

2016
Rhode Island
Executive Office of Health and Human Services
Ryan White Consumer Focus Groups

The Division of Medicaid, HIV Provision of Care Unit at the Executive Office of Health & Human Services (EOHHS)

Focus Groups Conducted by:
John Snow, Inc.

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Introduction

The Rhode Island Executive Office of Health and Human Services, Medicaid Division, HIV Provision of Care & Special Populations Unit (EOHHS) contracted with John Snow, Inc. (JSI) to implement focus groups about substance use and mental health with people living with HIV/AIDS (PLWHA) who access care services in Rhode Island. The goals were to

- (1) follow up on the quantitative consumer survey results by directly seeking input from consumers around their experiences with care, treatment, support services, substance use, and mental health
- (2) identify barriers, gaps, and needs associated with PLWHA, particularly as they relate to substance use and mental health.

The emphasis on mental health and substance use stemmed from the results from the 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey. Depression was the most common reported health issue beyond HIV with over half of the respondents reporting they were impacted by it. Fifteen percent (15%) of respondents reported substance use and those respondents were significantly less likely than their peers to report always taking their medications and achieving viral suppression.

The focus groups were offered to consumers through existing statewide and agency-specific consumer advisory boards (CABs) or consumer groups. The target population for the focus groups was PLWHA in Rhode Island who are 18 years of age or older and participate in a consumer advisory board or consumer group.

The focus groups are part of a broader effort by EOHHS to conduct a needs assessment of PLWHA in Rhode Island. The needs assessment includes the following components:

- Epidemiological profile
- Provider Capacity and Capability Survey
- Consumer Survey
- Focus groups with consumers
- Resource Inventory & Referral Guide

Results from each of these elements will be integrated to provide a better total picture of available resources, barriers to care, HIV epidemiology, and needs in the PLWHA population in Rhode Island. They will also support Rhode Island's *Integrated HIV Prevention and Care Comprehensive Plan*, including the *Statewide Coordinated Statement of Need, CY 2017-2021*, to be submitted to the Health Resources and Services Administration's (HRSA) and Centers for Disease Control and Prevention's (CDC) in September 2016.

Methods

Three focus groups were convened with three separate consumer advisory boards or consumer groups. Existing groups were chosen due to the fact that members already know the HIV-status of fellow group members and there was no additional risk of status-disclosure. Participants were offered a \$20 gift card to a grocery store, Stop & Shop, in exchange for their participation.

A focus group guide containing questions and probes was developed by JSI for use by the facilitator. Questions were designed to introduce a topic and probes were designed to follow up on a topic based on the group's response. Questions were carefully chosen to further explore trends identified in the 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey.

See Appendix A for the focus group guide.

The facilitator described the purpose of the focus group; the context of it (i.e. part of a needs assessment for the Ryan White HIV program in Rhode Island); and, how consumers' feedback, perspective and experiences are critical to HIV service delivery in Rhode Island. The facilitator also ensured that key questions were asked and facilitated discussion to identify key messages and ensure participation from all group members.

Participants were asked to not only talk about their own experiences, but also those of their peers—some of whom may be out of care.

Demographic information was collected from participants. No identifying information was obtained as part of the survey process. This demographic information was analyzed in aggregate for summary statistics including frequencies and percentages.

During all focus groups, a note taker was present to record the conversation. An audio recorder was also used to assist in the notetaking process. Notes were taken in a manner that listed participant comments sequentially. Comments were not grouped by individual.

The focus group notes were analyzed in aggregate using thematic narrative analysis. Topics were iteratively identified in the text and tagged with a corresponding topic code. Topic codes were chosen based on the content of the participant's comments and were not predetermined. They were organized under the following category headings: mental health, substance use, system of care, self-care, and other. Some text was tagged with more than one topic code. Text chunks were then aggregated by topic code. Themes were identified through a contextual analysis of participant comments by code.

The software program 'QDA Miner Lite' was used to code the text and compile by theme. Wordle.net was used to make the wordclouds.

The final report has been organized by theme category.

