COLLABORATION, STAFFING, AND PIZZA: COMMUNITY ENGAGEMENT IN THE BEGINNING STAGES OF A COMMUNITY-BASED INTERVENTION

by
Bryan M. Dougan

A thesis submitted to Johns Hopkins University in conformity with the requirements for the degree of Master of Science in Public Health

Baltimore, Maryland

April 2014

Abstract

In addressing the social determinants of urban health conditions, urban academic hospitals often form an academic-community partnership (ACP) with local community leaders and organizations to collaboratively intervene. ACPs bring together their collective resources to improve urban health, particularly for areas with poor health outcomes. Based in east and southeast Baltimore, Project CONNECT aims to work with local community-based organizations (CBOs) to produce resources to improve health in the seven ZIP Codes surrounding the Johns Hopkins Medical Institutions. This paper describes the formative stages of an ACP comprising local community-based organizations (CBOs) and a research team at Johns Hopkins University (JHU) to address urban social and health needs in east Baltimore. It explains how community engagement changed the directions of the project in three domains: 1) study design, 2) cultural humility, and 3) specificity of messaging. Our understanding of engagement is informed by our adaption of the African Partnerships for Patient Safety Community Engagement (ACE) Approach in combination with the paradigmatic Community-Based Participatory Research (CBPR). We found that, by having community involvement from the beginning of a project, the direction of the project will change. There are notions and barriers, such as different understandings of time, that will come through engagement. Implications for efforts to conduct future community engagement projects include earlier community participation for ACPs, openness to bidirectional flow for both community members and academics, and combining complementary models to strengthen theoretical frameworks and action.

Preface

This essay is to complete the degree of Master of Science Public Health in the Social and Behavioral Interventions program in the Department of International Health at Johns Hopkins University.

Support has been provided by the Patient-Centered Outcomes Research Institute (PCORI). A modified text will be one of the first writings to come out of this project.

There are a number of acknowledgements necessary:
To my readers, Mary F. Cwik, PhD, who also served as my academic advisor, and Albert W. Wu, MD, MPH.

To the Project CONNECT Team: Leon Purnell, BA, MSEd, co-PI; Lee Bone, MPH, BSN; Romsai Tony Boonyasai MD, MPH; Chindinma Ibe, PhD; Janice Gentry BA; M. Christopher Gibbons, MD, MPH; Deanna Loh; Mike Rogers, BA; and Christine M Weston, PhD, MSEd.

To the SBI faculty, especially Elli Leonstini, MD, MPH.

To my cohort and friends. And of course, my parents, Rich and Diane.

Table of Contents

List of Tables

List of Figures

Introduction

Health outcomes in the US are worse in low-income urban areas than other parts of the country (Galea and Vlahov 2005; Marmot et al. 2008; Murray et al. 2006; Vlahov et al. 2007; World Health Organization 2008). These disparities are often linked to poorer social conditions, such as: lack of quality housing, limited employment opportunities, higher rates of crime and incarceration, poorer quality education, and homelessness. To address these social determinants of health through public health interventions, urban academic medical centers (AMCs) have initiated partnerships with urban community members and organizations (Schulz, Krieger, and Galea 2002).

It can be challenging to build relationships between AMCs and members of neighboring low-income areas. Historically, skepticism of academics comes from the mistreatment of community members in academic studies (Skloot 2010). During studies, challenges to partnership building can include: unequal power relationships; mistrust of community partners to fulfill their roles by academics (Christopher et al. 2008); disagreement between the community and academicians over perceived wants or needs; appropriation of ideas, particularly academics usurping them; no feedback loop in study design, implementation, and evaluation; and the lack of sustainable interventions. Academic-community partnerships (ACPs), guided by principles of cooperation, trust, collaboration, and a shared vision to strengthen resources and services in the community, are designed to address these potential problems (Baker et al. 1999; Maurana and Goldenberg 1996; Meyer, Armstrong-Coben, and Batista 2005; Wolff and Maurana 2001). ACPs allow all parties to work together to design, implement, and sustain research and interventions. However, relatively little is known about the optimal way to create and sustain an ACP that focuses on addressing health disparities and services (Wells et al. 2006).

The existing literature related to partnership communication and urban health interventions has several limitations (Tyus et al. 2010). First, few papers have focused on community-based interventions that address healthcare and other unmet needs. Second, there is still limited knowledge of the processes that lead to sustainable partnerships and interventions and there is a need for a specific framework to address and understand urban health priorities.

Over the last thirty years, Johns Hopkins University has worked with community leaders in Baltimore to better the health of residents in different parts of the city through ACPs focused on specific health conditions, such as cardiovascular disease, depression, hypertension, and substance abuse (Cooper et al. 2013a; Cooper et al. 2010; Cooper et al. 2013b; Goldberg-Freeman et al. 2007; Levine, Becker, and Bone 1992a; Levine et al. 1994; Levine et al. 1992b; Smith et al. 2009; Tyus et al. 2010). Many of ACPs in Baltimore have focused on a specific problem, and have not addressed the broader health system in Baltimore. Project CONNECT (*C*ommunity-based *O*rganization *N*eighborhood *N*etwork *E*nhancing *C*apacity *T*ogether) is a three-year project funded as "Reverse Innovation and Patient Engagement to Improve Quality of Care and Patient Outcomes" by the Patient-Centered Outcomes Research Institute (PCORI) that forms a partnership to better communication between the Johns Hopkins Medical Institutions (JHMI) and community-based organizations (CBOs) to create a more cohesive urban health system in east Baltimore. Project CONNECT employs an innovative approach that addresses current limitations in the field by focusing on social and community level needs and examining the usefulness of combining two theoretical frameworks—WHO'S African Partnership for Patient Safety Community Engagement (ACE) Approach and CBPR— for partnerships between AMCs and the communities in which they operate.

In this paper, we seek to: 1) outline the adaptation of the ACE Approach alongside of CBPR and 2) address the ways in which communication with community investigators and leaders has changed the direction of Project CONNECT over its first seven months of intervention and study design planning. This process has implications for the field describing initial partnership-building efforts to address community health, as well as in introducing the ACE Approach to guide this process.

