

**NASSAU-SUFFOLK HIV HEALTH SERVICES PLANNING
COUNCIL
SUMMARY REPORT OF 2017
PROVIDER SURVEY**

Introduction:

The 2017 Provider Survey questions were developed by the Strategic Assessment and Planning Committee (SAP). The questions which were based on previous year's format were tailored to address the current needs of the Long Island region. This is a very important part of the Priority Setting Resource Allocation (PSRA) process. Through the PSRA process, we are able to gain a better understanding of the needs throughout the community. It also provides an additional viewpoint on where barriers exist and the struggles that service providers face where care is concerned.

BACKGROUND/METHODOLOGY:

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

It is important that we are gain an understanding from the agencies being funded through Ryan White as to the needs of their clients. Agencies were encouraged to consult their employees who work directly with clients for feedback before completing the survey. The importance of collecting data from the "front lines" is a vital part to understanding the overall need throughout the region. This survey was also open to agencies not currently receiving Ryan White Part A funding in order to gather more information about other programs and resources.

There is a total of 14 Part A. providers in the Long Island region. All Part A providers participated in this year's survey: Circulo de La Hispanidad, Inc.; 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: LGBT Network; Family Service League.

Besides Part A. providers, the survey was completed by an additional six additional providers in Nassau and Suffolk Counties. The feedback expressed throughout this survey will assist us in determining which areas, if any, need adjustments in the way they are currently being funded.

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 services to clients; effects of funding cuts on agencies; reasons people fall out of care; and ways to help reduce the spread of HIV/AIDS.

It is vital to understand the effects of funding cuts on agencies as this directly results in barriers to providing care to clients. Funding cuts truly hinder the ways in which an agency operates. When we compare the needs expressed throughout the 2015 Community Meetings with those expressed in the Provider Surveys, it is easy to see how funding cuts directly affect services. Many of the concerns expressed at those meetings were about services that had been cut back due to the lack of funding in the region. It is important to gain an understanding of what programs an agency currently offers in addition to those it may have had to eliminate, as this gives us a picture of service value.

Providers were asked to select their top 5 choices from a complete list of currently funded Part A services considering *only* their clients needs to stay healthy (not current funding issues).

**TOP RATED PART A FUNDED SERVICES BASED ON CLIENTS' NEED
PART A PROVIDER ANSWERS ONLY (14 TOTAL)**

1. Mental Health: 12 votes (**86%**)
2. Medical Case Management (including treatment adherence and maintenance to care) 9 votes (**65%**)
3. Medical Transportation: 10 votes (**72%**)
4. Substance Abuse Outpatient 10 votes (**72%**)
5. Outpatient Ambulatory Health Services: 6 votes (**43%**)
6. ADAP: 7 votes (**50%**)
7. Foodbank: 5 votes (**36%**)
8. Medical Nutrition Therapy: 5 vote (**36%**)
9. Oral Health: 4 votes (**29%**)
10. Other Professional Services including Legal Services: 3 votes (**22%**)
11. EIS (Early Intervention Services): 2 votes (**14%**)

**TOP RATED PART A FUNDED SERVICES BASED ON CLIENTS' NEED
COMBINED PART A & NON-PART A PROVIDER ANSWERS (20 TOTAL)**

12. Mental Health: 17 votes (**85%**)
13. Medical Case Management (including treatment adherence and maintenance to care) 13 votes (**65%**)
14. Medical Transportation: 13 votes (**65%**)
15. Substance Abuse Outpatient 12 votes (**60%**)
16. Outpatient Ambulatory Health Services: 9 votes (**45%**)
17. ADAP: 8 votes (**40%**)
18. Foodbank: 6 votes (**30%**)
19. Medical Nutrition Therapy: 6 vote (**30%**)
20. Oral Health: 5 votes (**25%**)
21. Other Professional Services including Legal Services: 4 votes (**20%**)
22. EIS (Early Intervention Services): 3 votes (**15%**)

After reviewing all of the data collected from both sets of providers, it is easy to see that there is a general consensus as to the funding priorities, as evidenced by similarly mirrored results for the top rated Part A. funded services based on clients' needs for Part A. Providers and Non-Part A providers. Mental health, medical case management, and medical transportation rank at the top of the chart for these needs. Mental Health services ranked highest on the list of services most needed by clients and continues to be a necessary service for consumers throughout the region. Not only are these services necessary to improve the overall well-being of individuals, there appears to be more of a need as many consumers have expressed increased feelings of anxiety and depression. These feelings have been attributed to uncertainty of benefits (given the current government administration and health insurance concerns) and as consumers are living longer, requests for assistance to help deal with life on a daily basis have been cited, Medical Case Management is an important service because it provides a range of client-centered services that link PLWH/A with health care, psychosocial services including coordination and follow-up of medical treatments. Public transportation on Long Island is not always convenient and accessible. Medical transportation provides the vital service of getting clients to their medical appointments. Without this needed service, many clients would have no access to their medical care . In terms of funding, these areas remain as top priorities throughout the region.

