A Roadmap for Authentic Community/Academic Engagement for Developing Effective Community Preterm Birth Education

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Evidence-based care, behavioral interventions, and new technologies applied during the perinatal period are insufficient by themselves to reduce or eliminate racial/ethnic disparities in infant mortality. Traditional health and behavioral interventions, and the structures through which they are delivered, do not facilitate adherence to behavioral or health recommendations at home or in the community. The translation of research into practice in the absence of community involvement often results in interventions that are irrelevant to community needs, insensitive to existing culture, inconsistent with the resources available, and strain existing community assets. Using a community-partnered participatory research (CPPR) process, the Healthy African American Families project in Los Angeles developed a multilevel, risk communications strategy to promote awareness about preterm birth in the local community. This paper provides a roadmap, giving insight into the CPPR model and processes involved in the development of the risk communications strategy. (*Ethn Dis*. 2010;20[Suppl 2]:S2-77–S2-82)

Key Words: Community, Participatory Research, Preterm Birth, Risk Communications, African American

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Introduction

Evidence-based care, behavioral interventions, and new technologies applied during the perinatal period, while necessary to reduce infant mortality and its underlying causes, are insufficient by themselves to reduce or eliminate racial/ethnic disparities in infant mortality.[1] Traditional health and behavioral interventions, and the structures through which they are delivered, do not facilitate adherence to behavioral or health recommendations at home or in the community. The translation of research into practice in the absence of community involvement often results in interventions that are irrelevant to community needs, insensitive to existing culture, inconsistent with the resources available, and strain existing community assets. Community partnered participatory research (CPPR) is one approach to community-based participatory research.[2–3] CPPR became popular in the health arena over the past few decades and has been used in research addressing racial and ethnic disparities in health and health care.[4] Many requests for proposals from government and private funders require community partnerships, thus spurring many health and medical practitioners to initiate community partnerships. However, while practitioners have worked closely with community stakeholders, few collaborations have resulted in authentic engagement with equal decision-making power and, community benefits have been limited, perhaps because the challenges of building a sustainable community/academic partnership are many.

Without a clear roadmap for operationalizing the CPPR process, attempts at community engagement can be misunderstood, misused, and may result in more harm than good in communities. There are many references on what CPPR is and what it should entail, but few discuss the paradigm from which it emerged and operates within, and still fewer present a roadmap that embodies the principles of CPPR. An understanding of the paradigm in which the CPPR process should operate, and having clear guidance on how to implement such a process in a systematic way, can assist communities and academicians in developing a strong collaboration, effective products to support health education and, can lay the foundation for a long-term collaborative partnership with communities. The Healthy African American Families project (HAAF) developed a multilevel, risk communications strategy to promote awareness about preterm birth in the local community utilizing an authentic CPPR process. The HAAF project is described elsewhere in this supplement.[5] In this article, we present the components of the roadmap to assist others in operationalizing the CPPR model and processes, in hopes that more community-university partnerships can utilize the model to produce effective health outcomes in their communities. Through application of this strategy, we demonstrate the importance and significance of process in creating an authentic partnership and laying the groundwork for community involvement in health planning and advocacy.

CPPR through a Biomedical vs a Critical Paradigm

Community partnered participatory research (CPPR), a form of community-based participatory research, is a con-

Table 1. Step One: Framing

People	Products	Funder	Specific Aims
Who are the people and the types of knowledge that we need at the table to make this project successful?	What products or deliverables are required by the funder?	How much money do we have and what can it be used for?	What are the specific aims as outlined by the grant?

