

2023 Community Forum Report

NASSAU-SUFFOLK HIV HEALTH SERVICES PLANNING COUNCIL

N-S HIV Health Services Planning Council

C/O UNITED WAY OF LONG ISLAND | [819 GRAND BLVD, DEER PARK, NY 11729]

631-940-3723, WWW.LONGISLANDPC.ORG

Introduction:

Each year, the Nassau-Suffolk HIV Health Services Planning Council engages in the Priority Setting and Resource Allocation (PSRA) process utilizing data that is collected by the Strategic Assessment and Planning Committee (SAP). Data collection is a vital part of the PSRA process and helps to determine which priorities will be funded and how much funding will be requested by the region as part of its annual HRSA grant submission request. A major component of the data that is collected includes information gathered directly from the public during annual community forums.

Discussion questions for the 2023 Community Forums were reviewed and revised by the Strategic Assessment and Planning Committee and five forums were scheduled. Two forums were scheduled in each county, one in Spanish and the other in English. The fifth forum was held virtually to accommodate those who could not attend during the day or felt more comfortable participating virtually. A sixth community forum (virtually for Spanish-speakers) was scheduled for July 18th when no one showed up for the May 13th forum.

Six community forums were scheduled:

1. Friday, May 19th Sun River Health (English)
2. Wednesday, May 31st Sun River Health(Spanish)
3. Tuesday, June 13th Nassau-Suffolk Law Services (Spanish)
4. Tuesday, June 13th Nassau Suffolk Law Service (English)
5. Tuesday, July 11th Virtual English (Zoom) 6:30pm -8:30pm.
6. July 18, 2023 Virtual Spanish (Zoom)

A total of fifty-one consumers attended and participated in the 2023 community forums, nearly double that of the previous year’s community forum.

Following is a summary of each forum as well as some of the needs and barriers that were identified.

MEETING FORMAT:

During each Community Forum, Planning Council staff and SAP Committee facilitators introduced themselves and reviewed the purpose of the meetings. A brief overview of the Ryan White Part A program was given and those present were informed that:

- Ryan White is the single largest federal program designed specifically for people with HIV in the United States, and how it is estimated to reach more than half a million people with HIV each year.
- Ryan White provides care and support services to individuals and families affected by the disease and Core and Support services currently funded by Ryan White Part A were explained.
- Ryan White helps fill the gaps for those who have no other source of coverage or face coverage limits.
- Ryan White plays an increasingly critical role as the number of people living with HIV in the United States has grown over time.

Following the introduction to Ryan White Part A, each participant was provided with a copy of the discussion questions as well as a list of fundable services. The participants were encouraged to answer the questions in a discussion-based format. For those who preferred not to verbally answer the questions, they were encouraged to write their answers down on the question sheets provided to them. In instances where participants needed assistance with reading or writing, one of the facilitators or United Way staff worked directly with them. All paperwork was collected following each meeting. The Planning Associate’s contact information was shared with the attendees. Feedback from virtually attendees was recorded and also captured through the chat discussion.

OVERALL SUMMARY:

The 2023 forums represented the first in-person community forums since the COVID-19 pandemic began in 2020. Attendance at most of the forums was up significantly from previous years when the process was conducted virtually due to the impact of Covid-19. The majority of those in attendance were actively engaged in the discussions and provided valuable input.

A summary of demographic data collected from all the meetings is included below. 64 people including 51 consumers, providers, and staff attended the five Community Forums.

The following breakdown on consumer Race/Gender/HIV status is self-reported:

African Americans	29%
Hispanic/Latino	43%
White/Caucasian	22%
Asian	4%
Native American	2%

The reported gender breakdown is as follows:
Male (57%), Female (23%), Trans (0%)

All meetings were open to people living with HIV/AIDS, people affected by HIV/AIDS, service providers, case managers and medical personnel.

LOCATION SPECIFIC SUMMARIES:

*Sun River Health
Facilitated by Joseph Pirone and Angie Partap
Friday, May 19, 2023*

The first community forum meeting of 2023 was held on Friday, May 19, 2023, at the Patchogue location of Sun River Health. 19 were in attendance including 15 consumers.

After introductions were made, Mr. Pirone opened the forum with an overview of the core and support services that are funded by Ryan White Part A, stressing that Ryan White is a payer of last resort. A list of Part A core and support services, which highlighted the funded services was distributed. An explanation of how the information gathered today will be used was given

including the importance of the community forums for planning in the regions. Confidentiality of information shared was also discussed and stressed. The 2023 Community Forum questions were distributed to aid in the discussion. In addition to being an excellent opportunity for consumer feedback, this forum also provided an opportunity for consumers to learn about the resources and services available to them.

Mr. Pirone and Ms. Partap continued with the question-and-answer section of the forum by reading the questions and facilitating discussions based upon responses.

Meeting trends:

- Most consumers reported using many of the Part A services, crediting Medical Transportation for getting them to their appointments.
- In the aftermath of the pandemic, the need and requests for Emergency Financial Assistance (EFA) and Mental health services have increased. The increased costs of food, utilities, housing, and reduction of benefits have resulted in fears about an uncertain future.
- Although not funded, Housing was the primary concern for most of the attendees. There is a significant lack of affordable and stable housing on Long Island.
- The importance of Oral Health Care (OHC) and its impact on general health was recognized. While having an oral health provider in Nassau County has increased access to this service, there was considerable concern about the limited services covered. As the population ages, more specialized dental services will be needed, but are not always covered.
- Services received by phone or computer instead of in person included: Legal, Medical Nutrition Therapy, and Mental Health care.
- The health insurance question prompted concerns about rising co-pay costs, and the recertification process, which could be somewhat overwhelming. One consumer expressed frustration about denials for necessary procedures.
- Most of the participants were aware of PrEP and U=U and felt comfortable with their level of knowledge.
- Most reported that there was never a time when they were out of care. Severe illness and relocating to a new area were the reasons given for returning to care.

