Morris Sussex Warren 2018 Regional Needs Assessment

Report to Stakeholders Prepared by Allison Delcalzo-Berens,
Chair of the Morris Sussex Warren HIV Advisory Committee
October 26, 2018

1 INTRODUCTION

1.1 ABOUT THE MORRIS, SUSSEX, WARREN HIV/AIDS ADVISORY COMMITTEE

The Morris, Sussex, Warren HIV/AIDS Advisory Committee (MSWHAC) was created in 1996 by the Board of Chosen Freeholders in Morris, Sussex and Warren Counties as a response to the HIV epidemic. The MSWHAC's mission is to serve as a united voice on behalf of HIV infected and affected consumers, service providers and county governments. It serves as the primary coordinating, planning and policy development entity on issues related to HIV/AIDS in the region. In addition, it advises and educates the Freeholders, health care providers, appropriate state and federal government agencies and the general public on matters associated with the prevention, care and treatment of HIV. The MSWHAC has several initiatives that fall under its umbrella to carry out its mission, goals and objectives.

Starting in 2012, the City of Newark has mandated that Ryan White funded providers participate in a local Early Intervention and Retention Collaborative or EIRC to provide seamless referral, linkage and integration of newly diagnosed individuals into HIV care by early intervention services. Since providers in the Morris, Sussex and Warren region were already meeting as part of the MSWHAC, it was determined that the two entities would merge, incorporating EIRC goals as part of its overall purpose.

In 2016, the providers in the MSWHAC agreed to form an HIV Collaborative. This is a formal agreement among providers who work together to establish a continuum of care for people living with HIV (PLWH) and high risk HIV negative individuals living in the tri-county region. Collaborating Partners are Ryan White funded entities who have a commitment to the MSWHAC while Resource Partners are not funded through Ryan White but are stakeholders in HIV service provision. All partners have pledged a responsibility to ensure that PLWH and high risk HIV negative individuals receive access to high quality, culturally appropriate care and treatment and prevention services; reduce barriers to medical treatment, supportive community-based services and prevention services that exist in the region, facilitate efficient communication with all other partners; and collaborate on projects that will maximize the quality of life for PLWH and high risk HIV negative individuals.

In 2015, the MSWHAC held a large Community Dialogue event at the Morris County Public Safety Training Academy which was attended by consumers from the local region. Findings from this event showed that consumer participants demonstrated a need for learning self-advocacy skills and expressed a desire for more learning opportunities. In response to this, the MSWHAC created an annual Lunch and Learn series in which each provider sponsors and plans an educational workshop or lecture targeted towards consumers. This initiative has grown to include five Lunch and Learns annually on topics chosen by consumers and have included a large range of topics.

In 2017, a joint consumer advisory board was initiated and incorporated as the Community Action Board or CAB. The CAB is an organization of community members living or receiving services in the region whose mission is to empower consumers of HIV services to self-advocate in a safe, peer-to-peer environment. The CAB's purpose is to inform the MSWHAC about treatment barriers and gaps that arise in the hopes of creating change; educate consumers on their rights, navigating and accessing services and service funding and availability; nurture peer relationships and support; facilitate dialogue and collaboration with the MSWHAC to achieve mutual goals; and create and maintain a bond between providers and consumers. This organization has a chair, secretary and treasurer and is represented by consumers of all Ryan White agencies in the region.

The MSWHAC coordinates with, reports to and receives advisory assistance from a number of stakeholders including the Morris County Department of Human Services, City of Newark Ryan White office, the Newark Eligible Metropolitan Area (NEMA) Planning Council, Rutgers HIV Prevention Community Planning Support and Development Initiative, and the AIDS Education and Training Center (AETC). It was recommended by these stakeholders that the region complete a local needs assessment due to the geographical uniqueness of the area and the differing local needs from the more urban centers in the NEMA.

1.2 Research Methodology

1.2.1 Needs Assessment Subcommittee and Early Planning

The MSWHAC selected a subcommittee to complete the Needs Assessment in November 2017. The subcommittee was composed of one volunteer representative from each of the four Ryan White providers in the region and a selection of consumer volunteers. The subcommittee also utilized the region's Community Action Board (CAB) to present ideas and solicit feedback and suggestions. In February 2018, the MSWHAC had a presentation from an advisory member of the Committee and staff of the AIDS Education and Training Center about what a needs assessment is and different ways it can be conducted. In March, the Needs Assessment Subcommittee had a training on the various stakeholders involved in the MSWHAC as well as the projected timeline and expectations of subcommittee members.

The Needs Assessment was projected to be conducted starting in January with a completion date of June. It was estimated that a full report could be made to the MSWHAC as well as the Newark EMA Planning Council by the end of the summer months. Poor weather throughout the spring, lack of vested and coordinated participation by providers and deficiencies in experience and knowledge about the process caused delays in the projected timeline. The original project plan was to have four teams composed of a provider team leader and two to three consumer volunteers. The responsibilities for these teams would be to develop surveys for distribution to consumers and to providers, organize focus groups and complete research relevant to the project.

Due to the geographic makeup of the region and local population of PLWH and the novelty of this type of work to the MSWHAC, it was determined that the needs assessment would have a narrow focus. The topic of the needs assessment was chosen via vote after lengthy conversation during a CAB meeting in late spring. Consumers voiced a particular interest in learning about how case management providers communicated information about mental health and behavioral risks to consumers. Since this topic is not directly related to a specific funding category, it was determined after this topic was chosen that there would be limited need for a research team. Later, due to waning interest from consumers, the determination was made to eliminate the focus groups from the process as well. Instead, the entire subcommittee became engaged in the development of the consumer and provider surveys.

1.2.2 Consumer Surveys

The consumer survey was developed by two providers and feedback was solicited from all members of the subcommittee via email. Originally the survey was several pages long and asked many questions that were not relevant to the topic chosen. Furthermore, some questions in the survey were found to be possible triggers for people with mental health disorders or trauma. Therefore, the survey was heavily edited and screened for IRB process requirements. The final survey was found to be more relevant and intentional and not to require IRB approval.

There was an attempt to utilize Survey Monkey to engage consumers in the process electronically; however, this proved too challenging as the questions often required adjustments to the logic model. Requests were made from providers to assist in translating the survey into Spanish; however, this request went unanswered by all but one provider.

The survey was distributed in paper version to consumers at the four Ryan White providers throughout the summer of 2018 and were collected at the end of September. A total of 49 surveys were distributed. Nine individuals chose not to complete the survey. Forty completed surveys were collected and reviewed. There was a large disparity in the number of surveys collected from each provider, indicating that some providers were more engaged in the process than others.

1.2.3 Provider Surveys

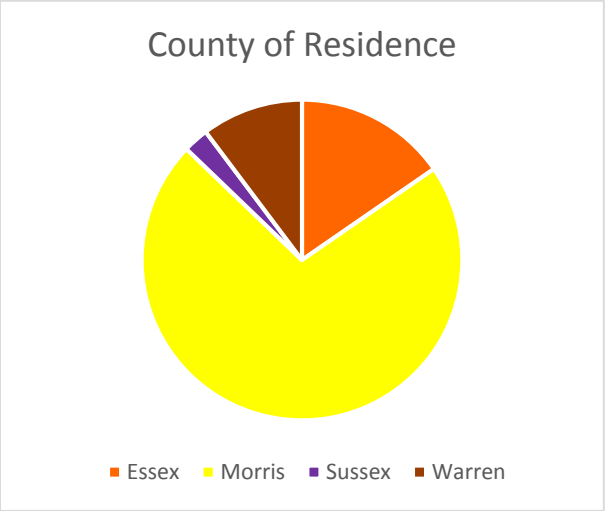
The provider survey was also developed by two providers and feedback was solicited from all members of the subcommittee via email. This survey was developed after the consumer survey was finalized and mirrored the goal of requesting only the information that is relevant to the topic. The provider survey included more free response questions than the consumer survey. The survey was distributed to all case managers and medical case managers in the region. Three agencies, one of which had two service arms, chose to complete the survey together and submit one from the agency, resulting in four returned surveys. One agency opted to have each of its two medical case managers complete the survey resulting in an additional two returned surveys for a total of six collected provider surveys.

