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Assessing Needs, Gaps, and Barriers

Hudson County TGA Integrated HIV Prevention and Care Supplemental Plan 2017-2021

REGION	Northeast
PLAN TYPE	TGA, Integrated city/county-only prevention and care plan
JURISDICTIONS	Hudson County TGA
HIV PREVALENCE	Medium

Hudson County TGA’s needs, gaps, and barriers section includes a very thorough description of the various ways they identified HIV prevention and service needs of PLWH and those at risk. This includes information about the focus groups and involvement of various populations as well as the ways this information was used to inform their Integrated HIV Prevention and Care Plan. They provide a strong narrative description and effective tables to demonstrate service needs, gaps, and barriers. The section also includes a descriptive table that includes all data gathered from the survey and an accompanying narrative description of findings.

SELECTION CRITERIA: ASSESSING NEEDS, GAPS, AND BARRIERS

Exemplary Assessing Needs, Gaps, and Barriers sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- Includes description of the process used to identify HIV prevention and service needs of those at risk and PLWH
- Demonstrates engagement of those at risk and PLWH in planning
- Clear and robust description of service needs
- Clear and robust description of service gaps
- Clear and robust description of barriers (social, policy, health department, program, service provider, and client barriers).



Additional exemplary plan sections are available online:
www.targetHIV.org/exemplary-integrated-plans

D. Assessing Needs, Gaps, and Barriers

D-a. Describe the process used to identify prevention and care needs of higher risk and PLWH and strategies used to target, recruit, retain participants in planning

In 2016 the TGA collected surveys, conducted a focus group with former inmates, and completed 3 key information interviews. 827 people completed the Hudson TGA's Needs Assessment surveys and 6 participated in the focus group, while key informant interviews were conducted with a medical doctor specializing in transgender medical care. These target populations were decided by the PC Needs Assessment Committee who looked at the EIIHA/TLC targeted populations, the previous three years of Needs Assessment data and material, current and emerging concerns, and the input from the committee itself; the committee is made up of consumers, providers, and community leaders. The committee decided to gather information that may assist in breaking down some of the barriers to getting tested since it was looking at an Integrated HIV Health Plan, bringing people into care as well as retaining people in care; therefore, the two primary surveys were of first priority, gleaned information from not only those in care but also those who participated in high risk behavior and sought to be tested. The focus group was selected because of some community programs that have been designed for this population; this group also receives Part A MAI funding so it was an opportunity to gather information from a population that we had access for a focus group. Part A MAI also funds a Transgender Outreach program; an area doctor [Dr. McNett] recently opened a transgender clinic. The Committee decided that we needed to hear from a doctor who was an expert in this field in order to better understand the Needs of the Transgender population and also to bring them into HIV care, if infected, and to keep an open dialogue if they were engaging in high risk behavior. The EIIHA/TLC Committee sought greater information with regard to the utilization of social media as a means of adherence and retention in care; with the help of our Project Officer we were put into contact with a SPNS recipient who freely discussed the project so that we could see its possibilities for our area.

There were 528 PLWH in care who completed the Service Needs and Barriers Survey, and 299 at-risk or PLWH not in care who completed the Waiting-to-be-Tested Survey. The *Services & Barriers Survey* asked what services people use now, what services they rank as the top in importance to PLWH, what services they need but cannot get, if substance abuse services are needed, and gender, race, sexuality, and socioeconomic demographic information. For those services needed, they were also asked what barriers prevented access to those needed services, and to offer their recommendations to improve access. This survey was distributed by Part A MCMs, HOPWA agencies, and consumers. The *Waiting to be Tested Survey* asked respondents how they found out where to get tested, what prevented them and people "like them" from being tested before, recommendations for getting more people tested, and demographics including gender, race, age, sexuality, and geography. This survey was distributed by various testing sites and initiatives throughout the County; this took place not only within the sites but also in mobile units and also at various health fairs, colleges, PC training events, Department of Welfare, etc., all were volunteered to take the survey as they were waiting to be tested.

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A Focus Group was convened in CY16 targeting ex-inmates who are PLWH to hear their priorities and recommendations related to the greatest service needs and barriers they encountered or observed. Prior Focus Groups have been held by the Council with PLWH working outside of the HIV system, substance users, Muslims, heterosexual black men, MSM, African Women, older adults, and Latinas. The TGA's Unmet Need data analyses also specify the demographic and risk characteristics of those who know their HIV status, but are not in care. A key informant interview was conducted with Dr. Michael McNett, the Ryan White Medical Director at Horizon who specializes in the medical needs and barriers of people who are transgender, he opened clinics specific to their needs at 2 locations in Jersey City.

