers who serve teens with perinatally acquired HIV were concerned about their clients’ ability to earn enough to live in the Bay Area:

> *“If these kids [many of whom have developmental disabilities] just barely passed high school, what kind of job are they going to get that’s going to help them support a lifestyle in the Bay Area? And can they find something full time that provides insurance coverage?”*

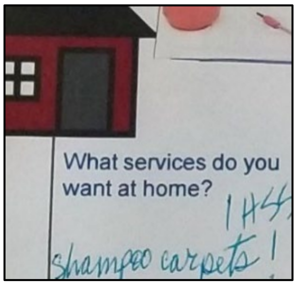
Finally, one participant described difficulties related to obtaining financial assistance:

> *“They make it so hard for you now. At one point, I was getting PG&E paid. Now, you have to show them a bill. They have to see how much you are paying, if you are paying for medical, pills, if you’re staying in the hospital. You have to show receipts*

> *and stuff now. So, it's harder now. It's like bus fare. I started off disabled, so I started off paying $20. Then it went to $26.50. It was $30. Now it's going be $34. So, everything, every year keeps going up. And you only get one check a month. I'm like, how do they expect us to be doing all of this?"*

In-home Services

In-home services were discussed by many in focus groups. FCN providers and clients recommended that women receive more support in their homes, including In Home Supportive Services (IHSS), mental health support, and home maintenance services such as carpet cleaning.



The ACPHD Disease Intervention Specialist suggested a home-based intervention for clients with chaotic lives who have substance use or mental health disorders and who are in poor health. If these clients could start HIV medications at home, they might become well enough to go into a clinic for medical care, where they will also be able to take advantage of mental health/psychiatric services. She suggested partnering with FCN on a small pilot whereby she would accompany a physician and a phlebotomist to a couple of home visits for select persons not in care. Not only will this enable very ill clients to lower their viral load, it will help medical staff better work with similar patients in the clinic.

> "**Doctors need to see the reality of patients' homes—this could lead to better services when they understand the challenges these people live with."**
>
> —Alameda Co. DPH HIV Disease Intervention Specialist

Legal Services

Several participants discussed their needs for legal services. Three African American cis women offered that they need legal services unrelated to HIV. "*I need a lawyer for other reasons: discrimination lawyer*." "*A Lawyer On Hand*." "*I go way out there to see an attorney, I needed to be represented in the court and they didn't offer that*." Providers at the FCN needs assessment meeting noted that trans women need "*Reduced legal barriers based on name and gender markers on ID*."

One Latina client's recommendation for service improvement is "*Legal assistance in this crucial time of new laws."* At the FCN needs assessment meeting, providers pointed to other needed expansion of legal guardianship and conservatorship services.

> **"With immigration and citizenship challenges….youth stay in [domestic or partner violence] situations they wouldn't choose.*"***
>
> –FCN provider serving youth

Support for Safety Concerns

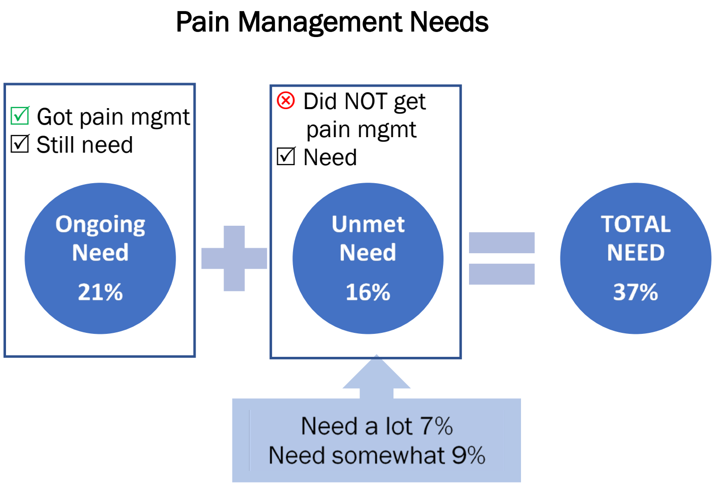
A strong theme that arose at the FCN needs assessment meeting was the need for safety for trans women, on the streets, in their homes, and with intimate partners. Those in two focus groups also stressed the need for safety for cis women, and survey results shown in the "Violence" section below also demonstrate this need. On the survey, 21% reported an unmet need for these services.

Childcare

Given that almost all respondents to this survey are women, there is surprisingly little stated need for childcare. This may be due, in part, to the high percentage of survey respondents age 50 years or older—48%–whose children are grown. The need for childcare was more strongly expressed among providers. FCN providers noted needs for "*Childcare during parents' appointments*," "*Need childcare for women to see their therapist without the children present*," "*Parenting support*," "*Support for young mothers*," "*More services for women as caregivers*," "*Support for women in the role of caregivers*," and other similar comments.

Pain Management

A relatively large unmet need is in the area of pain management. One-quarter of survey respondents have received this service and almost all those (21%) continue to need it; this indicates that a substantial proportion of clients experience chronic pain. Most of the 46% of respondents who have never received pain management services feel they do not need this service, although for 16%, pain management is an unmet need.



Pain Management Needs

Violence

Community, interpersonal, and intimate partner violence can all impact engagement in care. Violence affects not only the victim, but everyone in the community, said several women in a focus group. In particular, they discussed police violence: *"[African American males] cannot have any type of quality of life. Cops are killing people…That also affects the children's quality of life and the parents' quality of life – they are stressing*." One woman noted she is sometimes afraid for her physical safety when taking the bus to access HIV services.

Recommendations

2.1 Increase budgets for transportation and emergency uses such as utility bills.

2.2 Provide or link clients to in-home services, such as personal care services, basic home repairs, and cleaning.

2.3 Improve transportation options for clients to get to and from services, prioritizing those who live further from public transit routes, people who are too ill to travel to services on their own, people with young children, and people with disabilities.

2.4 Expand access to legal services such as accompaniment to court appointments and help with health insurance, eviction, and immigration issues; these services could be provided directly by FCN or through partnership/referral.

2.5 Consider partnering with ACPHD and others to bring medical care to very ill clients in their home environments, with the goal of getting them well enough to be able to engage in clinic-based care.

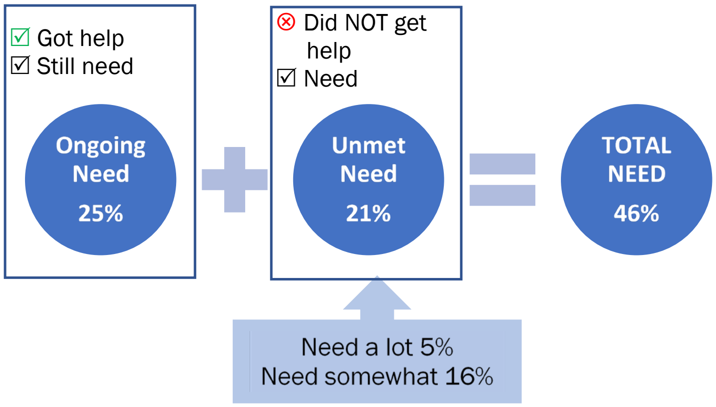
2.6 Ensure that all FCN partners have current knowledge related to federal, state, and local immigration policy and that clients have access to information about their rights.

NEED 3: PERSONAL AND SPIRITUAL WELL-BEING

Supports to Find Work, Finish School, and Develop Skills

Almost one-half (45%) of respondents indicated that they need services to help them find work, finish school, or take classes to learn new skills like computers, music, etc. This need ranked as the third highest unmet need on the survey (21%). This is noteworthy, because it demonstrates that pursuit of future goals is a high priority and support services are needed.