2 CONSUMER SURVEY RESPONSES

2.1 DEMOGRAPHICS

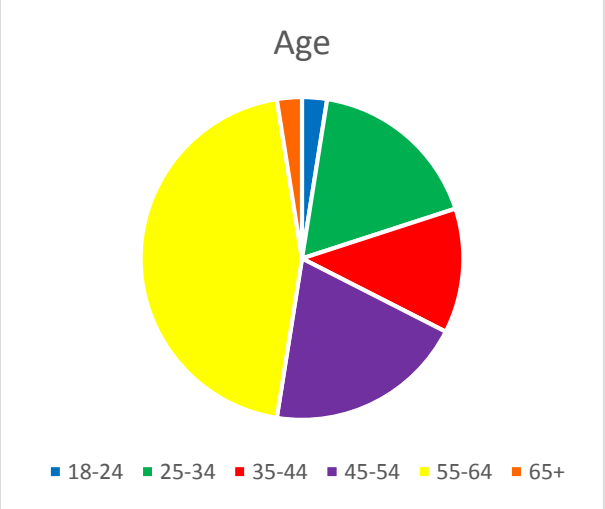
2.1.1 County of Residence

Essex	6	15%
Morris	28	70%
Sussex	1	2.5%
Warren	4	10%
Somerset	1	2.5%



2.1.2 Age

18-24	1	2.5%
25-34	7	17.5%
35-44	5	12.5%
45-54	8	20%
55-64	18	45%
65+	1	2.5%



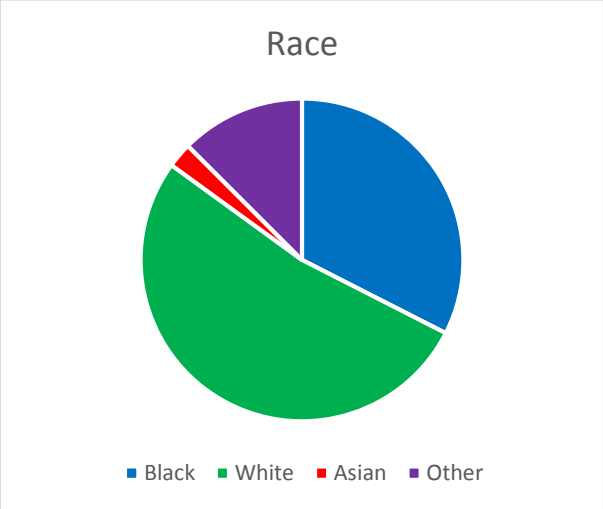
2.1.3 Race/Ethnicity

Black	13	32.5%
White	21	52.5%
Asian	1	2.5%
Other (Latino)*	5	12.5%

Ethnicity: Latino**	13	32.5%

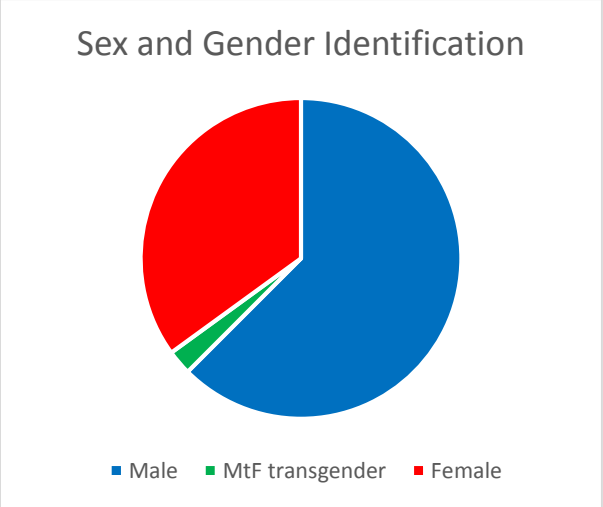
* All of the respondents who selected “other” wrote in the comments section that they identify their race as Latino.

** These same five respondents also indicated Latino as their ethnicity in addition to another eight who identified their race as “white”.



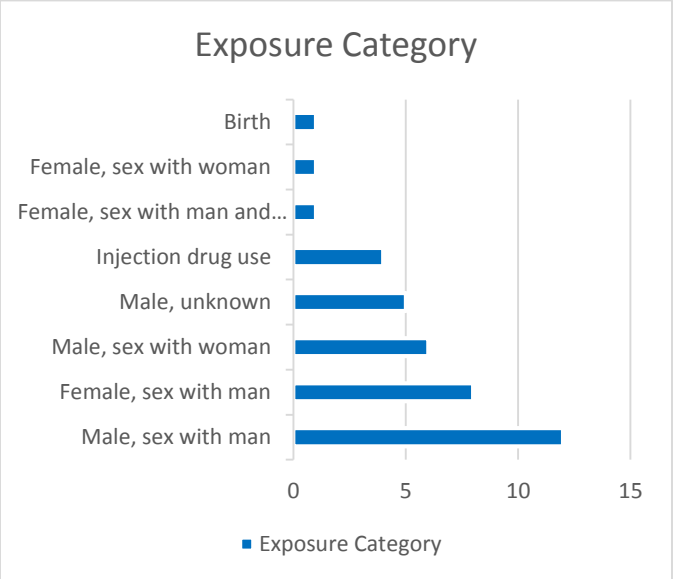
2.1.4 Sex and Gender

Male	25	62.5%
MtF transgender	1	2.5%
Female	14	35%



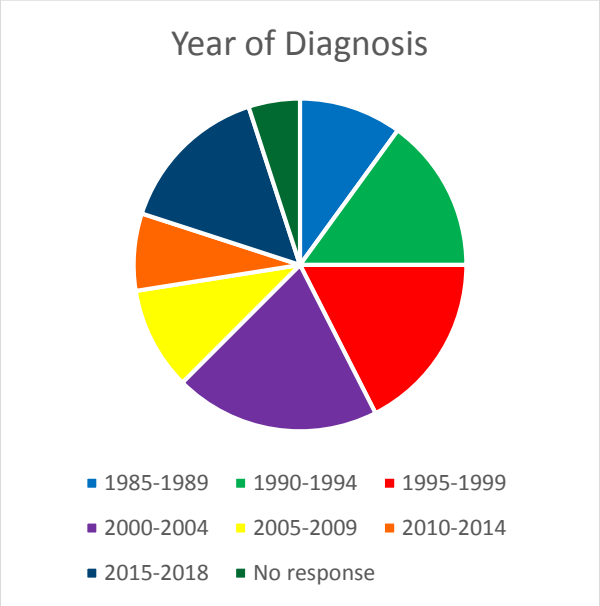
2.1.5 Exposure Category

Male, sex with man	12
Female, sex with man	8
Male, sex with woman	6
Male, unknown	5
Injection drug use	4
Female, sex with man and injection drug use	1
Female, sex with woman	1
Birth	1



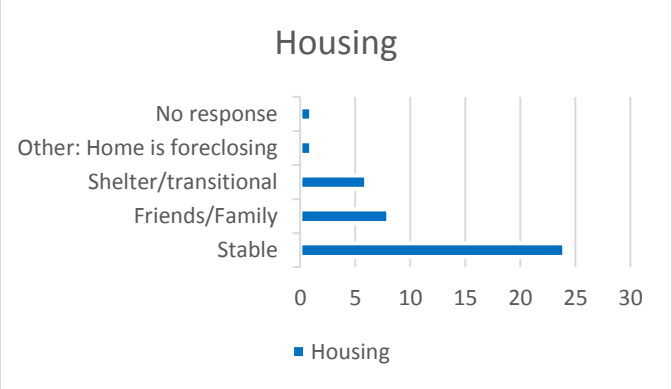
2.1.6 Diagnosis Year

1985-1989	4
1990-1994	6
1995-1999	7
2000-2004	8
2005-2009	4
2010-2014	3
2015-2018	6
No response	2



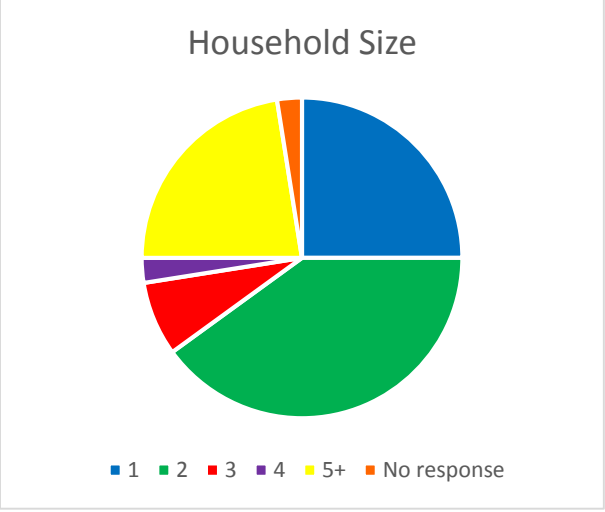
2.1.7 Living Situation

Stable	24
Friends/Family	8
Shelter/transitional	6
Other: Home is foreclosing	1
No response	1