As part of our Early Identification (EIIHA) planning, the Council's "TLC" (Testing Linked to Care) Committee collected Hudson-specific Continuum of Care (CoC) data on numbers tested/informed, linked to care within 90 days, retained in care, prescribed ART, and virally suppressed. Based on the analysis of those data, TLC strategizes regarding population-specific action steps that have been integrated into this plan.

The needs of historically underserved were also considered. Sub-Recipient Utilization Data, reported monthly, show the characteristics of those who access Part A/MAI services by gender, age, race/ethnicity, and risk category. When groups are underserved, compared to their epi data, the Council includes strategies to engage them in its recommendations to the Recipient. The underserved's needs were also integrated throughout our Plan. As cited previously, the TGA's FY16 Needs Assessment Surveys included 528 PLWH responding in English and Spanish language versions of our Planning Council's Service Needs Assessment Survey. Demographic and transmission category data, as well as municipality of residence, were also collected, so that service priorities and funding allocations could reflect not only service needs by RW allowable service categories, but geographic, as well as demographic, cultural, and exposure / risk target populations who were underserved and/or did not have easy access to certain services proportionate to their epi profiles. The Council Action Committee spent many hours revisiting FY16 Needs Assessment Survey results, as well as FY16 (and prior years) Focus Group findings, and other data cited above (eg: PLWH utilization of existing services etc.), to establish priorities and recommend allocation amounts to the Recipient for finalizing FY16 and projected FY17 need amounts. The Needs Assessment and Action Committees have members who are PLWH, including but not limited to the Secretary of the Consumer Planning Council and the TGA's Consumer representatives to the NJ HIV Planning Group.

For this plan, the Council integrated recommendations from each of these committees, reviewing the proposed 2017-2021 IP as well as all of the aforementioned data sources ensuring that each perspective and experience within the community is given voice in each part of our ongoing planning and implementation process.

D-b. Describe the HIV prevention and care service needs of persons at risk and PLWH

Data from the CY2016 Needs Assessment: Services & Barriers Survey to PLWH

TOP 10 “GET NOW” SERVICES (N=528)			
N=528	SERVICE	# Get Now	% of Respondents
1	HIV/AIDS Medical Services	519	98%
2	Medical Case Management	505	96%
3	HIV/AIDS Medications (Rx)	483	91%
4	Dental Care	466	88%
5	Eye Care	438	83%
6	Health Insurance	436	83%
7	Specialist Services	411	78%
8	Other (non-HIV) Meds (Rx)	393	74%
9	Transp to medical appts	308	58%
10	Food Vouchers	268	51%

The data from our 2016 TGA needs assessment (NA), featuring 528 PLWH, is a good place to start and confirms a lot of the anecdotal local data and nation-wide research. When asked the top services that were identified as most important to PLWH were: 1) HIV / AIDS medical services (73%), 2) HIV / AIDS medications (66%), 3) medical case management (45%), 4) food vouchers (34%), 5) health insurance (33%), 6) and housing assistance (30%). Across gender, results about service needs were generally the same with very slight variation, including looking specifically at women of color (as one of our target populations, described elsewhere in this Plan). Comparing MSM (as a key target population and a disproportionately affected subgroup) also indicates similar needs with some observed differences.

Analyzing multivariate disparities in NA findings a) Populations of MSM over 45 prioritized the need for transportation to medical appointments higher than other groups. b) Black MSM ages 27 to 44 indicated a greater need for specialist services than other groups, perhaps reinforcing what we already know (and described previously) about intersectionality of race, income, and health status. c) Young people (ages 13-26) in the survey reported similar service needs, though Dental Care was second in their reported priorities. Data also shows early indications that online outreach or contact through technology may be a more effective solution for some. In addition to exploring lessons learned from HRSA’s SPNS project on social media, the TGA plans (as described in our action steps) additional research in considering how best to implement and respond to the culturally appropriate use of social media to communicate to youth in particular.

The Council Action Committee of the Hudson TGA HIV / AIDS Services Planning Council also takes a role in voicing what services might be needed in the TGA after they have accessed all of the Needs Assessment material. The Committee is made up of providers, consumers, community members, and representatives of the Recipient. In August 2016 the Council Action Committee voted on the FY17 service allocation priorities, something they do each year in preparation for

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the Part A funding application. Projecting the needs of PLWH in FY17, they voted health care, medical case management, health insurance cost sharing, and oral health as the top four service priorities. Funding allocations for FY16 are slightly different, as health insurance cost sharing did not yet exist as an allowable care medical service category and mental health services were one of the previous year's top four funded services. Similarly, by looking at the Part A utilization data for FY15, we can see what services were needed by PLWH. The top five services based on agency utilization data were medical case management, primary medical care, emergency financial assistance, medical transportation, and oral health.

