

The Role of PLWH/A's in Addressing Un-met need in Part A and B Programs

AIDS Alliance for Children, Youth, and Families

Carole Treston, Executive Director

Linda H. Scruggs, Director of Programs



20 Years of Leadership
A LEGACY OF CARE



2018 RYAN WHITE ALL GRANTEE MEETING AND 17TH ANNUAL CLINICAL CONFERENCE

Overview of AIDS Alliance

AIDS Alliance for Children, Youth & Families is a non-profit organization dedicated to improving the lives of women, children, youth, and families living with HIV/AIDS. We seek to advance the partnership between providers and consumers. Education, training, research, and advocacy are the tools used to meet this goal.

What Roles Can PLWH/A's in Addressing Un-met need

- Peer supporters
- Case managers
- Community educators
- Friends
- Advisors
- Planning body members

Health Resources Services Administration (HRSA) HIV/AIDS Bureau (HAB) Expectations

- HRSA/HAB expects all Part A and Part B grantees to carry out three major types of activities to address the above Ryan White legislative requirements:
- Determination of the demographics and location of people who know their HIV/AIDS status and are not in care;
- Assessment of service needs, gaps, and barriers to care for people not in care;
- Efforts to find people not in care and get them into primary care

Legislative Mandates

- *RYAN WHITE HIV/AIDS TREATMENT EXTENSION ACT OF 2009*
- **Section 6: Amendments to the General Grant Provisions** (new section)
- In the new legislation, there are provisions to increase and incentivize early identification of those infected with HIV. This section requires the planning councils for Part A grant recipients to develop a strategy, in coordination with other appropriate community strategies or activities, to identify and diagnose individuals with HIV/AIDS who are unaware of their status and link them with the appropriate care and treatment.
- For the purposes of allocating competitive grants under Part A supplemental grant funding, one-third of the criteria on which allocations are made will be based on demonstrated success in identifying undiagnosed (unaware) individuals with HIV/AIDS, making them aware of their status, and linking them to appropriate care.

Additional PLWHA Involvement

- PLWH should participate in two ways:
- As sources of information for the needs assessment, and
- As partners in planning and overseeing the needs assessment process.
 - *Special outreach efforts may be needed to locate and obtain the perspectives of PLWH with severe needs (e.g., homeless, substance abusers), those who have never received primary medical care or have dropped out of the care system, and/or individuals who are not publicly disclosed as HIV-positive.*

Working Definitions

Unmet Need -An individual with HIV or AIDS is considered to have an unmet need for care (or to be **out of care**) when there is no evidence that s/he received *any* of the following three components of HIV primary medical care during a defined 12-month time frame:

- ✓ viral load (VL) testing,
- ✓ CD4 count, or
- ✓ provision of antiretroviral therapy (ART).

Met Need -A person is considered to have met need (or to be **in care**) when there is evidence of *any one or more* of these three measures during the specified 12-month time period.

HIV-Unaware - Unaware of HIV Status not tested or never received results

Why is this important to you?

- 1.
- 2.
- 3.

Public Health Principles

- Case Finding and Surveillance (Testing, outreach link to care)
- Interruption of Transmission (ART lower viral loads less HIV incidence??)
- Systematic Treatment and Case Management
- Population-Based Monitoring (Tracking linking to support services, partner services)

Paradigm shift

Testing, Linkage to Care Plus Treatment (TLC+)

- TLC + is HIV prevention. The strategy has the potential to decrease HIV transmission by increasing the percentage of people who know their HIV status, linking HIV positive and negative individuals to care, treatment, ancillary, and prevention services, and reducing the overall viral load in a community.
- By increasing and normalizing HIV testing, linkage to care, and treatment, TLC+ could reduce HIV stigma in communities. Stigma is widely recognized as a driver of the HIV epidemic, and its elimination is crucial to HIV prevention efforts.

Chicago Ryan White Planning Council Response

- 2009 Allocated Part A funding for 3 Outreach programs using Peer models as Support Services
- Council Chair, Priority Setting Co-Chair, and 1 staff attended MOSAICA LINC Training
- Planning Council members attended AIDS Alliance ASSCEND Training
- Additional TA from MOSAICA on Priority Setting and Resource Allocation (PSRA)

Planning Council Response

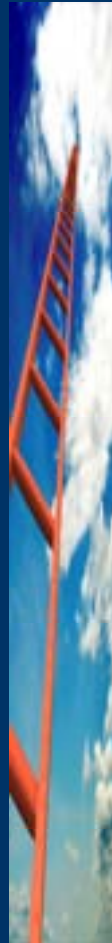
- 2010 Prioritized and Allocated Part A and MAI funding for Early Intervention Services (EIS) as Core Medical category
- Prioritized and Allocated Part A and MAI funding for Outreach in Support Services
- Directive to grantee to fund Peer Models

New Orleans Ryan White Planning Council Response

- Reorganized the Planning Council structure
- Prioritized and Allocated Part A and other funding for peer programming and outreach
- Provided Peer Leadership Training and Support for Council members
- MOSAICA LINC Training
- Directive to grantees to fund Peer Models

Advanced
Skills for
Consumer
Education and
National
Development

Leadership
Training program



“We need leadership that thinks about the future and asks us to invest ourselves.”