Help with Finding Work, Finishing School, or Developing Skills



Education. Two Latinas in their 30s want to improve their literacy and English language skills. For trans women, FCN providers said they need "*Life skills needed: budgeting, paying bills, applying for job*." A participant at the FCN needs assessment meeting commented that trans women have unmet needs related to "*Goals relative to career, family planning, owning a home, higher learning, etc.*"

> **"Trans women have goals relative to career, family planning, owning a home, higher learning."**
>
> —FCN service provider

The educational needs of youth living with HIV was a strong theme. A parent of a 15-year old girl and FCN providers emphasized the needs for education of youth (including job training and life skills), educational advocacy, and school services. In an interview, a male teenager said, "*I want to travel and go to college*." The parent of a different teenager wants, "*A positive school experience [for my child].*" The providers also said trans youth need more affinity groups in schools. Providers serving youth with perinatally acquired HIV told us that many of these youth have developmental disabilities that make academics extremely difficult, and only a handful go on to higher education.

> *"... very few of the 85 that transitioned out of our program over the years -- maybe 5-8 of them -- have gone on to higher education and 5 of those have graduated. For those few kids, college offers the ability to move out of a more restrictive environment and see more of the world and what they can give back. One of our kids...now she is Master's in Social Work [working] with [the] homeless population. Those success stories are really critical for those kids who can and do have the cognitive capacity to move beyond the high school academic course."*

In addition to higher education, clients told us of learning goals that were not predicated on a four-year college degree. A Latina in her 30s has the goal to, "*Study to become a medical assistant*." An African American cis woman in her 40s wants "*Computer skills*." An African American in her early 20s wants to "*Learn a lot about what I am passionate about*."

Spiritual Support

> **"Me? How do I have a positive headspace? Well, I like to meditate. Turn everything off and put on this meditation app. I have an app on my phone. And it just plays this type of music. And I just play it in my brain. Put my phone on silent, block my calls and just get a good headspace. Because if I don't it feels like I'm helping everyone else except myself."**
>
> --Participant

On the survey, there was a high level of need expressed for Spiritual Support (60%), and it ranked fourth on the list of unmet needs. On the survey and in focus groups, participants talked about the internal landscape of happiness, spirituality, and positivity, and, as one participant put it, *"Growth – spiritually, mentally, emotionally."* Many forms of spirituality were noted as important to participants, including religion and meditation. In addition, they want happiness and positivity in their lives, with comments such as: "*Happiness with self*" and "*Live abundantly*." Another was "*looking for a church to join*."

> "*Actually, quality of life has nothing to do with me. What it does have to do with is my maintaining and honoring the source that provides the opportunity of quality of life. So, for me it's all about that source... I've proven to myself in 55 years that I can't navigate through my human experience on earth without adhering to a spiritual life*."
> – Trans woman

Leadership and Advocacy Opportunities

Although not explicitly asked, many participants spontaneously brought up wanting leadership opportunities. The mother of an HIV-positive teen girl wrote that she wants, "*The opportunity to work for community change*." An African American cis woman in her 30s wrote, "*The ability to serve my community in a more positive way*." A Latina trans woman wrote that something she wants but does not have is a "*Position in the community*." An African American in a cis women's focus group noted, "*I'm looking to work at WORLD helping people and advocate and stuff like that. So, that's what I'm looking now to do. Slowly, see if I like it or not*."

> **"The more I learn, I can go out and teach people."**
>
> --African American woman

Women talked about using their HIV knowledge to teach others: *"As long as I've had the virus, it's always good to know a little more ... That's why I go to these groups to learn more and more and more, so I can go out and preach if somebody say something about the virus. I can tell them all about it."* Others said:

> *"I'm educated on [how HIV is transmitted] now. So now I educate them... you know some people still are ignorant...I'm gonna run it down to them...You can't catch it like this. You can't get it like this. You can only get it like this. That's what I do. The more I learn, I can go out and teach people."*
>
> "[*Quality of life] to me, it's living healthy. I do a lot of outreach and protests. I got groups in Berkeley. It's called Healthy Black Families in Berkeley. And I do stuff for women and children. I'm a water ambassador. I'm a Step member. I go out in the field in communities and get people to join our organization. And people start drinking water and stop drinking sugary drinks and drink more water. And I go to a chef class on Tuesday at the farmers market; she takes us around and shows us how to eat healthy... So, I'm in a lot of stuff*." – African American cis woman in focus group

One African American cis woman spoke of why she protests to organize the community for improved HIV services:

> "*…like the Serenity Prayer, you have to accept the things you can't change and change the things you can. That's why I go out there and protest to make stuff happen to change. I have kids. Ain't no sense in complaining about it if you are going to be part of the problem, not the solution. That's why I'm kind of put myself on the line, like Martin Luther King and all of them. I feel like I'm like them. Nothing's going to happen if you don't get out there, but you hear people complaining. But if you are not getting out there, nothing's going to happen*."

"The CAB should deliver a message of excitement and passion and activism."

--Cis woman

Both FCN providers and clients attending the two Community CAB recruitment events agree that client input is needed and engaging clients in CABs is a worthwhile endeavor. Said one participant, "*CABs hold organizations accountable for capacity building—to change services and structures to meet needs*." Another pointed out, "*The CAB is the centerpiece of the quality improvement effort. It is the group that is the vehicle of change at the agency and network levels*."

Recommendations

3.1 Ensure that clients have access to support to pursue educational, vocational, and other skills development opportunities, either by providing these support services directly or through partnership/referrals to other agencies.

3.2 Use CAB meetings as opportunities for leadership and skills development for CAB members, and create opportunities to use these skills on specific short-term projects.

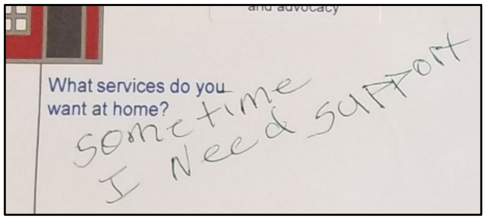
3.3 Create time and space for clients to receive spiritual support and engage in spiritual practice, including meditation.

3.4 Provide or link interested clients to workshops on political advocacy and community activism/mobilization.

NEED 4: SOCIAL CONNECTEDNESS

Overwhelmingly, participants described **social connectedness** as one of the most essential ingredients contributing to their quality of life and supporting their overall health.

Friends, Family, and Relationships



and advocacy

What services do you want at home?

sometime I Need support

Participants across all ages and ethnicities spoke of the great value they place on friends, family, and relationships. Friends, sisters, grandchildren, and spouses were all mentioned as people that participants would like to have more and better relationships with. "*Be able to grow and forge relationships with people*," wrote a young adult at the CAB recruitment event. An African American woman in her 30s wrote: "*Want a dog, a good husband*." An older African American woman, said she wants a "*better life with my fiancé and family*."

Social connection keeps people from falling into isolation and depression:

> *"I really like to stay to myself. But I'm learning I can't isolate myself because that's not good either. I miss out on different stuff because if I sit in the house and different stuff and she [points to another focus group participant] calls and tells me I have to communicate with people."*

> **"You're different [from anyone else you know] until you come to a group like this and we can talk about it. Support is important because you don't know when you're going to break down."**
>
> —Cis woman

> *"I'll say you have to have a personal good headspace and even try to like keep negative energy away. Even though it's hard for that to happen. And if you have close friends or family, a support system, it doesn't have to be a big system it could be one person or two people. You can just have somebody to vent to, so you don't keep all that stuff bottled in."*

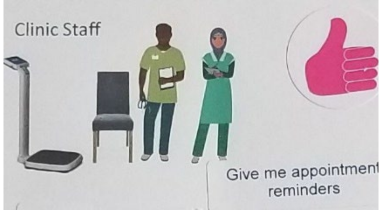
The following quotes also illustrate the importance of family and social connections:

- "My parents have allowed for me to grow up gay. And here recently my parents have agreed for me to have a sex change done." – Trans woman
- "What has helped me achieve my goals is love, religious beliefs, family members, and friends." – Cis woman
- "Some of us come from real fractured and real hurt lives. So many of us come from families that have rejected us and families that don't want no part of us. And most of us have had to create our families ourselves." – Trans woman

Given this expressed need for social connection, it is not surprising that 58% of respondents have attended support groups. Almost all those who have received these two services continue to need them. In addition, 14% of respondents need, but have never received, these services.

