One-Year
Consumer
Feedback
Presentation



FY 2020

CIA Meetings Findings

## March 2020 – Beginning of COVID-19 Pandemic

ALL the Newark EMA HIV Health Services Planning Council and Committees' meetings were on hold due to COVID-19 and until further guidance was received.



## **April 2020 – Beginning of Virtual Meetings**

- > A brief activity was held with meeting attendees to explain the needs assessment.
- ➤ Using this activity as a discussion starter, Support Staff explained that the Needs Assessment aims to investigate the needs of People Living with HIV in the community.

## May 2020 - Needs Assessment Update with a focus on Housing

- 17 Attendees, including 2 PC Support Staff, 2 Planning Council members and 1 provider.
- > FY 2020 Needs Assessment (Housing) The Research and Evaluation Committee is updating the Needs Assessment with a focus on Housing.
  - An attendee mentioned that **Housing** has been the number 1 topic for the past years during CIA and Planning Council meetings and that it has become "redundant" and continued "until the Federal Government puts Housing as a priority, the state can't do much."
- Discussed the impact and challenges of PLWHA are facing due to COVID-19, including the impact on mental health, worries about COVID-19, preparation to go back, doctor visits via telehealth, and getting medications.
- Issues reported by attendees
  - Bumps on hands when using gloves. (Medical concern)
  - Issues with current apartment building due to odors. (Housing)
  - Food prices increased since the pandemic and seems like are likely to continue to go up.
  - Issues with stimulus check.
  - Some dentist offices were closed, and someone needed a dental appointment.
  - Use of telehealth was "easy".
  - Do not own a smartphone. (Technology issue)

## June 2020 – Prioritization of EMA-funded service categories

- > 11 attendees, including 2 PC Support Staff, 2 PC members and 1 provider.
- Attendees received an update on the Needs Assessment
  - Unstable housing makes it difficult to stay healthy specially if a person has mental issues or substance use.
- ➤ **Telehealth services** were listed as a tool that could help clients keep appointments and reach viral load suppression. However, **not having access to technology** was a big barrier to care.
- Discussions on the impact and challenges of PLWHA are facing due to COVID-19 continued:
  - Sleeping issues
  - Following COVID-19 social distancing protocol despite missing being around others
  - Rents are increasing.
- FY 2021 Priority Setting
  - The FY2020 Priority Setting was shown as a guide to provide feedback.
  - Attendees heard the service categories definitions.
  - After some discussion, attendees agreed that the 16 service categories in the Newark EMA should be prioritized as follows:



#### **June 2020**

Prioritization
of EMAfunded
service
categories
(Cont'd)

	Service Category	Rank	Reason
	Medical Case Management	1	This was #9 but was changed to #1 because
			A Medical Case Manager advocates for clients and help them solve any problem, give referrals to the right service, connect clients to
n			different services such as Housing, and talks about changes in medications.
			"They are able to advocate for you."
			"Medical Case Managers are very important to help clients become virally suppressed"
	Housing	2 Studies have shown that people who have stable Housing achieve viral load suppression and are more likely to remain virally	
			suppressed.
	Medical Transportation	3	Transportation is a barrier to access to care since people must go back and forth from their medical appointments. Bus tickets,
1			mileage and/or gas reimbursement should be offered.
			Transportation is needed to maintain appointments and overall good health
	Foodbank/Home-Delivered Meal	4	Food is a big issue, especially with the pandemic. "There is no point of having a house with no food"
			Medications need to be taken with food and having food can help take medications on time. "Some people live meal to meal."
	Mental Health Service	5	Clients are worried about the new deadly virus.
			"We need someone to talk about what is going on with us"
			"Cannot do anything if your mental health is not right."
			"If you can't comprehend what is going on and you are going through a certain situation, how can you hold an apartment – how can
			you know how to go about your transportation?"
			"You have to have the mental capacity to do the rest."
	Psychosocial Support Services	6	Psychosocial services allows people to talk in groups about certain issues they might be facing. These groups provide food/meals so
			people are more likely to attend.
			Psychosocial Support Services and Mental Health Service's definitions are similar to each other, and both are needed. Therefore,
			psychosocial was placed after mental health.
	Oral Care		Oral Care affects overall health
	Outpatient/Ambulatory Health Service	8	
	Early Intervention Services		"Early Intervention plays a key role in our mental status and medical health"
	Emergency Financial Assistance	10	
	Non-Medical Case Management	11	
	Substance Abuse (Residential)		People with substance abuse, whatever the substance is, "they are not going to keep their appointment, they are not going to get the
	HIPCS	13	food; they are not going to use the food; they are going to sell the food"
	Other Professional Services	14	
	Substance Abuse Outpatient Care	15	
	Medical Nutritional Therapy	16	
	medical Nutritional Therapy	10	