2.1.8 Household size

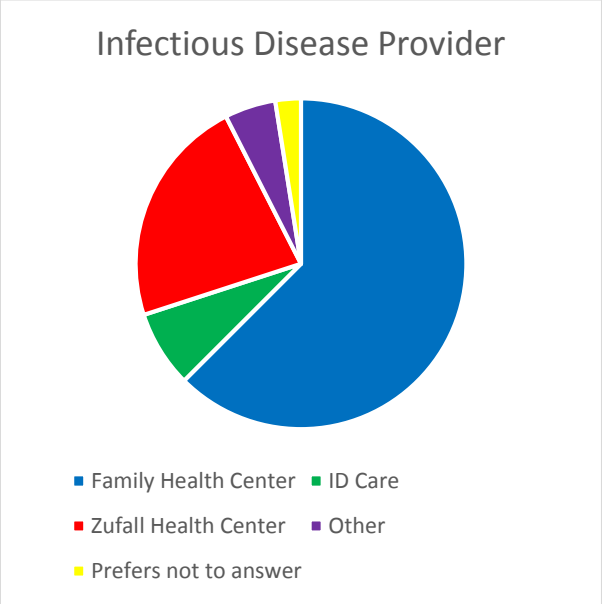
1	10
2	16
3	3
4	1
5+	9
No response	1



2.2 MEDICAL CARE

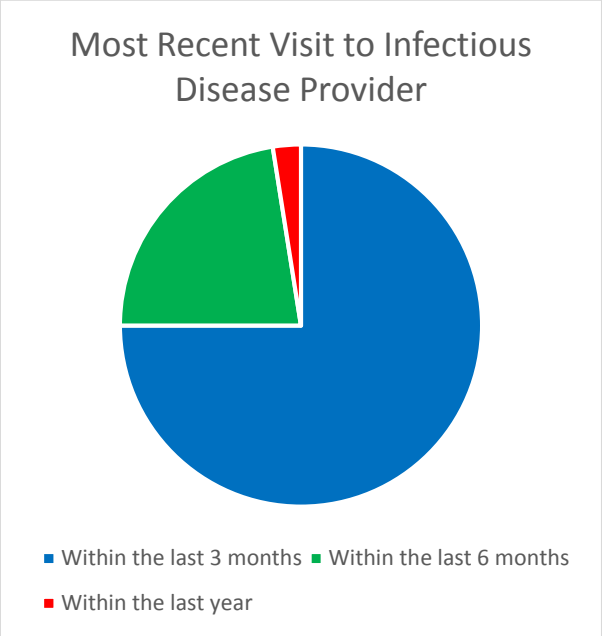
2.2.1 Medical Provider

Family Health Center	25
Zufall Health Center	9
ID Care	3
Other	2
Prefers not to answer	1



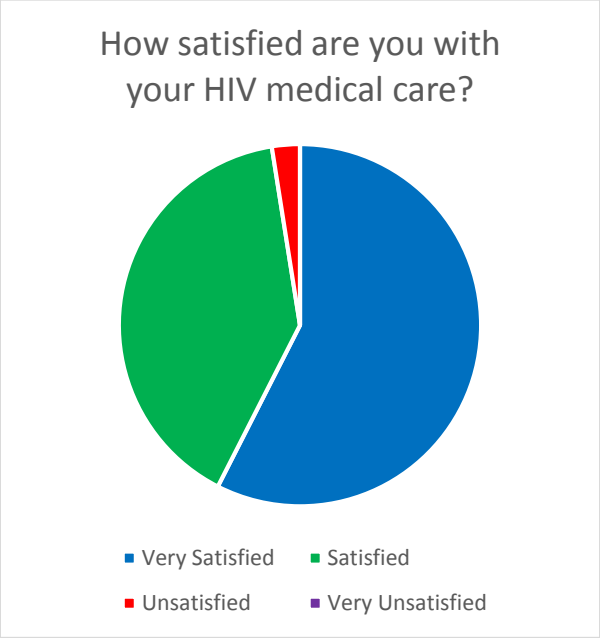
2.2.2 Most Recent Visit to Medical Provider

Within the last 3 months	30
Within the last 6 months	9
Within the last year	1



2.2.3 Satisfaction with Medical Care

Very Satisfied	23	57.5%
Satisfied	16	40%
Unsatisfied	1	2.5%
Very Unsatisfied	0	

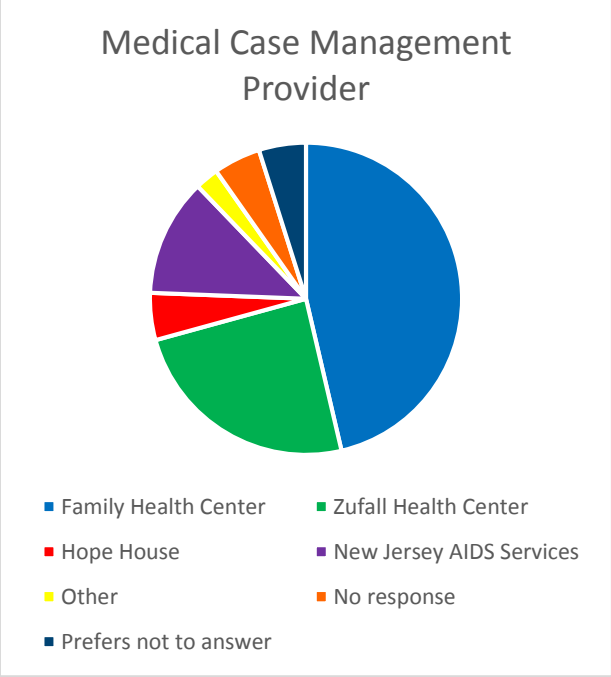


2.2.3.1 Suggestions for improvement about HIV Medical Care

Closer
Easier transportation
Health insurance access
If the FHC would have a support group since I feel very comfortable here
More support groups to maintain sobriety
Not changing doctors often
Pharmacy could be better
Psychiatry
Text messages before appointments

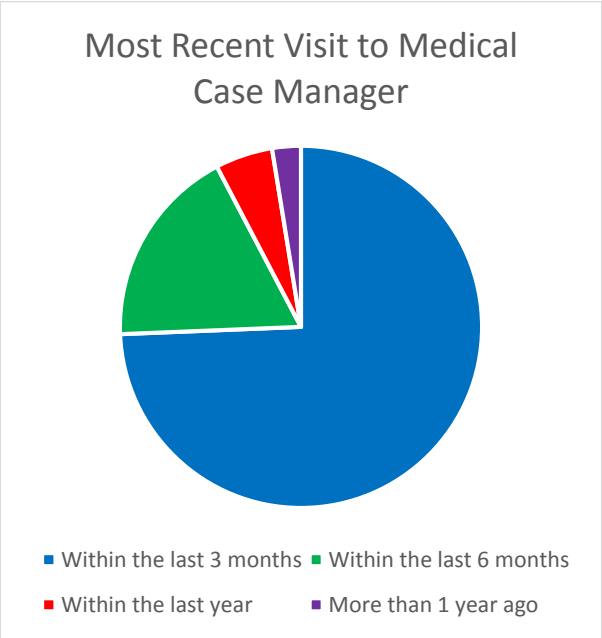
2.2.4 Medical Case Management Provider

Family Health Center	19
Zufall Health Center	10
Hope House	2
New Jersey AIDS Services	5
Other	1
No Response	2
Prefers not to answer	2



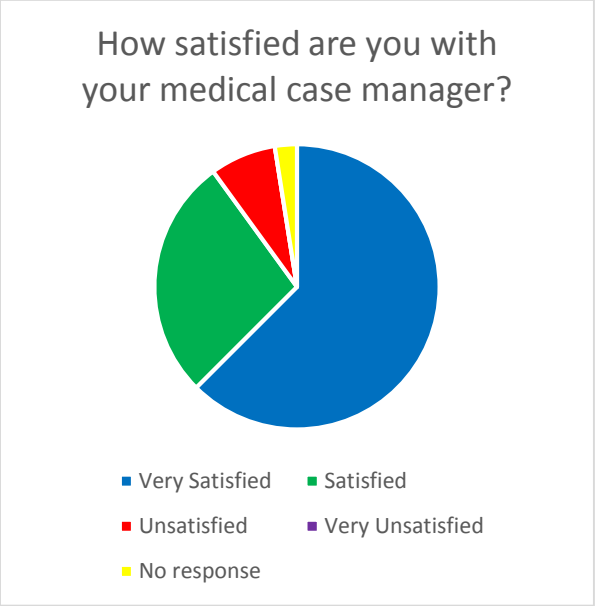
2.2.5 Most Recent Visit to Medical Case Manager