Persons at-risk generally identified their priority needs as: information / education and affordable care options. At-risk individuals indicated they needed communication to reduce stigma and to know the importance of early treatment. If we consider how the at-risk individuals who completed the "Waiting To Be Tested" surveys learned about testing, we can perhaps understand some of the service needs. Of 299 total respondents, 32% learned from friends and family where to get tested, 23% went to get tested on their own, 15% came through medical clinic staff, and 11% were present at an event.

Serving the ex-inmate population is complicated by a multitude of intersectional reasons previously discussed including lower income, stigma, and race. Layered on top of that is the stigma from having been incarcerated and the barriers that creates. Our focus group members indicated that they had three key needs: stable housing (which relates to their medication adherence), medical case management (which all were presently enrolled in), and mental health services, the PC Consumer Committee also identified mental health services as a need that may be underutilized do to cultural misconception and misunderstanding of what constitutes mental health needs.

Among the 3.3 million HIV testing events reported to CDC in 2013, the highest percentages of newly identified HIV-positive persons were among transgender persons^{xxx}. In 2013 the estimated HIV prevalence among transgender women was 22% in the United States^{xxxii}. 28% of transgender women had HIV infection, while 12% of transgender women self-reported having HIV, suggesting many transgender women living with HIV don't know their HIV status^{xxxii}. In this same meta-analysis, black transgender women were most likely to test HIV positive: 56% of black transgender women had positive HIV test results compared to 17% of white or 16% of Latina transgender women. In order to understand the needs of this vulnerable and marginalized population within Hudson, a key informant interview was conducted with a leading doctor on the needs of people who are transgender. The needs identified by Dr. McNett were in line with national research on the transgender community and their HIV care and prevention needs. They need nonjudgmental and accessible medical care above all else. That medical care must incorporate an understanding of hormone therapy and the interplay with HIV medications, including lab work, monitoring, and costs. Prevention needs are for peer-based outreach and known, trusted medical providers to be accessible and affordable.

Additional Part A Primary Medical Care priorities and needs identified through consumer and provider feedback follow up:

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- Provide consistent comorbidity screenings as part of routine HIV care (TB, Hepatitis A-C, Pap Smears, STDs, age appropriate mammograms, colonoscopies, etc.);
- Assertive and intensive follow-up / outreach for missed appointments & drop-outs to care;
- Continuity of medical care (seeing same practitioner every visit);
- Consumer Education on Medications & Labs – adherence strategies;
- How to alleviate potential side-effects & interactions;
- How to integrate meditation into daily schedule, etc.;
- Initial and ongoing assessments including risks (sexual behaviors and substance use), sexual orientation;
- Mental health and substance abuse assessments at least annually, preferably every 6 months, with access to culturally competent treatment, so that appropriate prevention messages and referrals to other needed services.

D-c. Describe the service gaps identified.

Data from the CY2016 PLWH Needs Assessment: Services & Barriers Survey

TOP 10 “NEED BUT CANNOT GET” SERVICES			
N=259	SERVICE	# NEED	% of Respondents
1	Food Vouchers	105	41%
2	Housing Assistance	81	31%
3	Transp to medical appointments	78	30%
4	Employment/Job Related Services	69	27%
5	Utilities Assistance	67	26%
6	Food Pantries	66	25%
7	Home Delivered Meals	61	24%
8	Legal/Advocacy Services	54	21%
9	Health Insurance	43	17%
10	Home Health Aide Services	38	15%

Hudson’s “service gaps” have to do with over-burdened capacity and lack of sub-specialty care. The top services needed but that PLWH cannot get are described above, and the top five have generally remained the primary service gaps from year-to-year, particularly as RW and non-RW resources such as food, housing, transportation, and advocacy. Comparing gender specific service gaps reveals little differences although there are a few observations. Firstly, females tended to report that utility assistance was needed but not obtained more often than males (31% v 25%). Second, males tended to prioritize transportation to medical appointments more than females, ranking second for males with 30% (and 4th for females with 26%). The most significant difference might be that child care and outpatient drug / alcohol counseling appeared only in the females’ top 10 services needed but not obtained and neither appeared on the list for males. Looking specifically at black females, the one major difference is that employment and job-related services are prioritized first.

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Looking at MSM of color (as a disproportionately affected group) does reveal a few key differences in services needed but not obtained. Black and Latino MSM 27 to 44 had similar reporting, with health insurance and food vouchers in the top three of the services needed but not obtained. Younger Latino MSM indicated a need for drug and alcohol outpatient and inpatient services, though the sample size was small (n=5). Black MSM over 45 needed but could not get housing assistance, food vouchers, and employment / job services. Latino MSM over 45 needed but could not obtain transportation to medical appointments, health insurance, and food vouchers. Young people (ages 13 to 26) had similar top items, with one exception: utility assistance was first ranked amongst youth.

