Mobilizing & Powering Community Partnerships to Increase Engagement and Health Equity: Challenges, Lessons, & Opportunities

April 2024
CHAC Community Partnerships Workgroup

Roster:
- Meredith Greene (Chair)
- Johanne Morne (for 3/6 only)
- Robert Riester
- Keiva Lei Cadena-Fulks
- Marah Condit (CDC DFO)
- Shalonda Colins (HRSA DFO)

Meetings: 3/6/24, 3/19/24 (special guest Kali Lindsey), 4/4/23
Scope: The Community Partnerships Workgroup’s primary charge is to provide evidence-based examples to CHAC to further define, structure, and retain effective public health community partnerships that foster trust and adapt to public health context.
Workgroup Focus

How should CDC/HRSA define community partnerships and community engagement

- Fall 2023
- Emphasis on partnerships

Share Best Practices

- Fall 2023
- Syndemic approach
  *Involvement PWLE

What metrics of success that CDC/HRSA can and should use to measure its support of community partnerships?

What kind of structure should CDC/HRSA support to provide technical assistance to jurisdictions and community partnerships?
# Fall 2023: Community Engagement to Partnerships

## Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

<table>
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<tr>
<th>Outreach</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Shared Leadership</th>
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<td><strong>Some Community Involvement</strong>&lt;br&gt;Communication flows from one to the other; to inform.&lt;br&gt;Provides community with information.&lt;br&gt;Entities coexist.&lt;br&gt;Outcomes: Optimally establishes communication channels and channels for outreach.</td>
<td><strong>More Community Involvement</strong>&lt;br&gt;Communication flows to the community and then back, answer seeking.&lt;br&gt;Gets information or feedback from the community.&lt;br&gt;Entities share information.&lt;br&gt;Outcomes: Develops connections.</td>
<td><strong>Better Community Involvement</strong>&lt;br&gt;Communication flows both ways, participatory form of communication.&lt;br&gt;Involves more participation with community on issues.&lt;br&gt;Entities cooperate with each other.&lt;br&gt;Outcomes: Visibility of partnership established with increased cooperation.</td>
<td><strong>Community Involvement</strong>&lt;br&gt;Communication flow is bidirectional.&lt;br&gt;Forms partnerships with community on each aspect of project from development to solution.&lt;br&gt;Entities form bidirectional communication channels.&lt;br&gt;Outcomes: Partnership building, trust building.</td>
<td><strong>Strong Bidirectional Relationship</strong>&lt;br&gt;Final decision making is at community level.&lt;br&gt;Entities have formed strong partnership structures.&lt;br&gt;Outcomes: Broader health outcomes affecting broader community.&lt;br&gt;Strong bidirectional trust built.</td>
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Reference: Modified by the authors from the International Association for Public Participation.

Figure adapted from the International Association for Public Participation and titled “Increasing Level of Community Involvement, Impact, Trust, and Communication Flow.”

[https://www.cdc.gov/endhiv/partners-grantees/community-involvement.html](https://www.cdc.gov/endhiv/partners-grantees/community-involvement.html)

Source: [https://www.atdsr.cdc.gov/communityengagement/community-engagement-continuum.html#print](https://www.atdsr.cdc.gov/communityengagement/community-engagement-continuum.html#print)
Innovative Partnerships

Federal Agencies

Grants, technical assistance

Aggregated & summarized feedback and data

Robust context-rich community-specific feedback and data

State/Regional DPH/DOHs

Smaller grants, subawards

CBOs

Meaningful Involvement
People with HIV

Research/Academia

NIH Grants

Smaller grants to DPHs for help coordinating research participation from CBOs

- 2022 PACHA presented to CHAC their Resolution:
  - Concern about lack of meaningful community engagement
  - Called on CDC to provide guidance to health departments to adapt approach
    - to include meaningful engagement people living with HIV and how can be adapted to avoid harm in jurisdiction (regards to HIV criminality)
  - Require jurisdiction that use MHS establish CABs
    - Not just CABs but that the CABs directly influence the MHS/CDR programs and show how the CABs are being used to move programs forward
CDC Updated MHS/CDR guidelines: February 2024

- Includes wording based on PACHA resolution of engaging PWLE
- But already mistrust in community which needs to be addressed
- Perception that less involvement at state than local levels
  - Need for Meaningful Involvement PWLE all levels government