## July 2020 – Resource Allocation

- > The meeting was rescheduled from July 22<sup>nd</sup> to July 24<sup>th</sup> to due to low attendance.
- There were 6 attendees from Essex County, including the CIA Chair and both Support Staff.
- Priority Setting
  - Committee members talked about what priority setting means and mentioned that:
    - Medical Transportation is needed to go to medical appointments. (3)
    - Housing funds should increase. (3)
    - COVID-19 changed things and affected different service categories.
    - Mental Health and Emergency Financial Assistance (EFA) should increase.
    - All service categories funding should increase.
- COVID-19 Conversations
  - Housing programs prioritize county residents, which is a barrier when trying to move.
  - Attendee mentioned having issues with refrigerator a couple of weeks ago and is not sure if can be covered under EFA.
- Meeting (Technology) Issues:
  - Some attendees were not able to see the allocation ranking worksheet on their smartphone or the phone option and were not able to access their email while using GoToMeeting.
  - Some attendees also had technical difficulties with their connection.

## August 2020 – Break



## **September 2020 – Recruitment and Engagement**

- 5 attendees from Essex County.
- > The consumer representation in the Planning Council was mentioned. Attendees shared:
  - Being interested in applying but helping with outreach for Hyacinth. Will need to check availability.
  - Applying for PC membership
  - Considering applying
  - Not being sure if able to join due to housing issues.
- Discussed canceling the in-person holiday party due to the social distance measurements.
- Someone reported not being able to reach the Department of Veteran Affairs and needing a Case Manager to receive medical care.

## October 2020 — Healthy Living, Healthy Weight and HIV – Janssen

- > 7 attendees from Essex County and 2 Planning Council members
- ➤ The Needs Assessment on Telehealth will try to assess if telehealth services were used during the pandemic and if it will be used afterwards. All were encouraged to participate in the surveys.
- Discussed the possibility of a virtual holiday party.
- "Healthy Living, Healthy Weight and HIV" Presentation by Mike Valentin from Janssen.

\*\*Uber vouchers

## November 2020 - "Working Behind the Scenes"

- > 11 consumers from Essex county, 1 from Union, 2 Support Staff and 3 PC members
- Presentation on "Working Behind the Scenes" about the work of the PC and its committees.
  - Dr. Bagchi gave an overview on the REC including all the REC deliverables.
- Discussions after the presentation
  - "COVID-19 crisis in a way pushed things in a direction that was necessary and so our goal is to ensure that it continues because I've used the telehealth".
  - "I'm not crazy about telehealth... I will talk on the phone, but when it comes to my doctor... I don't feel the connection from the computer to talk about my health."
  - "I'm looking at [telehealth] as a backup when you cannot go outside".
  - Someone reported having heat issues because tenant turned the heat off.
  - Barriers or concerns on joining the Planning Council
    - Not wanting anyone to know HIV status or be looked at different because of it (Stigma).
       However, the youth needs to be aware and would like to be educated to educate the youth.
    - Not being interested due previous commitments and perceived age-related impediments.
    - Two consumers were interested.
  - Recommendations
  - Give Uber Eats vouchers to participants to use while in the meeting.
  - Have a go-to person for PC questions; perhaps a buddy they can talk to as a new member.