MAIN REPORTED BARRIERS TO CARE:

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. Providers, whether Part A or not cited similar barriers to care.

Part A. Providers

There were many reasons that Part A. Providers cited as barriers for clients to access care and services. Among those reasons are:

- Eligibility documentation*
- Transportation
- Economic issues; low-income and financial instability
- Immigration concerns
- Insurance **
- Language barriers, not all agencies have bilingual staff
- Limited education, including literacy and health literacy
- Restrictive hours of operation, more flexibility needed.
- Untreated mental health and substance abuse issues.
- Confidentiality concerns

*Eligibility documentation, specifically income, is often difficult to obtain. Clients fail to submit documentation. The amount of paperwork because of program requirements can be daunting and overwhelming.

** Insurance issues are varied:

- Patients have co-morbidities and limited or no insurance.
- Limitations on insurance accepted by other providers.

- Undocumented can obtain ADAP, but are unable to access other medical services because they are not eligible for other insurance.

Many of the factors that Part A. Providers listed as barriers for themselves to provide clients with care and services echoed the barriers mentioned previously.

- Issues of client eligibility services
- Lack of transportation for services
- Limitations of insurance that are accepted by other providers
- Immigration concerns
- Limited literacy/health literacy of clients
- Not enough funding to provide comprehensive programming
- Community unaware of the availability of services at our agency
- Client co-morbidities
- Not enough funding to provide comprehensive program.
- Community is unaware of availability of agency services

One agency cited that the community is resistant to the services provided and can serve as a barrier to provide the needed services.

Non-Part A. Providers

There were many reported reasons that Non-Part A. Providers felt were barriers for clients to access care and services. Among those reasons were:

- Lack of transportation options
- Eligibility requirements- providing documentation
- Economic issues: low incomes and financial insecurity
- Inadequate case management
- Mental health issues
- Substance abuse issues
- Health insurance issues

There were many reported reasons that Non-Part A. Providers felt were barriers for themselves to provide clients with care and services. Among those reasons were:

- Transportation
- Shortage of community linkages affecting referrals for our clients
- Not enough funding to provide comprehensive programming
- More staff training is needed
- Lack of other supportive services at agency.
- Not all agencies have bilingual staff to assist non-English speaking clients.

Medical transportation continues to be a vital service, upon which many consumers rely to get to their medical appointments. Public transportation can be limiting and unreliable. While the situation has improved with greater availability of bi-county transportation, it is important to remember the continued need for transportation.

When reviewing the list of currently funded services under Part A, both sets of providers were asked to list any additional services that their clients may need that are not currently funded. This feedback will help determine if there are service areas which may require reevaluation.

Housing and emergency financial assistance, both support services, ranked at the top of services that clients need that are not currently funded. Housing and housing assistance programs, specifically for PLWH/As are decreasing, which impacts their access to healthcare and treatment adherence. There is a need for financial assistance to help with expenses related to medications, housing, utilities, bills, and other expenses. The importance of mental health and substance abuse services, both core services, was repeatedly stressed and correlates with the increased need for psychosocial services (including support and counseling) that was cited as well.

Reported gaps in service and care cited: limited mental health services, prevention outreach to MSM of color and people of color, as well as employment and immigration concerns. One respondent stated that psychosocial support services are needed and should include financial support for both therapeutic and education support groups as well as structured socialization to address isolation, alienation, and stigma.

FUNDING CUTS:

Funding cuts negatively impact programs. Many providers reported that limited funds or the threat of reduced funding prevents them from offering a comprehensive program for their clients. One provider reported that the proposed minimal cuts will not prevent delivery of services. Another client opined that with the increasing costs of rent, utilities, insurance (the costs of running an office) receiving level funding should be viewed as a funding cut. However, the majority of providers stated that funding cuts would affect their agency. Those reported responses appear below:

PART A PROVIDERS	NON-PART A PROVIDERS
Reduced staff results in inability to maintain high quality of service and need to cut back on some programs	Potential loss of funding for 2018-2019 will no longer allow program to train clinical providers and provide outreach services
Reduced staff may have to fundraise to secure funds which in turn can affect productivity and availability for clients.	
Program requirements for more eligibility documentation and outreach to CBOs have been scaled back due to limited staff availability	
Cuts in mental health and supportive services	

OUT OF CARE POPULATION:

It is estimated that 33% of people living with HIV/AIDS on Long Island are out of care. We provided this statistic to the providers and asked of them two things:

Add new questions about EIHHA Aand retention in care to replace. Tie in with governor’s initiative

New York states estimates that 24% of people living with HIV/AIDS on Long Island are out of care. Which programs are effective in improving retention in care?

