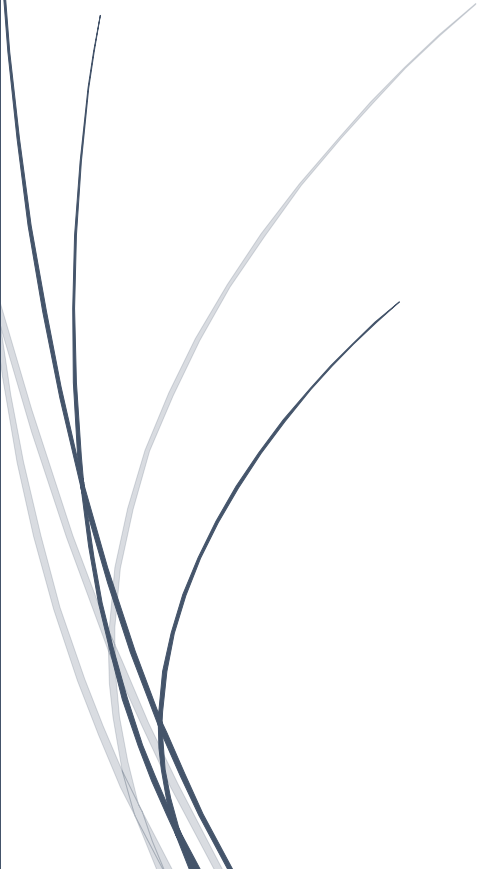June 10, 2019

2019 N-S EMA Provider Survey Report

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NASSAU-SUFFOLK HIV HEALTH SERVICES PLANNING COUNCIL
SUMMARY REPORT OF 2019 PROVIDER SURVEY

Introduction:

The 2019 Provider Survey questions were updated and approved at the May 1, 2019 Strategic Planning and Assessment Committee meeting. A provider survey from another region was reviewed for comparison and clarity. The 2019 Provider Survey revision addresses the current needs of the Long Island region.

This survey and other needs assessments are an important part of the Priority Setting Resource Allocation (PSRA) process which enables the region to gain a better understanding of community needs. It also provides an additional viewpoint to identify existing barriers and the struggles that service providers face regarding care.

BACKGROUND/METHODOLOGY:

Providers of services for persons living with HIV/AIDS (PLWHA) were asked to complete the 2019 Provider Survey with the purpose of assisting the Nassau-Suffolk Health Services Planning Council in setting priorities and allocating resources.

Agencies were encouraged to consult their employees who work directly with HIV positive clients for input before completing the survey. The importance of collecting data from the "front lines" is a vital part of understanding the overall need throughout the region.

In fiscal year 2018-2019 there were a total of 13 Part A funded providers in the Nassau-Suffolk EMA (Eligible Metropolitan Area). All of the Part A providers participated in this year's survey: Southampton Hospital (David E. Rogers Center); EOC of Suffolk, Inc; Hispanic Counseling Center, Inc; Options for Living, Inc: Nassau University Medical Center; Nassau/Suffolk Law Services; North Shore University Hospital Center for AIDS Research & Treatment; Suffolk County Department of Health Services; Thursdays Child; Hudson River HealthCare and Stony Brook University Medical Center: LBGT Network; Circulo del la Hispanidad.

OVERALL SUMMARY:

The purpose of this survey is to determine which Part A funded services are of highest need to clients; barriers to care that clients face; main reported barriers for service providers in terms of providing service to clients; effects of funding cuts on agencies; ways to identify individuals with HIV/AIDS; retention in care; ways to reduce the spread

of AIDS: and what type of training and/or assistance that would be helpful to agencies to build their capacity to serve PLWHA, improve service coordination and client outcomes.