Topic Codes

The topic codes used in the analysis of the text are listed as follows:

Mental Health

- MH Treatment General
- MH Treatment Access
- Diag_Depression
- Diag_PTSD
- Diag_Bipolar
- Long Term Survivor
- Loneliness

Substance Use

- SU Treatment General
- SU Treatment Access
- Type_Marijuana
- Type_Cocaine
- Use Patterns

System of Care

- HIV Med Care General
- Peer Recovery Specialists
- Barriers to Care
- Case Managers
- RI System of Care
- Outreach MH or SU
- Transportation
- Housing
- Doctor Patient Relationship
- Referrals to Non-HIV Care
- MH/SU Screening

Self-Care

- Adherence / HIV Medication
- Seeking Help
- Illness Narrative
- Telling Other People
- Finding Community
- General Advice

Other

- Stigma
- Identity
- Comorbidities
- Family
- Minority Populations
- Testing and Prevention

Participants

The following two tables present summary demographic statistics for the 36 participants aggregated from the three focus groups.

Table 1: Demographic Composition of Focus Groups

<i>Question</i>	<i>Response</i>	<i>Count</i>	<i>%</i>
Gender (n=36)			
	Male	21	58.3%
	Female	15	41.7%
Age (n=36)			
	30-34	2	5.6%
	35-39	0	0.0%
	40-44	2	5.6%
	45-49	4	11.1%
	50-54	10	27.8%
	55-59	8	22.2%
	60-65	5	13.9%
	65+	5	13.9%
Sexual Identity (n=36)			
	Straight (Heterosexual)	20	55.6%
	Gay or Lesbian (Homosexual)	14	38.9%
	Bisexual	1	2.8%
	Other	1	2.8%
	Queer	0	0.0%
	Questioning	0	0.0%
Race (n=36), m.			
	White	22	61.1%
	Black or African-American	11	30.6%
	Other	5	13.9%
	American Indian/Alaska Native	3	8.3%
	Asian	0	0.0%
	Native Hawaiian/Other Pacific Islander	0	0.0%
Ethnicity (n=31)			
	Not Hispanic or Latino /a	27	87.1%
	Hispanic or Latino /a	4	12.9%

Notes: 'm.' indicates multi-select question – the percentages will not sum to 100% because participants were allowed to select more than one response.

Data Source: 2016 Rhode Island Executive Office of Health and Human Services
Ryan White Consumer Focus Groups

Table 1: Demographic Composition of Focus Groups (Continued)

<i>Question</i>	<i>Response</i>	<i>Count</i>	<i>%</i>
Education (n=35)			
	I have never attended school	1	2.9%
	8th grade or less	2	5.7%
	9th to 12th grade	5	14.3%
	Graduated high school or received GED	12	34.3%
	Associates degree or Vocational/Technical School	1	2.9%
	Some college	8	22.9%
	College or university degree (e.g., BA)	5	14.3%
	Graduate degree (e.g., MA or PhD)	1	2.9%
Employment (n=35)			
	Working full time	2	5.7%
	Working part time	2	5.7%
	Currently unemployed—looking for work	0	0.0%
	Currently unemployed—not looking for work	1	2.9%
	Disabled or unable to work	21	60.0%
	Working informally “under the table”	0	0.0%
	Volunteering (unpaid)	4	11.4%
	Retired	5	14.3%
	Other	0	0.0%
Household Income (n=33)			
	No Income	1	2.9%
	Less than \$10,000	13	38.2%
	\$10,000-\$19,999	13	38.2%
	\$20,000-\$29,999	2	5.9%
	\$30,000-\$39,999	2	5.9%
	\$40,000-\$49,999	0	0.0%
	\$50,000-\$59,999	1	2.9%
	\$70,000+	2	5.9%
Insurance (n=34), m.			
	Medicaid (offered by government)	25	48.1%
	Medicare (offered by government)	24	46.2%
	Private Insurance (paid by an employer or an individual)	1	1.9%
	Other	2	3.8%
	Veteran Insurance (offered by government)	0	0.0%
	Don't know	0	0.0%
	I do not have health insurance	0	0.0%

Notes: ‘m.’ indicates multi-select question – the percentages will not sum to 100% because participants were allowed to select more than one response.