ceptual framework in which collaborative research projects emphasize equal partnerships between community and academic partners, while building capacity for partnered planning and implementation of research informed programs.[2] CPPR uses a set of tools that can be applied toward improving health in a community.[6] The question of how those tools are used is important, one that spells the difference between maintaining the existing power structure in health (eg hierarchical or top-down) or developing an equitable power arrangement conducive to the development of effective and community acceptable products and strategies to improve health. Using the CPPR tools within a biomedical paradigm can result in exploitation of community and a continuation of the cultural rift between planners and participants. For example, the CPPR tools can be used to identify ways to recruit more African Americans into clinical trials. While this can be seen by academicians and clinicians as an ultimate "good" for the community, if that benefit was defined outside of the community and the community did not have an opportunity for critical thought to examine the problem and develop their own conclusions regarding increased participation in clinical trials, then efforts to learn from the community can be seen as exploitive. In this scenario, the question being posed is "how can we better and more effectively get the community to do what we want them to do?" In contrast, CPPR applied through a critical paradigm holds sacred the principles of equity and nonexploitation and seeks to employ them at every stage of community interaction. It holds that process is everything because it affects the daily activities of real people, and having and pursuing a good "goal" does not justify any means. Embodying the principles of equity in community engagement in actual practice is challenging and little guidance has previously been provided to practitioners on how to do this. This article serves to provide a guide or roadmap in defining and illustrating authentic community partnerships for addressing prevalent health issues, such as health disparities.

PROCESS FOR CREATING AUTHENTIC COMMUNITY/ ACADEMIC PARTNERSHIPS

In the implementation of a CPPR project, process matters significantly and can determine the success of the collaboration and the effectiveness of the products developed. To embody the principles of equity and democracy, we developed a process that will significantly improve the possibility that an authentic partnership with effective products will be developed. The roadmap to effective community partnership includes three component processes: a) framing, b) tree tops, trunks, grass, and roots, and c) visioning.[7] This process is synergistic and interrelated, thus cherry-picking components to include and/or exclude is not an option that leads to effective partnership.

Step One: Framing

Most projects are funded by existing agencies or universities and are not conceptualized initially at the community level. There is a danger the funded agency can easily subvert any community-identified needs because they hold all of the power to control the process and direction of the work. Furthermore, agencies that receive funds must operate under strict legal and regulatory guidelines that are not always well-known or understood at the community level. While these requirements must be considered, the academic partner must be honest about which constraints are immovable, which are flexible, and which are perceived constraints. It is critical to come to the community table with honest and full disclosure about funder requirements and parameters (Table 1). Thus, in the first step, the project planners, who will facilitate engagement with community, will initiate the planning process by clearly framing the absolute parameters within which any ideas would have to conform. This includes specific information on:

- People. Who are the people and the types of knowledge needed to make this project successful?
- Product. What products or deliverables are required by the funder?
- Funding. How much money is provided and what can it be used for?
- Aims. What are the specific aims as outlined in the grant?

This information should be recorded and used when communicating with potential community partners.

Step Two: Treetops, Trunks, Grass, and Roots

The second step on our roadmap to forming authentic community partnerships is a process for ensuring the development of an equitable and representative group. It is critical to identify all potential stakeholders in a community and what segment of the community they represent. This allows for a