Participants reported that this forum provided necessary information and provided an opportunity for consumer feedback. They also appreciated returning to an in-person format.

A Suffolk County forum was held for Spanish-speakers on Wednesday, May 31, 2023 at the Patchogue location of Sun River Health. Unfortunately, there were no attendees. Two case managers shared some of their clients' issues. Confidentiality concerns were at the top of the list. Many of the clients are very private, not wanting to share their HIV status or receive HIV notifications that others may have access to.

In addition, more accessible times for their appointments would be beneficial. Many of them are working or have small children, so a 9-5 availability is not convenient time for them. Language is not a barrier as Sun River health has a bilingual staff.

Hispanic Counseling Center (ZOOM meeting in Spanish)

July 18, 2023

Facilitated by Carmen Feliciano

An additional Zoom meeting was scheduled for July 18th to receive additional feedback from Spanish-Speaking clients since participation at the May 31st forum was very low. Ms. Feliciano reached out to clients and facilitated the meeting on Zoom. Thirteen consumers attended the forum.

Meeting trends

- Many were unaware of many of the available services, especially Legal services.
- Without ADAP, many reported that they would be unable to survive without this assistance.
- No one reported a problem accessing the services they needed.
- Participants cited long wait times for a dental appointments and assistance needed to access vision services.
- No one reported a time when they were out of care.

Nassau Suffolk Law Services (Spanish Forums)

June 13, 2023

Facilitated by Joel Gonzales

Fifteen people attended the June 13 forums for Spanish speakers including 7 consumers and 8 staff. Many bilingual staff from funded agencies assisted Spanish-speaking clients, resulting in a one-to-one experience that greatly helped get much needed feedback.

Meeting trends-

- ADAP, EFA, and Medical Transportation were the most used funded services. With rising costs, there were more assistance request for food, rent and other expenses.
- OHC services are limited and should be expanded beyond basic services.
- Better access to Mental Health resources.
- Insurance concerns included rising costs and dental services which are not always covered. One response was the changes in pharmacy resulting in delays in receiving medications. Another said the process of renewing expired insurance should be more accessible and simpler.
- Some of the clients have childcare issues making it difficult to get to medical appointments. Childcare assistance would be helpful.
- One person felt that there should be more access to services for immigrants and vulnerable population, suggesting a program for laborers.
- Few reported being out of care, learning about available resources and getting really sick brought them back into care.

Nassau Suffolk Law Services

June 20, 2023

Facilitated by Joseph Pirone & Angie Partap

Fifteen were in attendance, twelve of whom were consumers.

Meeting trends-

- Services utilized most often were ADAP, MT, legal services, EFA, MH and OHC.
- Lack of affordable housing, rising costs of living, are constant concerns.
- Many responded that Mental Health services are most needed for their care, the impact of COVID and fears of an unknown future have taken their toll.
- EFA is beneficial and should have increased funding.
- Oral health care coverage is basic and limited. Specialty services are not covered. Despite having an oral health care provider in Nassau County, which offers more access, consumers are still experiencing long wait times for OHC services. More dental coverage is needed as dental needs increase because of aging.
- Lack of affordable housing and the rising costs of living are constant concerns.
- One participant shared that physical therapy and medical massages would provide a better quality of life.
- Health insurance concerns were higher copays and not all services are covered (physical therapy was given as an example).
- Consumers were familiar with PrEP and U=U campaign.
- One person noted that long-term service care is getting limited for the services being accessed.
- Encouragingly, almost all consumers did not report a time when they were out of care. Relocating to another area was cited by one participant as reason why they were out of care in the past.

Virtual via Zoom (English)

July 11, 2023

A virtual Zoom was scheduled to accommodate those who were unable to attend the other in-person community forums or who felt more comfortable in a virtual setting. Thirteen people attended, eight of whom were consumers.

Meeting Trends

- ADAP, OHC, MNT, MH, and OAHS were the most used funded services.
- Rising costs, reduction of benefits and lack of affordable housing remain a constant worry for many.
- Mental Health services are necessary to help cope.
- High staff turnover impacts access to some services
- Long wait times for OHC, limited service, not everything is covered by insurance.
- High staff turnover impacts access to some services.
- Although some prefer in-person appointments, many felt it would be more convenient to do it virtually, especially when labs are not required and only a few minutes were spent with the health care professional.
- Services and a focus on the aging population is needed.

As many lamented the loss of or limitations to accessing EAC nutrition program, (not a RW Part A service). More assistance is needed to help with food and nutrition services.

CONCLUSION:

The focus of the 2023 Community Forums was to gather valuable consumer input about services and needs to assist in the Priority Setting and Resource Allocation (PSRA) process. Community forums offer the opportunity to address consumer concerns and needs with the goal of improving their quality of life.

Overall, consumers had the opportunity to participate in a process that has the potential to impact their care and well-being as we begin the grant submission process.