Furthermore, when asked what they would do to improve services, numerous clients and providers recommended more support groups, citing particular populations in need including youth, transgender youth, working women, and parents and families of infants and children with HIV. Several providers noted that it would be helpful to apply a model of peer support/peer advocacy to their populations, as well, for example: "*WORLD has peer advocacy for women, but there's been no peer advocacy for youth with perinatally acquired HIV, and this would be very helpful. Even some mentor type – Big Brother, Big Sister, etc.—would help. There's been nothing for the youth*."

Relationships with Service Providers



Although it may not be perceived by providers as social support, many participants gave examples of how valuable it is when their doctor, social worker, support group leader, or other provider reaches out to them. One-quarter of clients told us they feel supported and cared for by Family Care Network providers. This included both Latinas and African American women, trans and cis, alike. "*[What I like about the services is] the care they give us,*" wrote a Latina.

"*They have really helped and when I have a problem. I can reach out to someone at the clinic I use and they help me solve my problems*," wrote a Latina.

This sense of feeling cared for by providers is important as this statement by a trans woman who told us that after her diagnosis, no one called to check in on her. "*[People] need to know there is somewhere they can go to talk to someone…Otherwise the diagnosis will eat you up*."

> **"People need to know there is somewhere they can go to talk to someone…Otherwise the diagnosis will eat you up."**
>
> —Trans woman

In focus groups, interviews, and on the survey, clients recommended appointment reminders and check-in calls after missed appointments – and not just medical appointments. Some clients said they would like to receive a call when they miss a support group or other service. One noted that a check-in call to learn more about the programs and benefits available would have helped: "*Today I just made an appointment with my social worker. Because I've been going here for like 5 years now and have not talked to social workers*."

Recommendations

4.1 Provide reminder calls and do follow up calls for missed appointments, including medical appointments and other services such as support groups and social worker appointments.

4.2 Provide well-being check-in calls periodically, even if clients have not missed appointments.

4.3 Create more opportunities for peer support, in the form of groups, peer advocacy, or other means, especially for youth, including those who acquired HIV perinatally and trans youth.

4.4 Explore ways to support clients to maintain and strengthen family connections, as many noted family support as key to their resilience.

NEED 5: AN END TO STIGMA AND DISCRIMINATION

Stigma

HIV-related stigma emerged as a significant part of many clients' life experiences. An FCN provider explained that in her experience, many clients "*don't get support because they won't disclose their status. Many don't disclose their status because they don't want it to be public, for fear of stigmatization*." Some patients feel uncomfortable being seen in the clinic due to HIV-related stigma. Several focus group participants used the pre-printed label, "Don't want people to see me there," on the Waiting Area space or in the Primary Care Provider office. An FCN provider told us the strategies some people use who feel stigmatized. In a dual-use clinic, they may tell others they are attending the pain clinic, or a few might wear scrubs or get a visitor badge so other people might think they work there or are visiting a patient. It is noteworthy that despite these concerns, only 8% of participating clients had criticisms about the lack of confidentiality and their lack of trust for FCN programs.

> **"I've had that experience of going to the doctor and seeing someone in the waiting room I recognized. So, I'm like ok, 'you can't say nothing; I can't say nothing. We here for the same thing. We both know what hospital it is. So, you can't say nothing cause we in it for the same thing. So, we good.'"**
>
> --Cis woman

Stigma has far-reaching consequences for individuals, families, and communities. A youth-serving medical provider shared this experience:

> "*We have kids who have grown up for 20 years where the dad has not told the stepmom that the kid was infected. No one knows about the meds besides the dad. He rips the labels off so if anyone finds the meds they won't be able to figure out what the kid has. Then when the dad dies, where is the kid? He's abandoned emotionally from people who are in his family and for years there have been negative things being said about people who have HIV and AIDS allowed in the home. Then when his dad dies the young man is lost in the world. He's not taking meds and he's 73 pounds and 22 years old. It's devastating because we can't get him into care*."

Another FCN provider said, "*If women are in a domestic abuse situation, they have to hide their medicine because of the stigma associated with HIV and they worry the boyfriend will find the medicine*."

Whether to disclose one's HIV status is a difficult decision for many people. "*I've got friends who are open with their [status]. It's like they don't even care no more. They'll get on billboards and everything. I can't say I won't get to that point but it's very hard for me. Like I say, my own kids don't know. Not too many people in my family know*."

Even within the community of people living with HIV, stigma exists. When there are scarce resources, it is not uncommon for a feeling to arise that someone else's community is benefiting at the expense of one's own. This can manifest in racial and gender-related stigma. One white woman noted, "*What gets in my way of achieving my goals are racism toward Caucasians with illness and lack of respect from my community, as well as my peers*." One cis woman wrote on her survey, "*I feel like trans has taken over and they play both sides as male and female*."

Experiences of Racial Discrimination in Services

One-fifth (20%) of clients participating in the needs assessment described racism, bias, or discrimination against members of their group, including Latinas and African Americans. These comments were offered by trans women and cis women across most age groups. Comments regarding problems participants experienced with FCN services included “*Racial bias. Policies and politics*,” “*A little bit of discrimination*,” and “*Discrimination in some of the support groups.*” Women at a CAB recruitment meeting widely agreed when one said: “*Racism and racial bias are issues. The political climate makes things worse*.”

A trans woman in her 30s spoke about racism in housing services “*I don’t need to see my white sister living well while I don’t live well. The housing they have for the white transgender women is nice. The housing opportunities they have for the African American transgender women, it’s kind of like they think [the white clients] won’t be safe in that type of environment*.”

Experiences of Gender Discrimination in Services

Almost all the trans women participating in this needs assessment identified as at least partly African American, and some described how being Black and trans compound each other. “*The people who struggle the most are the African American trans women. We struggle the worst*,” said an attendee at the FCN CAB recruitment event. Referring to class issues, as well as trans issues, one trans man at the CAB recruitment event said, “*People in the health care field judge you—how comfortable are they with how you look?”*

> **“We have to be unapologetically Black. Then we have to be unapologetically trans. I am mad; you should be mad,”**
>
> --Trans man

Some keep the feelings tamped down “*When I come out into these communities [at the clinic] I have to swallow a whole lot and I have to ignore a whole lot. And be calm sometimes. And when something is wrong, I don’t speak out on it*.” Others speak up. “*I am a marginalized Black trans women. Anytime you feel as though you have issues with the agency, shouldn’t nobody tell you you’re not relevant and your issues don’t matter*.”

One trans woman shared her story:

> *“I was disrespected by this one lady for five years [at the clinic]. For five years I took her calling me by [my former name]. Five years! One day I wasn’t having it, so I went up in her face and I said, ‘Lady I’m tired of you disrespecting me. And if you call me [by a man’s name] one more time, something could happen to you. I’m not going to do it.’ I was mad and I was loud. I think they heard me over the whole hospital that day. And the lady walked away crying when the police was talking to me, so I got to keep my respect. A week later, HR called me and I went to that office and she was crying like she was traumatized and they made her apologize to me. She retired a couple weeks later but they made her apologize. And I soaked it up for all it was worth.”*

Fighting Community Stigma Through Awareness

At a CAB recruitment event one member said, “*As African Americans, wherever we walk in a place we see discrimination—because we are Black or trans [or not professional-looking]. We are resilient: This community has survived Stonewall and we survived AZT. We need to come to the table to not just talk about the bad things. What are we going to do about it?”* – Trans woman

Some participants asserted that Oakland needs social marketing campaigns with trans women and cis women, because even simple HIV-related messages are not reaching them. For example, the ACPHD HIV Disease Intervention Specialist described a monolingual Spanish-speaking 65-year old woman who was dying because she didn't know that effective antiviral medications had been developed. "*There are no bus ads that have someone like her*," she noted. She thinks promotion of simple messages are needed for cis women, trans women, and youth who don't know "*You can live with HIV*."