Looking at the “Waiting To Be Tested” survey data, just 4% saw a mobile unit or walked by a testing site. This perhaps indicates a need for more mobile units or more visible testing sites, more strategic locations or hours, better outreach, and more effective stigma reduction. A gap is also revealed by the theme among respondents that fear of cost prevents many people from accessing care, so there is a service gap in medical care, treatment, and counseling for these at-risk individuals.

Gaps identified by ex-inmates included the importance of a peer navigator to follow-up as soon as they leave jail. The timing is key, in addition, they suggested that more peer support be a component for other services and that ex-offenders conduct outreach to get more people tested. Finally, the group identified that support to be retained in care, including transportation and food vouchers, was a missing gap for them.

The lack of cultural proficiency/competence among all providers, at every site, in terms of the transgender community can be considered another gap. Comprehensive non-medical case management that can link PLWH to all resources needed is a gap often cited by most PLWH, it is especially important for transgender individuals, as each resource (housing, financial assistance, workforce development, etc.) must be transgender competent, aware, and free of transphobia. While the case manager or advocate might be aware and supportive, other systems they encounter (such as housing, food pantries, homeless shelters, etc.) may not be.

Additional service gaps identified by consumers and providers:

- Gaps related to Primary Medical Care and Secondary or Supportive Services: improved accessibility -- evening and weekend hours; in-home visits for medical practitioners when needed; etc. Expanded numbers of practitioners are needed to reduce caseloads and expand time with PLWH for comprehensive and individualized prevention messages and consumer education; expanded transportation resources so that consumers can get to non-clinic essential services such as mental health, substance abuse counseling, support groups, etc. to reinforce primary care retention; linkage to timely sub-specialty / tertiary care (oncology, cardiology, etc.) and availability of specialists willing to treat uninsured Medicaid/Medicare patients; Peer facilitated support groups, food, and child care.
- Gaps related to Housing: the lack of quality, affordable housing impacts PLWH’s ability to engage / adhere to HIV care; “housing is health care” and should be a “core” service.

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Non-Part A resources such as HOPWA have been cut and waiting lists are closed or years long (i.e.: Section 8, public housing, etc.) PLWH “are on the verge of homelessness more than any other population.” LGBT Youth and people who are transgender are often homeless; no appropriate placements in N.J. Long-term, affordable, safe housing is desperately needed. Part A and many HOPWA programs focus on short-term, transitional, and emergency housing assistance. Without a stable place to stay, people are less likely to keep medical appointments and/or adhere to medication regimens; this is now documented in research findings.²³

- Gaps related to Providers (medical, MCM, etc.): there may be a perceived lack of sensitivity - some providers do not ask correct questions (about risk behaviors – sexual activity / substance use, sexual orientation, mental health, etc.); as a result, appropriate tests, prevention messages, and referrals are not given; others ask questions about risk behaviors and transmission in an insensitive manner and they repeat the same questions at every visit; there is little continuity. Risk behaviors may change and updated assessments are important, but transmission category and other information remains the same; lack of cultural competence related to youth, people who are transgender, gay men, heterosexual males, and people over 50; limited African American or Black Medical Practitioners, particularly Doctors; turnover of staff is a barrier to successful engagement and retention; multiple trust-building encounters have to start all over again - when medical practitioners change, it is difficult for consumers to transition, to “tell their story” and answer questions and build trust over and over again.

Gaps in Sub-Specialty Care:

Despite diligent efforts by the Planning Council, the Recipient, and Hudson’s Ryan White provider agencies, this TGA has serious gaps related to specialty care. There are long waiting lists for, or the non-availability of, sub-specialty care for PLWH in areas such as, but not limited to: oncology, dermatology, ophthalmology, neurology, gastroenterology, orthopedics, and cardiology. Medical management of advanced renal disease is also scarce. Tertiary care after an abnormal test finding is particularly difficult to access for many patients. Gynecological care, and colposcopies, for women with abnormal Pap smears, is another example. The Recipient has attempted to contract for the more often utilized sub-specialty cares but no one responded to the RFPs due to the lack of funding available.

Care Complexities for Aging PLWH

PLWH are aging; many are now above 50. They have lived with HIV/AIDS for many years, in many cases for more than twenty years. The combined effects of aging, chronic illness, and long-term use of toxic medications take a toll on their overall health. Sub-specialty care for these PLWH is widely needed, but often unavailable. Medical practitioners often do not ask senior citizens about their sex life and risk behaviors, and therefore do not give them the prevention messages that they actually need, this includes the status of their partner if the person is in a relationship. The discussion of PrEP is often ignored according to discussions within the PC Consumer Committee. The medical practitioner is often ignorant about the consequences of unprotected sex and updates with regard to new initiatives with regard to HIV.