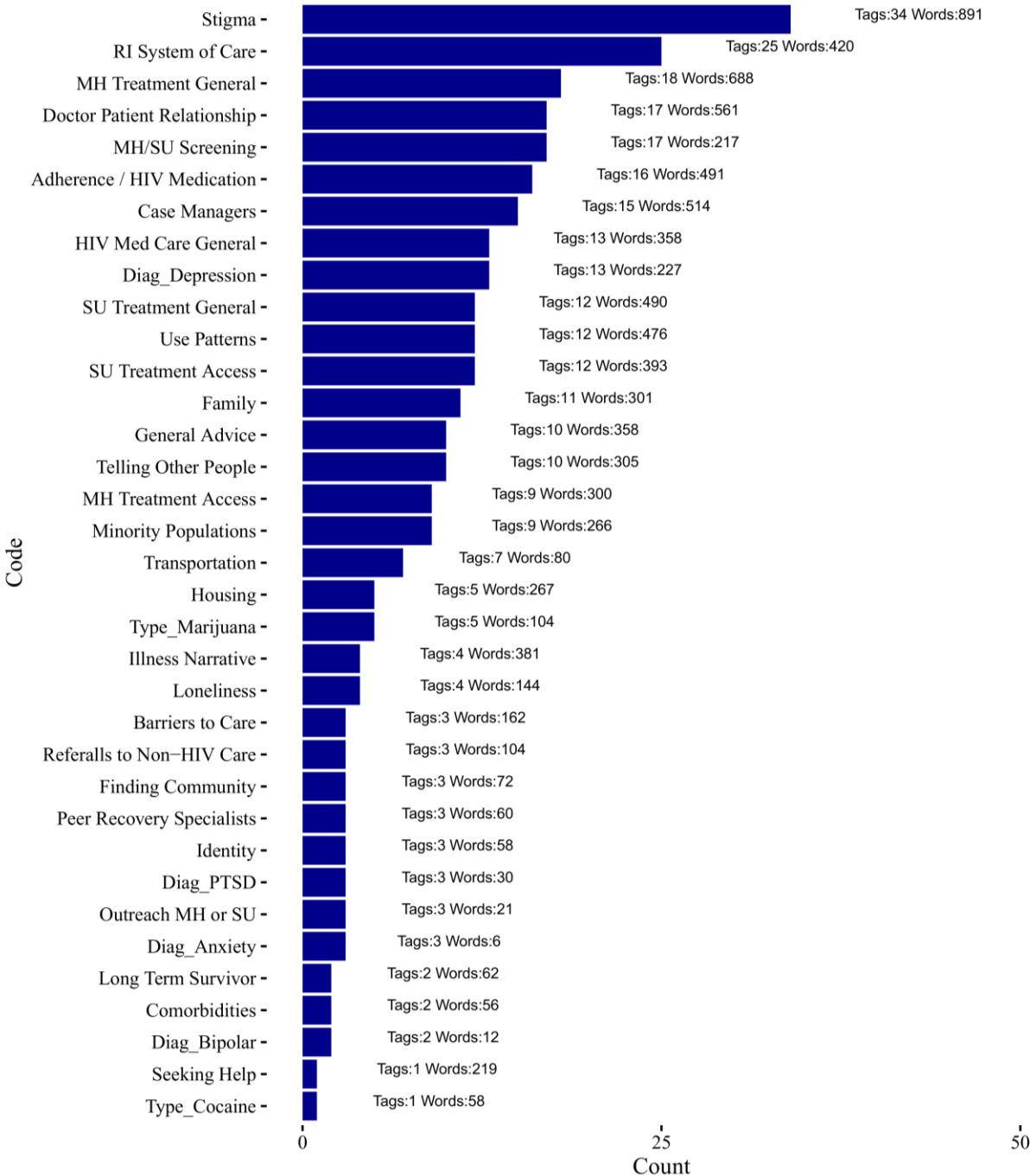
Data Source: 2016 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Focus Groups

Results

Topic Codes

Figure 1 shows the frequency that each topic code was tagged in the text notes from all three focus groups.