Recommendations

5.1 Develop norms and expectations for addressing racial and gender bias behaviors both on the part of service providers and clients.

5.2 Establish expectations for trans cultural competency within FCN, provide appropriate trans cultural competency training to all FCN providers (including but not limited to use of correct pronouns), and set policies for trans-friendly service environments (e.g., non-gendered restrooms, trans-inclusive brochures in the waiting room).

5.3 Advocate for HIV-related social marketing campaigns for cis and trans women, especially women of color.

NEED 6: RESPECT

Respect: An Antidote to Stigma

Focused discussion participants noted the ways in which respect is an antidote to stigma and discrimination, when asked what they need to have a pretty good quality of life. Two trans women gave specific examples that indicate the deep need for respect:

> *"So, quality of life for me is getting my needs met. And being honored when I go into places. And being able to say, "Thank you Ms. P_____" and "How are you doing today, Ms. P___". Those kind of things. As a transsexual woman that is my quality of life."*

> *"A good quality of life for me starts out with respect. It starts out with understanding. It also includes integration. It includes equality. It includes equity. It includes Black excellence for trans women and no mis-gendering and no disrespect and no hidden agendas. And with all that, I have to respect myself as a Black elder in the community. And I have to be willing to show different communities the excellence of trans women. Make sure we get equal healthcare. And make sure we get equal and sufficient housing."*

> **"Respect in any clinic setting–it's all about respect. You ask the person what they want to be called. You don't think. You don't make your own judgements or assumptions. You ask them what's their pronoun."**
>
> --Trans woman

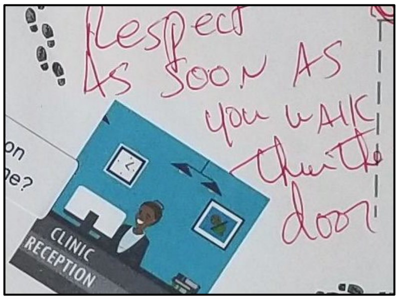
Experiences of Respect and Disrespect in Services

One-fifth (21%) of participating clients brought up issues of respect in focus groups or on the survey; 60% of these indicated they received respect, and 40% said they were disrespected by service providers.

Examples of Experiences of Respect

- Two trans women and six cis women pasted the pre-printed label "They respect me" in a variety of rooms on their My Clinic Map, including on the primary care provider, receptionist, counseling room, support group room and rooms for non-clinic agencies. Others wrote "Respect" on their maps.

- A trans woman: "*I get to be the boss of my care and I can feel a part of my doctor's agenda.*"
- Biracial woman: "*My doctor [and] the staff are professional, courteous, friendly, and compassionate*." Cis woman: "*I've been going [to this clinic] since 1997. The doctor is nice. If you call and leave a message the doctor will call you and they have the time to call their patients back. She actually calls me back, my doctor. I'm like wow, she called me back, because I know that it be so busy.*"
- A Latina: "*They always ask me if everything is going well with the medicine or what I need. They are always attentive to me.*"



- A male young person: “*[My social worker] talks to me about social and emotional issues and how I’m doing.*”
- A cis woman: “*The social worker makes sure stuff happens and I get stuff when I needed it.*”
- On their My Clinic Maps, six clients gave thumbs up, hearts, and super-hero stickers to their support group leaders. Some added text, “*I love my support group leader and now I have my own support group*.”
- Two trans women and two cis woman offered comments about their therapist or counselor, all positive.
- A trans women noted that the receptionist at her clinic is friendly and shows respect “*as soon as you walk in the door*.”

Examples of Experiences of Disrespect

- Paperwork gets lost repeatedly or delayed
- Lack of understanding of how health insurance works when youth turn 18
- An Asian cis woman wrote, “*Sometimes the nurse is rude. They shouldn’t treat people with illness that kind of way*.”
- “*Although it's a teaching hospital, the staff could use more training on how to deal w/patients and their health issue*.”
- An African American cis woman wrote, “*Stop referring to me as a patient. I prefer being referred to as a client*.”
- An older woman with multiple ethnicities wrote, “*They need some more compassion when talking to a positive (newly) diagnosed person and keeping contact with real wrap around services*.”
- A trans woman in her 40s wrote, “*Rudeness, misgendering, poor service, not doing their jobs! Needs better customer service*.”

One trans women in her 30s described what respect looks like for her: “*We need to feel like we’re priority. We don’t need to feel like we’re pushed to the back burner…It’s the ambiance, the attitude. When I go into an agency, I want to feel like you want to help me instead of like it’s your obligation*.” Women at the CAB recruitment event described it as “*…someone who is relatable*.” One participant said, “*I want services so that when you show up the professional says, ‘I’ve been waiting for you for 10 years. Welcome!’ I don’t want to go into a space where I feel I’m not welcomed. I want to go somewhere where I see someone who is passionate about serving me, not just someone is doing their job*.”

> **“People working in the health field in Oakland need to learn to respect and accept everyone. Look past my diagnosis. I’m a person. I breathe, bleed, the same way you do. Respect that.”**
>
> -Trans woman

Recommendations

6.1 Train staff and providers in client-facing positions on respectful practices and provide support, feedback, and coaching as needed, with the goal of creating a welcoming attitude throughout all agencies providing services.

6.2 Consider ways for clients and Community Advisory Board (CAB) members to be involved in helping service providers learn what respect looks like for them (e.g., developing patient respect guidelines for providers).

6.3 Provide “live” customer service-oriented assistance on the phone (reduce use of automated systems and voicemail).

6.4 Apply a trauma-informed system model to care delivery and provide appropriate training for all FCN providers and staff.

NEED 7: ACCESSIBLE SERVICES

Informational Needs

Simple lack of information was noted as a barrier to fully benefiting from services. Several participants recommended providing more information about services available. Access to educational information was also noted as a need. Two Latinas, both age 50+, recommended more information or education on HIV medications in the clinics or at support groups. The two providers recommended, "*Education for women: Help with disclosure*," and "*More knowledge about legal rights*." One parent recommended that the social worker at Children's Hospital provide information about what happens when the youth turn 18 years old:

> *I don't know what the program is for when kids [with perinatally acquired HIV] go off to college. I'm trying to figure out what that means, because right now, I'm getting an adoption assistance stipend where we get a little extra cash and we qualify for Medi-Cal and on top of that he gets the HIV stuff. The original thing with the adoption assistance stipend is that it keeps the kids out of foster care; it's better from an economic view. When he turns 18, do we lose his Medi-Cal insurance? I mean theoretically, between that and the stipend, we could see another $500 hit every month, right when we start picking up his tuition along with everything else. To me that's this whole big event that is freaking me out."*

Appointments, Wait Times, and Service Hours

Ten clients (12% of all those participating in the needs assessment) and a provider commented **positively** on the hours of the service, convenience of appointment times, or wait time to be seen.

In response to a question about the experience in the waiting room, an older African American cis woman said, "*It's fast. The longest that I'm waiting is about 10 minutes at the most.*" A Latina in her 40s wrote on the survey what she likes best about the FCN services, "*They are accessible and the appointments [are convenient]*." Several focus group participants indicated on their My Clinic Maps that they experience a short wait time and that many appointments are available, such as for support groups.

Six clients commented **negatively** about the wait time and appointment availability. An African American noted a problem with services, "*Time Management too long of a wait*." A Native American complained that it is "*hard to reach staff*." Several others had similar comments, including two who commented on this topic on their My Clinic Maps, "*Sometimes I get tired, sometimes they take a long time [in the waiting room]*," and "*It is hard for me to get an appointment [for the Social Worker/Case Manager]*."