Anita DeFrantz

(US Rowing Team--1st Woman & black ever to run for presidency of the International Olympic Committee)

ASCEND Leadership Training program

The **A**dvanced **S**kills for **C**onsumer **E**ducation and **N**ational **D**evelopment (**ASCEND**) Leadership Training program is a commitment to the community from AIDS Alliance to address the “**unmet need**” for **HIV-related primary healthcare among individuals who know their HIV status but who are not in care.**

Program expansion to include HIV-unaware persons

Providers and Consumers require updated training related to the Ryan White Treatment Modernization Act

AIDS Alliance has worked with HAB to produce and provide the most up-to-date information related to legislation, best practices and decision-making processes that will benefit Part A and Part B grantees, planning bodies and consortia, Consumer Advisory Boards and other stakeholders.

Providers require education regarding the capability of consumers to deliver prevention, recruitment and treatment messages.

- Nearly thirty years after the devastation of the AIDS epidemic, providers in many clinical, support service and administrative organizations still perceive consumers as a monolithic population that is poorly educated, impoverished, and diminished by substance abuse and incarceration.
- Providers still perceive consumers as lacking cultural competence and the appropriate skills, talents and experience to be viable partners in the dissemination of information to their peers.

AIDS Alliance continues to break down these barriers within the Ryan White communities in order to engage consumers as critical members of the response team throughout the Ryan White programs.



AIDS Alliance Believe

Consumers need to be reached with accurate and compelling information that both recruits and retains them in care.

AIDS Alliance has a proven approach to increase peer-to-peer trainings, peer-led and innovative outreach interventions, and nationwide community dissemination through a train-the-trainer model.

Program Goals

The goal of ASCEND is:

- to increase leadership awareness and involvement to address “unmet need” through discussions and tools such as a local resource directory;
- to foster partnerships to establish and maintain stronger consumer/provider commitment.

The method is:

- to provide training and technical assistance that strengthens the leadership skills and increases the capacity of PLWHA to be informed advocates and skilled leaders in their local community.

The ASCEND Program is Provided Through

- ✓ The delivery and application of curriculum designed specifically to address “unmet need” related to access to HIV primary care to engage and retain persons into care.
- ✓ Regional 3-day training inclusive of direct “hands-on” instruction, and, “teach-back” application. This process provides practical realization and interaction to maximize learning techniques.
- ✓ Value of cohort “cadre” experience that charges participants to be role models that conduct outreach; one-on-one and group discussions.
- ✓ Follow-up telephone consultation “one-on-one”; monthly “cadre” conference calls and web-based resources available to each participant.

Approaches to the provision of TA

AIDS Alliance - ASCEND Program includes self-efficacy modules such as:

- ✓ self-management
- ✓ clinical compliance
- ✓ advocacy skills

The approach is designed to improve the participants' ability to maintain their involvement in local planning activities (i.e. planning councils; consortia; Consumer Advisory Boards (CABs) and specific responses to unmet need that are consumer-oriented.

Approaches to the provision of TA

The ASCEND target audience is comprised of consumers who have participated, often as leaders, in Ryan White HIV/AIDS program strategic planning bodies; consumer advocacy boards; outreach programs; or, in their own care.

They come from Part A & B grantees that have either experienced difficulty in recruiting and retaining consumers, or, have a high estimated unmet need (approx. 20% or greater of persons known to be HIV+ and not in care).

3 Day Program Framework

Day 1 – Program/ community/personal
overview and readiness

Day 2 – Preparing to talk to the community

Day 3 – Hosting an Open House with
community providers and stakeholder

AIDS Alliance for Children, Youth & Families

Advanced Skills for Consumer Education and National Development (ASCEND) Leadership Training Program

Excerpts of the Trainer's Manual Program 10 Steps



ASCEND Step One

Defining Unmet Need
and a look into
the local EMA or TGA



ASCEND Step Two

Defining Unmet Need
and a look into
the Local EMA or TGA



ASCEND Step Three

Addressing Unmet Need “Inside & Out”

ASCEND Step Four

Benefits & Challenges of Getting Involved and Scenario Planning



ASCEND Step Five

Program Framework



ASCEND Step Six

Re-Cap Program Charge

A Major Element of ASCEND Project

ASCEND Step Seven

Making Effective ASCEND Presentations

A Major Element of ASCEND Project

ASCEND Step Eight

Consumer Unmet Need: Preparation and Practice



ASCEND Step 9

Administrative Procedures & Evaluation



ASCEND Step 10

Personal Action Planning





ASCEND Training Program

Day 3 Open House Celebration



Open House Celebration Purpose

The ASCEND Program will host an Open House Celebration led by the local Cadre leaders as they introduce themselves to the Part A, B and other community leaders and organizations in their community.