Within the last 3 months	29
Within the last 6 months	7
Within the last year	2
More than 1 year ago	1



2.2.6 Satisfaction with Medical Case Manager

Very Satisfied	25	62.5%
Satisfied	11	27.5%
Unsatisfied	3	7.5%
Very Unsatisfied	0	
No response	1	2.5%



2.2.6.1 Suggestions for Improvement about Medical Case Manager

I do not receive any medical insurance

I really don't need her to do anymore. I need to communicate better with her

More group options

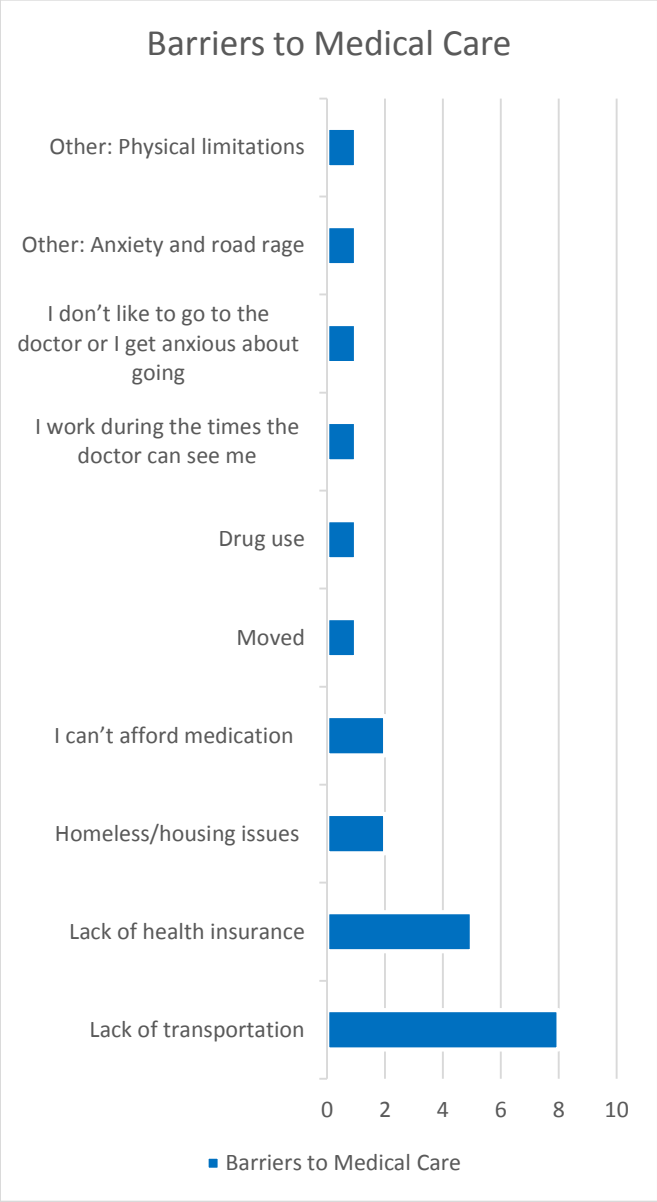
Pharmacy

Too early because I just started the program

I have received HIV and mental health care at RW Morristown for over a year. I would not change anything about the clinic. People here are just amazing Forever I be grateful since when I came I was very sick with AIDS. From the first day I was treated with compassion, dignity and respect. I am undetectable now and with the care at Ryan White Clinic I am well. I would like if they would have support group here because people here over all treat the patient with respect and for the visit is always the same. I would attend support group here since I feel incredibly comfortable here.

2.2.7 Barriers to Care

N/A (I have been to the doctor in the last year)	17
Lack of transportation	8
Lack of health insurance	5
Homeless/housing issues	2
I can't afford medication	2
Moved	1
Drug use	1
I work during the times the doctor can see me	1
I don't like to go to the doctor or I get anxious about going	1
Other: Anxiety and road rage	1
Other: Physical limitations	1
I have not found a doctor that I like	0
Lack of childcare	0
I can't afford to go to the doctor	0
Mental health condition	0
I don't understand the language my doctor uses	0
HIV-related stigma	0
My doctor or nurse told me I do not need care right now	0
I don't need care because I don't feel sick	0
Recent loss of family or significant other (separation/divorce/death)	0
I don't feel comfortable with my doctor or the office	0



2.3 Access to Mental Health and Substance Use Support

2.3.1 In the last 12 months, do you feel that your case manager has helped you improve the problems, feelings or situations that you talk to them about?

Yes	37
No	0
Don't Know/Don't Remember	1
No response	2

2.3.2 In the last 12 months, have you reported an issue you need assistance with to your case manager?

Yes	20
No	16
No response	4

Out of the 20 who said they reported an issue, 16 said they received a referral from their MCM, 2 said they did not, and the remaining did not respond. One write in said, "[Medical Case Manager] helped with the issue" indicating there was no need for a referral.

Out of the 16 who received the referral, 13 said they used the referral and the remaining did not respond.

Of the 13 who used the referral, 8 said it took less than one month to see the referral and the remaining did not respond.

2.3.3 Are you comfortable talking to your case manager if you feel depressed or want to speak to a counselor?

Yes	36
No	0
No response	2
Don't know	2

2.3.4 Are there materials that you can look at about mental health support, counseling, or support groups in the waiting room or office of your case manager?

Yes	32
No	2
Don't Know/Don't Remember	4
No response	2

2.3.5 Do you feel that you could benefit from mental health education?

Yes	19
No	17
No response	4

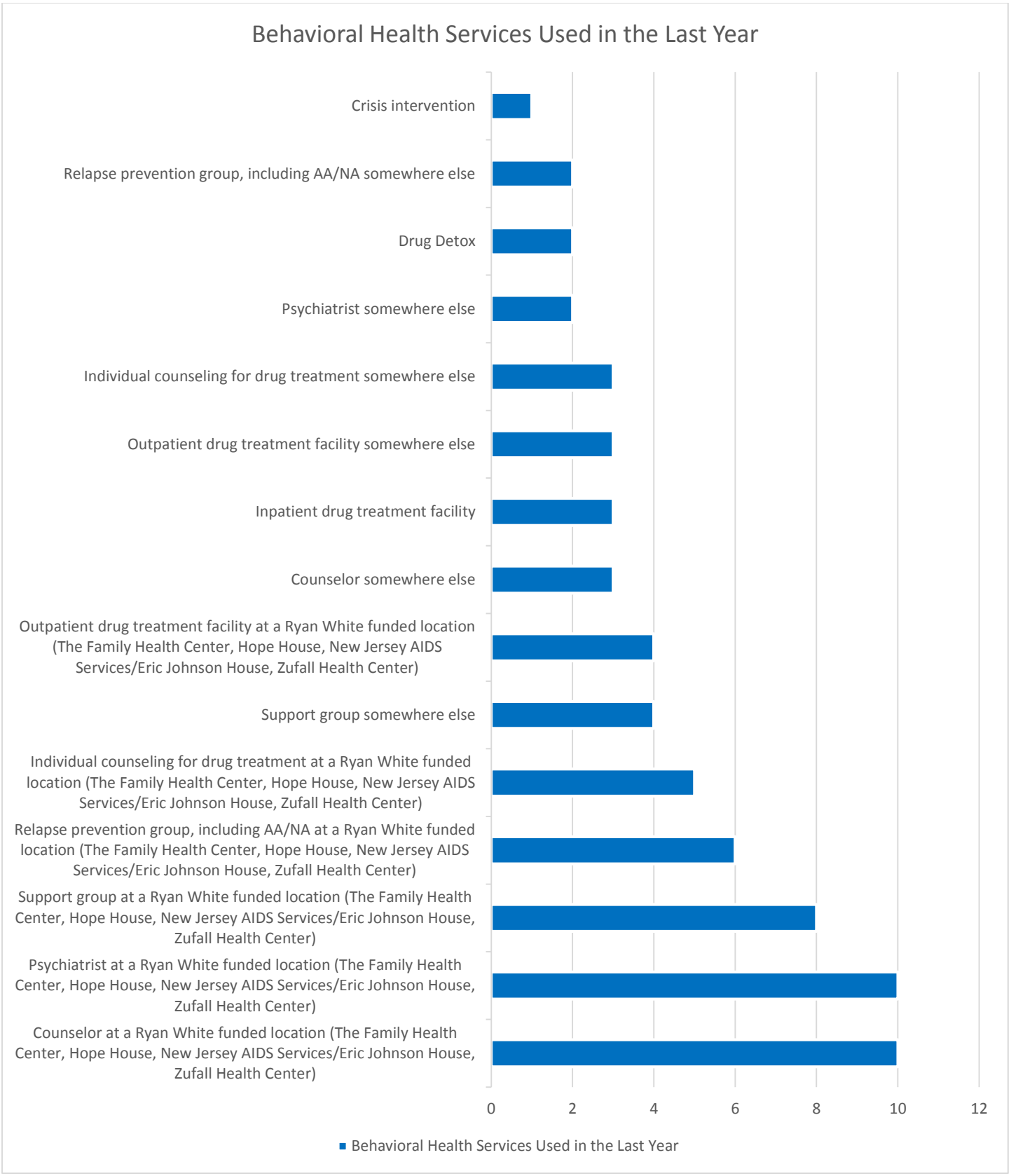
2.3.6 Have you ever been to a support group?