Community Engagement: One Model of Success

Source: NIH All of Us Research Program
All of Us Research Program

- Division of Engagement and Outreach
  - Communications Design
  - Engagement & Retention Innovators
  - Community advocate Network
  - Community Engagement Partners

- Community and Provider Gateway Initiative
  - Infrastructure including an outside firm helped establish and maintains
  - Regular meetings for Continuous quality improvement and information sharing

Source: NIH All of Us Research Program, Community and Engagement Partners
Examples of meaningful involvement of PWLE

- **Legislatively mandated spots on HRSA planning bodies**
  - In some cases PWH >50% of membership, active leadership roles

- **5280 Fast Track Cities Task Force**
  - [https://www.5280fast-trackcities.org/](https://www.5280fast-trackcities.org/)
  - CBOs, Universities, Hospitals – different groups PWH at the table and others willing to listen

- **HIV One on One – Peer Mentor Program (2010)**
  - Train the trainer; Long term survivors are mentors and newly diagnosed are mentees

- **People Organizing Positively (POP) Grant through AIDS United (2015/2017)**
  - Hawaii: Leadership Workshop series
    - Self-advocacy, person first language, understanding funding streams, understanding RW, elevator speech for key stakeholders
    - Motivated the community to volunteer, write testimony, secure funding, involvement in the local HIV services/concerns
  - Long lasting engagement; seat at the table; made a huge impact on how HIV services are implemented

- **Kumukahi Health & Wellness Sexual Health Clinic**
  - Ryan White Part C; first clinic integrated into ASO in HI; addressed lack of specialists
CHAC Considerations: Examples Best Practices

- PWLE must have a seat at the table— but must be meaningful involvement!
  - Funding and mandates can help start but need to create sustained, shared leadership

- Trainings and opportunities for discussion can help achieve
  - Bi-directional; departments, organizations must know community-based engagement
Objectives:
1. Increase leadership capacity, representation, and engagement in RWHAP planning, development, implementation, evaluation, and clinical quality management (CQM)
2. Develop skills and support knowledge transfer through peer learning for people with HIV
3. Support the readiness of PWH to meaningfully engage in activities that impact HIV systems of care and operations
Metrics: Needs to be an area of research

- OUTCOMES:
  - Improved health, reduction in disparities
  - Community building & Empowerment
  - Meaningful Engagement
  - System & Capacity Improvement
  - Skills that last beyond funding

- METRICS:
  - Less literature on how to measure (qualitative & quantitative; logic models)
  - MIPA/GIPA frameworks
  - HIV & Aging SPNS surveys examples
  - National Academy Medicine for community based participatory research

Example Emerging Metrics

SPNS Capacity Building Survey Questions:

- types activities
- Self-assessment
- What is still needed

Technical Assistance Considerations

**Emphasis on skill building that can have long lasting effects beyond grant lifespan**

- Infrastructure for meetings with community partners to share best practices that can continue beyond grants
  - Opportunities for real discussion, open dialogue, listening and including diverse voices
  - Consistent policies, cultural competency, pay people for time

- Train the Trainer models and skill building **trainings** – bi-directional, within and separate from grant mechanisms
  - Train PWLE to have a seat at the table and what to do with that seat
  - Ensure universities/health departments/fed agencies expertise in community engagement & can actively listen
Other Considerations for TA from the CHAC survey

- Infrastructure to continue capacity building to organizations that receive funding after the formal grant ends
  - Technical support esp. Around data
  - Leadership development

- Consider looking at all levels grant process/project development including maybe grant review and awardee selection for Meaningful involvement PWLE
Summary of Considerations

- Ask CDC/HRSA to ensure that PWLE have meaningful involvement at all levels (local to national, including employment)

- Ask CDC/HRSA to support Bi-directional TA – trainings for PWLE and health departments/organizations for skills that last beyond funding

- Ask CDC/HRSA to support opportunities for knowledge sharing (bi-directional)

- Ask CDC/HRSA to research further and prioritize developing Metrics to assess meaningful involvement of PWLE and successful community partnerships
  
  ○ Shared metrics across agencies considering syndemic, status neutral approaches, translating CBPR to service delivery