Lack of Affordable Housing

As cited earlier, quality, affordable housing continues to be a serious service gap for PLWH in Hudson County, noted by many PLWH as a top service gap and a top barrier to engagement and retention in care in TGA Needs Assessments. Many PLWH are in unstable housing, (likely to move within six months); many are doubled up with family or friends, particularly young MSM. When someone does not know where s/he will sleep the next night, s/he is not likely to see a doctor. Local data mirrors findings of New York City studies.¹²

The main housing gaps in this TGA, and resulting problems, which the Council's Housing Committee has previously identified include:

- a) Lack of any new low income rental units being developed;
- b) Transitional / Supportive housing specifically for women, and women with children;
- c) Scattered site projects – these are not HIV specific; therefore, have extremely limited access and have long waiting lists;
- d) Ignorance of landlords and realtors about HIV and resulting stigma; landlords are often leery of accepting third party payments.
- e) No agency which specifically assists low income people with securing low cost housing;
- f) Lack of housing for PLWH with mental health and/or substance problems;
- g) Lack of housing for recently incarcerated and restrictions regarding felony histories and ineligibility for public housing and public subsidies;
- h) Lack of low cost housing for low income families and those on fixed incomes; and
- i) Lack of financial management education and services for PLWH.

In response to these gaps / needs, the Housing Committee continues to develop detailed Plans with specific recommendations to address each gap. Those action steps are updated / monitored by the Housing Committee. This Plan reflects the general directions recommended by the Committee.

Food:

As cited earlier, Food continues to be a top need of PLWH in the TGA. Even though RW funds continue to provide nutritional meals for those who are home bound and with limited mobility, food continues to be a service which is identified as “missing” or as an unmet need by Consumers in Focus Groups and Surveys. Given the economic recession, with high unemployment rates and lower charitable giving, pantries and food banks in the Hudson TGA are facing much higher demand with much lower supplies and contributions. Many have closed in the past several years. More people are hungry and the availability of food for the area pantries cannot keep up with the need; therefore many of them have placed restrictions on what they distribute.

Support Groups:

Support Groups are not as numerous as they were when there was more federal funding coming into this TGA. Peers who co-facilitate the groups want to be compensated, yet the TGA can no longer afford to pay them. Consumers continue to voice the importance of having peers “who

have walked in my shoes” help them by providing ongoing support, encouragement, and adherence assistance. You will see in our action plan our attempts to try and build some support groups that target the adherence needs we have and any disparities we observe in the data.

D-d. Describe barriers to prevention and care.

i. Social and structural barriers

Data from the CY2016 Needs Assessment Survey to People Waiting to Get Tested – Responding to “Why did you, or people you know, not get tested before?”

N=383 (Multiple Responses)	REASONS	#	% OF TOTAL RESPONSES
1	None of these	69	18%
2	Did not know where to get tested	54	14%
3	Did not think about it	51	13%
4	Fear of being seen getting tested	36	9%
5	Trusted my partner to not have sex with anyone else, and I had one partner	35	9%
6	Did not think at-risk of getting HIV/AIDS ("too old", "not having sex", etc.)	32	8%
7	Did not want to test HIV positive and find out	29	8%
8	Testing site (location) was hard to get to	27	7%
9	Other reason(s)**	23	6%
10	Location was known as a place for HIV services	15	4%
11	Fear of medications (Rx) would have to take if HIV +	9	2%
12	Religious or cultural beliefs	3	1%

**The other reasons reported included: fear of the results, married and monogamous, want to know my status, learning people are “shady,” too busy, cost prohibitive, and not enough education.

The at-risk individuals waiting to be tested in this survey reveal quite a bit about the social and structural barriers to prevention, testing, and care. The largest proportion of them reported that there might have been no reason they did not previously get tested, yet this indicates an inaction and therefore a potentiality for behavior change that needs to be addressed. Trying to understand what it could be that has prevented them from entering the contemplation or planning stages of behavior change becomes a bit easier by looking at the other responses. 14% of people did not know where to get tested, which is a low number, but not one that the TGA is satisfied with. A barrier here is access to information and awareness. 9% reported they trusted their partner and 8% thought they themselves were not at-risk, so at least 17% of respondents were not assigning any risk to themselves, though they were likely engaging in some risk behavior which resulted in them eventually going for a test. 9% reported fear of being seen while 4% did not test because the location was known as related to HIV, representing that at least 13% of respondents then are facing stigma issues. 8% reported fear of testing positive while 2% reported fear of the

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medications. This means that 10% had a fear about what it means to be HIV positive and how to deal with that, so strong a fear that they did not see the value of early diagnosis and treatment (or prevention if they tested negative).

From the qualitative data submitted through these surveys, we can also see that perception (or misperception) is one of the greatest barriers to prevention and care services. Respondents indicated that many people have a fear of high prices (not realizing what kind of support may be available to reduce care to low or no cost). Others indicated that people do not think care and treatment have improved since the 1980s and 1990s and that learning you have HIV may still be a death sentence. These responses continue to reinforce the stigma, fear, and taboo nature of HIV prevention, testing, and care within and across communities. In particular, many of the marginalized communities in Hudson have a history of mistrust related to medicine and stigma related to care or treatment (particularly as it relates to HIV or sexual health): communities of color, especially Latinos and blacks; immigrants, especially undocumented residents; young people; gay and bisexual men, especially MSM not out or on the down-low; and people who are transgender.

