### The Food As Medicine Advocacy Initiative:



## Using New Research to Secure Public Funding for Food and Nutrition Services for PLWHA

Karen Pearl, MA, President & CEO, God's Love We Deliver

	GOAL	ACTIVITY	RESULT
City/State	New York City Health and Human Services Planning Council (PC) •Increase the priority of FNS in the NYC EMA •Explore the inclusion of FNS and MNT as core medical services (per HRSA) in our EMA** **In 2009, our national coalition of FNS providers, the Association of Nutrition Services Agencies (ANSA), succeeded in its advocacy with HRSA to have FNS and MNT recognized as core medical services within Ryan White. However, the prioritizing of FNS as a core medical service is a complex funding decision made by each EMA.	<ul> <li>Research : In late 2011, the CHAIN study white paper (at right) was released. From Dec. 2011-Feb. 2012, our Advocacy Associate presented it multiple times to various Committees of the PC, spreading awareness of the results.</li> <li>Priority Setting: Over a sixth-month period leading up to the PC's Priority Setting and Resource Allocation Committee 's priority setting decision in July, we organized the FNS providers in NYC to conduct advocacy with us through our coalition organization, the New York Coalition of HIV/AIDS Nutrition Services (NYCHANS), which our Director of Government Relations jointly leads. We presented two seminars on FNS and healthcare reform, piloted a letter writing campaign to the PSRA from our clients about the importance of services, and organized concerted public testimony by NYCHANS providers at PSRA meetings.</li> <li>Core Services: As more medical costs for PLWHA are covered through private and public insurance through the ACA, EMAs may have difficulty spending down their allocations. We advocated at various PC meetings about food insecurity among PLWHA in NYC, and argued for our EMAs to move FNS from the support services category to the core medical service category.</li> </ul>	<b>Big Wins:</b> In July 2012, the PSRA committee ranked FNS second only to ADAP in priority for our EMA, a huge advocacy win. The white paper was included on the list of official PC publications on the PC website, expanding its reach and acceptance among policy makers and service providers.
	<b>Essential Health Benefits (EHB)</b> •Include FNS for PLWHA in the Prevention, Wellness and Chronic Disease Management category in the public exchange through the choice of a "Secretary-Approved" benchmark plan	<b>Advocacy Visits</b> : When the EHB decision was handed to the states, we worked with a consultant to identify and meet with many key administrative decision-makers at the state level. We subscribed to alerts and email updates on the Exchanges and attended the first meetings of the Regional Health Benefits Exchange Council for NYC, which were designed to garner stakeholder input. We have made the case successfully in person and via a public comment letter to the NYS Department of Health that FNS improves health care outcomes and lowers healthcare costs.	<b>Decision</b> : The decision on the benchmark for the public exchange will be made before January 2013.
	<ul> <li>Medicaid Number for FNS</li> <li>Ensure payment for FNS in NYS Health Homes (HH) (FNS is currently part of HH, but is not reimbursable without a Medicaid billing number)</li> <li>Meet the need for a Medicaid billing number to comply with HRSA guidelines for Ryan White core medical services contractors**</li> <li>**If FNS becomes a core medical service, as described above, God's Love would need a Medicaid billing number, per HRSA guidelines to complement of the payment of t</li></ul>	<ul> <li>Provider Education: Many of the managed long term care (MLTC) plans in our Community Partners</li> <li>Program applied to become Health Homes. We did additional outreach and education to these</li> <li>partners about the importance of FNS for the HH population, such as PLWHA. Through outreach, we were included on 3 applications for HH status in NYS, one of which was awarded. Many more</li> <li>wanted us to be part of their networks, but we were told they required us to bill Medicaid directly.</li> <li>NYS does not have a mechanism for FNS providers to get Medicaid numbers.</li> <li>Advocacy Visits: We have met with the head of the HH program, the Department of Finance and Directors of several Medicaid departments about our request.</li> </ul>	<b>Movement:</b> We now have a roadmap to follow to potentially amend the state plan so that FNS providers (that offer MNT) can secure a Medicaid number.

comply with RW as payer of last resort.