Project CONNECT

Project CONNECT has two overarching aims: 1) To adapt a community engagement approach to develop an intervention to strengthen the relationship and bidirectional flow of information and knowledge between Johns Hopkins Hospital, Johns Hopkins Bayview, Johns Hopkins Primary Care clinics, select community-based organizations (CBOs) and residents in seven east Baltimore ZIP Codes and 2) Evaluate the effectiveness of the intervention using a cluster-randomized trial of eleven intervention CBOs and eleven control CBOs with a wait-list design. Part of the intervention will be the development of a toolkit for better communication and referral among CBOs and JHMI, as well as for increased effectiveness and improved networking among CBOs.

Our research team members have diverse backgrounds. Three are community members that work at local CBOs and have experience in community activism. At least four members, who are Johns Hopkins faculty, have extensive experience working in the Baltimore community. Many of the faculty involved have an appointment in the Center for Health Outcomes and Services Research.

In following other definitions in the CBPR literature, Project CONNECT defined the community geographically (MacQueen et al. 2001), focusing on the seven ZIP Codes surrounding the JHMI facilities in east Baltimore (21201, 21202, 21205, 21213, 21218, 21224, and 21231).

Theoretical Frameworks

Project CONNECT's theoretical foundation is guided by two related frameworks: the African Partnership for Patient Safety (APPS) Community Engagement (ACE) Approach and Community-Based Participatory Research (CBPR). The ACE Approach was developed for the WHO's APPS program (Syed et al. 2009). The overall focus of the ACE Approach is to build relationships between partners to produce the following objectives (Table 1; Figure 1). Objective 1: partnership, collaboration, and bidirectional flow of communication. Objective 2: specific products and outcomes that result from each partner contributing to the partnership. For example, a primary outcome for APPS is hospital safety improvement. A product for CONNECT is a toolkit to facilitate addressing social and health-related needs in the seven ZIP Codes around JHM. Objective 3: dissemination of ideas, information, products, and programs.

CBPR comes out of a tradition of action research to address inequality (Israel et al. 1998). The focus is on engaging a particular population to find relevant ways to address issues specific to that population. Organized around nine principles (Israel et al. 1998; Israel et al. 2008; see Table 1), the focus of CBPR is on engaging a particular population to work together on finding ways to address issues specific to that group. CBPR is organized around principles of equality, empowerment, and engagement. It recognizes the knowledge and power differences

between community and academic actors, seeking to create a more equitable methodology for input and design.

The ACE Approach and CBPR are similar in that both emphasize the need for all partners to have open dialogue in the planning, implementation, and evaluation phases (see Table 1). Such ideas comes out in the use of terms such as "co-learning" (Israel et al. 1998), "bidirectional flow" (Ross et al. 2010; Syed et al. 2013), and "reverse innovation" (Immelt, Govindarajan, and Trimble 2009; Syed et al. 2012). This way of communicating is essential for academic partners to be able to learn from the community partners, and vice versa. Ideas from all parties are taken seriously and implemented in a consensus manner within the nature of the study and intervention.

There are also differences between the frameworks that make it useful to bring them together. First, the ACE Approach explicitly adds the notion of accountability, which is not discussed in the CBPR literature (Syed et al. 2013; World Health Organization 2009). This principle encourages all partners take responsibility for making and implementing decisions. Second, CBPR is largely focused on research outside of a clinical setting; in contrast, the ACE Approach is a more clinically focused framework. In CBPR, information and action flow from outside the clinical setting into it; the ACE Approach is the reverse.

Adapting the ACE Approach for Project CONNECT rethinks the actors engaged in reverse innovation. By applying reverse innovation to a local health system in Baltimore instead of an international system, there is a new opportunity to understand bidirectional flow of knowledge when partners occupy the same space.

Use of the two frameworks allows us to measure outcomes in clinical and non-clinical settings that reflect Project CONNECT's linkages with other JHMI and community programs

and interventions. Figure 1 reflects the adaptations we have made for our project based on an effort to bridge the two settings. We made two changes: 1) making the arrow between each partner and the second aim double-ended instead of just moving from the partner to the objective and 2) adding an arrow between the bidirectional flow and partnership and second objective. These adaptations reflect how each partner and the collective communication contribute to creating and sustaining the second objective. These changes also show how both each individual partner and the collective partnership are strengthened through working towards the second objective.

Methods

To determine the ways in which community members – including both organizational leaders and employees and the community leaders who serve as investigators on our research team – we recorded instances in which community member involvement changed the direction of Project CONNECT. We also reviewed our progress in planning and conducing our project by examining our initial project goals and timelines from July 2013 until March 2014. This entailed reviewing our research team meeting notes, correspondences with possible participant CBOs, and reflection on the actions we have taken.

In the first seven months of our project, community investigators, who serve on the research planning committee, contributed valuable insights and influenced the actions taken by the research team and in the length of time taken to make decisions. CBO leaders have also not been afraid to share their thoughts during this time. These suggestions, comments, and criticisms have allowed the research team to consider the planning phase as an important phase of the project design (Jones, Koegel, and Wells 2008).

As Table 2 shows, the process started by working towards selecting CBOs to participate in the trial phase of the study. During this time, Project CONNECT held a large meeting with community leaders to present the project and receive feedback. Subsequently, the research team continued to discuss and debate the CBO inclusion and exclusion criteria, the nature of good partnership, and the specific elements of participation. Researchers received feedback that led us to refine our message and what was being asked of the participating CBOs. In January 2014, a kick-off meeting was held with potential CBOs, which further refined the message and led to the consideration of the amount of time CBOs would commit to the project. In March 2014, 22 participating CBOs were randomized.

Results

In general, there are three themes into which feedback from community leaders can be categorized: 1) study design, 2) cultural humility, and 3) specificity of the project. These categories are not mutually exclusive, as feedback often influenced different domains (Table 3; Appendix 1). Also, there are no distinct phases at which one theme dominated the others. What these themes indicate is the importance of having community partners from the beginning. Doing so fosters feelings of respect and collegiality and an atmosphere of valuing for community input that promotes bidirectional flow.