Elements of Training Curriculum



ASCEND Program Overview

Purpose

A comprehensive educational program that engages consumers of HIV services in addressing the unmet need in their community.

Training Objectives

- To identify and understand why people with HIV are not getting regular HIV medical care.
- To develop a personal action plan to address this on a local level.

Methodology

- By providing an interactive 3-day comprehensive skills building and leadership training; and
- By providing concrete and follow-up support for four to six months post the training.

Program Charge

The ASCEND *Cadre* will directly decrease the challenges and barriers that have prevented their counterparts within their local community from achieving positive health outcomes due to their inability to access and remain in care with HIV and/or AIDS diagnoses.

Achieving the Program Charge

- Become educated on unmet need in your local community
- Learn techniques to address HIV- unaware in your local community
- Learn vital presentation and negotiation skills in order to confidently share information with peers and services providers within your local community

Achieving Program Charge

- Identify community resources available to consumers within your local community
- Use your individual and collective voices to teach and empower others
- Serve as an asset to both the consumers and service providers of your community

Why Are We Here?



Here are the Facts...

The estimated number of persons living in EMA or TGA with HIV disease (status aware) for calendar year 2007 was ..,....

The total number of cases estimated to have primary medical care was ..,.... or ..%.

The total number of cases with an unmet need for primary medical care was ..,.... or ..%.

This further translates to the estimated number of persons living with HIV (non-AIDS) with unmet need as ..,.... compared to ..,....persons living with AIDS.

Comprehensive HIV Care Plan Goals

- Shorten the time between diagnosis and entry into care
- Reduce the transmission of the virus to others
- Reduce the transition to AIDS diagnosis
- Reduce the number and severity of complications and episodes of illness
- Reduce AIDS-related mortality

The ASCEND Breakdown of Unmet Need

- _____ people living in the EMA or TGA know their HIV status, but are not in HIV - related primary HIV health care
- Some of these people may have entered health care but have not accessed HIV - related primary health care in at least 12 months

ASCEND Breakdown Who's Not In Care

1. Newly diagnosed
2. Receiving other HIV/AIDS services (often not in the CARE Act System) but not in primary care
3. Formerly in care-dropped out
4. Never in care

Who else?

ASCEND Communities

- ✓ Baltimore –EMA (08/09)
- ✓ Illinois' statewide including Chicago EMA (10/09)
- ✓ San Antonio & Huston, TX (2/10)
- ✓ Washington, DC -EMA (6/10)
- ✓ North Carolina and South Caroline -TGA's (8/10)

From the Voices of the Trainees

S.F. from the Baltimore Cadre reported that she has established with agency leaders who did not take her seriously before, but, now recognize credibility and commitment to the process.

R.K. from the Illinois Cadre has partnered with other cadre members to expand discussions in areas in Southern Illinois that have never been tapped previously with such training and information. He describes it as...”an awakened energy and commitment to get PLWHA back into care.”

From the Voices of the Trainees

“It feels good to talk the talk and walk the walk to make an impact.” S.F. (Baltimore Cadre)

“This training is filled with tools to help me make a difference back home. Seeing myself on video will shape my skills.” R.K. (Illinois Cadre)

“Thanks for realizing that our needs must be met and I feel better as a consumer.” J.B (Illinois Cadre)

“As a Planning Council Chair we can take this training and put to action to help others and not just another certificate for consumers”. C.S (Houston Cadre)

“I know a lot of people not in care and now I know what to say to them”. EF (Washington, DC Cadre)

Acknowledgments

- ASCEND applauds local leaders as their roles expand to critical thinkers, program advisors, and decision makers. Consumer leaders are often over extended; not supported or appreciated for the many missions they pursue daily.
- This program serve as a framework to energize and motivate persons to take ownership of their healthcare needs and responsibility to self and others and be role models.

For more information contact



Linda H. Scruggs, Director of Programs
202-785-2535
lscruggs@aims-alliance.org

Carole Treston, Executive Director
ctreston@aims-alliance.org