



The Center for Nonprofit Development
and Pluralism

Project Consumer LINC (Linking Individuals into Needed Care)

Summary: Project Consumer LINC (Linking Individuals into Needed Care) is designed to identify, document, disseminate, and support the implementation of models and strategies that involve Ryan White consumers in linking other PLWH, aware and unaware of their status, into primary medical care and other needed services.

This cooperative agreement, funded by the HIV/AIDS Bureau, enables Mosaica to provide intensive training and technical assistance (T&TA) to selected Part A and Part B grantees, planning bodies, consumers, and providers, so programs can choose and implement appropriate *direct* consumer-based strategies (e.g., outreach) as well as *indirect* models (e.g., consumer-led review of the system of care to remove access barriers). Project LINC focuses on four strategies for engaging consumers in linking other PLWH into care:

1. **Understanding and Refining the System of Care:** PLWH serve as skilled peers and volunteers, through Ryan White planning bodies, committees, and caucuses, to understand, assess, and recommend refinements in the system of HIV/AIDS care. The intent is to make it easier for PLWH with various backgrounds and characteristics to find out about available services, establish eligibility, and obtain needed services – both HIV-related health care and support services needed for retention in care.
2. **PLWH Caucus/Committee:** PLWH members of Ryan White planning bodies, committees, and caucuses use results from the assessment of unmet need along with their own experiences as consumers to reach and engage other PLWH. Their focus is typically on raising awareness of the HIV care system and providing information on how to access and remain in care. Some models go farther, having consumers serve as mentors or informal “patient navigators” to help individuals enter care.
3. **Linking PLWH to Care:** PLWH serve as part-time or full-time community health workers, linking other PLWH into HIV-related primary medical care and other needed services. PLWH identify and reach out to other PLWH who know their status but are not in care, increase their awareness of the care system, provide assistance in navigating the system, and build trust and acceptance of the care system. The peers serve as full- or part-time provider staff (or in some cases receive stipends). Their period of contact with an individual PLWH is typically 3-6 months, long enough to help the individual become fully connected to care.
4. **Integrated Clinical Care Teams:** PLWH serve as members of an integrated clinical care team and may maintain an ongoing relationship (six months or more) with client PLWH, helping first to connect them to care and then to keep them in care and adherent to prescribed treatments. Peers are employed by providers and work with the clinical care staff, typically with access to some clinical information about the client, provide clinical support, and offer insights used by clinicians. Because roles include adherence and other clinical support, such peers receive considerable training, particularly on clinical topics.

Consumer LINC training and technical assistance services are tailored to meet local needs, but typically include the following activities:

- Introduce promising models and strategies at multi-program or regional sessions involving representatives of at least two Ryan White Part A and/or Part B grantees.

- Provide in-depth training and follow-up TA on a specific model of interest for selected staff and consumers from programs that have participated in the initial overview training and are seriously interested in supporting one of the models or strategies presented.
- Disseminate information such as documented models, “how to” materials, and model curriculum and provide long-distance TA to other Part A and Part B programs.
- Collect baseline and follow-up data and evaluate process and outcomes.

Need for the Project: State estimates suggest that more than one-third of people living with HIV/AIDS (PLWH) in the U.S. who know their status are not receiving regular HIV-related primary medical care. Since current treatments can enable them to live long, healthy, productive lives, it is critically important that all PLWH have access to appropriate medical care and enter care as soon as possible after infection and diagnosis. In addition, as HIV/AIDS becomes a chronic illness, PLWH who enter the system are likely to continue needing care and medications for many years. To ensure adequate resources to continue bringing people into care, Ryan White programs need to review and refine their systems of care so they ensure necessary support for new consumers, while encouraging disease self-management and minimizing unnecessary gatekeeper or service costs for experienced consumers.

Certain populations are especially hard to reach and likely to be out of care. These populations vary by area, but often include communities of color, immigrants, rural residents, young men, transgenders, and other low-income, uninsured or underinsured PLWH. Reaching them is extremely challenging. A number of promising strategies that engage current consumers to use their social networks to bring others into care and maximize retention have been identified – yet many Ryan White programs lack capacity to engage consumers or to choose and implement such efforts. The project will help build such capacity.

Mosaica and the Project Team: Mosaica: The Center for Nonprofit Development and Pluralism is a multicultural, values-based capacity-building nonprofit that provides tools to nonprofits to build just, inclusive, and thriving communities. Nearly half its work is HIV/AIDS-related, and it has provided training and technical assistance (T&TA) to Ryan White grantees, planning bodies, and consumer groups and assisted the HIV/AIDS Bureau since 1994. The project team includes **Emily Gantz McKay** and **Harold J. Phillips**, two of the most experienced Ryan White Technical Assistance Contract (TAC) consultants; **Hila Berl**, who has special expertise in unmet need; **Johanna Contreras**, program evaluator; **Patricia Cruz**, Mosaica fellow with experience in HIV-related projects; and an experienced Ryan White Planning Council leader and peer (**Robert Hewitt**).

Working Group: The project team benefits from the experience and advice of a working group of nine Part A and Part B grantee and planning body staff and PLWH. Members of the working group previewed and critiqued the draft project models and training curriculum, and many will serve as sites for training and TA.