First, community investigators offered suggestions and criticism of the study design. Working with CBOs, the research team had to consider different selection criteria for their participation than individual persons or regionally defined clusters. Because of their intimate knowledge of the organizational landscape in east Baltimore, they were able to direct the JHSPH partners in particular directions. They knew which CBOs were still operational and which were

not. JHSPH partners used available online resources to find possible participants, but some CBOs may not have been considered without suggestions from our community investigators. When some organizations refused participation, our community investigators provided suggestions and contacted organizations to ask if they were interested. Without bringing community members on at the onset of the planning phase, our study would not have the diversity in organizational size and services it does that can contribute to network creation and building. Figure 2 illustrates the selection and randomization process of CBOs, along with what each group will do over the course of the study.

Secondly, community input from investigators and organizational leaders showed us that what we had to be sensitive to their organizational and cultural needs and the potential additional burden on CBOs. This meant we had to respond in humility to their requests and suggestions. It was not initially apparent to the research team that CBO leaders have limited time and resources; many of them rely on a few staff and/or a large volunteer base to fulfill their operations. In asking them to participate, CBO leaders alerted us to how participation would remove a staff person from doing their paid work to volunteer time to our study. Community investigators suggested to the research team we provide an honorarium to CBOs as a way of compensating a set amount of time for staff effort. Culturally, we learned CBOs have use different words in describing their operations and those whom they serve. Some are programs, whereas others are ministries. Some CBOs serve clients; others neighbors. We also learned community members have different expectations about meetings. For example, at our meeting in January 2014 with potential CBO partners, we had decided to serve pizza for dinner; however, community investigators explained that pizza has come to be regarded as basic rations and that pizza might be perceived as a sign of low regard for attendees. Therefore, we served baked ziti instead of

pizza. Table 4 indicates further places where community leaders and investigators provided organizational and cultural insight.

Lastly, this process forced us to learn we had to refine our message and refocus what we wanted in partner CBOs. Refining our message also related to organizational capacity and participation. We were asking for organizations to participate in the study, yet we had not yet operationalized what we meant by participation. We knew we wanted to co-develop an intervention, but we had yet to determine the necessary commitment to do so. It was only after CBO leaders hesitated that we understood we had to determine what it meant for CBOs to join us. In our communications and meetings, as Table 5 lists, we realized we would need to help facilitate more in the beginning as we work towards continuing to build an ACP.

Because of considering such feedback from community investigators and CBO leaders, the timeline for study implementation was considerably altered. The initial plan was to select organizations by the end of October or November. We did not complete this process until March 2014. During these six months, the team had extensive debates that surrounded from the aforementioned themes. By allowing community input to drive the study, we were placed behind our original plan. However, the delayed produced conversations and actions detailed above (also see Appendix 1).

Discussion

Our findings indicate how engaging the community from the beginning in participatory research can help build ACPs. By creating forums for bidirectional flow, we were able to meet community needs in our study design, understand specific sensitivities, and refine our message.

This study is important because it demonstrates what can occur at the onset of partnership building. By inviting feedback our community investigators and CBO leaders, we added time to the recruitment phase of the study. However, we avoided mistakes that could have delayed us further at the beginning the intervention design phase. Wallerstein and Duran (2006) note that it takes three years for the community to own the process of intervention design and the collected data. In what we have observed thus far, the investment of our community investigators will help drive the process of intervention design and ownership. By including community activists and leaders as integral members of our research team, who are able to communicate with both the academic and community partners, we have seen that if involvement is shifted to earlier in the process (Jones et al. 2008; Jones and Wells 2007), then interventions and studies would be able to work out barriers to bidirectional flow earlier.

Combining community-based research and randomized trials is an emerging study design. Despite wariness of many community members to being "experimented on," Wells et al. (2013) successfully combined participatory methods with a cluster-randomized trial. They showed that building community engagement into trials was more effective than individual programs themselves attempt to improve their quality and services. Community organizations were integral parts to developing toolkit and aiding in all aspects of the study. However, there is no literature yet from their study on the community engagement itself.

Being culturally sensitive and refining messages are not new topics to participatory research (Israel et al. 1998). It is in part why CBPR is used. However, because the nature of our intervention is specifically on organizations, it is important that we recognize that their needs, wants, and constraints might be different than working with specific individuals. Further, refining a message and the terms of participation are different for the locus of collaboration and

intervention. In this regard, it is important to remember both with whom you are collaborating, as well as the place of intervention.

Our study has some limitations. This paper is limited in its scope of time. Project CONNECT has been underway for only seven months, partnerships are not yet fully formed, and results have not been obtained. Despite this, in considering these issues early on, we have the advantage of not relying on our long-term memories in considering lessons learned. We have shifted our focus and generated early opportunities for open communication, which is important to recognize.

There are a number of implications that come from our initial experiences. First, for Project CONNECT, reflecting on these lessons and themes allows us to recognize the progress we have made, but also consider what should have occurred differently in order to prevent making similar mistakes for the duration of the study. It shows that our attention to detail and emphasis on bidirectional flow between community investigators and CBO leaders has produced trust and respect among those participating. Our course of action has changed for the better because we valued community members' input and constructive criticism.

For those who attempt to either replicate this partnership or to conduct a related one, there are implications for lessons for methodology and collaboration building. From the last seven months, it is clear it is possible to conduct a rigorous, quantitative study within the context of participatory research (Wells et al. 2013). These methods are not mutually exclusive. It requires attention to balancing community asks and input with the requirements of a randomized trial. For collaboration building, regardless of methodology, it provides three specific themes of places where feedback and bidirectional communication are integral.

For the WHO, it is evident the ACE Approach can be adapted for community engagement studies and programs fully conducted in developed nations. Following the models and examples for intervention more prominent in the Global South to the Global North, such as community health workers (Sachs and Singh 2013), our beginning stages indicate this model is useful and can be applied in many settings. Further, it can inform issues other that the patient safety context in which it was developed. As such, the WHO can and should consider the ways in which ACE can come to inform other projects and interventions that require engaging the community in which organizations are embedded.