Figure 1: Focus Groups: Codes by Number of Tags



Data Source: 2016 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Focus Groups

“Perhaps there can be a back door way for counseling so that others don’t see.”

Access to Mental Health Treatment

Participants generally reported being very satisfied with the accessibility of mental health services. Participants who used the services in Woonsocket seemed particularly with the diversity of services available in the city. One focus group stated that they were excited about the upcoming introduction of mental health services into [one of the major HIV clinics].

The most commonly discussed barriers to mental health services were insurance and money. Participants stated that those who were able to pay had more mental health treatment options than who could not but did not provide any specific examples of being refused mental health care for financial reasons.

One participant talked about how his physical health prevented him from accessing some services, including mental health services.

“I ain’t accessing them because my body won’t let me, unless you got them right down on the first floor of my building.”

Diagnoses

Depression and anxiety were the two most common diagnoses discussed during the focus groups. Several individuals also stated bipolar and PTSD. Depression was attributed to many different causes including the experience of stigma, trying to hide HIV status from others, isolation, loneliness, and side-effects from HIV treatment medications. Several individuals conveyed dismay over the need to prescribe drugs to treat the depression that was originally caused by the HIV medication.

“Depression, anxiety, isolation, guilt.”

There were several discussions of how depression can lead individuals to not take their medication as prescribed.

“Whenever I feel depressed, I don’t take my HIV meds.”

Loneliness

Loneliness and isolation came up repeatedly. Participants shared many stories of times when their friends or family pulled away from them or stopped seeing them entirely after they learned about the HIV diagnosis.

“Seems like all my other friends push me away. Or maybe it’s me pulling away.”

One individual discussed how she felt isolated from her old friends who were currently using substances while she was trying to stay sober.

One focus group shared how many poor people with HIV use the free transportation that the Rhode Island Public Transportation Authority (RIPTA) provides to the disabled as a means to get out and be around other people, perhaps even without a particular destination in mind. They expressed concern

about the proposed rise in rates for the elderly and the disabled because it might prohibit this means for isolated, disabled individuals to see other people.

“It’s lonely but I press on.”

Long Term Survivor & Aging with HIV

A few participants mentioned the guilt that comes along with still being alive after their friends with HIV had died. One participant shared how it was psychologically difficult for him to deal with how HIV/AIDS had altered his physical appearance (i.e. lipodystrophy) after many years. Others agreed that aging with HIV means experiencing additional diseases, or comorbidities, that can complicate their HIV treatment.

“I have to continue the chemo. Went to see my kidney doctor. ‘You might have to go on dialysis,’ he said. Right now, I am fighting one dragon at a time! After I get wrapped up with the cancer, we can talk about that. Too much on my plate.”

Access to Substance Use Treatment

Participants thought that substance use treatment was generally easy to access but offered a few key pieces of feedback.

The most prominent access issue that was raised had to do with lack of adequate dissemination and promotion of available services.

“[substance use and mental healthcare agencies] could help. But how do you know this stuff? If you don’t know, how do you find out?”

“Word of mouth that’s how we find out what’s going on”

Participants shared that they thought that HIV medical providers should be able to connect patients with addiction services ‘right away’ and even recommended collocating an intervention team within the HIV medical clinic. Several stated that their HIV medical provider had never asked about substance use issues or offered treatment options.

“I think the doctor should set you up right away with addiction services if you come into the immunology clinic with substance use issues. [Have] an intervention team right in the office.”

“I’ve had substance abuse issues for a long time and I have never been offered help once from doctors. I have been locked up in psyche units and in the morning when I wake up they just let me go.”

Another recommendation by participants was to increase the number of residential homes that provide substance use services to residents. They shared that they felt there were too few ‘transitional’ housing opportunities and that they knew PLWHA who were at risk of losing their housing due to ‘co-occurring mental health and substance issues.’