One FCN provider and several clients recommended longer hours or evening hours at the clinics. Other cities have found a successful model to be one that included late hours and the co-location of services such as the medical clinic, pharmacy, and social work services once a week to serve specific populations such as youth or homeless persons.

Many FCN providers at the needs assessment group discussion recommended adopting a flexible approach to working with clients, when possible. This need is particularly acute for youth. To effectively serve youth, it must be understood that many will skip appointments, especially during transition from a time when their parents took them to the appointments to one when they need to get there on their own. One provider described challenges with "no-shows":

> *"I had eight people scheduled the other day, and one showed up…I think flexibility is really important. …We can schedule these people. We even talk to them on the phone the day before and they say they're coming, then they no show. And then they show up randomly. Or they won't show up to their appointment with me but a few days later they drop in to see a social worker. So, I think there has to be flexibility to catch them when they do arrive."*

> **"I feel like adults are more willing to put up with the 'you have to go here, and now here' etc. Whereas I don't think you have that much forgiveness with youth. The youth is not going to want to come to an hour visit with me, then 45 minutes with the financial benefits person, and then an hour check-in with the social worker."**
>
> --FCN service provider

This same flexibility is needed with those experiencing mental health issues, substance abuse, homeless and near-homeless persons, and those who are very ill from untreated HIV.

Co-Located, Coordinated Services

Two clients at two different clinics provided positive comments about the co-location of services in one place. A Latina in her 20s said, "*I like the psychological, dental, vision, medical support. It makes me feel that I don't have to worry about my health because they are always there for me*." An African American in her 30s, commented, *"It's good to come here because everything is in the same place."*

While clients were overwhelmingly positive about the people who provide their services, many were critical about how these services were organized. Twelve percent of clients providing comments in focus groups, interviews, or on the survey had criticisms. On the survey, a parent commented that the clinics her child uses "*need to communicate with each other more effectively*." A focus group participant discussed the disconnect between her clinic's social work and medical departments regarding approval signatures from the physician that are needed by the social worker, such as for medical cannabis. Another indicated on the survey that an application for a program was not given to her.

Part of the sense of disjointed service delivery is due to changes in staffing. A client described the frustration with staff turnover and the challenges to educate a new staff member about his concerns and background. A youth-serving provider noted, "*There's been a number of changes at that clinic over the years, where if a youth has connected with a provider and that provider leaves, what is that youth's impetus to connect with another provider over time?*"

> **"I don't know what happened with these Centers of Excellence, with the idea that everyone can go to one place and get everything all at once. I do feel for a while we provided that. We had a therapist, nutritionist, a gynecologist. But now I feel like.. [trails off]."**
>
> --FCN service provider

Providers and clients alike commented on a disconnect between HIV care and other medical care. For example, with pregnant women living with HIV, an FCN provider recommended better coordination among the HIV provider, the obstetrician, and the pediatrician. A medical case manager also noted this issue as she spoke of the funding cuts that make women's care take a giant step backwards: "*It is the same issues now as we had 30 years ago. For women, there is no comprehensive program here. For a while, we had a nurse who could do pap smears, and the women's clinic, and program services. There was a women's care doctor and an HIV doctor who worked together*."

Services for Populations Not Being Reached Sufficiently

A need was noted for more services in non-English languages, especially Spanish. One provider (not working for La Clinica) specified that more hours of therapy with a fluent Spanish-speaking therapist at La Clinica should be a priority. Another provider noted that there are people living with HIV from non-English-speaking African countries living in Alameda County who would benefit from services in their native languages, especially those with histories of trauma and brutality in refugee camps prior to reaching the U.S.

Multiple providers recommended that all Family Care Network staff know the legal rights of immigrants without legal status living in the state and keep abreast of current policies and rules affecting immigrants and their families in order to 1) provide them with all the services they are entitled to; 2) extend empathy and compassion to those traumatized by federal policies and practices, such as the detention of children and other family members; and 3) to make agency plans for the sudden appearance of I.C.E. officials at clinics and service organizations.

Several FCN providers recommended providing services to trans men and to those identifying their gender as non-binary, as well as to trans women. The topic of serving trans men also arose at the CAB recruitment event. "*Do we turn away trans men? No, let's not close the door, because they have some of the primary care needs of cis women*." A trans man at this CAB meeting related the experience of getting scheduled for surgery. Upon arriving, he was put in OB/GYN clinic, and they asked him where his wife was. Other patients looked anxious, so he went outside, called the front desk, and asked to come in the back door. He continued:

> "*We trans men used to go into women's spaces, but not so much anymore. Trans men need their own spaces. Two things need to happen: 1) Get trans women's needs met, get them in the door, then 2) Partner with other agencies to serve trans men. Many haven't had a breast exam or pap smear. Medical issues of HPV aren't being communicated to trans men. They need to see providers who understand their needs. For emergency care: serve them, because it is an emergency, but make them feel comfortable*."

Recommendations

7.1 Provide clients with more information about available services within and outside of FCN.

7.2 Develop partnerships and referrals for services for trans men.

7.3 Provide more services in Spanish and ensure translation/interpretation services are available when needed.

7.4 Where feasible, expand the number of appointments available and provide longer hours or evening hours.

7.5 Improve flexibility in service delivery, such as providing drop-in options, to accommodate clients who cannot adhere to appointments or other expectations, (especially for youth and young adults).

7.6 Co-locate services when possible.

7.7 Improve care coordination and communication across FCN partners and between FCN partners and non-FCN providers working with FCN clients.

NEED 8: SKILLED AND CULTURALLY HUMBLE PROVIDERS

Provider Skills and Knowledge

Most clients who spoke about the topic indicated that their provider is highly knowledgeable about HIV treatment. One adolescent said, "*I like my doctor. I've had her for a long time. She knows what she's doing*." An older patient said of her medical providers, "*First of all, they help me with a lot of knowledge, skills, and stuff I didn't know about. Doctors come in and they say stuff and I'm like 'Oh ok I've never heard that before.' As long as I've had the virus, it's always good to know a little more*."

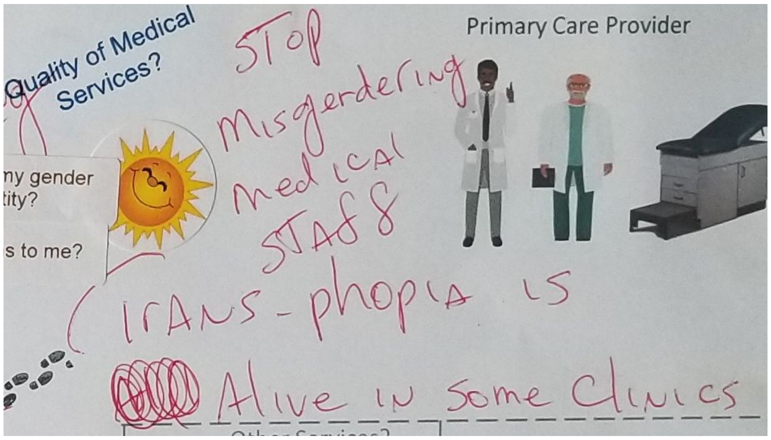
A few clients expressed dissatisfaction on the survey, indicating that the providers may understand HIV care but need improvements in explaining complex issues to the patients.

Clients also made it a point to mention experiences of both culturally appropriate services as well as times when providers displayed their lack of understanding as to how best to serve a particular group.

Trans women. Trans women's experiences with their providers was mixed, indicating that work remains to bring up the level of cultural competency in care for trans women.

> *"Within the last four years I've been a client at _____. I was a client there in the 90s but…you know…things happen. They have really stepped up to the plate and are really paying homage and are really participating in the transgender experience. They are willing and welcoming and understanding and have 360 degree wrap around services to really reach out and help trans women, no matter what their need and no matter where they are at in life*."