For community members and organizations, bidirectional flows indicate that local knowledge is valuable. Researchers may be unaware of certain needs in the community, political issues among leaders and organizations. Bringing this knowledge to the table allows for researchers to gain a broader picture of the community and understand how the study and intervention can move forward. Taking a posture of learning is also required for community members. There are certain actions researchers may not take because they want to show this study and intervention is useful and made a difference, both statistically as well as in people's lives. Particularly with randomization, community members must recognize treatments or interventions will be delayed or not given for some time.

To be successful in addressing the community health needs, AMCs would benefit from involving the community earlier on in the process. This allows for a greater chance for bidirectional communication. In working with and communicating from the start, barriers can be broken down and translated in a palatable manner for all potential partners. AMCs should recognize the value of community members as contributors to the project. The goal of community-oriented projects is always sustainability within the community. Therefore, AMCs

must allow communities to have ownership over ideas and programs instead of claiming them as theirs alone. Credit must be given where credit is due.

In generating this trusting, community-oriented focus and space for an open dialogue, we aim to shape the way in which both involvement and the flow of information occur between academic and community partners through proposing the ACE Approach as a model for ACPs. Further, we suggest researchers consider using blended models because principles from different frameworks can inform the direction of interventions and studies to make up for where others lack. Complementary frameworks can help enrich and enhance our understanding of health behavior and health systems. With blending the ACE framework with CBPR, we have more quickly opened up lines of communication between current researchers, community investigators, and CBO leaders through putting their priorities first while balancing the need to uphold the scientific integrity of the study. Bringing these together has enriched our work thus far and been able to guide all aspects of study design and preparations.

Conclusion

Participatory methods allow academics to learn a great deal from community members about the areas in which collaborations occur. In combining CBPR and the ACE Approach, we have learned a great deal about working with the east Baltimore community. Innovations include having paid community investigators and being open to critique and advice from CBO and community leaders. They have forced us to refine our message, how we interact, and the possible directions for the intervention to go. Academic partners are able to guide community leaders in the formal research and data collection process, allowing for the transference of skills and knowledge between all partners. There are times when compromise must occur. Sometimes the

academic partners must compromise certain aspects to better the community; likewise, community partners must sometimes be willing to compromise when guided by the scientific process and scientific principles. In all of this compromise, we are able generate open lines of communication for understanding and the betterment of the project and, more importantly, the community itself.

Table 1 – Comparison of Principles: ACE versus CBPR

Ten Key Principles (World Health Organization n.d.-b)	CBPR Principles (Israel et al. 1998; Israel et al. 2008)
1. Primary Health Care Approach	1. Recognizes community as a unit of identity
2. Access and Participation	2. Builds on strengths and resources within the community
3. Social Justice and Equity	3. Facilitates collaborative partnerships in all phases of the research
4. Demand-Driven Programmes	4. Integrates knowledge and action for mutual benefit of all partners
5. Local Action	5. Promotes a co-learning and empowering process that attends to social inequalities
6. Family Action	6. Involves a cyclical and iterative process
7. Health System Integration	7. Addresses health from both positive and ecological perspectives
8. Policy-making Integration	8. Disseminates findings and knowledge gained to all partners
9. Human Rights	9. Requires a long-term process and commitment to sustainability (added in Israel et al, 2008)
10. Country Focus	

Table 2 – Timeline of General Academic-CBO Interactions

Date	Event
07/2013	Awarded grant, begin planning
09/2013	Have a kick-off meeting with community leaders to get ideas and feedback on ideas and study/intervention
10/2013-03/2014	Communicate with CBOs and leaders about study and intervention
01/2014	Host a meeting with all potential CBOs to share more information on study/intervention
02/2014	Contact CBOs about interest in participating
03/2014	Select and randomize CBO categories

Table 3 – Examples of Community Feedback Related to Study Design

Date	Suggestion/Comment	Origin of Suggestion	Result	Thematic contribution to project change
08/2013	Have a kick-off meeting with community leaders to get ideas and feedback on ideas and study/intervention	Community investigator	Held meeting in September 2013	Study design
09/2013	Publishing a weekly newspaper	Community investigator	Nothing yet	Specificity of Project
09/2013	Consider the status and place CBOs are in	Community leader	Put an emphasis on creating a coalition and partnerships between organizations	Study design, cultural humility
09/2013 – 12/2013	Questioning whether or not larger CBOs should be included in our study	Community investigator	Looked to find a balance in the size of an organizations	Study design
09/2013-03/2014	Selecting CBO categories	Community investigators	Community members had knowledge of the needs of the community and were able to help direct the conversation towards helping find categories that had organizations we could match	Study design
10/2013 – 03/2014	Knowledge of what community leaders would be good partners	Community investigators	Considered when looking at Community Action Board members and partnered CBOs	Study design
12/2013	Inclusion of Faith-Based organizations	Investigator with community experience	Faith-based organizations included as participating organizations	Study design
12/2013	Host a meeting with all potential CBOs to share more information on study/intervention	Community investigator	Held meeting in January 2014	Study design, cultural humility
01/2014	Sensitivity to food served at meetings	Community investigator	Instead of pizza or sandwiches, we served baked ziti	Cultural humility

01/2014	Organizations do not have the time or personnel capacity to give a staff member yet another task to do.	Community leader	Led to decision to direct some funding allocated for CBOs to help pay for staff members' time spent on project	Cultural humility, specificity of message
01/2014	Refining of message in engaging possible participants	Community leaders	Research team was forced to consider what exactly we are asking of organization in participating.	Specificity of message
01/2014	Frequency of CBO meetings in intervention design phase	Community leaders & investigators	Research team designed a new schedule and action plan for co-developing the intervention was created to reflect the need to decrease pressure on organizations.	Study design, Cultural humility, specificity of message
01/2014	Need to develop a working language between organizations and academic partners	Community leader	Need to be specific in language and recognize 1) different CBOs use diverse terminology and 2) some terms have different meaning to CBO and JHSPH partners.	Cultural humility, Specificity of message
01/2014	Consider the definition of "strengthening" CBOs	Community investigator	Placed an emphasis on point-person at each organization in focusing on co-development of intervention	Study design