“They need more [transitional] homes. They need more than two homes. They housing got me on track. If I didn’t go there, I wouldn’t be who I was today. I might not even be alive today.”

One participant brought up how she has known individuals to lose access to substance use or mental health services due to prior offenses or infractions of facility rules.

“[Some people] have no other choices because they have already used what they have. Medical won’t take them because they have used what they have [policy benefits]. This place won’t take them because they are violent, or used drugs on the premises, or beat up a doctor. I dealt with someone who couldn’t go to many places because of a prior offense or issue.”

Types of Substances

Crack, cocaine, and medicinal and non-medicinal marijuana were the most common substances mentioned by participants.

Peer Recovery Specialists

One participant mentioned that it would be helpful to be connected with someone who could help them through substance use recovery—like a ‘buddy.’ Others expressed their agreement.

“Buddy system for mental health and drug rehab. Like a coach or someone who has had the experience”

“When you feel like you want to use, you call that person.”

System of Care

Figure 4: System of Care Wordcloud



Rhode Island System of Care

Participants communicated a general sense of satisfaction and appreciation for the quantity, quality, and diversity of HIV services offered in Rhode Island.

“Excellent job”

“Very good”

“Lots of places that you can go to if you have HIV. You can get help.”

“The place I go to has doctors, nurses, psychiatrists, housing for everybody – not only for those with HIV.”

Many thought Rhode Island compared very favorably to other states in the country based what they had heard from friends or from their own experience living outside of Rhode Island.

“Compared to North Carolina, Rhode Island is good.”

“When I talk with people across the country, they say ‘we don’t have that [service] here’”

“Rhode Island is one of the best states for HIV”

However, many comments indicated that *active* involvement by the patient was a crucial component to successfully receiving needed services. Services are available but they require the individual to seek them out. Savvy consumers, who know the system, are more likely to be successful.

“It takes a lot of work to navigate the system of care and some people don’t have that will.”

“Everything in RI is accessible. If you want to get your needs met, you have to get [out] and ask.”

“Logistics of care drive me crazy. I got to remember all my appointments. Sometimes I forget whether I took my medication because I have so much on my mind.”

HIV Medical Providers

Individuals reported both strongly positive and strongly negative experiences with HIV medical providers.

One theme centered on a desire to not only receive care from a high quality provider but also one that is a good fit for the individual.

“My doctor is fantastic. Because of him, I had tests done I wouldn’t have thought of. He has been an advocate for me more than my case manager.”

“I am particular in who I see. I want to speak with someone who is high up on the Richter scale.”

Participants frequently shared how they had switched physicians after a bad experience or that they were currently considering looking for another.

“You [my doctor] are going to be on that list of change.”

A primary complaint about physicians among participants was that they felt the physicians often did not understand them as people, only focusing on their HIV and lab values.

“You don’t know me, you know my labs. The same things that bothered me ten years ago bother me today. Get to know me as a person, not a lab.”

Participants articulated that their needs go well beyond medical care and that their physicians did not always seem concerned about those other needs.

“[The doctors] think: ‘You got HIV meds, so you can live.’ But HIV is no picnic! There are still things you need.”

Multiple participants recommended to their peers to be as active as possible during conversations with their doctors. At several points during all three focus groups, other participants responded to an individual sharing a personal problem with a HIV medical provider by saying that the person should be more of an advocate for themselves or try to find a different provider.

“A closed mouth doesn’t get fed.”

“Require that the patient be more actively involved. Don’t let him or her be a victim. Volunteer information as opposed to [the doctor’s] checklist.”

Case Managers

Participants noted that they had experienced significant variation in quality of case managers between agencies and individuals.

“As far as case workers, they are like a free agent. You never know who you are going to end up with.”

“I think the issue is that there are no guidelines. It is a free-for-all for everyone.”

Some reported feeling like they were being treated like paperwork instead of people.

“How can these people take a job and treat all these people as paperwork, and then still sleep at night?”

“I think that case managers and case management has to realize that we are not your patient, we are your client.”