	GOAL	ACTIVITY	RESULT
City/State	<ul> <li>State-specific Medicaid Redesign (MR)</li> <li>Include FNS for PLWHA in mainstream Medicaid programs**</li> <li>**As part of the work of the Medicaid Redesign Team, Medicaid fee-for-service (FFS) will be rolled into managed care plans (MMC). Many PLWHA will be enrolled in these plans for their primary care. We believe FNS should be an allowable benefit in MMC for those whose diagnosis requires it, to manage chronic illnesses that, if left unchecked, may cause individuals to require the more expensive MLTC plan.</li> </ul>	the Director of the Division of Long Term Care and the Director of the Quality Management Division of NYSDOH. We also submitted a public	measures study with NYSDOH for the dual eligible population on the efficacy of FNS. The final decision on the
	<b>Essential Health Benefits (EHB)</b> •Include FNS for PLWHA in the Prevention, Wellness and Chronic Disease Management category of the EHBs	<b>Public Comment Letter</b> : In January 2012, in response to the December 16, 2011 bulletin from HHS, we submitted a public comment letter to HHS concerning the inclusion of FNS in EHBs in every state. A coalition of 60 FNS organizations from around the country signed on. We also advocated for this issue during our visits to the Hill in June.	<b>Voice:</b> Many of our federal representatives offered to contact state representatives to discuss the issue.
Federal	Ryan White (RW) Reauthorization •Demonstrate the medical efficacy and cost-effectiveness of FNS and its necessity for PLWHA •Ensure coverage of FNS for PLWHA through ACA and/or through Ryan White	<ul> <li>•Monthly Advocacy Committee: We keep FNS providers across the country in the loop on healthcare reform and its impact on PLWHA through monthly advocacy conference calls.</li> <li>•Symposium: In June, we hosted an advocacy symposium in DC, where FNS providers met for a day of education and coalition building. Members of our community, AIDS United and FRAC, spoke of their work around key issues for PLWHA: Ryan White and SNAP/The Farm Bill. We prepared participants for Hill visits and also delivered a seminar on funding opportunities within the ACA. The FNS programs spent a day on the Hill, speaking about issues from RW to EHB and presenting the white paper to their representatives.</li> <li>•Public Comment Letter: Using new research from our partner agency MANNA in Philadelphia, in July 2012, we drafted and submitted a public comment letter on behalf of HIV/AIDS FNS providers across the nation to HRSA on FNS as a priority for Ryan White Reauthorization in 2013 The letter was signed by over 80 agencies.</li> </ul>	<b>Groundwork</b> : As a result of the many in- person meetings and education sessions, the foundation was laid for critically-needed advocacy on FNS during Reauthorization next year.

#### **CHAIN Study Sources:**

Aidala A, Yomogida M, and the HIV Food & Nutrition Study Team (2011). *HIV/AIDS, Food & Nutrition Service Needs. Community Health Advisory Fact Sheet. New York Health & Human Services Planning Council.* Available at:

http://www.nyhiv.com/pdfs/chain/Food%20Need%20Medical%20Care\_factsheet%20v8.pdf

Aidala AA, Yomogida M, Sorgi A, Miller-Vazquez R. *Food Insecurity, Medical Care, and Health Outcomes among PLWH in a High Resource Setting: The Importance of Food and Nutrition Services.* Poster presented at the XIX International AIDS Conference. Washington DC, July 2012. Available at: <u>http://pag.aids2012.org/EPosterHandler.axd?aid=20339</u> Mailman School of Public Health - Columbia University



Community Health Advisory & Information Network

Fact Sheet

## HIV/AIDS, Food & Nutrition Service Needs

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Several conditions associated with HIV/AIDS can be managed with proper nutrition. Good nutrition reduces the risk for or helps manage other chronic diseases such as heart disease, diabetes, and cancer. Food security and good nutrition are linked to improved health outcomes for PLWHA both directly and indirectly. Food insecurity is a source of chronic stress that has consequences for immunological functioning, as well as for mental health and for adherence to medical treatments. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

This Fact Sheet summarizes food and nutrition service needs, use of food and nutrition services, and medical care and health care outcomes associated with food insecurity among representative samples of adults living with HIV in New York City and the northern suburban region of Westchester, Putnam, and Rockland counties.

#### Need for food and nutrition services is almost universal

Based on rates seen in the study population, the great majority of persons living with HIV/AIDS (PLWHA) in New York City (89%) and in the Tri-County region (85%) are experiencing food insecurity or rely upon food and nutrition programs to address their most basic needs (Figure 1).

#### Many PLWHA rely upon food programs

Eighty percent (80%) of cohort members in NYC and 62% in Tri-County participate in SNAP, the Supplemental Nutrition Assistance Program commonly known as the food stamp program.