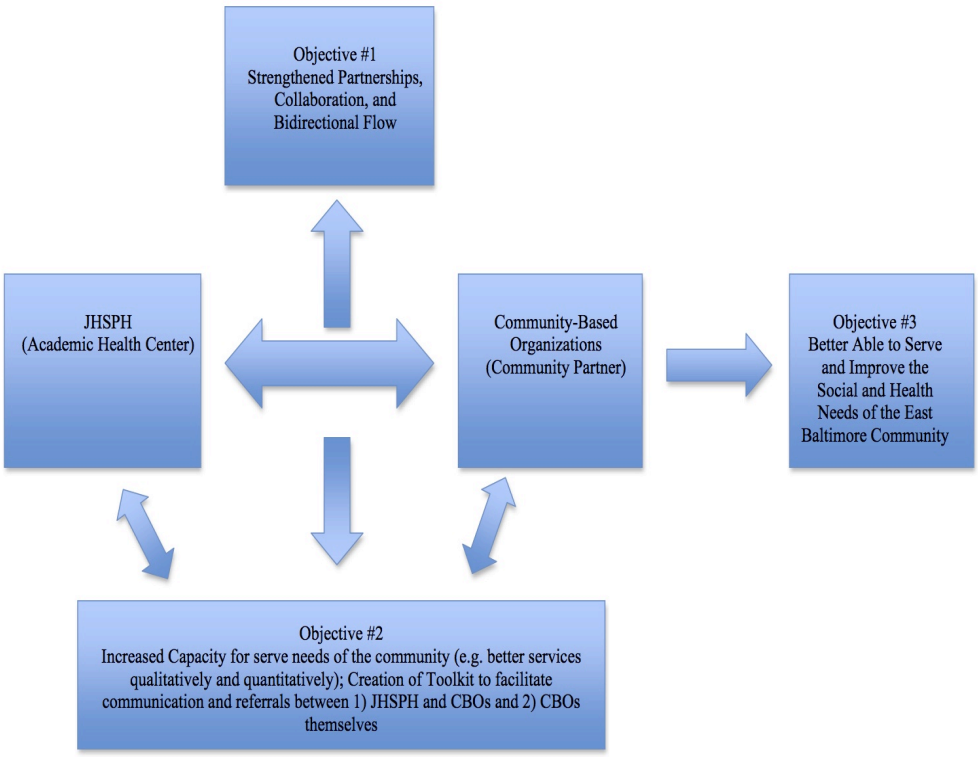

Figure 1: Adapted ACE Approach

(Adapted from (World Health Organization n.d.-a))

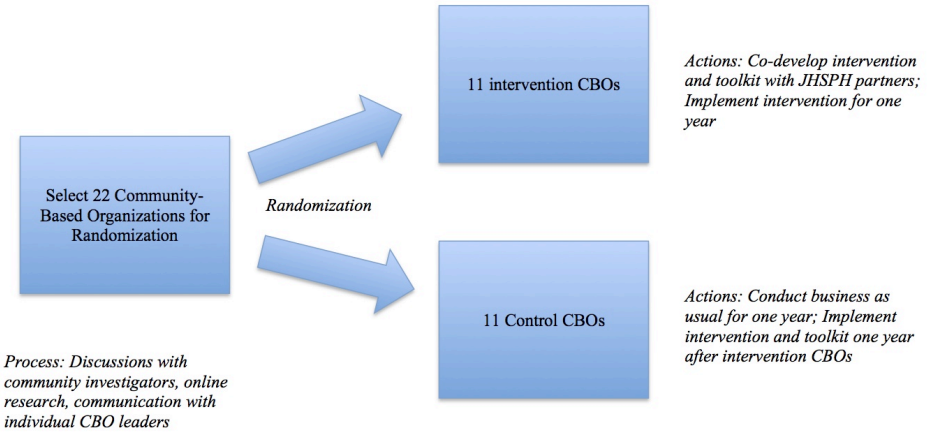

Figure 2: Study Design Implementation and Actions

Appendix 1: Explanations of Events (Supplement to Table 3)

Date	Suggestion/Comment	Result	More Detailed Action
08/2013	Have a kick-off meeting with community leaders to get ideas and feedback on ideas and study/intervention	Held meeting in September 2013	In August 2013, one of our community investigators suggested we have a kick-off meeting with potential community partners and local CBOs. There was some discussion over whether this would be a good idea and whether we needed to engage with partners at this juncture. In September 2013, the research team decided to host this meeting, with around 25-30 individuals in attendance. For this meeting, the same community investigator suggested attendees have a discussion time around tables, focusing on questions of academic and community strengths and considering potential solutions.
09/2013	Publishing a weekly newspaper	Nothing yet	Nothing yet
09/2013	Consider the status and place CBOs are in	Put an emphasis on creating a coalition and partnerships between organizations	The research team realized it had to consider the place and status of individual CBOs. This meant to consider the size, the services, and whether we believed they might be able sustain participation. This led to conversations around CBOs having 501(c)3 status. It also led to a focus on coalition building and partnerships. It brought us to consider what the strengths of each organization might be and what each CBO could possibly bring to a coalition. These discussions helped inform the

			beginning of inclusion/exclusion criteria.
09/2013 – 12/2013	Questioning whether or not larger CBOs should be included in our study	Looked to find a balance in the size of an organizations	One community investigator suggested that larger organizations should not be included in the study. He wanted to ensure the study help and support organizations that needed could significantly benefit from partnership building and collaboration with other CBOs. He wanted a focus on organizations that might have a presence within the community. In the end this was not feasible because of the desire for 501(c)3 organizations. It was also decided that the project should have a balance in the size of organizations, which could help with different strengths in coalition building.
09/2013-03/2014	Selecting CBO categories	Community members had knowledge of the needs of the community and were able to help direct the conversation towards helping find categories that had organizations we could match	Community investigators were vocal and helpful in directing CBO service selections and CBOs in general. They had knowledge about particular CBOs that JHSPH investigators did not have, such as which CBOs would make good partners and whether a CBO found online was still functioning. In selecting categories of CBOs, they helped share what kinds of services would be helpful and beneficial to include in a coalition, e.g. transportation services, drug abuse, food providers. These suggestions helped guide where to direct searches and conversations, ultimately shaping which CBOs the team considered. This forced the team to also relax its definition of a CBO, as neighborhood associations were included. The