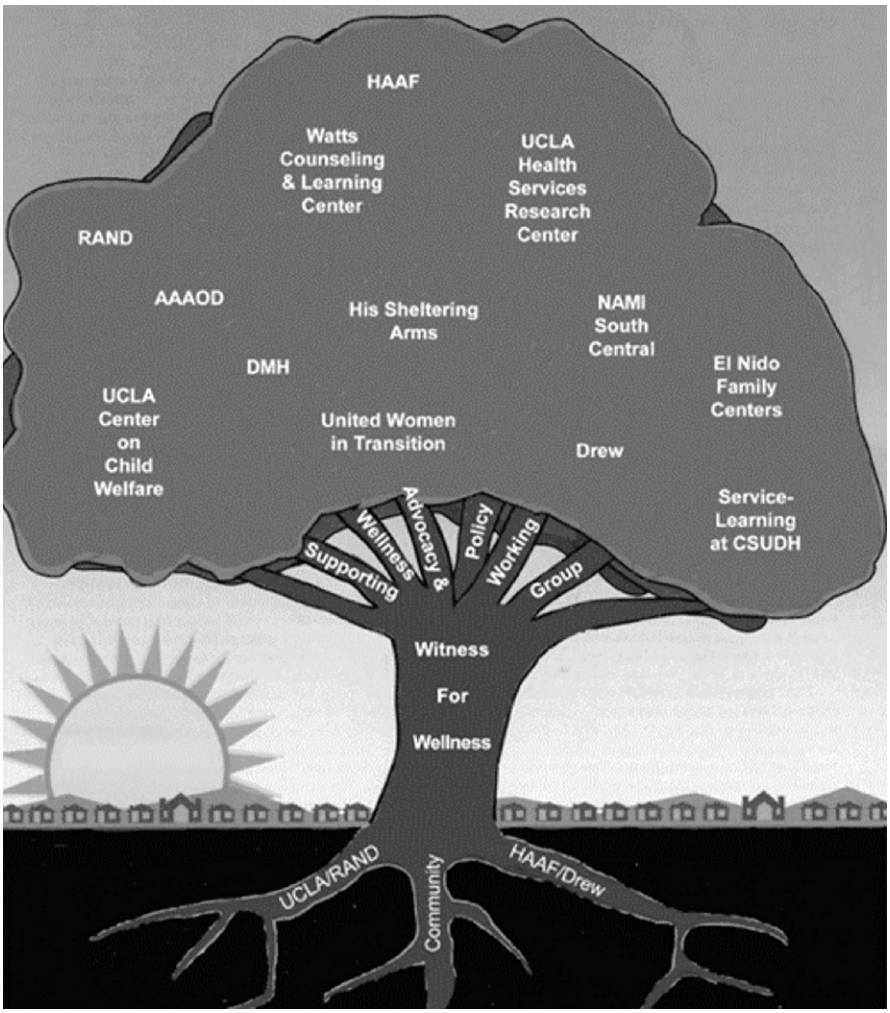

Fig 1. Step Two: Treetops, Grass and Roots

more informed and balanced choice of the stakeholders to engage. We use the analogy of a tree to illustrate the potential stakeholders in any endeavor (Figure 1).

A community consists of many different types of stakeholders who have differing levels of power and voice in the community.

- **Tree Tops** include elected officials, funders, corporate heads and agency heads. These stakeholders directly control most of the needed resources and have the power to decide actions that can affect their organization and/or community residents.
- **LowerTree Tops** include service providers, service workers, church leaders, and academicians. These have access to knowledge and resources that can have major impact on community members. These additional stakeholders have frequent contact with other community members, but often do not live in the community and experience all of the challenges that other members of the community face.
- **Trunks** include activists, advocates, and other community members who are aware of community conditions and are vocal in advocating for community needs. These stakeholders tend to be connected to an organization and promote the interests of that organization, albeit in support of communities. Trunks tend to be the "community representatives" included in community/academic partnerships. This group may or may not have power to change communities, but usually have a voice.
- **Grass** include community members who are rarely heard from and rarely engaged in partnership efforts, yet visible in and to the community. These are people from the community who come to community-based agencies to use their services. Our continual connection to them is usually through their use of services provided by health and social service agencies. This group generally exerts little power to create change in the community and may not have a "voice" to advocate for and express community needs; yet they are responsive and become active when the Trunks mobilize them around a community issue. This group is often the focal point of research outreach strategies.
- **Roots** are the people who are the least likely to be engaged or sought after. This group tends to be invisible in a community—not because they have no needs, but because they are likely to have so many needs, requirements, and responsibilities that they do not make noise; they are too busy surviving. This group tends to perceive that they have little power to change things in their community. They may be the most in need and/or have the most constraints affecting whether and how they can participate.

Many efforts to engage the community only engage stakeholders from the Tree Tops and Trunks, perhaps because they are vocal and easily identified. Community members who may be the most in need are often not included in these partnerships. As such, their needs are not always represented and solutions and interventions are often not appropriate to their life situations. Researchers often brand this group as "hard-to-

reach'' or ''lacking social capital'' or ''unengaged,'' ''uninterested'' or ''apolitical.'' They may make attempts to engage people in this group, but often fail because their life circumstances may not facilitate their ability or willingness to attend meetings at the times we usually meet and under the circumstances we generally set for these meetings. As a result, they risk developing interventions that exclude them and their interests as well.

Understanding all stakeholders in a community, and what they represent, is critical to ensuring that appropriate, comprehensive representation is attained. When a community group is invited, there should be people representing each of these levels. Additional dedicated efforts to engage **Grass** and **Roots** must occur. A diversity table should be drawn to assess and document the levels of representation within every project. Representation from these underrepresented groups should be documented and assured. If this occurs, the likelihood of developing effective and relevant solutions for the entire community is considerably increased.