Over half of PLWHA interviewed in NYC (55%) and in the Tri-County region (58%) receive services from a food/ nutrition program in the form of (1) meals provided in a group setting, (2) prepared meals delivered to the home, (3) receipt of a food voucher or a grocery bag from a food pantry, or (4) some other help with food or meals. Tri-County residents are more likely to receive food pantry bags than participate in a meal program; the reverse is true for NYC study participants who are more likely to use meal programs (Table 1).

#### Food insecurity remains widespread

Using standard measures of food insecurity, more than two of every five (42%) study participants in both NYC and Tri-County currently experience food insecurity. Regardless of receipt of food stamps or participation in a food or meal program, they report not having enough money for food that they or their family need, describe their food situation as sometimes or more often not enough to eat, have gone a whole day without anything at all to eat in the past 30 days, or report a continuing need for assistance regarding food, groceries or meals (Figure 1).

#### METHODOLOGY

- Data for analysis were provided by an ongoing study of persons living with HIV/AIDS in the NYC area: the CHAIN Project.
- The sample was designed to be representative of the HIVinfected population receiving medical and/or social services in either New York City or the Tri-County suburban area.
- Over 1000 individuals were interviewed in 2008-2010.
- Study participants answered questions about food and nutrition experiences, need for services and use of services
- Need for food and nutrition services was determined using a composite measure that took into account both "objective" criteria based upon reports of behaviors and experiences (e.g. not having enough money for food, going an entire day without eating anything at all, etc.) as well as self-reported need for services. The use of any food or meal services was also taken as evidence of need for these services.

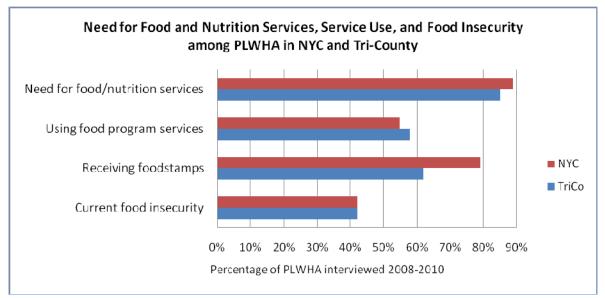


Figure 1. Indicators of Need for Food and Nutrition Services among Study Participants

#### Nutritional counselling is needed

Fewer than one-third of the study sample in either NYC or Tri-County report receiving nutritional counselling in the six to 12 months prior to interview – most often in the form of group presentations.

Approximately half of cohort members in NYC never reported receiving nutritional counselling during the past 5 years or longer, despite an increase in rates of nutrition-sensitive chronic conditions during this time period, and 60% of study participants were either under or overweight according to BMI at most recent interview. (Over time information on nutritional counselling is not available for the Tri-County sample).

#### Food insecurity is associated with poor medical care outcomes

Analyses of the CHAIN data show that PLWHA who are food-insecure report more missed appointments for HIV primary care and more emergency room visits compared to those who do not report difficulties obtaining enough and appropriate food. The food-insecure are less likely to be receiving medical care that meets minimum clinical practice standards with regard to number of recommended visits, tests and procedures to monitor HIV disease, and antiretroviral medication therapies as indicated (Table 2).

#### Food insecurity is associated with poor functional health and clinical markers of HIV

Study results also show that PLWHA who are food insecure score lower on standardized measures of physical health functioning, mental health functioning, and quality of life. They have lower CD4 counts and are less likely to have undetectable viral loads than the food secure (Table 3). Other research has shown that food insecurity is associated with increased morbidity and mortality among HIV infected persons.

#### Conclusions

Food insecurity has long been recognized as a serious problem for PLWHA in low-resource countries. There is ample evidence that food and nutrition issues are increasing among PLWHA in the U.S. as well. Given the broader economic downturn and multiple service cuts, the need for food and nutrition services among PLWHA would only be expected to increase over the next several years with deleterious consequences for individual health and well-being and for the continuing HIV epidemic and associated health disparities.

- Food insecurity or continued unmet need for food/ nutrition services is widespread and associated with poor engagement with HIV medical care and poor health outcomes
- Food and nutrition services are essential to promote treatment effectiveness and maintain health among PLWHA

This report was prepared by Angela Aidala with the assistance of Maiko Yomogida at Columbia University, in collaboration with an Advisory Group of food and nutrition service providers listed below. The CHAIN project is supported by HRSA grant HA00015. Funding for this report was provided by the MAC AIDS Fund.