Providers were asked to select the HIV/AIDS services that they provide regardless of funding sources. These services are listed in order of percentages and are currently RW Part A funded, with the exception of Substance Abuse. Substance Abuse is a fundable priority that was a ranked priority, but not funded for FY19-20.
(14 TOTAL Responses)

1. Mental Health: 9 votes **(64.29%)**
2. Medical Case Management (including treatment adherence and maintenance to care) 9 votes **(64.29%)**
3. Substance Abuse Outpatient 6 votes **(42.86%)**
4. Outpatient Ambulatory Health Services: 6 votes **(42.86%)**
5. Medical Nutrition Therapy: 6 votes **(42.86%)**
6. ADAP: 3 votes **(21.43%)**
7. Emergency Financial Assistance: 4 votes **(28.57%)**
8. Medical Transportation: 4 votes **(28.57%)**
9. Oral Health: 3 votes **(21.43%)**
10. Foodbank: 3 votes **(21.43%)**
11. EIS (Early Intervention Services): 4 votes **(28.57%)**
12. Other Professional Services including Legal Services: 1 vote

HIV/AIDS services that agencies provide which are ranked but not currently funded include:
- Health education/ risk reduction (71.43%)
- Outreach services (57.14%)
- Referral for health care/support services (57.14%)
- Case management (non-medical) 35.71%
- Linguistic services (35.71%)
- Child care services (21.43%)
- Housing (14.29%)

HIV/AIDS services that are provided but are neither ranked or Part A funded:
- Psycho-social support services (57.14%)
- PEP and PREP (50%)
- Prevention (42.86%)

Other responses included permanency planning, benefits advocacy for PLWHA, child care services for support groups, and linkage to health insurance programs for PLWHA such as ADAP, Medicaid, Medicare and programs available through the New York State Marketplace.

When asked, other than what your agency provides, what HIV-related services are needed by clients in the Nassau-Suffolk region? (Which services do your agency make the most referrals?)

The responses are as follows:
Housing topped the list of services at 71.43%, followed by Legal Services (OPS) and Substance Abuse, both at 64.29%, Oral Health Care (OHC) and Mental Health (MH) were both at 50%, Medical Transportation (MT) and Emergency Financial Services (EFA) reported at 42.86%. Agency referrals food bank/delivered meals were at 35.71% and medical nutrition therapy services were at 28.57%.

57.14% of respondents make referrals for HIV/AIDS primary care. 21.43% do not make referrals and 21.43% provide HIV/AIDS primary care.
Regarding referrals for HIV/AIDS primary care, only public agencies were cited.
No private agencies were mentioned.
One agency noted that as soon as there is a positive diagnosis, the individual is referred to hospital/clinic where treatment is offered. That referral may be in either county and the individual is monitored until it is confirmed that help is being received.

A review of the collected data, indicates that housing, although an unfunded priority, remains a need and cause of concern. Housing instability was the number one barrier to care as reported in this survey. This sentiment was echoed throughout the 2019 community forums, as HIV consumers are now competing for the limited spaces that are available.
Legal services (OPS), is an important service for many, as evidenced by 2019 community and the high percentage of referrals noted in the provider survey.

Mental health, medical case management, and medical transportation are also highly ranked. These services are necessary to provide and improve health outcomes and general well-being of individuals. Mental health services correlate to the feelings of anxiety, uncertainty, and depression about housing, immigration concerns, benefits and changing policies. The amount of paperwork and documentation required can be overwhelming and assistance is often requested. Without medical transportation, the challenge of getting to medical appointments and treatments is increased; Safety concerns regarding hours of operation and agency location and Long Island public transportation is not always convenient or acceptable.

<u>Services needed by clients that are not currently funded</u>
Are there any additional services your clients need that are not currently funded by Ryan White Part A in the Nassau/Suffolk region? Note: there were only 8 respondents.
<u>Responses below:</u>
- Housing services topped the list at 50%.
- Emergency Financial Assistance (EFA) came in second at 37.5%
- Child Care services, Substance Abuse (residential), and Home Health Care were tied at 25%

The following services were reported at 12.5%:
- Mental Health services
- Substance Abuse (outpatient)
- Outreach services
- Home and community based services
- Rehabilitation
- Respite care
- Linguistic
- Substance abuse services (outpatient).