#### **December 2020 – Core Service Waiver Conversation Session 1**

- 49 attendees including 3 PC nominees, 2 support staff, 2 Planning Council members, 1 REC member, 1 Janssen representative, and 2 recipient's representatives.
- Learned about Building a Plan to Manage HIV as a Chronic Disease from Debbie Mohammed and Janssen Pharmaceuticals.
- Core Service Waiver Recipient's Office
  - Discussed the Core Service Waiver application to reallocate funds outside the 75/25 split for core medical and to support services due to COVID-19. All attendees agreed to support the core service waiver application.
- Issues mentioned
  - Needing help with the light bill. Public service assistance can be covered under the Emergency Financial Assistance (EFA), which covers any emergency.
  - Using a machine for sleep apnea and needing help with electric bill.
  - Needing help to pay medical bills. A portion of the funds are for Health Insurance
     Premium and Cost Sharing (HIPCS), which helps with lab payments or copayments.
  - Not being aware of all the services in the Newark EMA.

\*\*Uber Eats and Raffle





## January 2021 – Core Service Waiver Conversation Session 2

- > 25 attendees.
- Continued the core service waiver discussion about the need to fund more support services due to COVID-19. All attendees agreed to support the core service waiver application.
- Issues Mentioned
  - Emergency Financial Assistance (EFA) (2)
    - Do funds help with utility assistance? EFA covers back rent up to 3 months, and PSEG assistance as well as other emergency situations.
    - Union county residents pay for public service and gas bills separately. EFA can cover gas bills.
  - Are medications covered by agencies? If a service provider does not have HIPCS funds to cover for Co-payment or medication but has EFA funds, these can be cover through the EFA.
  - Transportation issues (2)
    - A Dover resident mentioned that agency was providing bus cards but due to the pandemic this stopped. Such bus cards
      were being requested from LogistiCare, a Medicare program. Hope House in Dover provides transportation services.
    - Are bus cards given for those who have transportation issues? Bus cards are not issued by the Ryan White Program
      because the program asks to spend the funds on core and support services.

## February 2021- PrEP as a prevention method for HIV.

- > 12 attendees including Poole. 2 attendees from Union County and 10 from Essex County.
- Support Staff encouraged everyone to complete the Needs Assessment consumer survey.
- PrEP as a prevention method for HIV Presentation by Alison Modica from Gilead.
- An attendee provided information on Dr. Kimberly Smith in commemoration of Black History Month.





## Service Categories Mentioned at Meetings

Service Categories	Suggested
Early Intervention Services	
Emergency Financial Assistance	✓
Food Bank – Home Delivered Meals	✓
Health Insurance Premium and Cost Sharing Assistance	✓
Housing Services	✓
Medical Case Management	✓
Medical Nutrition Therapy	✓
Medical Transportation	✓



Mental Health Services  Non-Medical Case Management  Oral Health Care  Other Professional Services  Outpatient/Ambulatory Health Services  Psychosocial Support Services  Substance Abuse Outpatient Care  Substance Abuse Residential	Service Categories	Suggested
Management  Oral Health Care  Other Professional Services  Outpatient/Ambulatory   Health Services  Psychosocial Support   Services  Substance Abuse Outpatient Care  Substance Abuse	Mental Health Services	✓
Other Professional Services  Outpatient/Ambulatory Health Services  Psychosocial Support Services  Substance Abuse Outpatient Care Substance Abuse		✓
Services  Outpatient/Ambulatory Health Services  Psychosocial Support Services  Substance Abuse Outpatient Care  Substance Abuse	Oral Health Care	✓
Health Services  Psychosocial Support Services  Substance Abuse Outpatient Care  Substance Abuse		
Services Substance Abuse Outpatient Care Substance Abuse	,	✓
Outpatient Care Substance Abuse		✓

### Conclusion

- Meeting attendance increased when big events and/or presentations on a specific topic were held and/or incentives were given (October, November, December, January, February)
- More input was gathered when attendees were asked about one specific topic.
- The barriers to care according to attendees most mentioned were
  - Transportation
  - Housing including utilities
  - Mental Health
  - Food
- > Attendees had issues with the transition between in-person and virtual meetings.
- The recommendations most mentioned were:
  - Increase representation from other Counties
  - More transportation resources
  - Additional housing funds
  - Provide Uber Eats vouchers to participants to use while in the meeting
  - Have a go-to person for any questions about PC matters; perhaps a buddy they can talk to as a new member.
- Attendees liked knowing what the Planning Council is working and that their input is being considered.
- Some attendees applied for Planning Council membership since meetings are held via Zoom.

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