A few individuals reported that they felt like some case managers ‘play favorites’ with certain people or populations.

“You take care of who you know”

“If you are Spanish, you get everything. They are catered to.”

“If I was working as a social worker, I would treat all my patients the same—not one better than another.”

Some individuals reported that their case manager helps them receive substance use and mental health services and some did not.

“My case manager always checks in with me around mental health and substance use issues.”

“If [the client] has no history then [the case manager] wouldn’t ask [about mental health or substance use]. Otherwise, it would be evident.”

One recommendation that emerged from the focus groups was to ask case managers to provide a standardized list of available services to their client and develop a more rigorous plan for their clients.

“Case managers should have a list of offered services. Here is a list of things that we offer, what do you need?”

“Used to be that they had a 6-month plan.”

Transportation

Participants shared that they find public transportation in Rhode Island to often be inconvenient and difficult to use. They expressed concern about RIPTA' plans to start charging the elderly and the disabled a small fee per ride. They said that some people who are poor and suffering from depression take the bus just to get outside and be around other people. Charging them to ride the bus might prohibit them from seeing being able to even see another person some days.

“Very difficult”

“I just hope that RIPTA tries to get better”

One participant shared how in another place that he used to live, they would organize volunteer PLWHA to drive others to appointments when needed.

“Where I came from, they used to ask patients to volunteer drives. After a while, they paid you per mile.”

Housing

Beyond the need for more transitional housing opportunities (discussed in Substance Use section), a few participants mentioned the need for housing opportunities that allowed medicinal marijuana.

“I don’t like taking my pains meds. I don’t know how to solve that problem. I do have to take my medication with food. I have to eat food, then take pills, then eat more food.”

One participant shared a strong recommendation to other PLWHA to never take a ‘drug holiday’ due to the lasting impact that it had had on his wellbeing.

“Don’t take your own drug holiday. Do it with a doctor’s supervision. I took a month-long break, huge huge huge mistake. My T-Cell counts were in the millions. My viral load went crazy. Previously, I was undetected.”

Finding Community

Many participants shared how important it is to find community as a PLWHA. Found or created community was often referred to by participants as ‘family.’

“Sometimes you have to create your own family.”

“I feel like everyone here is my family.”

Many conveyed how their family had pulled away from them after learning about their HIV diagnosis—although some participants did report positive relationships with their family.

“Just because they are genetically connected to you doesn’t mean that they are going to act in the way that you expect.”

“My family uses the excuse of the police, even though I don’t have any police action. I can’t lie to them and say that I am not using, but I can keep them safe.”

“My family isn’t like that, they visit me all the time.”

However, participants did note that creating community was particularly challenging when one is depressed.

“It’s hard to do when you are depressed.”

Telling Other People

Participants shared many different attitudes towards telling other people about their HIV status. Most common was participants neither being fully open about their status nor fully closed, making decisions about sharing on a person-by-person basis.

“I just want to say that I got one foot in the door and one out about telling people. It’s on a need to know basis.”

Some participants shared that their whole family knew and others that their family did not know.

Some participants shared stories about how they had been ‘burned’ by telling one person. Other’s shared how they anticipated a person or group would react if they told them.

“It really pisses me off, when I tell someone in confidence and they go out and tell someone else and all of a sudden I have five people calling me saying so and so told them I have AIDS.”

“Ambulance driver went to the coffee shop and told everyone I knew that I had AIDS and a drug overdose.”

“If my family knew about this, they would treat me different.”

Illness Narratives: Opening Up and Seeking Help

Several individuals offered short narratives that were structured in a before-and-after style around, not their diagnosis, but the moment in which they decided to accept their disease, open up to their providers, and start taking care of their health.

“It took me a long time to come to the realization that it’s not about them, it’s about them. I had to slowly begin to pull walls down and pull off the masks and open up. I had to pick and choose who I seek for help because I don’t expose everything to everyone. Now today, I have a network of people: peers, providers, case managers, all of the above.”

“At first, I would come here and wouldn’t really talk. When you are living a secret life, it just sucks. It’s getting to the point that I am telling more and more people.”