Other barriers that may be specific to these populations:

For Youth – their “shield of invincibility”; their inability to link high risk behaviors to certain consequences and to defer gratification; lack of awareness about HIV and other STDs and safe sex. “It won’t happen to me.” Fear that their parents will “find out” about their being HIV+ and/or about being gay. Not acknowledging or regarding their behavior as high risk for becoming infected with HIV or any other STDs.

For Undocumented – Fear of deportation if “register” for any tests or services.

For Men – discomfort with questions about sexual behavior; low expectations of “confidentiality”; fear they will be found out regarding condom use and additional sexual contact outside of their primary relationship. Fear if test for HIV that others will assume they are gay; those fears are particularly strong in communities of color (i.e.: African American, Middle East, Asian, and Latino communities).

For Young Men Having Sex with Men (YMSM) – complacency due to effectiveness of current HIV medications; AIDS is no longer an “immediate death sentence”; use of alcohol and recreational drugs reducing inhibitions and forward thinking with regard to consequence of actions. Transmission rates continue to increase among YMSM as a result.

For Women – lack of childcare; difficulty using public transportation and/or going to a clinic with several young children in tow. Child care resources are needed on-site or there needs to be reimbursement for private at-home child care. The TGA’s previous private source of funding is no longer available for child care. Women also fear taking HIV medications because of word-of-mouth communication of serious side-effects (diarrhea, fatigue, etc.) and concern that they will be unable to function in their caregiver capacities – working and taking care of children, elderly

family members, etc. Women often address their medical needs last; as a result, they come into HIV care later in disease progression sometimes resulting in less positive health outcomes. Many women believe that they are in a monogamous relationship; therefore, that they do not need to be tested even when an opportunistic disease occurs.

For People >50 Years Old – lack of knowledge about risk behaviors and consequences; erectile dysfunction medications have enabled this age group to be much more sexually active than in past generations and HIV transmission is increasing significantly. Seniors need to be educated, tested, and linked to care. Some “mainstream” medical providers do not ask “the difficult questions” about Sex, number of partners, type of sex, etc. because they assume the elderly are not having sex, they are embarrassed, etc. As a result, important screenings may not be done, and prevention messages are not given. Providers also need to be educated about age-related incidence / prevalence and how to provide age-appropriate / culturally competent routine primary care.

For All Groups – Fear of knowing status; fear of disclosure; stigma of being HIV+; denial; overwhelmed by and prioritizing day-to-day survival issues (food, housing, lack of money); distrust of “confidentiality” promises; embarrassment; shame. Many doctors do not routinely ask about patient’s risk behaviors, including sexual behavior or substance usage, and testing is still not part of routine medical care. Lack of education about risks, availability of testing and other services. Fear of medication side-effects; perception that side-effects may be worse than the illness.

ii. Federal, state, local legislative / policy barriers

Constant policy changes in entitlements (i.e.: Welfare, Medicare, etc.) and individual staff’s varied interpretations of existing policies are burdensome to consumers, who become tired of what they perceive as a “run-around”. This necessitates constant updating of medical case managers and consumers with regard to policy changes. Since 2007, N.J. requires testing of pregnant women and newborns for HIV, which has resulted in the near elimination of perinatal transmission in N.J. In practice, however, we are limited by public misconceptions, and by capacity and funding issues. Examples include limited resources to support routinized testing in Hospital Emergency Rooms (ERs) 24 hours/7 days a week with immediate access to counseling / linkage staff for the newly diagnosed. Private physicians’ lack of knowledge about services available to PLWH, and limited resources to “get the word out” in general awareness campaigns that clarify who should get HIV tested, where to get tested, and the availability of free and confidential testing (including youth ≥ 13 , undocumented, and ex-inmates often thought to be ineligible) continue to be barriers.

N.J. public health policy strongly encourages routine testing in ERs, however there is no law to mandate routine ER testing statewide despite its effectiveness. The cost of staff coverage to make it happen is rejected by for-profit hospitals. Voluntary rapid testing at ERs was initiated in N.J. in 2004. In 2011, a NJ State Department of Health (DOH) study found that testing for HIV in ERs in N.J. comprised the highest percentage of new HIV diagnoses among all publicly

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funded testing sites in the State. Groups most often utilizing ERs for health care – the poor and uninsured or under-insured, which include many people of color – directly overlap with high-risk Part A EIIHA Target Populations in Hudson County. A recent nationwide study, conducted by the Colorado Hospital Association’s Center for Health Information and Data Analytics, examined post-ACA data from 450 hospitals and 25 states through mid-CY14. States which expanded Medicaid, like N.J., saw a significant increase (6%) in new Medicaid enrollees’ use of ERs nationwide compared to a year before. That increase (although costly for the system) expands local opportunities for HIV testing. Expanded, mandatory ER testing is critical to increase the number of PLWH who are aware of their HIV status and who enter HIV treatment early in disease progression.