Yes	20
No	18
No Response	2

Of the 20 who have been to a support group, 18 said it was helpful. One said it was not helpful and one wrote in "n/a".

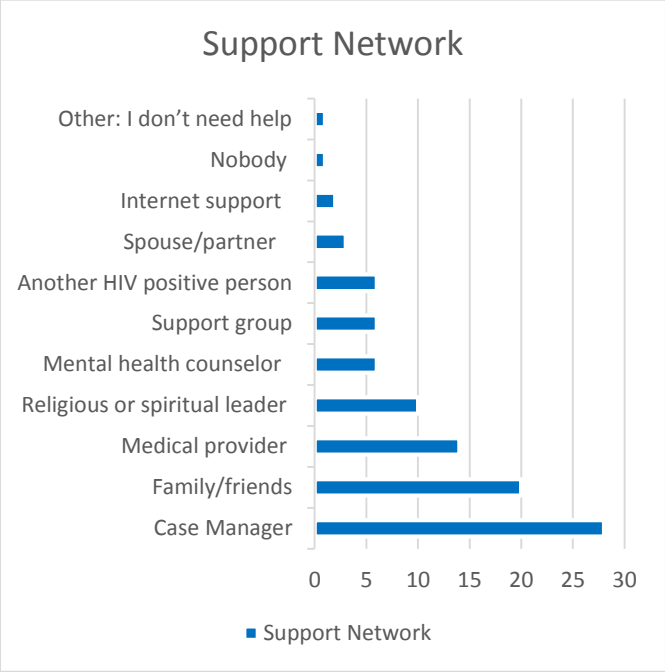
2.3.7 Please check off any mental health or behavioral health services that you have used in the last 12 months:

None	12
Counselor at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	10
Psychiatrist at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	10
Support group at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	8
Relapse prevention group, including AA/NA at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	6
Individual counseling for drug treatment at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	5
Support group somewhere else	4
Outpatient drug treatment facility at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	4
Counselor somewhere else	3
Inpatient drug treatment facility	3
Outpatient drug treatment facility somewhere else	3
Individual counseling for drug treatment somewhere else	3
Psychiatrist somewhere else	2
Drug Detox	2
Relapse prevention group, including AA/NA somewhere else	2
Crisis intervention	1


Behavioral Health Services Used in the Last Year
Crisis intervention
Relapse prevention group, including AA/NA somewhere else
Drug Detox
Psychiatrist somewhere else
Individual counseling for drug treatment somewhere else
Outpatient drug treatment facility somewhere else
Inpatient drug treatment facility
Counselor somewhere else
Outpatient drug treatment facility at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)
Support group somewhere else
Individual counseling for drug treatment at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)
Relapse prevention group, including AA/NA at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)
Support group at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)
Psychiatrist at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)
Counselor at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)
0
2
4
6
8
10
12
Behavioral Health Services Used in the Last Year

2.3.8 Who do you ask for help or support when you need it (check all that apply)?

Case Manager	28
Family/friends	20
Medical provider	14
Religious or spiritual leader	10
Mental health counselor	6
Support group	6
Another HIV positive person	6
Spouse/partner	3
Internet support	2
Nobody	1
Other: *I don't need help*	1



2.4 Case Manager Assistance with Behavioral Risks

2.4.1 In the last 12 months, have you needed help figuring out ways to be sexually active and keep yourself and your partner(s) healthy?

Yes	3
No	35
No response	2

2.4.2 Has your case manager talked to you about condoms?

Yes	13
No	5
No response	22

2.4.2.1 (Of the 13 who said yes to question in section 5.1) Did you understand what your case manager was telling you about condoms and other barriers?

Yes	13
No	0
No response	0

2.4.2.2 (Of the 13 who said yes to question in section 5.1) Did you feel confident to make good decisions after your conversation with your case manager?

Yes	12
No	1
No response	0

2.4.3 Has your case manager talked to you about U=U?

Yes	16
No	3
No response	21

2.4.3.1 (Of the 16 who said yes to question in section 5.3) Did you understand what your case manager was telling you about U=U?

Yes	14
No	0
No response	2

2.4.3.2 (Of the 16 who said yes to question in section 5.3) Did you feel confident to make good decisions after your conversation with your case manager?

Yes	14
No	0
No response	2

2.4.4 Has your case manager talked to you about PrEP?

Yes	14
No	9
No response	17

2.4.4.1 (Of the 14 who said yes to question in section 5.4) Did you understand what your case manager was telling you about PrEP?

Yes	14
No	0
No response	2

2.4.4.2 (Of the 14 who said yes to question in section 5.4) Did you feel confident to make good decisions after your conversation with your case manager?

Yes	14
No	0
No response	2

2.4.5 In the last 12 months, have you needed help figuring out ways to stay healthy if using drugs and how to use drugs more safely?

Yes	3
No	34
No response	3

2.4.5.1 (Of the 3 who said yes to question in section 5.5) Has your case manager talked to you about syringe access programs?

Yes	1
No	0
No response	2

2.4.6 In the last 12 months, have you needed help figuring out if, when and how to tell people about your HIV status?

Yes	2
No	32
No response	6

2.4.6.1 (Of the 2 who said yes to question in section 5.6) Have you received disclosure guidance from your case manager?

Yes	2
No	0
No response	0

3 PROVIDER SURVEY RESPONSES

3.1 PROGRAMS AND SERVICES

There are four Ryan White-funded providers in the MSW region including two medical providers, the Family Health Center and Zufall Health Center, and two community-based organizations, Catholic Family and Community Services, d/b/a Hope House and New Jersey AIDS Services. Ryan White-funded services provided by all of these agencies together include primary medical care, medical case management, case management, transportation, mental health counseling, substance use counseling, psychiatry, oral health care, HOPWA, transitional housing, transportation, nutritional services and pharmacy.

3.2 BEHAVIORAL HEALTH QUESTIONS

3.2.1 How frequently do you ask your clients each of the following:

If they are feeling sad, lonely or depressed?	Every Visit	4
	Semi-Annually	2
	Annually	1
	At Intake	0
	If signs are present	3
	Do not ask	0
	Other	0
If they are having trouble concentrating or focusing?	Every Visit	0
	Semi-Annually	3
	Annually	1
	At Intake	1
	If signs are present	3
	Do not ask	1
	Other	0
About their eating habits?	Every Visit	1
	Semi-Annually	2
	Annually	2
	At Intake	1
	If signs are present	3
	Do not ask	0
	Other	0
If they have thought about hurting themself or others?	Every Visit	1
	Semi-Annually	6
	Annually	1
	At Intake	1
	If signs are present	2
	Do not ask	0
	Other	0
If they are receiving or have ever received counseling, psychiatric or other mental health services?	Every Visit	0
	Semi-Annually	4
	Annually	2
	At Intake	2
	If signs are present	3
	Do not ask	0
	Other	1

If they have ever been diagnosed with or treated for a mental health disorder (such as bipolar, depression, anxiety, schizophrenia, post-traumatic stress disorder, etc.)?	Every Visit	0
	Semi-Annually	4
	Annually	2
	At Intake	2
	If signs are present	3
	Do not ask	0
	Other	1
If they are taking any psychiatric medications?	Every Visit	0
	Semi-Annually	4
	Annually	2
	At Intake	0
	If signs are present	3
	Do not ask	1
	Other	1
How frequently they are using alcohol?	Every Visit	0
	Semi-Annually	5
	Annually	2
	At Intake	1
	If signs are present	4
	Do not ask	0
	Other	0
If they are using recreational drugs (marijuana, cocaine, heroin, crystal meth, etc.)?	Every Visit	0
	Semi-Annually	5
	Annually	2
	At Intake	1
	If signs are present	4
	Do not ask	0
	Other	0
If they need any help preventing a relapse if they have an addiction history?	Every Visit	2
	Semi-Annually	3
	Annually	1
	At Intake	1
	If signs are present	3
	Do not ask	0
	Other	0
If they smoke?	Every Visit	2
	Semi-Annually	4
	Annually	2
	At Intake	1
	If signs are present	2
	Do not ask	0
	Other	0
If they are taking medications as prescribed?	Every Visit	6
	Semi-Annually	2
	Annually	2
	At Intake	1
	If signs are present	0
	Do not ask	0
	Other	0