“When I first go diagnosed, I was a [job title] and I almost didn’t come to the clinic for the shame of it. The Health Department CAB gave me hope that I can open up and tell someone that I am HIV positive. It gave me the confidence to open up. I ain’t trying to please anybody but Jesus.”

experienced more stigma. The three most identified minority populations were people who identify as black, Hispanic, or women.

“In the Hispanic community, there is a lot of stigma. A lot of Hispanics don’t like to get tested, even if they have been with a partner who is positive. They just go into denial.”

“As a white man, I have noticed that black elderly men and woman have the hardest time getting what they need.”

“Women have a big stigma... They will show up but then they will start missing appointments. They won’t take time off to come and speak to someone. They don’t want to be seen at the clinic either.”

Recommendations

This section presents some key recommendations that arose from the focus groups.

- Explore means of increasing integration between substance use and mental health services and HIV medical services, perhaps including colocation of services or refined referral processes.
- Increase promotion of substance use and mental health recovery services to ensure that the services that already exist are well-known to consumers.
- Promote consistent screening for mental health and substance use issues by HIV medical providers and case managers.
- Explore how to make case management services more effective and consistent. This could include implementing a standardized training curriculum, developing a statewide HIV case manager certification, providing regular training opportunities for professional development, and sharing robust resources with case managers that describe available services from organizations in RI that they can share with clients.
- Explore ways to increase communication between case managers and consumers in regards to information, referrals, policies, and procedures in cultural appropriate ways.
- Recommend that case management services develop a simple written means of communicating available support services at their agency (e.g. a 'one-pager').
- Increase the number of transitional housing opportunities for people with substance use issues.
- Investigate and summarize existing research on stigma. Identify strategies to address it in cultural appropriate ways.
- Ensure consumer participation in discussion about stigma and facilitate opportunities for consumers to share their experience and their suggestions for how to address it.
- Explore ways to involve existing consumer groups in meetings to share experiences, develop leadership opportunities, and participate in trainings.
- Increase opportunities for consumers to identify ways to share their experiences and information with each other.

Conclusion

The results from this focus group demonstrate the tremendous value in engaging the consumer voice and truly listening. Qualitative methods excel at revealing the human context around statistical trends. In this case, the focus groups were able to shed further light on the results from the 2015 RI Ryan White Consumer Survey, exploring the actual 'lived' impact of mental health and substance use on the lives of PLWHA in RI. Many of the resulting recommendations were suggested directly by consumers based on their own experiences with barriers to treatment and their thoughts on how the system could be improved.

Lastly, the results from these focus groups also highlight this population's incredible collective strength and power of will. Behind each comment is a person striving for a meaningful life amidst great hardship. Such grit and determination is an inspiration for those working on this epidemic.

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Authors

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Appendix A: Focus Group Guide

RI HIV+ Consumer Focus Groups: Qualitative Assessment of Mental Health and Substance Use Care, Treatment, Recovery and Support Services among PLWHA

Introduction: Stated Purpose of the Focus Group

Mental Health and Substance Use among HIV+ Rhode Islanders:

For some Rhode Islanders with HIV, issues related to mental health and substance use can impact their ability to effectively engage in care and treatment, not only for mental health and substance use disorders, but also across the HIV care continuum. If you are living with HIV, drug and alcohol use can significantly affect your health and well-being, and complicate your HIV care and treatment. It can also put you at risk of transmitting the virus to others. Some people develop *substance use disorders*—the use of alcohol or drugs that is compulsive or dangerous (or both).

Also, mental health issues are a concern for anyone, but they present special challenges for people living with HIV/AIDS (PLWHA). Like substance use disorders, mental health issues affect your ability to cope and carry out typical functions in your life, which can make it hard to adhere to ART. They also interfere with your healthy behaviors, such as getting enough sleep, exercise and avoiding risk behaviors such as having unprotected sex.

Getting treatment for substance use disorders and mental health issues is an important part of staying healthy with HIV.