			team had to think on a broader scale about the role of an organization within the community.
10/2013 – 03/2014	Knowledge of what community leaders would be good partners	Considered when looking at Community Action Board members and partnered CBOs	Community investigators and those with experience in community engagement used their knowledge about what leaders would be good partners, particularly for the Community Action Board. Their knowledge of community politics, as well as local philanthropy, helped provide direction for selecting individuals to serve in an advisory capacity.
12/2013	Inclusion of Faith-Based organizations	Faith-based organizations included as participating organizations	The team debated whether to include churches that provide services that would be of benefit to the target population. There were a number of issues. First, almost all churches have 501(c)3 status, so it would be difficult to decide on which to include. Second, the sheer number of churches in our catchment area meant the team would have had to vet each congregation to see if they might qualify for the study. At the persistence of a JHSPH investigator with 25+ years of community involvement, churches with substantial ministries related to our study were included. Congregations to contact were selected based on the suggestions of the JHSPH investigator and the three community investigators
12/2013	Host a meeting with all potential CBOs to share more information on study/intervention	Held meeting in January 2014	A community investigator suggested we hold an information session after we selected approximately 30 CBOs. There was some resistance from the academic investigators from a fear of contaminating the

			control group and building a coalition among that group, which would generate a bias in the results. After consulting with a number of statisticians, the team was informed it had a unique problem on its hands: this was something the statisticians had not seen before. With this the team decided to have this meeting, held in January 2014. The effect of it is not known from a partnership building perspective.
01/2014	Sensitivity to food served at meetings	Instead of pizza or sandwiches, we served baked ziti	Instead of pizza or sandwiches, we served baked ziti
01/2014	Organizations do not have the time or personnel capacity to give a staff member yet another task to do.	Led to decision to direct some funding allocated for CBOs to help pay for staff members' time spent on project	Some academic investigators had conversations with CBO leaders who expressed concern over what was required to participate. Many of the CBOs have a small staff, rely on a large number of volunteers, and/or do not have the ability to volunteer time, among others. It became clear were not sensitive to the temporal needs of CBOs. They may not have the flexibility to do something not related to their specific services or those whom they serve. They may not have the resources to allow a staff member or volunteer to devote time to participating in the study. The team realized the importance of needing to value the time that CBOs would put into the study. Out of these conversations, the team realized participating CBOs should be compensated for their time in a way that a staff member would be compensated for work. This compensation also provided a scientific rationale for remaining engaged with control

			CBOs. By compensating them for their participation, the team saw this provided an opportunity for continuing to collect data from control CBOs and to decrease the possibility of losing participating CBOs.
01/2014	Refining of message in engaging possible participants	Research team was forced to consider what exactly we are asking of organization in participating.	The research team had to consider what the nature of participation was. What did it mean to participate? What exactly was required of CBOs to be part of our study? Given the nature of participatory methods, the intervention is not pre-determined; it is co-developed. What did it really mean to "co-develop" an intervention? CBOs had to see that co-development meant creating and receiving something tangible and valuable to their organizations. The team had to make it less ambiguous that it was in their best interest, despite the constraints on the organizations, to participate. The team was forced to determine expectations for CBOs in each group, as intervention and control expectations would be different
01/2014	Frequency of CBO meetings in intervention design phase	Research team designed a new schedule and action plan for co-developing the intervention was created to reflect the need to decrease pressure on organizations.	Community investigators provided the team at large suggestions for the purposes of meeting. Also, because of the desire to be sensitive to time, the team wanted to minimize the amount of meetings. Therefore, the research team decided to take on responsibility for collecting data and designing a survey to understand what are possible directions for intervention. With community investigator support, instead of having multiple meetings to discuss this, it was

			determined it would a better use of time to administer a survey and present the findings to the intervention group. The team developed a new schedule to decrease potential pressure on CBOs.
01/2014	Need to develop a working language between organizations and academic partners	Need to be specific in language and recognize 1) different CBOs use diverse terminology and 2) some terms have different meaning to CBO and JHSPH partners.	The research team learned there were a number of language barrier in discussing the study. First, individuals whom CBOs serve have different names. Some are "clients"; others are "neighbors." Churches may refer to individuals as "parishioners." In this, the team had to be sensitive to the language and acknowledge such differences. Second, who implements programs is different. Some programs have only staff; others are staff alongside of volunteer-based. Third, there are differences in how community members refer to Johns Hopkins itself; "Hopkins" is not a universally understood term. How researchers and community members understand and refer to the hospital, departments, and specialties is different. There is not "one" Hopkins. In recognizing this, it become important for the research team to incorporate this into the future co-developed intervention and toolkit.
01/2014	Consider the definition of "strengthening" CBOs	Placed an emphasis on point-person at each organization in focusing on co-development of intervention	the team recognized that what it meant to strengthen an organization was different for some CBOs and for researchers. For some CBOs, strengthening means to be able to meet their current needs and capacity, not necessarily taking on more clients or adding more

			programming. It is to do what they do now better. For others, it is to increase their capacity to serve more individuals in addition to meeting their current demand. In understanding this, the team noted it had to be open to the co-developed intervention having components to simply meet present capacity. This also led to the team realizing there needed to be a point person who will represent the organization in the study, if possible

Appendix 2: My role as a research assistant

I have served as a research assistant for Project CONNECT since August 2014. During this time, I have attended weekly meetings and CBO information sessions. The main result of my time on this project is the production of this manuscript. I have reviewed meeting minutes, communicated with our research team, and written this as the first paper to introduce our project.

Bibliography

Baker, E. A., S. Homan, R. Schonhoff, and M. Kreuter. 1999. "Principles of practice for academic/practice/community research partnerships." *Am J Prev Med* 16(3 Suppl): 86-93.

Christopher, S., V. Watts, A. K. H. G. McCormick, and S. Young. 2008. "Building and maintaining trust in a community-based participatory research partnership." *American Journal of Public Health* 98(8): 1398.