About HIV related stigma?	Every Visit	3
	Semi-Annually	2
	Annually	1
	At Intake	3
	If signs are present	2
	Do not ask	0
	Other	0
If they need an extra level of support?	Every Visit	5
	Semi-Annually	2
	Annually	1
	At Intake	1
	If signs are present	1
	Do not ask	0
	Other	0
If they have any sexual partners?	Every Visit	4
	Semi-Annually	4
	Annually	1
	At Intake	1
	If signs are present	1
	Do not ask	0
	Other	0

3.2.2 Do you feel that you are adequately trained to do mental health and substance abuse screenings?

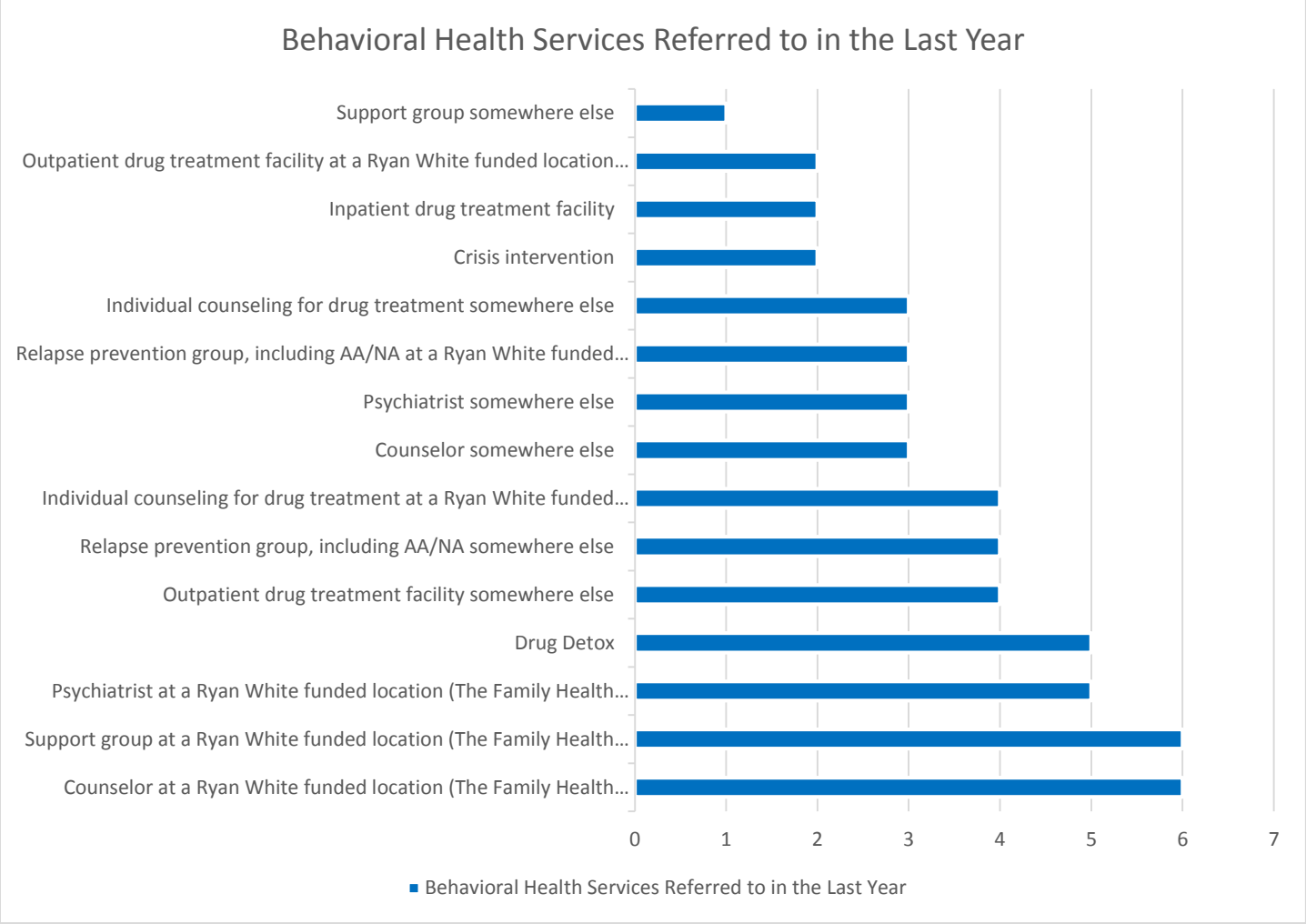
Yes	6
No	0

3.2.3 Do you feel that other members of your agency are adequately trained to do mental health and substance abuse screenings?

Yes	5
No	1

3.2.4 Please check off mental health or behavioral health services that you referred clients to in the last 12 months.

Counselor at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	6
Support group at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	6
Psychiatrist at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	5
Drug Detox	5
Outpatient drug treatment facility somewhere else	4
Relapse prevention group, including AA/NA somewhere else	4
Individual counseling for drug treatment at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	4
Counselor somewhere else	3
Psychiatrist somewhere else	3
Relapse prevention group, including AA/NA at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	3
Individual counseling for drug treatment somewhere else	3
Crisis intervention	2
Inpatient drug treatment facility	2
Outpatient drug treatment facility at a Ryan White funded location (The Family Health Center, Hope House, New Jersey AIDS Services/Eric Johnson House, Zufall Health Center)	2
Support group somewhere else	1



3.2.5 Please describe your process for making a referral when a client presents a need for support with behavior change, mental health or substance use issue:

CM meets with client, screens client using BHS referral sheet, CM presents case to BHS, BHS determines proper course of action

Ask if they are interested in our services and link them to care by a champ referral and have counselor contact client directly

We first find a provider that takes our clients insurance. We also want to understand the client's expectation/outcome to ensure we refer them to the correct provider

Assess --> link them to BH

Internal or External: phone call to agency-champ

MCM will complete a MH assessment, discuss referral with patient, link patient to referral, explain process, follow up with patient

3.2.6 If a client requires a referral but you do not know a resource, what do you do?

Contact RW, refer to supervisor if necessary

Contact and ask other partnered agencies for help with connecting client

Discuss with colleagues or other agencies to problem solve with the client

Look for resources

Our team works together (doctor, social worker, CMC, pharmacist, etc.)