(Adapted from: <https://www.aids.gov/hiv-aids-basics/staying-healthy-with-hiv-aids/taking-care-of-yourself/substance-abuse-issues/>)

Additionally, potential stigma surrounding being HIV+ may impede health-seeking behaviors and access to mental health and substance use/abuse services must be addressed. Structural conditions, such as stigma and potential discrimination, must be addressed in order to promote unfettered access to HIV care and treatment that can increase the health of PLWHA who are affected by mental health and substance use issues.

As members of one of RI's HIV Consumer Advisory Boards, your input is very important and helps us to understand issues that may be impacting those with HIV both in this group, but also for those PLWHA throughout the State. Please note, we are interested in understanding what you are seeing and hearing among others with HIV in the State around these issues and if you are comfortable sharing any of your own experiences, if appropriate. We are interested in understanding not only with mental health and substance use potentially impacts HIV, but how being HIV+ affects issues related to mental health and substance use.

Participation in today's group is completely voluntary. We will record today's session; however **we will NOT attach your name to any of your responses**. Additionally, you will receive a \$20 gift card for your participation in today's group.

I. What are the most common mental health (diagnosed or undiagnosed) and substance use (recreational or chronic use) issues among PLWHA in RI?

Probes:

Do PLWHA in RI access mental health and substance abuse services to address these needs?

If no, why do you think PLWHA do not access mental health and substance abuse services?

Have you or others experienced barriers to accessing these services?

Are there particular disparities, or differences between groups that don't receive the same care as others related to access of MH and SU services?

Thinking about care, treatment and recovery, what is good about accessing mental health and substance use in Rhode Island?

II. How well do you think Rhode Island has provided MH and SU services to address these needs among PLWHA?

Probes:

Have you or others experienced particular challenges, or barriers in accessing MH and SU services for PLWHA?

Is it more difficult for some populations of PLWHA to access these services? Why? Why not?

Do MH and SU providers understand issues that are unique, or specific to PLWHA?

Are RI MH and/or SU providers culturally competent in providing services to PLWHA?

*Do you **trust** your **clinical providers** (doctors, PAs, nurses) in discussing issues around MH and SU?

Do your clinical providers screen for MH and SU issues? Need for needle exchange?

*For those who use **case management**, do you **trust** your **case manager** in discussing issues around MH and SU?

Do your case managers screen for MH and SU issues? Need for needle exchange?

III. For PLWHA who experience MH and SU challenges in the State, how have these challenges/issues impacted: becoming engaged in treatment after diagnosis; scheduling and keeping appointments; and, treatment adherence? Sexual risk-taking behaviors?

Probes:

Does MH and SU impact PLWHA ability to stay in care? Move in/out of care?

Be adherent to ART?

Have you taken a "treatment holiday" from taking your medications as prescribed? For MH issues? SU?

Does HIV impact MH and SU?

Does this impact certain groups more than others?

IV. Do stigma and/or discrimination impact PLWHA's ability to access MH and SU services RI?

Probes:

If yes, in what ways? (Internalized vs. institutional)

Are you concerned about issues related to confidentiality, or anonymity?

How does this impact seeking MH and SU services?

V. Do you, or those you know with MH and SU issues, feel safe sharing/disclosing your HIV positive status when accessing MH and substance use services? among peers with MH and SU issues?

Probes:

If no, have you, those you know, experienced discrimination within healthcare settings? Within social networks? Family?

Does discrimination or stigma affect an individual's ability to access healthcare? MH and SA?

Connect or find support with peers or others within your social networks?

If yes, has sharing your status helped you access healthcare? For MH and SU?

VI. In the past six months, have you received any information or materials about MH and/or SU? Tailored specifically to the needs and concerns of PLWHA? Information about care, treatment, recovery, and/or support?

Probes:

Where?

What MH and SU services are available in your community?

Do PLWHA seek out MH and/or SU services?

If yes, what services are most helpful?

If no, why not?

VII. What resources are not available in RI for PLWHA in need of MH and SU services?

Probes:

For MH? For substance abuse treatment or recovery?