<u>Barriers to Care:</u>
Throughout the survey, providers were asked to explain the main barriers they felt made it difficult for clients to access services. In addition, they were also asked to explain the main barriers they felt made it difficult for them to provide services.
There were many reasons providers cited as barriers for <u>clients to access</u> care and services. Among those reasons are:
- Housing instability
- Clients are worried about others finding out they have HIV
- Various systems of care difficult to navigate
- Clients struggle with transportation
- Clients have substance use issues that impact their ability to access care
- Clients have work and/or family issues
- Clients are afraid of being reported to authorities due to citizenship status
- Clients can't qualify for services because of program eligibility requirements
- Clients have food security issues that impact their ability to access care
- Clients are unaware of available services
- Mental health issues impact their ability to access care

One of the choices, insufficient communication between our organizations and others who serve our clients did not register one response. This speaks to the collaboration of successful partnerships

Just as many reasons exist as barriers for consumers to access care, barriers/limitations exist that make it difficult for <u>providers to deliver services:</u>
- The first and foremost barrier as reported by providers is client comorbidity which includes mental health and substance use. The rationale is that patients who have co-morbities experience more issues with compliance to staying engaged in care.
- Immigration concerns of clients
- limited literacy, health literacy
- Lack of funding
- Transportation
- Limitations on insurances accepted by agency and other providers.
- Local community resistance to agency services

As mentioned previously, housing is a major concern for many. Housing and housing assistance programs, specifically for PLWH/As are decreasing, which impacts their access to healthcare and treatment adherence.

Reported gaps in service and care cited: limited mental health services, specifically Suffolk County and vision services. While not necessarily a gap in care, one response was that there should be outreach particularly to youth, young gay men and transgender women,

Serving Non-English Speaking Clients:
In order to serve non-English speaking clients the following strategies are utilized:
- Use bi-lingual staff hired by agency
- Post notices and signs in different languages
- Contracted translation services
- Use interpreter telephone line
- Use volunteer interpreter service
- Use TTY services (for the hard of hearing)
- Use of pictographs

In the comment section of this question, one response was that language classes are offered bi-annually at staff retreat.

Funding cuts:
Funding cuts in terms of cuts or restrictions did not have an impact of HIV/AIDS programs as neither were decreased nor discontinues as reported in this provider survey.

Early Intervention Services:|
EIS has been shown to reduce viral suppression. Agencies are implementing the following to identify individuals with HIV/AIDS and bring them into care:
- The agency has a dedicated outreach program. The program guides individuals how to navigate the health system and help individuals with appointments.
- Attorneys in other units do inquire, and if someone reports that they are HIV-positive, refer to our unit. If out of care, our social workers will refer.
- We provide free and confidential rapid HIV testing, among testing for other STI's. We also do extensive community/online outreach, mobile testing, as well as community education.
- We test all patients coming in for care at least once a year. If a positive is identified we begin Rapid Start.
- CART has an extensive testing program at this time. We are doing ongoing testing as we have our own testing van and team. We are also connecting with the community to do testing at sites such as pharmacies, local bars etc.
- Promote testing at entry and do Linkage to Care with those who are positive. Referrals to PrEP if appropriate. HIV education and posttest counseling.
- HIV testing in emergency room visits, annual primary care visits and all other visits. Generally, within 3-5 days, if positive patients are linked to care.

- Linkage to care. Direct notification from the emergency room when there is a positive HIV test result. Direct notification from Hospital staff for admitted patients who are or test positive. Direct contact to staff who can schedule appointments within appropriate time frame.
- Conducting community outreach to various programs and fairs, participating in networking events and meetings in order to reach out to agencies who may come into contact with these individuals. Increasing social networking exposure.
- Persons tested positive are referred to either our HIV Program or a list of other programs available.