Search for possible services via the web, colleagues

3.2.7 What percent of referrals that you make do you estimate that clients follow through with?

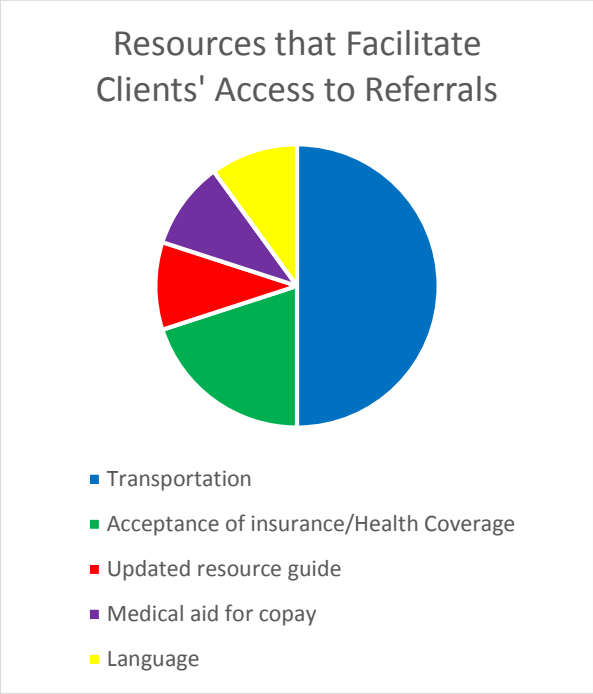
90% *60%*

80-90% *50%*

70% *50%*

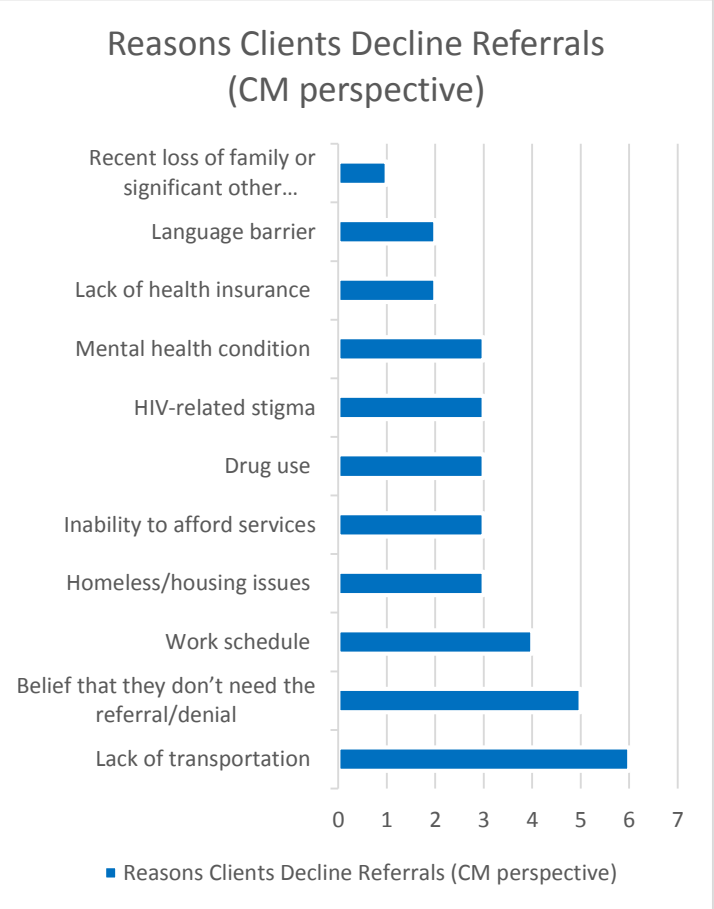
3.2.8 What factors or resources are particularly helpful in facilitating clients' access to referral services?

Transportation	5
Acceptance of insurance/Health Coverage	2
Updated resource guide	1
Medical aid for copay	1
Language	1



3.2.9 What are the reasons you think clients decline referrals?

Lack of transportation	6
Belief that they don't need the referral/denial	5
Work schedule	4
Homeless/housing issues	3
Inability to afford services	3
Drug use	3
HIV-related stigma	3
Mental health condition	3
Lack of health insurance	2
Language barrier	2
Recent loss of family or significant other (separation/divorce/death)	1
Lack of trust in the system	0
Lack of childcare	0
Moved	0
Wait time for referral	0
Confusion about referral/how to navigate	0
Lack of linkage to providers/follow up by case manager	0



3.2.10 What barriers or challenges do you face when making referrals for behavior change, mental health or substance use issues?

Limited funding at my agency to serve all who need the service	3
Difficulty identifying resources where clients can afford services	3
Inadequate capacity at referral agencies to serve all who need the service	2
Insufficient community partnerships/linkages to provide clients with the referrals they need	2
Limited funding at referral agencies to serve all who need the service	1
Lack of coordination/collaboration between service providers	1
Other: lack of health insurance to cover services	1
Other: Non RW resources for Medicaid and Medicare clients	1
Other: Providers that take our clients' insurance are not always near public transportation	1
Inadequate capacity at my agency to facilitate referrals	0

3.2.11 How do you approach barriers and challenges with facilitation of referrals or client lack of follow through?

Address resistance to treatment, continue to encourage

Send to RW clinic if the service is provided and follow up with client if it is working

Refer back to client's ITP and remind them of why such items were a goal in the first place. Reassess needs if client's priorities have changed.

Phone calls/advocating/charity care

Follow up with phone calls, advocating, charity care referral

Continuous encouragement and follow up

3.2.12 What gaps exist in the area for people living with HIV who need support with behavior change, mental health or substance use issues? What resources would you propose need to be added?

Insurance being accepted by providers

Prescribing psychiatrist that accepts Medicaid. Also bundling of RW services. Establish better relationship with non RW providers

Lengthy wait lists for treatment/detox centers. Not enough providers who take their insurance and understand the specific needs of those with HIV.

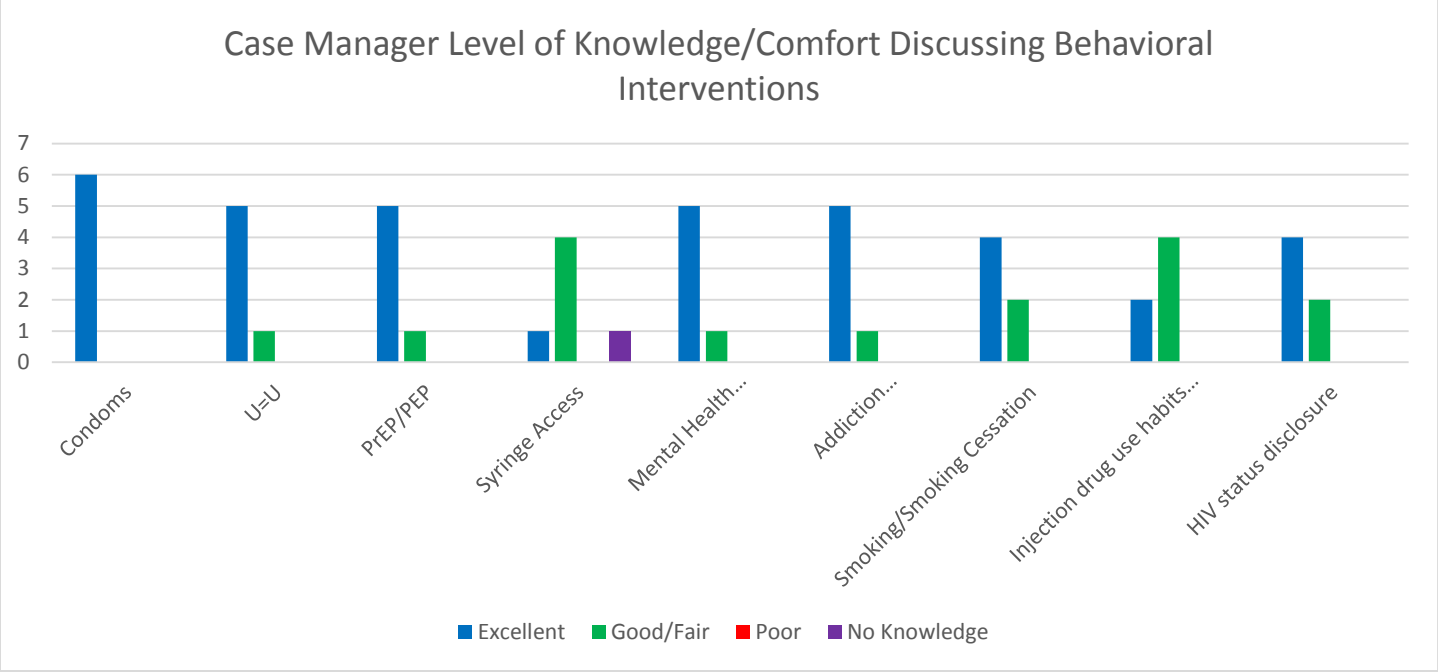
Inpatient for BH without insurance

Agency that provide services without health insurance to our clients (in-patient)

MH-IOP, CD-IOP, dual diagnosis programs

3.2.13 Please rate your level of knowledge and comfort in discussing the following

	Excellent	Good/Fair	Poor	No Knowledge
Condoms	6			
U=U	5	1		
PrEP/PEP	5	1		
Syringe Access	1	4		1
Mental Health Screening/Assessment	5	1		
Addiction Screening/Assessment	5	1		
Smoking/Smoking Cessation	4	2		
Injection drug use habits and behaviors	2	4		
HIV status disclosure	4	2		



3.2.14 Do you keep materials about mental health support, counseling or support groups in your waiting room or office?

Yes	6
No	0

3.2.15 Do you think that mental health (diagnosed condition or feeling stressed/anxious) interferes with HIV treatment of your patients?

Yes	6
No	0

3.2.15.1 If yes, please explain how:

Impacts compliance to medical care	4
Medication adherence	3

3.2.16 Does your agency provide mental health education?

Yes	6
No	0

3.2.17 What additional resources are needed within your agency to ensure that clients have access to services for which there is currently an unmet need?

Transportation (1 respondent said current services are too limited)	4
Housing/Housing Assistance	3
Psychiatric	2
HIPCS	1
Mental health counseling providers	1
Better funding and more space	1
none	1

3.2.18 What changes would you make to your organization to better facilitate referrals and provide access to behavior change, mental health and substance use services?