Step Three: Vision, Valley and Victory

The third and final stage of our roadmap to effective community engagement consists of a process called Vision, Valley, and Victory.[7] The symbol of an open hand is used to illustrate this concept and to function as a memory aid (Figure 2). Vision, Valley and Victory is used to define a 3-step process for developing a joint vision among the diverse stakeholders and completing the work necessary to reach those goals.

- **Vision**. Each group and each individual within a group comes to the partnership table with differing interests and needs. It is critical to define a common vision, mission and framework to guide the collective work of the group. This requires facilitating a process where each stakeholder has an opportunity to define and express what they expect to get out of the project. However, since all stakeholders do not come to the tables with the same amount of power and voice, two preliminary steps are necessary to ensure equality when the full table is convened.
  - **Visioning separately with Grass and Roots.** Dialog groups should be conducted with these two groups (without the presence of other stakeholders) to assist them in releasing their prior misconceptions about health issues and health care and to release ''blaming the victim'' attitudes. In this process, each group is given the opportunity to develop and articulate their own critical analysis of the problems to be addressed and community needs.
  - **Orientation with Tree Tops, and Trunks**. Meeting separately with these groups enables specifying rules of engagement, which are guidelines for conducting meetings that help to avoid alienating stakeholders from the other levels of the community. These include: listening, having a shared group mission, defining inclusion for membership to the group, having transparent decision-making processes, and a commitment to share the data with the community so that the community can partake in their improvement. In addition, the guidelines comprise addressing language that is commonly used but tends to offend community members.[8] We also address the effects of power differentials on participation and the science driving the research project. Community-based participatory research and CPPR, unlike traditional public health research, strives to understand and acknowledge expertise among all of the members participating in the research project.[9] While academicians and other ''treetop'' members bring a certain expertise, community members contribute local knowledge about the resources in the community and the ways in which the community works. Because knowledge is both intrinsically linked to power and a core element of science, inclusion of community knowledge into the scientific process can radically shift the shape and direction of the research and, more fundamentally, the power dynamics of science production itself.[10–11] Therefore, defining early on that all members of the group are valuable and necessary to the success of the research project, is a critical step in the CPPR process.
  - **Bring all levels of Tree to a common table**. In this step, we convene all of the members of the collaborative team. By this time, all members are appropriately oriented and ready to begin work.
  - **Defining our collective vision**. Once everyone is at the table, the development of a collective vision for the project begins. We do this by posing several questions:
    - What do you want us to do about Issue X?
    - Why do you want to be involved with this effort to address issue X? What is in it for you?
    - How will this fit into your current job/agency mission? Family life?
    - What do others in your community want and need with respect to this issue?
    - Despite the advance preparation, we believe the power differentials still exist and may serve to silence some Grass and Roots, thus we take additional steps during meetings to ensure all voices are heard. We pair each Grass and Root member

with a Trunk member and facilitate the seating arrangement so they are seated next to each other. When a Grass member appears hesitant to express a thought, or their ideas are glossed over, the Trunk will speak up and ensure that time and attention is given to assist them in expressing ideas. The end product of this stage is agreement on a collective vision for the diverse group of partners. This vision is documented and guides all subsequent work.

- **Valley**. In this step, we define what work needs to be done to achieve the vision and determine who will do the work. This step is critically important and the end result of the collaboration will be dependent on the ability to complete the work. Subcommittees are usually formed with the work appropriately divided among stakeholders. It is critical to distribute the work equitably and to always pair members across stakeholder levels. We often pair Trunks and Grass or Roots to ensure that the resources are available to complete all work.
- **Victory**. In the end, if the process is followed and everyone is able to play their role, victory is achieved and every stakeholder in the collaboration is able to see a win that they wanted. Not every "win" needs to be the same, but all stakeholders should walk away from the collaboration with something tangible. At this point, the collaboration can be seen as successful and the stakeholders are likely to collaborate again.