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. What is your agency doing to identify individuals with HIV/AIDS and bring them into care?

What do you think prevents individuals from entering care?

Stigma, Fear, and denial ranked high on the list of reasons that prevents individuals from entering care. Immigration and fear of deportation prevents some for entering care.. Some individuals do not enter into care because they are unaware of what services are available to them. Other main themes throughout the survey revolved around multiple factors affecting one's life such as: poverty, untreated mental health or substance abuse issues; no health insurance; transportation issues; undocumented immigration status; lack of a support system, and homelessness. Many providers indicated that they feel people are more focused on their basic needs such as obtaining food and shelter, rather than worrying about their immediate healthcare. On Long Island we see the living expenses continue to increase, so it is understandable that people would be focusing on making ends meet before attending to their own health needs.

What do you think causes individuals to fall out of care?

The majority of reported reasons for individuals to fall out of care was similar to those reasons reported preventing individuals from entering care. Mental health and substance abuse issues compound the difficulty individuals have with entering and retention of care. All of the previously mentioned life issues were reiterated pointing out that a person's current life situation will continue to affect the ways they obtain treatment.

Treatment fatigue was mentioned as a reason people fall out of care. This highlighted the feeling one gets after being in treatment for many years and falling into a category where it eventually becomes difficult to maintain. Other reported reasons were: lack of available supportive services; economic loss; untreated mental health and substance abuse issues; medication side effects; complacency, and personal choice to fall out of care. As one provider commented, the perspective can be- *"I'm too young it's not going to affect me to later or "I'm too old-I've already lived my life"*.

Some providers also mentioned that that a lack of medical case management would allow for people to fall out of care. In addition, it was mentioned that there can be a lack of trust and rapport with the medical providers throughout the community, which could deter seeking out treatment.

CONCLUSION:

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 can look at opinions on how to reduce the spread

of HIV/AIDS throughout the region. Providers, when asked what they are doing to identify individuals with HIV/AIDS and bring them into care responded that

Northwell Health implements the effective-based individual level intervention known as A.R.T.A.S. to help identify and connect individual who have tested HIV positive with their initial appointment for HIV medical care. ARTAS stands for Anti-Retroviral Treatment and Access to Services and uses a strengths based approach to resolving client's barriers to linking to care. This strategy is funded through a grant provided by the CDC.

It is our job number 1; if we had more resources to fulfill it, we could do even more than we are. Our HIV+ Early Intervention Services are effective and vital, however they are woefully underfunded. With more staff, we could double our efforts to partner with medical providers from every single hospital to Urgent Care Centers to private practices. But first we need to educate and advertise regionwide to advocate routine HIV testing as part of everyone's health goals. We presently do what we can: attend 6 to 12 outreach events per month; partner with every single HIV supportive and medical provider in the region; when a new + is identified, we spring into action to link that person to care, assess for needs such as insurance, safety, housing, ability to care for self, and HIV health literacy to learn to live with HIV and not pass on the virus.

We work closely with the HIV care provider network as well as with other medical providers in the community such as local doctors, county health clinics, walk in clinics, and HIV testing programs to identify HIV+ people and educate them regarding the resources and services available to engage and maintain individuals in care. The DRC staff provides outreach efforts in the community. This promotes awareness of the services offered by the DRC. Staff continues to provide HIV prevention education and testing to our community by collaborating whenever possible with the existing community service providers and social networks. The staff coordinates a World AIDS Day in December every year. The DRC provides free confidential HIV testing on site. Referrals come from a number of community partners including local hospitals, service organizations, medical providers, area health clinics, as well as referrals from existing clients. We continue to promote all program services. Flyers have been mailed to the AIDS Treatment Center at Stony Brook. Also, phone calls have been made to the coordinator and providers at the Treatment Center. Flyers and brochures have been mailed to area hospitals, medical providers and community agencies. Flyers and brochures are posted in the David Rogers Center waiting room and on bulletin boards at Southampton Hospital. Staff continues to coordinate services with local providers. Flyers are distributed to case management providers when meeting with clients. Additional promotion is provided in-kind on the Southampton Hospital web site and the Southampton Hospital Foundation development department provides mailings, press releases and advertising. at the Center.