An older trans woman depicted the following on her My Clinic Map and clarified in the verbal discussion that while the quality of medical care is good, primary care provider's knowledge of trans issues, such as what gender to use, is lacking.



Youth. The FCN clinics serving youth understand that it is a specialty, and even within the category of "youth" the needs are diverse. As providers pointed out, young men who have sex with men have different needs compared with their older counterparts. The needs of youth with perinatally acquired HIV are different than those who acquired it through sex or drug use. Those born with HIV who are now in early adulthood were born before effective antiviral treatments and, as a result, some have developmental disabilities that make it challenging to transfer them to an adult HIV clinic; others need providers with extensive knowledge about adjusting the HIV medications due to increasing drug resistance from lifelong treatment. The youth-serving providers understand the medical issues of HIV in youth; they also understand the processes that make delivering these services effective.

> *"We can only follow clients until their 21st birthday. So somewhere along the 12 to 14 years of age we start building in the educational components that they'll need in order to transition into young adult care. And that's not only learning about their diagnoses and their medications but also about what their school trajectory is like, what their career goals might be, what their insurance status is, how to fill a pill bottle, how to order your meds, getting a job – start to make them think forward so when they are between 18 and 21 we can transition them to the young adult program."*

From the parents' perspective, there is still room for improvement, although not for the medical knowledge. One parent lamented the lack of opportunity to speak with the medical provider privately, without the child present. In the support groups at one of the clinics, a parent thought that the staff too readily let the youth pick the topics of discussion. She felt that the young people would avoid difficult discussions necessary for their transition to living on their own and being responsible for their HIV care.

Hiring and Training

One of the ways to create the welcoming feeling that many clients want is to provide training to providers. A focus group participant said, "*Trans-competency should be included in all community-based agencies*." Two trans women provided identical comments on their surveys: "*Transgender sensitivity classes*." FCN providers noted the importance of supporting the "*competency of providers AND support staff.*"

> **"The agencies don't have to hire a Black trans doctor—it should be the first face they see when they come to the agency."**
>
> --African American trans woman

Not only is it important to provide training to all staff in the FCN agencies, both provider and client participants recommended hiring more trans women at FCN agencies. One provider noted the need for "*services that are more inclusive and have more trans representation*." A respondent wrote, "*More trans doctors or trans knowledgeable [doctors]*." A trans participant at the CAB recruitment event asserted, "*I won't go somewhere that doesn't have someone who looks like me*."

Another trans woman said that hiring trans women is not enough. She said that development of transgender staff is critical. "*Not only when you hire a trans woman, just like when you are hiring anyone, if that person needs help with the job, don't just fire them. Work with them, help them, train them. Don't just say that we hired you and it's been six months and you're not getting it…DUH! You hired me; you need to work with me*." Said another:

> "*[Agencies] maybe can't have the capacity to bring on new staff, but even if they can't hire a professional, they can get intentionally trained to serve Black trans women. The CAB members should get training on how to talk with the agencies to educate them. We have to get educated to know how to talk with them.*"

Several FCN providers also indicated a need to hire more or increase access to female providers.

Recommendations

8.1 In addition to Recommendation 5.2, develop an overall quality improvement plan for better serving trans women, including hiring and investing in the professional development of more trans female service providers.

8.2 Increase partnership and communication between medical providers and the parents of youth clients living with HIV to ensure that all perspectives are included in care planning and when transitioning youth to the adult system of care.

Two Stories of Resilience

Trans women were a priority population for this needs assessment, because their needs are less well understood than cis women's. Two in-depth interviews with trans women helped illustrate the numerous roadblocks trans women, especially trans women of color, face in life and what helps to support them.

Kari's Story

Kari (not her real name) is a Black woman in her 30's. Growing up, she always knew she was a "unicorn" but didn't always know how to express herself. She was in and out of jail as a young person. "*I went to jail when I was 16 years old, and It was one of the most scary occurrences that happened in my life. But if you saw me [today] you wouldn't know that. I'm good at surviving.*" Despite jail stays, being targeted by bullies, and watching her mom experience domestic violence during her youth, she feels strong and resilient. Where did that inner mental strength come from? *"I have a wild imagination*," she said. "*I idolized characters that were strong – like Buffy the Vampire Slayer. I wanted to be like her*." And her mom was someone who never gave up, through many hardships.

That inner strength became incredibly important when Kari was recently diagnosed with HIV. She was in a relationship with a heterosexual man. "*We were good, we were really good*." With him, she was treated as a woman and she knew and was accepted by his mother. But then, he started experiencing some minor illnesses and Kari purchased an HIV home test kit. He tested negative but was angry that she had made him get a test, which frustrated her. "*There shouldn't be a stigma about testing*," she pointed out.

Then she started noticing some odd things going on with her body. "*I'm very in tune with my health….of course, I'm praying that I'm not positive, but if I am, I'm not gonna let it break me*."

She went to get a test. Later she got a call to come into the clinic but wasn't able to. "*They sent someone to my house to talk to me, and that's when I knew it was real.*" After the person left, she called her boyfriend and told him she was positive. Knowing she hadn't been with anyone except him, she knew he had to be positive too, and was probably in the window period when he took the home test. The relationship ended for good with that phone call. "*He was in denial. He fucked up and it directly affected me and he can't live with that.*" She described how this experience affected her: "*It really humbled me and made me realize…no matter how long you're there for somebody, they will turn your back on you*." She doesn't hate him though. "*I know he misses me. It's a traumatized situation for him [to have passed HIV on to me]. As a friend and someone who loves him, I want him to get on treatment*."

Initially, Kari's diagnosis left her feeling *"devastated and disappointed."* But she stays strong and cultivates a positive attitude. *"[My diagnosis] motivated me to just become more proactive and [make] myself knowledgeable about HIV and transmission…I'm undetectable, I'm taking my treatments, I'm employed doing something I like…To me I* *feel like I am cured. I just go about life…I don't let it fester…I take my meds and I live my life."*

All the same, she has only shared her diagnosis with a handful of people. *"In Oakland…[there is] ignorance. People are not educated. They still have this mind frame from 1980's."* There is still a lot of stigma, and she doesn't want people to use her status against her. She wants to talk about it though, when she's ready. *"I wanna show that this is the face [of HIV]. I look just like [any] person, you can't tell I'm positive."*

Her experience with health care since moving to Oakland has been mixed. After her diagnosis, no one called to check in on her. *"[People] need to know there is somewhere they can go to talk to someone…Otherwise the diagnosis will eat you up."* At one clinic, the receptionist tried to make Kari state why she was there, in front of everyone in the waiting room. She was *"stressed and frustrated,"* having just moved here and having run out of medication. Having this negative experience at a clinic where the staff were "her people" was very difficult for her. She went somewhere else, was treated with respect, and got her medication the next day. *"Some places [in Oakland, the staff are] not doing something they're passionate about. They're going to work to collect a check, and it shows."* Now she goes to Kaiser, and she says they are trans-friendly and she gets everything she needs. However, she has to see three different people for primary care, HIV, and hormones, and it's a co-pay each time. It would be better, she noted, if they could take care of all her needs in one appointment.

The Oakland HIV prevention, testing, and care systems could use some improvement, she says. She used to live in New York City, where there were partnerships with LGBT bars, clubs, and other community venues, and you could get tested there. There were billboards and pamphlets that she could relate to. She'd like to see those things in Oakland.