Cooper, L. A., L. E. Boulware, E. R. Miller, 3rd, S. H. Golden, K. A. Carson, G. Noronha, M. M. Huizinga, D. L. Roter, H. C. Yeh, L. R. Bone, D. M. Levine, F. Hill-Briggs, J. Charleston, M. Kim, N. Y. Wang, H. Aboumatar, J. P. Halbert, P. L. Ephraim, and F. L. Brancati. 2013a. "Creating a transdisciplinary research center to reduce cardiovascular health disparities in Baltimore, Maryland: lessons learned." *Am J Public Health* 103(11): e26-38.

Cooper, L. A., D. E. Ford, B. K. Ghods, D. L. Roter, A. B. Primm, S. M. Larson, J. M. Gill, G. J. Noronha, E. K. Shaya, and N. Y. Wang. 2010. "A cluster randomized trial of standard quality improvement versus patient-centered interventions to enhance depression care for African Americans in the primary care setting: study protocol NCT00243425." *Implement Sci* 5: 18.

Cooper, L. A., B. K. Ghods Dinoso, D. E. Ford, D. L. Roter, A. B. Primm, S. M. Larson, J. M. Gill, G. J. Noronha, E. K. Shaya, and N. Y. Wang. 2013b. "Comparative effectiveness of standard versus patient-centered collaborative care interventions for depression among African Americans in primary care settings: the BRIDGE Study." *Health Serv Res* 48(1): 150-74.

Galea, S. and D. Vlahov. 2005. "Urban health: evidence, challenges, and directions." *Annu Rev Public Health* 26: 341-65.

Goldberg-Freeman, C., N. E. Kass, P. Tracey, G. Ross, B. Bates-Hopkins, L. Purnell, B. Canniffe, and M. Farfel. 2007. “"You've got to understand community": community perceptions on "breaking the disconnect" between researchers and communities.” *Prog Community Health Partnersh* 1(3): 231-40.

Immelt, J. R., V. Govindarajan, and C. Trimble. 2009. “How GE is disrupting itself.” *Harvard Business Review* 87(10): 56-65.

Israel, B. A., A. J. Schulz, E. A. Parker, and A. B. Becker. 1998. “Review of community-based research: assessing partnership approaches to improve public health.” *Annu Rev Public Health* 19: 173-202.

Israel, B. A., A. J. Schulz, E. A. Parker, A. B. Becker, A. J. Allen, 3rd, and J. R. Guzman. 2008. “Critical Issues in Developing and Following CBPR Principles.” In *Community-based participatory research for health: From process to outcomes*, edited by M. Minkler and N. Wallerstein, pp. 47-66. San Francisco, CA: John Wiley & Sons.

Jones, L., P. Koegel, and K. B. Wells. 2008. “Bringing Experimental Design to Community-Partnered Participatory Research.” In *Community-based participatory research for health: From process to outcomes*, edited by M. Minkler and N. Wallerstein, pp. 67-90. San Francisco, CA: John Wiley & Sons.

Jones, L. and K. Wells. 2007. “Strategies for academic and clinician engagement in community-participatory partnered research.” *JAMA* 297(4): 407-10.

Levine, D. M., D. M. Becker, and L. R. Bone. 1992a. “Narrowing the gap in health status of minority populations: a community-academic medical center partnership.” *Am J Prev Med* 8(5): 319-23.

Levine, D. M., D. M. Becker, L. R. Bone, M. N. Hill, M. B. Tuggle, 2nd, and S. L. Zeger. 1994. "Community-academic health center partnerships for underserved minority populations. One solution to a national crisis." *JAMA* 272(4): 309-11.

Levine, D. M., D. M. Becker, L. R. Bone, F. A. Stillman, M. B. Tuggle, 2nd, M. Prentice, J. Carter, and J. Filippeli. 1992b. "A partnership with minority populations: a community model of effectiveness research." *Ethn Dis* 2(3): 296-305.

MacQueen, K. M., E. McLellan, D. S. Metzger, S. Kegeles, R. P. Strauss, R. Scotti, L. Blanchard, and R. T. Trotter, 2nd. 2001. "What is community? An evidence-based definition for participatory public health." *Am J Public Health* 91(12): 1929-38.

Marmot, M., S. Friel, R. Bell, T. A. Houweling, S. Taylor, and H. Commission on Social Determinants of. 2008. "Closing the gap in a generation: health equity through action on the social determinants of health." *Lancet* 372(9650): 1661-9.

Maurana, C. A. and K. Goldenberg. 1996. "A successful academic-community partnership to improve the public's health." *Acad Med* 71(5): 425-31.

Meyer, D., A. Armstrong-Coben, and M. Batista. 2005. "How a community-based organization and an academic health center are creating an effective partnership for training and service." *Acad Med* 80(4): 327-33.

Murray, C. J., S. C. Kulkarni, C. Michaud, N. Tomijima, M. T. Bulzacchelli, T. J. Iandiorio, and M. Ezzati. 2006. "Eight Americas: investigating mortality disparities across races, counties, and race-counties in the United States." *PLoS Med* 3(9): e260.

Ross, L. F., A. Loup, R. M. Nelson, J. R. Botkin, R. Kost, G. R. Smith, and S. Gehlert. 2010. "The challenges of collaboration for academic and community partners in a research partnership: points to consider." *J Empir Res Hum Res Ethics* 5(1): 19-31.

Sachs, J. D. and P. Singh. 2013. "We are already applying lessions from Africa in New York's Harlem" [accessed on April 1, 2013]. Available at.

Schulz, A. J., J. Krieger, and S. Galea. 2002. “Addressing social determinants of health: community-based participatory approaches to research and practice.” *Health Educ Behav* 29(3): 287-95.

Skloot, R. 2010. *The Immortal Life of Henrietta Lacks*. New York: Broadway Books.

Smith, K. C., L. Bone, E. A. Clay, K. Owings, S. Thames, and F. Stillman. 2009. “Partnering with education and job and training programs for sustainable tobacco control among Baltimore african american young adults.” *Prog Community Health Partnersh* 3(1): 9-17.