There are two statute changes which are needed in N.J. One law still criminalizes the transmission of HIV; it discourages testing and the identification, notification, and testing of partners. It also perpetuates stigma. Our TGA is collaborating with the State Department of Health to advocate for decriminalization, consistent with national guidelines such as those released in 2014 by the U.S. Department of Justice -- *Best Practices Guide to Reform HIV-Specific Criminal Laws*. Also, the U.S. Preventive Services Task Force recommends that all pregnant women, adults aged 15 to 65, and adolescents under 15 at high risk be screened for HIV. ⁸ NJ laws should be revised to mandate routine testing and follow-up (i.e. linkage to HIV care) for Federally Qualified Health Centers (FQHCs) and other primary care settings, including ERs, to be offered with other key screenings, consistent with CDC Guidelines and the U.S. Task Force recommendations.

iii. Health department barriers

The Recipient for the Hudson TGA is the County Department of Health. The County Office on AIDS has traditionally been under resources, with the only stream of funding supporting the County DOH efforts related to HIV / AIDS coming through the Part A grant. This is a barrier and limitation. Without additional streams of funding, resources, and staff capacity, there is no County level DOH role to provide coordination across prevention and treatment, particularly when an agency receives private funding or unreported federal funds for their HIV prevention efforts. It falls on the Part A program coordinator to also ensure these services are connected into the Continuum of Care. This barrier is inherent in the structure of funding, particularly public funds, in the County.

The State Department of Health also has a number of barriers that relate to Hudson’s Integrated Plan and planning process. As mentioned throughout this plan, obtaining data that is useful for understanding specific populations is limited, if even available. The state data for testing is not consolidated, and often will take upwards of a year to receive. Once received, the data is in one aggregate summary, so no multivariate or cross-sectional analyses can be conducted with it. Similarly, the reporting data for PLWHA is summarized. So, for example, data cannot reveal how many of the 13-24 year olds newly diagnosed were female or Latina, nor can it reveal how many females infected were 13-24 or Latina, and so on. The State has also recently funded Care Coordinator / Patient Navigator positions designed to help navigate the entire cascade system.

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However, as mentioned in our plan actions, there is a need to develop clear roles and responsibilities and an effect memoranda of understanding for how those people can work within the CoC. Another challenge was the 2 week and longer delay in getting PLWH enrolled in ADDP; this has recently been rectified due to the collaborative efforts of the State its EMA and TGAs, including Hudson TGA. In some instances RW medical agencies still have to assist some patients in immediately starting their ART or in accessing critical non-HIV medications for comorbidities until ADDP is secured, rather than compromise their health. The Council allocated Part A funds for this purpose. In order to discuss and jointly resolve these issues, the TGA participates in Statewide Quality Assurance (QA) Conference Calls with TGA/EMA and State representatives from the HIV/ AIDS Division, including the Assistant Health Commissioner's office. Our concerns have been heard, and State representatives appear to be trying their best to advocate for us and to improve ADDP's enrollment turnaround time as well as areas' ability to get State testing data sooner.

iv. Program barriers

There are some barriers particularly related to the continued HIV Continuum of Care model implementation. We are not able to get timely Hudson TGA-specific testing, ART, retention and/or Viral Load Suppression (VLS) from the State Department of Health for the most recent calendar year, even for the first six months. There is a time lag for most data of about 18 months. Our CoC model contains our RW funded agencies' testing / linkage data only; there are other non-Part A testers in the county whose data we cannot readily access, although we are working on increasing Part A Planning Council Committee membership to include some of those agencies and obtaining their data in a timely manner.

In addition, the Hudson County data which are obtained from the State also include PLWH residing in Hudson at the time of diagnosis who may no longer be Hudson residents and may be receiving care elsewhere.

And finally, because of funding cuts and continuing new infections and resulting demand for increased care capacity, this TGA lacks the Part A resources to devote to networking CARE-Ware data so that aggregated and unduplicated Provider data can be available to the Recipient for real time analyses. The Recipient continues to explore technology infrastructure solutions at the individual RW agency level, despite the lack of a TGA-wide network.