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• Testing in the community • Testing patient's partners • Testing in Primary Care • Assisting SBM with updating policies on routine testing in accordance with the updated NY HIV Testing Law – 2016 • PrEP Screenings • Linkage to care coordination

7/20/2017 10:25 AM [View respondent's answers](#)

Collaborating with Northwell Health in raising awareness and provided an opportunity to get tested early and educated about early detection and treatment.

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Circulo de la Hispanidad - Early Intervention Services program helps to identify those who are unaware of their HIV status and those who are aware and out of care; we inform them of their status and services available to them, and ensure they are linked to medical care.

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newly diagnosed clients are usually referred by our outreach team at our agency and by medical providers

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We routinely offer HIV testing to all patients accessing services at the Health Centers and if a patient is positive, immediately link them to HIV care. Our EIS program targets those who are HIV positive and out of care or newly diagnosed within Nassau County. Unfortunately, linkages with local hospitals and emergency rooms have been difficult as many of the case management departments within the hospitals refuse to work together and make outside referrals for services.

Retention in care Medical Case Management • Medical Transportation • Linkage, Retention, and Treatment Adherence Program • EFA • MNT • Part D – Food Cards • Mental Health Services • Substance Abuse Services

Planning council strategies

unlikely to transmit HIV to others. We should look at NYC Campaign U=U (Undetectable=Untransmittable)

7/28/2017 9:41 AM [View respondent's answers](#)

continued prevention education for community members and providers regarding PrEP and accessibility and .

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Yes encourage greater participation in planning by OASAS and OMH as partners

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Marketing available services.

Any/all strategies supporting Early Identification and/or linkage to care should be supported by the Planning Council. Mobile testing initiatives, behavioral interventions, transportation fund specific for getting individuals into initial care.

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Coordination of care between HIV treatment providers has been helpful to support our clients to better engage care.

7/24/2017 3:58 PM [View respondent's answers](#)

Several; advertising works. Be more aggressive in publicly advocating for more resources to promote HIV testing. NY State has seen fit to put HIV in a back seat. Our ability to provide HIV testing upon demand is hampered by grant makers interested in serving only small, targeted groups. We ought to open back up again and serve all AND target the traditionally marginalized as well. We can do both. We can also broaden our horizons and partnerships for common cause; such as advocating for public transportation, public housing, and join the battle against the scourge of opioid and heroin use.

- Centralize the process of eligibility documentation – add to the Part A Grievance a release of information to Part A Agencies as needed to provide Part A Services • Look at other EMAs to see how they are documenting eligibility to see if it can be simplified. • Improve referral feature in CAREWare.

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To encourage providers to coordinate services in order to recover patients that abandon treatment and other services.

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advertisements in TV and radio stations. .

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yes they should be a outreach team designated to target positive individuals who have fallen out of care. similar model use by health homes. Many of our program have been overwhelmed with program requirements and less time dedicated to find clients who have fallen out of care. With the introduction of health homes case management providers have taken on a lot more clients that also has impacted the time

allotted to do follow up with those individual who may be going through a difficult time. Intensive targeted outreach team is needed to support programs and get individuals back into care.

Based on the responses by all participating providers that education remains the most consistent way to get the message about HIV/AIDS out to the communities. Education of both consumers and providers, which can be accomplished through public campaigns, targeting the youth, MSMs, and populations that are at-risk; One provider suggested that the state needs to reach out to each and every practicing MD in New York and require them to inform them about HIV testing, most providers were in agreement that doctors should be familiar with PEP and PreP.

Patient education is viewed as an area that is not efficiently meeting the standards of providers or clients for that matter. If individuals are unaware of HIV/AIDS, they are less likely to protect themselves from something they don't understand. The need for more education in general about the disease, including rates of transmission/infection, and treatment options needs to be made more apparent to the people throughout the region. Education is also linked to poverty-more needs to be done to alleviate poverty - which is the largest driver of poor health and life-choices. Maintaining HIV+ individuals in care and keeping viral loads suppressed

Suggested ways to do this revolved around aggressive testing methods by offer testing at key places. More funds may be be needed to message to a wider community. Providers also mentioned the importance of keeping up with policy makers alerting them of the importance of continuing to make prevention and HIV/AIDS services a priority to ensure funding continues.

Suffolk ETE