What it boils down to is that the people working in the health field in Oakland need to learn to respect and accept everyone. *"Look past my diagnosis. I'm a person. I breathe, bleed, the same way you do. Respect that."*

Fiona's Story

Since she was a little girl, Fiona (not her real name), a Black trans woman in her mid-30's, always wanted to stand up in front of people and convince them to buy what she was selling. Decades later, she proudly graduated with a degree in marketing. *"There were times where I felt like giving up,"* she said, because it was very challenging on so many levels. The stigma and ignorance are especially intense in the Southern U.S., where she grew up and went to school. *"My professors did not understand me at first…My professors taught me, but I taught them at the same time."* There were a lot of challenges related to using the correct pronouns. *"You had a group of people that would say 'he,' then you had a group of people that would respect me and would call me by my correct pronoun, then you had a group of people who just didn't give a damn."*

She made it through, she says, because of something her dad told her when she was little. *"My father was the first man who accepted me… Some transgenders have horrible stories of where they are and where they came from, but I don't have that.…I* *had a father who protected me. My father knew [about my gender identity, and he said] 'Regardless of what you do in life, make me proud.' That stays with me today. I know him and my grandmother are extremely proud of the woman I am today."*

Her parents gave her a strong foundation in life. She almost wishes she could have had some of those damaging experiences so she could better empathize with what most Black trans women have to deal with. She does recall one really low point in her life, when she was living in the South. Her mother took her to the health department to get services related to transitioning. The health department called law enforcement. *"That was a low blow for me....if you're not strong minded like I am, that'll take your dignity...It almost did."* Her memories of her dad's hopes for her and her strong relationship with God helped her get through this really rough period.

Now she wants to help other trans women who might not have been as fortunate as she has been. *"The world is so cruel already to us, especially African American transgender women. There's 12 of us who've died this year already. That's a lot. We have so many issues to deal with. We're Black on top of that, then we're transgender, and to the world it just looks like we're confused. But we're not confused, we just are who we are."* Lots of women like her just want to be *"productive members of society"* but discrimination gets in the way. She wants to tell trans women *"You can prosper, you don't have to settle with being a sex worker....I'm not against that. That's how some women have been surviving for years, but that's the result [of] society not giving them a fair equal opportunity."* She wishes there were spaces in Oakland for trans women – ideally 24 hours – where they could just drop in, get something to eat, "chill," take a shower, and "rest a little."

A few years ago, she moved to the Bay Area and overall, California has been a *"beacon of hope"* for her. She says there are still things that could be improved, especially regarding services for African American transgender women. *"I don't need to see my white sister living well and I don't live well."* She sees this differential treatment, especially in housing services. *"The housing they have for the white transgender women is **nice**. The housing opportunities they have for the African American transgender women, it's kind of like they think 'they won't be safe in that type of environment.'"* She described the lack of transparency in decision-making as to who gets placed in which housing units, when a person is accessing housing services. She noted that Black trans women are often placed in unsafe environments and not supported to maintain their housing, and they end up homeless; their white counterparts get nice units in safe neighborhoods. *"I want to live comfortable,"* she says. *"I don't ask you to put me in a condo where I can see the Bay Bridge. I want something nice, clean, comfortable, and safe."*

How could Oakland service providers better service Black trans women? *"We need to feel like we're priority. We don't need to feel like we're pushed to the back burner...It's the ambiance, the attitude. When I go into an agency, I want to feel like you want to help me instead of like it's your obligation."* She says it's all about respect. *"What I would say to health care providers [is] don't get to be where you forget to serve the community."*

IV. CONCLUSION AND RECOMMENDATIONS

This needs assessment identified numerous needs, both met and unmet, for women, children, and youth living with HIV. The needs range from those seemingly simple to address, such as transportation vouchers, to solving large and complex social issues such as stigma and discrimination. Through surveys and focused discussions, many clients made it clear how well FCN meets their needs and how grateful they are for the support they have received. Trans and cis African American and Latina women shared that they feel supported and cared for by FCN providers.

> **"I went [to an FCN agency providing ancillary services] 15 years ago and I left feeling on top of the world."**
>
> -African American trans women
>
> **"When I need help with anything the staff has always been there for me. I'm so grateful."**
>
> -Participant

The following is a summary of the recommendations presented earlier in the **Qualitative Findings** section:

Housing, Mental Health, and Substance Health

1.1 Expand housing services, both to address homelessness and to help clients find and keep safe, affordable housing.
1.2 Increase collaboration across FCN partners to share information about housing opportunities.
1.3 Expand residential care beds for people with HIV who have complex medical, mental health, and substance use disorders.
1.4 Improve access to appropriate mental health care by adding psychiatric services within FCN.
1.5 Streamline the pathways within the FCN mental health continuum of care, to ensure timely access to appropriate care, such as addressing referral processes.
1.6 Make mental health services, including psychiatric services, available in Spanish and other languages to the degree possible (e.g., consider medical interpreters if needed).

Foundational Stability and Financial Well-Being

2.1 Increase budgets for transportation and emergency uses such as utility bills.
2.2 Provide or link clients to in-home services, such as personal care services, basic home repairs, and cleaning.
2.3 Improve transportation options for clients to get to and from services, prioritizing those who live further from public transit routes, people who are too ill to travel to services on their own, people with young children, and people with disabilities.
2.4 Expand access to legal services such as accompaniment to court appointments and help with health insurance, eviction, and immigration issues; these services could be provided directly by FCN or through partnership/referral.
2.5 Consider partnering with ACPHD and others to bring medical care to very ill clients in their home environments, with the goal of getting them well enough to be able to engage in clinic-based care.
2.6 Ensure that all FCN partners have current knowledge related to federal, state, and local immigration policy and that clients have access to information about their rights.

Personal and Spiritual Well-Being

3.1 Ensure that clients have access to support to pursue educational, vocational, and other skills development opportunities, either by providing these support services directly or through partnership/referrals to other agencies.
3.2 Use CAB meetings as opportunities for leadership and skills development for CAB members, and create opportunities to use these skills on specific short-term projects.
3.3 Create time and space for clients to receive spiritual support and engage in spiritual practice, including meditation.
3.4 Provide or link interested clients to workshops on political advocacy and community

activism/mobilization.

Social Connectedness

4.1 Provide reminder calls and do follow up calls for missed appointments, including medical appointments and other services such as support groups and social worker appointments.
4.2 Provide well-being check-in calls periodically, even if clients have not missed appointments.
4.3 Create more opportunities for peer support, in the form of groups, peer advocacy, or other means, especially for youth, including those who acquired HIV perinatally and trans youth.
4.4 Explore ways to support clients to maintain and strengthen family connections, as many noted family support as key to their resilience.

An End to Stigma and Discrimination

5.1 Develop norms and expectations for addressing racial and gender bias behaviors both on the part of service providers and clients.
5.2 Establish expectations for trans cultural competency within FCN, provide appropriate trans cultural competency training to all FCN providers (including but not limited to use of correct pronouns), and set policies for trans-friendly service environments (e.g., non-gendered restrooms, trans-inclusive brochures in the waiting room).
5.3 Advocate for HIV-related social marketing campaigns for cis and trans women, especially women of color.

Respect

6.1 Train staff and providers in client-facing positions on respectful practices and provide support, feedback, and coaching as needed, with the goal of creating a welcoming attitude throughout all agencies providing services.
6.2 Consider ways for clients and Community Advisory Board (CAB) members to be involved in helping service providers learn what respect looks like for them (e.g., developing patient respect guidelines for providers).
6.3 Provide “live” customer service-oriented assistance on the phone (reduce use of automated systems and voicemail).
6.4 Apply a trauma-informed system model to care delivery and provide appropriate training for all FCN providers and staff.

Accessible Services

7.1 Provide clients with more information about available services within and outside of FCN.
7.2 Develop partnerships and referrals for services for trans men.
7.3 Provide more services in Spanish and ensure translation/interpretation services are available when needed.
7.4 Where feasible, expand the number of appointments available and provide longer hours or evening hours.
7.5 Improve flexibility in service delivery, such as providing drop-in options, to accommodate clients who cannot adhere to appointments or other expectations, (especially for youth and young adults).
7.6 Co-locate services when possible.
7.7 Improve care coordination and communication across FCN partners and between FCN partners and non-FCN providers working with FCN clients.