Given our severe needs, the Hudson TGA tries diligently to tap into "mainstream" resources, and monitors carefully to ensure that Part A is the payer of last resort; however, other funding has also been cut. We see fewer PLWH getting approved for SSI/SSDI. Single adults on General Assistance (GA) are no longer eligible for Medicaid. Medicaid-funded transportation eligibility has become very restrictive. Pantries are closing and those which are open are overburdened. Homeless shelters cannot meet the need, and Part A emergency placements, when funded, only support PLWH up to 45 days. Cuts in urban hospital funding, despite growing numbers of uninsured, the privatization of the majority of area hospitals which restrict insurance acceptance, and growing poverty converge to cause a serious crisis for Hudson County's PLWH.

Current core medical service capacities are full, yet we are required to and continue to try to engage more new patients who either know their status and are not currently in care (Unmet Need population), as well as getting more people into testing and linked to care if positive (our Early Identification – EIIHA initiatives). As cited earlier, in order to serve these individuals in a quality manner, more capacity, and therefore more funding, is needed.

v. Service provider barriers and missing stakeholders

As described elsewhere in this plan, there are a few stakeholders that are missing in order to effectively close all gaps in the Prevention and Care programming continuum within the TGA. The first is making sure that we have all community healthcare workers who are doing HIV-related prevention work with people who are at-risk. This includes the local jurisdictional community centers that also include health screenings and outreach within their own mission. It also includes all shelter providers and substance abuse treatment providers. As described below, we also have action steps to help bring in information from private providers, as that is a complete segment of the care landscape that is missing as it relates to PLWH who see private doctors.

vi. Client barriers

Client barriers are deeply connected to the previously discussed service gaps and social barriers. Clients encounter stigma, socioeconomic challenges, and an inability to navigate an often complicated and under-resourced system for their various care needs. We are currently working with the NJHPG on doing a Statewide Stigma Index which will be a survey conducted by consumers to consumers. It was hoped that this project would have been started or completed in order to be a part of the State's Integrated Plan; however, this has yet to be completed.

As clients indicated in our service gaps and barriers reporting, their needs around financial assistance are paramount to their ability to remain in care (or to remain healthy). When someone does not know where s/he will sleep the next-night, s/he is not likely to see a doctor. If they cannot get to a doctor without taking two buses, a train and a bus, or any public transportation, they may choose instead to use that money that day on food and skip the doctor. If they do not know where their next meal is coming from, they are less likely to remember to take medication or to prioritize their nutritional well-being. All of this relates to the detailed discussion previously about socioeconomic barriers and poverty, which has an extreme effect in the Hudson TGA. Stigma is also a barrier cited above (and planned for below in our action steps) that continually needs to be revisited to ensure that we are making all PLWH and at-risk individuals comfortable with their ability to access services.

Additionally, co-morbidities in our TGA are a constant challenge (or threat), as seen in the data cited here. Treatment for multiple issues may cause consumers to choose one treatment over another, and the one they choose might be the one that seems the easiest to treat or the most immediate need (instead of the long-term, ongoing care that HIV requires). All of these barriers

are apparent in our previous needs, service gaps, and data sections, and are things that deeply informed the actions within this plan.

E. Data: Access, Sources, and Systems

E-a. Describe the main sources of data used

Hudson County's HIV related data are cited throughout. Our main sources of data were:

- TGA RSR Data which is continually updated and made available through the reports given to the PC during the Recipient's monthly report at the PC meetings.
- NJ State eHARS,
- TGA Needs Assessment,
- Center for Disease Control
- U.S. Census Bureau
- Kaiser e-health updates and reports
- Various up-to-date peer-reviewed research reports and publications (referenced as endnotes).

E-b. Describe any data policies that facilitated or were barriers to needs assessment / CoC

The Hudson TGA has continually mandated the use of CAREWare for all contracted agencies so that there is uniformity; this has been difficult for some larger hospitals that may use a different system but in most instances their IT departments have been able to merge the systems. The Recipient also has a data person that assists any of the agencies who may be having difficulty with the system or understanding some of the changes and updates. This has been helpful to the agency and has assured that the data is clean, comprehensive and standardized. The County data person then chairs that Clinical Quality Management Committee where all data material is discussed and concerns raised and has been most beneficial to our agencies since its inception. The TGA also participates in the State's H4c program which gives us a snapshot as to where we stand in relationship to the other segments of NJ and various trends in the CoC.

E-c. Describe any data planning participants would have liked to have used but was unavailable.

As already described, multivariate or cross-sectional data is key. Much of the data the TGA has access to, from providers and from the State Department of Health, is in aggregate form. This prevents us from being able to closely examine trends that affect specific populations (such as young black gay men or older Latina women) because it is not multivariate. TGA data is not unduplicated across providers hindering an completely accurate picture. We have explored various technological options over the years, but a centralized server has been delayed because of cost, and privacy concerns the TGA has not had the resources to address. The Planning Council and especially the consumers were hoping that the Statewide Stigma Index Project would have already had some initial data to help us further identify some of the barriers which exist not only within the state but also within our catchment area.