IMPLICATIONS FOR DECREASING HEALTH DISPARITIES IN PRETERM BIRTH

Health disparities result from a long history of social inequity that translates into current social, economic and cultural conditions that are not conducive to health for some population groups. Addressing health disparities in a consistent, effective and sustainable way is strongly dependent on being able to examine and modify the operational processes within existing social and health structures that present barriers affecting the community culture and the community's ability to practice healthy behaviors. In an effort to decrease preterm birth, especially among medically underserved or minority populations, it is imperative to develop strategies for communicating risk of preterm birth, and developing ways to make proposed medical, behavioral and clinical interventions work more effectively in the real world. The success of this process is dependent on the development of authentic partnerships with the community.

Fig 2. Step Three: Vision, Valley and Victory

We outlined an operational process for developing and sustaining authentic partnerships and presented this process with visual aids to assist non-professionals and professionals alike in understanding and negotiating this process. The process we outlined provides specific steps toward equalizing the power between researcher and community, in non-technical language, while maintaining focus on the ultimate goal, which is achievement of birth outcomes and overall health improvement in a community. We applied this method successfully toward the development of a preterm delivery risk communication strategy in the Los Angeles community,[7] described in detail elsewhere in this issue. In short, the initiative focused on increasing social support for pregnant women, providing current information on preterm birth risks, and improving quality of health services. The initiative included components addressing community education, mass media, provider education, and community advocacy. Products include 100 Intentional Acts of Kindness toward a Pregnant Woman©, a doorknob brochure on signs and symptoms of preterm labor, and an education manual on preterm birth and other African American health issues. Applying the process in that case resulted in the development of unique and community-specific ways of communicating the risk of preterm delivery and current medical knowledge about preterm delivery prevention to the African American community. The methods of risk communications developed could not have resulted from a top-down approach, where the clinicians and public health specialists defined the risk communications and health education material formats without the community knowledge of what ways would work best in the community. The approach also could not have worked if the community partners did not feel they understood the medical and public health issues sufficiently to provide relevant advice to the development of the risk communication strategies and tools. Authentic community engagement is a critical step toward the development of strategies and tools that can facilitate movement toward equity in health.

CONCLUSION

When applied correctly, this process of community engagement will result in successes and tangible results for the community and other stakeholders. The stages of the roadmap presented herein are easily replicable and, when followed completely, can ensure authentic community engagement and effective collaboration.

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REFERENCES

1. Lu MC, Halfon N. Racial and ethnic disparities in birth outcomes: a life-course perspective. *Matern Child Health J*. 2003; 17(1):13–30.
2. Jones L, Wells KB. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*. 2007;297:407–410.
3. Jones L. Partnership building. In: O'Fallon LR, Tyson FL, Dearry A, eds. *Successful Models of Community-based Participatory Research*. Bethesda, MD: National Institute of Environmental Health Sciences; 2000.
4. Chen DT, Jones L, Gelberg L. Ethics of clinical research within a community-academic partnered participatory framework. *Ethn Dis*. 2006;16:S1–118.
5. Jones L, Wright K, Wright A, Dillon Brown N, Broussard M, Vijaya H. The healthy African American families' risk communications initiative: using community-partnered participatory research to address preterm birth at the local level. *Ethn Dis*. 2010;20(1, Suppl 2):S2-30–S2-35.
6. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19:73–202.
7. Jones L, Wells K, Norris K, Meade B, Koegel P. Chapter 1: the vision, valley, and victory of community engagement. *Ethn Dis*. 2009;19:-S6-3–S6-7.
8. Jones L, Koegel P, Wells K. Bringing experimental design to community-partnered participatory research. In Minkler M, Wallerstein N, eds. *Community-based Participatory Research for Health: From Process to Outcome*. San Francisco, CA: John Wiley & Sons; 2008.
9. Minkler M, Baden AC. Impacts of CBPR on academic researchers, research quality and methodology, and power relations. In Minkler M, Wallerstein N, eds. *Community-based participatory Research for Health: From Process to Outcome*. San Francisco, CA: John Wiley & Sons, 2008.
10. Wells K, Koegel P, Jones L, Meade B. Chapter 6: Work through the valley: evaluate. *Ethn Dis*. 2009;19(Suppl 6):S6-47–S6-58.
11. Wells K, Jones L. Research in community-partnered, participatory research. *JAMA*. 2009;302(3):320–321.