None	2
Cultural competence training (agency-wide) to fight stigma	2
Expand relationships with providers to increase referral information to clients in need	1
Hire a MH bilingual counselor	1
Add support groups	1

3.2.19 What changes would you make to the region to better facilitate referrals and provide access to behavior change, mental health and substance use services?

Mutual collaboration/Improve communication between providers	3
Stigma free campaign	2
Hiring a psychiatrist that will work with our HIV non-RW clinic clients	1
Provide seminars to employees in regards to BH/mental illness	1
Increase number of providers	1
Reduce wait time for linkage to programs	1

4 KEY FINDINGS

4.1 DEMOGRAPHICS

The county, age and sex/gender demographics captured during the survey are generally reflective of the population served throughout the region, with the majority living in Morris County. The population is aging with the highest concentration of surveys capturing results from people over 45. The region has a higher overall percentage of women living with HIV, which is also reflected in the survey. Despite the failure of the subcommittee to translate the survey into Spanish, the number of surveys completed by people who identify as Latino is in line with the demographics of the region. Exposure category is also in line with the characteristics of the region, mostly favoring sexual exposure over injection drug use exposure. The survey captured a fairly even diversity of diagnosis years, demonstrating a fair balance between long term survivors and recent diagnoses. The majority of the population has stable housing, including voucher and subsidized housing. A high percentage of consumers who completed the survey are living in single person households, while the same percentage of consumers are living in households with five or more people, demonstrating a variety of socio-economic needs amongst consumers.

4.2 INFECTIOUS DISEASE AND MEDICAL CASE MANAGEMENT CARE

The region includes two Ryan White-funded clinics and two major private infectious disease specialty offices. Of the four providers who provide Ryan White-funded services, all four provide medical case management services. The majority of the surveys were completed by patients of the Family Health Center, which is in line with the percentage of patients who receive their medical and medical case management care at that facility. All consumers who were surveyed indicated that they are compliant with their medical care and treatment with 75% having a medical visit within the last three months and all but one consumer having a medical visit within the last six months. One consumer indicated that they are "unsatisfied" with their medical care with the remaining choosing either "very satisfied" or "satisfied". Similarly, the majority of the surveys were completed by consumers who receive their medical case management from the Family Health Center and demonstrated that consumers are engaged in their medical case management services.

The most commonly listed barriers to care include lack of transportation and health insurance. Lack of transportation was also highly rated by providers as the primary barrier to consumers accepting or following through with referrals. Other barriers identified by consumers that demonstrated a lower statistical significance include housing issues, inability to afford medication, moving, drug use, work schedule, anxiety and physical limitations. Providers rated "belief that they don't need the referral/denial" as the second most common reason that consumers decline referrals. The survey topic was centered around behavioral health access but mental health and stigma were not identified as barriers to engagement and participation by consumers who completed the survey. Conversely, all six provider surveys stated that they believe consumers' mental health interferes with HIV treatment, specifically with medication adherence and medical visit compliance. Half of providers indicated that drug use, HIV-related stigma and mental health conditions limited consumer follow through with referrals. Other barriers to making referrals listed by providers included limited funding and inadequate capacity at the referring agency as well as referral agencies.

4.3 ACCESS TO MENTAL HEALTH AND SUBSTANCE USE SUPPORT

A high percentage of consumer surveys indicated that 1) consumers feel that their case manager helps them improve the problems, feelings and situations they experience (92.5%) and; 2) consumers feel comfortable talking to their case manager if they feel depressed (90%). Furthermore, the case manager was the most commonly selected person that consumers chose that they go to when they need help or support. Fifty percent (50%) of consumers indicated that they had reported an issue to their case manager within the last year. These results demonstrate that consumers in the MSW region place a large amount of trust in their medical case managers and that the relationship between the consumer and the medical case manager is integral to consumer psycho-social success and development.

A large percentage of consumers who stated they received a referral from their medical case manager (80%) indicated that they used the referral. Provider perception of the percentage of consumers who use referrals ranged from 50-90%, with most providers selecting 70% or fewer who actually use referrals. This indicates that medical case managers' perception of how many consumers use referrals may be skewed. The number of providers who consider denial to be a barrier to consumer acceptance of referrals demonstrates a potential bias of providers that consumers do not follow through. Providers listed a number of gaps in the continuum of care for people who need support with behavior change, mental health or substance use issues including provider acceptance of insurance, lack of programs that specialize in dual diagnosis and insufficient capacity of providers to accept consumers without a wait.

The most common behavioral health services used by consumers in the last year (25%) were a Ryan White-funded counselor and a Ryan White-funded psychiatrist, followed closely by Ryan White-funded support group (20%) then Ryan White-funded relapse prevention group (15%) and finally Ryan White-funded individual counseling for drug treatment (12.5%). Non Ryan White-funded facilities are utilized less frequently indicating an opportunity to research and attempt to access programs that are not specific to PLWH. The provider survey produced similar findings with Ryan White-funded locations being the most frequently referred services. In free responses, providers demonstrated a high level of engaging in processes that included making internal referrals or referrals within the Ryan White network but did not list as many processes that included engaging with agencies outside of the Ryan White network. Furthermore, provider free responses did not indicate a high level of problem solving outside of the agency or Ryan White network when a referral or resource is unknown.

Case managers reported a high degree of confidence in their mental health and substance use screening abilities and indicated no training needs. Provider survey responses about the frequency of screening questions for each consumer indicate that providers are providing screening and assessment in line with or better than the NEMA standards of care. Some providers suggested that there are no changes needed to their organization to improve services, however most were able to consider ways of doing so including expanding relationships to increase referral networks, additional training for staff of larger agencies and the inclusion of additional support groups and bilingual counselors. Recommendations for improvements to services regionally included additional collaboration and communication, the initiation of a stigma-free campaign and additional training about behavioral health issues.

About half of the consumer respondents felt they could benefit from mental health education. While all providers stated that their agency provides this education, it appears that consumers do not feel they have received it. All providers stated that there are materials about mental health support, counseling or support groups in their agencies' waiting areas, however about 15% of consumer responses indicated they did not see or did not know if there were materials there, indicating placing these materials in more prominent locations may be necessary.

Half of consumer respondents reported they had attended support groups and most found it useful. All providers indicated that they commonly refer consumers to counselors and support groups, demonstrating an acknowledgement that these services are generally helpful to PLWH.

4.4 Case Manager Assistance with Behavioral Risks

In addition to mental health and substance use issues, the surveys attempted to assess access to information about behavioral risks to consumers, including sexual risk, injection drug use risk and smoking risk. Provider perception is that they generally possess a good or excellent knowledge and comfort about behavioral risks and interventions related to these topics, such as condom use, PrEP and PEP, the Undetectable = Untransmittable Campaign, syringe access programs and smoking cessation programs.

Consumer surveys indicated a low level of need for sexual health or injection drug health prevention messaging and information. In spite of the apparent lack of need, consumers indicated that their medical case managers still engaged them in conversations about behavioral interventions and that the conversations were successful in helping consumers feel confident to make healthy choices.

4.5 Conclusions About the Needs Assessment

4.5.1 Acknowledgements

I would like to thank everyone who participated in the 2018 needs assessment process including the four volunteer providers Caroline Schenkman of the Family Health Center, Ricardo Salicido of Zufall Health Center, Antonella Andrade of Catholic Family and Community Services and Kelly Martins of New Jersey AIDS Services. Thank you to the case managers and medical case managers who participated by distributing surveys to their consumers. I would also like to thank advisors Jennifer McGee-Avila of the Northeast Caribbean AIDS Education and Training Center and Heidi Haiken of the Francois-Xavier Bagnoud Center in the Rutgers School of Nursing. Thank you to my colleague and editor, Summer Brown of the Family Health Center of Morristown for her feedback and support.

Above all, I would like to thank the most important of our stakeholders, our consumers, for volunteering their time and providing thoughtful responses to the surveys.

4.5.2 Next Steps

The purpose of this report is to provide closure to the 2018 needs assessment process and inform stakeholders about the findings. The MSWHAC is scheduled to discuss and review this Needs Assessment Report during its November 2018 regularly scheduled meeting. During that time, the committee will debrief about the process and discuss challenges and limitations as well as recommendations for next year. The MSWHAC has invited special presenter Heidi Haiken to the February 2019 meeting to provide additional training on needs assessments in order to prepare the committee for the 2019 needs assessment process. Furthermore, a providers meeting will be organized in the spring of 2019 to discuss the findings and conclusions as well as recommendations for changes to regional services.