#### Table 1. Use of food and nutrition services by PLWHA<sup>1</sup>

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	NYC	TRI-CO
Total Sample (n=)	(702)	(394)
Food stamps	79%	63%*
Home delivered meals	3%	10% *
Meals in a group setting	38%	22%*
Food from a food pantry	34%	23%*
Nutritional counseling/ group presentation	23%	38%
Received any assistance with food or meals (other than food stamps)	55%	58%*
Home delivered meals		
<ul> <li>Meals in group setting</li> </ul>		
<ul> <li>Food from food pantry or</li> </ul>		
<ul> <li>Other help with food or meals</li> </ul>		

#### Table 2. Food insecurity and health care outcomes among PLWHA<sup>1</sup>

	Food INSECURE	Food SECURE
Total Sample (n=)	(441)	(606)
No visit with HIV primary care provider 6+ mos	3%	2%
Care does not meet minimal practice standards	36%	30% *
Missed 2+ scheduled medical appointments 6mos	28%	12%*
One or more ER visits past 6 months	34%	23%*
Any indicator of poor connection to medical care		
No primary care visits	70%	60%*
Care does not meet minimal practice standards		
<ul> <li>Multiple missed appointments or</li> </ul>		
ER visits		

#### Table 3. Food insecurity and health outcomes among PLWHA<sup>1</sup>

	Food INSECURE	Food SECURE
Total Sample (n=)	(441)	(606)
Low mental health score	53%	46% *
Poor physical health functioning	54%	46% *
CD4 T-cell count		
Below 200	22%	13%*
200-499	39%	42%
500 or higher	39%	45%
Viral load		
10,000+ or 'bad'	16%	10%*
9999- 400	9%	8%
Undetectable, below 400	75%	83%

1. New York City and Tri-County study participants interviewed in 2008-2010

\* Statistically significant differences comparing NYC and Tri-Co cohort members (Table 1) or comparing Food-Insecure and Food-Secure cohort members regardless of residence (Tables 2 & 3).

#### CHAIN Brief Report 2011-5 October 2011

#### HIV Food & Nutrition Study

#### ADVISORY GROUP MEMBERS

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Connection to Care & Viral Load	2+ Missed Med Visits	Undetectabl e Viral Load
(n=971)	(AOR)	(AOR)
FOOD INSECURITY	2.16 ***	0.73 *
Household below poverty line	(1.12)	(0.91)
Low mental health functioning	(1.25)	(0.79)
Current problem drug use	1.54 ***	(0.69)
Appropriate medical care	(0.88)	(1.27)
HAART	(0.86)	2.61 ***
Medical case management	0.59*	(0.88)
Social services case management	(1.11)	(0.82)

#### **CHAIN Study: Newest Analysis**

Multivariate logistic regression also controlling for age, gender, race/ethnicity, risk exposure group, unstable housing, need for transportation services, and area of residence.

# About God's Love We Deliver

God's Love is a non-sectarian, 501(c)(3) non-profit and the New York metropolitan area's **leading provider of life**sustaining meals and nutritional counseling for people living with severe illness. Begun as an HIV/AIDS service organization, 10 years ago we expanded our mission to serve people living cancer, renal failure, Parkinson's disease, multiple sclerosis, severe diabetes, Alzheimer's disease and more than 200 other life-threatening illnesses. We serve all age groups and demographics. God's Love also supports families by providing meals for the children and senior caregivers of our clients. Last year, we hit a major milestone of cooking and delivering 1.1 million meals.

Every God's Love meal is individually tailored for each client by one of our 5 Registered Dietitians, and all clients have access to unlimited medical nutrition therapy sessions. **Medical nutrition therapy** is an evidence-based application of nutrition diagnostics, nutrition counseling services and prescribed diets focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention. We offer **specific diet modifications**, such as pureed, minced, vegetarian, renal and diabetic, with many more available depending on the client's specific medical condition. When included as complementary to medical treatment for chronic diseases, programs like ours have been shown **to add significant cost-savings even as they promote better health outcomes**.

In 2005, we began our **Community Partners Program (CPP)** where we provide meals and nutritional counseling for members of managed long-term care (MLTC) programs in New York State. Over the last 7 years, meal numbers in our CPP have increased from 3,500 to over 120,000 (in FY12). Meal numbers continue to rise, as we hear from providers that they find our program an efficient way to cut costs by keeping members in their homes and out of more expensive forms of care, such as hospitals and nursing homes.