Skilled and Culturally Humble Providers

8.1 In addition to Recommendation 5.2, develop an overall quality improvement plan for better serving trans women, including hiring and investing in the professional development of more trans female service providers.
8.2 Increase partnership and communication between medical providers and the parents of youth clients living with HIV to ensure that all perspectives are included in care planning and when transitioning youth to the adult system of care.

APPENDIX A: CLIENT SURVEY

☐ Someone helped me fill this out

FAMILY CARE NETWORK

Community Needs Survey

For women, trans women, and youth of all genders

Agencies that are a part of the Family Care Network are asking clients about their experiences with services. This survey is really important. It is an opportunity for YOU to have a voice in how services are run. Can you help with this? **Thank you so much!** And please accept our small gift to you.

1. Where do you usually go for HIV primary care?

☐ East Bay AIDS Center or Downtown Youth Clinic (Sutter Health)	☐ Highland Hospital (Alameda Health Systems)
☐ UCSF Benioff Children's Hospital	☐ La Clinica de la Raza
☐ Other: ______________________________	

2. What is your age?

☐ 0-17 ☐ 18-24 ☐ 25-29 ☐ 30-39 ☐ 40-49 ☐ 50 or older

3. What is your zip code: 94____________________

4. What is your gender? (check <u>one</u> that best describes your current gender identity)

☐ Female ☐ Male ☐ Genderqueer/ Gender Non-binary ☐ Trans Female ☐ Trans Male

☐ Not listed. Please specify ______________________________

5. What is your ethnicity/ cultural identity? ______________________________

6. How often are you coping well with HIV?

☐ Almost never ☐ Some of the time ☐ Most of the time ☐ Almost always

7. What are 2 things you want in your life that you don't have?

Think about your housing situation, health, position in the community, relationships, job, etc.

1. ______________________________

2. ______________________________

8. Please tell us about the services you have received and need.

If you RECEIVED the service, check <u>one box</u> in this column. **OR** If you DID NOT receive the service, <u>check one box</u> in this column.

	YES I received this service and:		**NO I have not received this service and:**		
	I continue to need it	I don't need it anymore	I don't need it	I need it somewhat	I need it a lot!
MEDICAL					
Dental care	☐	☐	☐	☐	☐
Eye care	☐	☐	☐	☐	☐
Gender affirming medical services	☐	☐	☐	☐	☐
Nutrition counseling	☐	☐	☐	☐	☐
Pain management	☐	☐	☐	☐	☐
EMOTIONAL					
Support group	☐	☐	☐	☐	☐
Counseling or therapy	☐	☐	☐	☐	☐
Peer support or peer advocacy	☐	☐	☐	☐	☐
Spiritual support	☐	☐	☐	☐	☐
Help from a psychiatrist to adjust my medications	☐	☐	☐	☐	☐
Substance use or alcohol counseling or group	☐	☐	☐	☐	☐
Substance use or alcohol treatment where I check in to a program	☐	☐	☐	☐	☐

If you RECEIVED the service,
check one box in this column.

OR

If you DID NOT receive the service,
check one box in this column.

8. Continued…

	YES I received help for this and:		NO I have not received help for this and:		
	I continue to need it	I don't need it anymore	I don't need it	I need it somewhat	I need it a lot!
LEGAL					
Help from a lawyer for child custody, immigration, medical insurance, updating name/gender, etc.	☐	☐	☐	☐	☐
FOOD, HOUSING, AND MONEY					
Benefits assistance like SSI, MediCal, SNAP, etc.	☐	☐	☐	☐	☐
Finding or keeping my housing	☐	☐	☐	☐	☐
Food pantry or food bank	☐	☐	☐	☐	☐
Transportation vouchers	☐	☐	☐	☐	☐
PERSONAL					
Child care	☐	☐	☐	☐	☐
Disability adaptive equipment e.g., wheelchair, hoyer lift	☐	☐	☐	☐	☐
Finding work, finishing school, classes for new skills like computers, music, crafts, etc.	☐	☐	☐	☐	☐
Group social or recreational outings	☐	☐	☐	☐	☐
Help in the home with personal care	☐	☐	☐	☐	☐
Support for my safety concerns	☐	☐	☐	☐	☐

9. Please rate the services at each of these agencies.

	Needs much improvement	Needs some improvement	Are pretty good	Great just as they are	I haven't used this agency
WORLD	☐	☐	☐	☐	☐
La Clinica de la Raza	☐	☐	☐	☐	☐
Highland Hospital (Alameda Health Systems)	☐	☐	☐	☐	☐
East Bay Community Law Center	☐	☐	☐	☐	☐
EBAC or Downtown Youth Clinic	☐	☐	☐	☐	☐
Children's Hospital	☐	☐	☐	☐	☐

10. What are two things that should be done to improve the services for you?

1. ____

2. ____

11. What problems, if any, have you experienced with the agencies listed above?

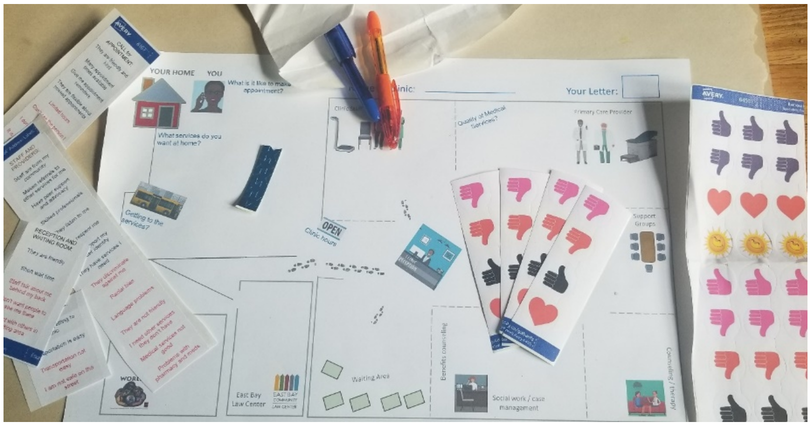
12. What do you like about the services you receive?

Thank you so much!

APPENDIX B: FOCUS GROUPS USING “MY CLINIC” MAPS

In the needs assessment focus group, the facilitator not only guided a verbal discussion, she also collected pictorial data from a procedure dubbed “My Clinic Map”, although this is somewhat of a misnomer, since the “Map” had spaces drawn in for all FCN services, not only the clinics. The first half of each focus group was a guided verbal discussion; the second half continued the verbal discussion and also involved the use of the My Clinic Activity. Focus group participants appeared to enjoy this activity.

Purpose: The purpose of the My Clinic Maps was to collect information about clients’ experiences with HIV services in a way that let people convey these experiences other than verbally. Thus, the needs assessment collected data through visual (survey), verbal (focus group discussion) and kinesthetic (My Clinic Map) means. An additional advantage of using the My Clinic Maps in focus groups is that everyone could be working on their map all at the same time while people contributed verbally, one at a time. This meant that more qualitative data could be collected.



Procedure: About half-way through the focus group, each participant received an 11x17 map with preprinted “rooms” or areas such as the receptionist desk, social work office, support group room, and primary care provider exam room. They also received an envelope with a variety of stickers, two colored gel pens, and pre-printed labels on a variety of topics. The facilitator guided people in placing any of the stickers and labels anywhere on the map and adding text or drawings—anything that best represented their experiences and opinions. The facilitator clarified that some services, especially the Support Groups, might not necessarily be provided in the clinic—an easy clarification since the activity was conducted in three locations, only two of which were in a clinic. People wrote the letter from their name tents onto their Map, so that their verbal contributions could be matched with the visual contributions of the Map.

Analysis: The qualitative software used for analysis has the capability to capture segments of an image, turning them into visual “excerpts” just as small segments of text are turned into excerpts.