OUT OF CARE POPULATION:

It is estimated that 22% of people living with HIV/AIDS on Long Island are out of care. Providers were asked which programs are effective in improving retention in care. Responses below:
- Viral Suppression program
- Transportation, Early Intervention Services, Case Management, Pharmaceutical Delivery, ADAP.
- Medical Case Management, MH and Substance Use Services. Note- Some patients choose to not take medication
- Our Retention Adherence Program is very effective as the program targets patients who are out of care. The program has an outreach worker who does home visits to reach those patients. The retention program also keeps track of patients with retentions issues to reduce loss of care. The program does reminder calls and text messages to engage patients in their care.
- Linkage to Care program
- Robust Retention Adherence Program generally keep in constant contact with patients to engage in care.
- The support staff such as case management and psychosocial support, who are available to meet with patients during their appointments and can remain in contact in between visits. Transportation programs. Programs that focus on retention in care.
- Medical case management, health education (individual and group sessions), outreach programs
- Outreach programs

When asked about specific tools and strategies the Nassau-Suffolk region or Planning Council should use to get people into care, outreach and education were the common thread. Examples included community outreach workers, aggressive outreach activities program to assist establish RW program, with a focus on youth, young gay men, gay men and transgender women of color, and transgender women. Other tools were to increase exposure on social media platforms, outreach to younger population (through high schools, colleges, other youth social venues), employ younger staff including peers, increase awareness and education, advertising of the services within the region funded by

Ryan White Part A and more EIS Programs in presence in communities which have gay men of color; trans-females of color specifically.

An additional recommendation was to decrease the eligibility requirements and allow anyone who is living with HIV the ability to access services through any funding source.

When asked what the Planning Council do to help your agency/program better coordinate services with other providers? Difficulty coordinating and maintaining communication with other agencies and/or service providers did not appear to be an issue and providers should continue to encourage meetings to connect agencies and educate each other of their service, host meetings and networking events, committees etc. for agencies and consumers to collaborate and brainstorm, share ideas and concerns. Some suggestions included scheduling meetings with other agencies funded under the same priority. We could compare notes, share what works for us and areas that need improvement, a HIV-specific health fair, with all providers participating, and open to clients

CAREWare suggestions included:
- Sharing client data and program requirements on CAREWare among providers.
- Connect the agencies' patient information on the main database, CareWare.
- Make CAREWAre entries/notes viewable to all users.

It should be noted that some of these suggestions regarding CAREWAre suggestions have confidentiality concerns attached.

This last question has been added to the 2019 provider survey. What training, assistance, or other action arranged by the Ryan White Part A recipient or administrative agents would be most helpful to your agency in building its capacity to serve PLWHA or improve service coordination and client outcomes?

Responses below:
- Outreach and publicity
- Anything that makes access to substance abuse services easier
- Basic language skills for English speaking staff in Creole and Spanish
- Restructure the Mental Health funding so that we can provide ongoing mental health services to the clients in our care.
- Ryan White A contract management staff to meet with our program staff to review what is being done at the Council meetings, CQM meetings, since not all staff participate
- Connecting Careware information, such as making a network of HIV patient database

<u>CONCLUSION:</u>

The views of the participating providers expressed throughout this survey afford us the opportunity to consider ways to improve the current system. Aside from funding allocation, which is the main goal of the PSRA process, we need to know what HIV-

related services are needed and to identify any barriers to care. As stated earlier, the National HIV/AIDS strategy places special emphasis on Early Identification of Individuals (EIIHA) with HIV/AIDS because this has been shown to reduce transmission. It is important to provide education, information, to reduce the spread of HIV/AIDS in the region. Education, testing, and prevention are key. it is imperative that we review and evaluate the recommendations on how to best coordinate services in order to better serve the clients.