Syed, S. B., V. Dadwal, P. Rutter, J. Storr, J. D. Hightower, R. Gooden, J. Carlet, S. Bagheri Nejad, E. T. Kelley, L. Donaldson, and D. Pittet. 2012. “Developed-developing country partnerships: benefits to developed countries?” *Global Health* 8: 17.

Syed, S. B., V. Dadwal, J. Storr, P. Riley, R. Paul, J. D. Hightower, R. Gooden, E. Kelley, and D. Pittet. 2013. “Strengthening the evidence-policy interface for patient safety: enhancing global health through hospital partnerships.” *Global Health* 9(1): 47.

Syed, S. B., R. Gooden, J. Storr, J. D. Hightower, P. Rutter, S. Bagheri Nejad, A. Lardner, E. Kelley, and D. Pittet. 2009. “African partnerships for patient safety: a vehicle for enhancing patient safety across two continents. [corrected].” *World Hosp Health Serv* 45(4): 24-7.

Tyus, N. C., M. C. Gibbons, K. A. Robinson, C. Twose, and B. Guyer. 2010. “In the shadow of academic medical centers: a systematic review of urban health research in Baltimore City.” *J Community Health* 35(4): 433-52.

Vlahov, D., N. Freudenberg, F. Proietti, D. Ompad, A. Quinn, V. Nandi, and S. Galea. 2007. “Urban as a determinant of health.” *J Urban Health* 84(3 Suppl): i16-26.

Wallerstein, N. B. and B. Duran. 2006. “Using community-based participatory research to address health disparities.” *Health Promotion Practice* 7(3): 312-23.

Wells, K. B., L. Jones, B. Chung, E. L. Dixon, L. Tang, J. Gilmore, C. Sherbourne, V. K. Ngo, M. K. Ong, and S. Stockdale. 2013. “Community-partnered cluster-randomized comparative effectiveness trial of community engagement and planning or resources for services to address depression disparities.” *J Gen Intern Med* 28(10): 1268-78.

Wells, K. B., A. Staunton, K. C. Norris, R. Bluthenthal, B. Chung, L. Gelberg, L. Jones, S. Kataoka, P. Koegel, J. Miranda, C. M. Mangione, K. Patel, M. Rodriguez, M. Shapiro, and M. Wong. 2006. “Building an academic-community partnered network for clinical services research: the Community Health Improvement Collaborative (CHIC).” *Ethn Dis* 16(1 Suppl 1): S3-17.

Wolff, M. and C. A. Maurana. 2001. “Building effective community-academic partnerships to improve health: a qualitative study of perspectives from communities.” *Acad Med* 76(2): 166-72.

World Health Organization. 2008. *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health: Commission on Social Determinants of Health Final Report*: World Health Organization, Commission on Social Determinants of Health.

World Health Organization. 2009. "Building a Working Definition of Partnership: African Partnerships for Patient Safety (APPS) " [accessed on April 1, 2009]. Available at: http://www.who.int/patientsafety/implementation/apps/resources/defining_partnerships-apps.pdf?ua=1.

World Health Organization. n.d.-a. "African Partnership for Patient Safety" [accessed on April 1, n.d.-a]. Available at: http://www.who.int/patientsafety/implementation/apps/en/.

World Health Organization. n.d.-b. "Evidence-Policy Strengthening: The APPS Approach" [accessed on April 1, n.d.-b]. Available at:

http://www.who.int/patientsafety/implementation/apps/resources/APPS_approach_evidence-policy_memory-aid_2012-12_EN.pdf?ua=1.

Curriculum Vitae

Bryan M. Dougan

Home Address:
1607 Myamby Rd
Towson, MD 21286
(443) 622-9779
bmdougan@gmail.com

Office Address:
Johns Hopkins Bloomberg School of Public Health
615 N. Wolfe St E5035
Baltimore, MD 21205
bdougan@jhsph.edu

DOB: 09/08/1989
Location: Baltimore, MD

Education

Expected 05/2014 — Master of Science in Public Health (MSPH)
Department of International Health
Program in Social & Behavioral Interventions
The Johns Hopkins University, Bloomberg School of Public Health

05/2011 — Bachelor of Arts (BA) in Sociology, Cum Laude
Franklin & Marshall College

01/2010-05/2010 — Development Studies - Uganda Study Abroad Program
World Learning/School for International Training

Academic Scholarship

2008 — Charles A. Dana Scholarship, Franklin & Marshall College

Academic Honors

2010 — Alpha Kappa Delta, Sociology Honor Society, Franklin & Marshall College
2010 — John Marshall Pre-Law Honorary Society, Franklin & Marshall College
2009 — Eta Sigma Phi, Classics Honorary Society, Franklin & Marshall College

Honors List, Spring 2008, Fall 2010, Franklin & Marshall College
Dean's List, Fall 2007, 2008, 2009; Spring 2009, 2011, Franklin & Marshall College

Awards Received

2011 — The Benjamin Peralta '89 Award, Franklin & Marshall College (with others)
2011 — Franklin & Marshall Community & Public Service Group Award (with others)

Publications

2012 — Dicklitch, Susan, Berwood Yost, and **Bryan M. Dougan**. "Building a Barometer of Gay Rights (BGR): A Case Study of Uganda and the Persecution of Homosexuals." *Human Rights Quarterly* 34(2): 448-471.

Invited Talks/Presentations

03/2013 — "International and Domestic Perspectives: Gender-Based Violence and Mental Health." Given for the Health Committee of the Baltimore Chapter of the NCCAP, Baltimore, MD

03/2012 "Trauma and War in DR Congo" Given at *Preparing for Global Tomorrow Symposium* at Washington & Lee University, Lexington, VA.

Grants Received

2013 Global Health Established Field Placement, awarded by the Center for Global Health, The Johns Hopkins University, to work on Chronic Consequences of Trauma, Injuries and Disability (Chronic-TRIAD) project in Uganda.
Amount awarded: $3,500

Research Experience

08/2013-Present Research Assistant, Center for Health Services and Outcomes Research, Department of Health Policy & Management, The Johns Hopkins University

06/2013-12/2013 Research Assistant, International Injury Research Unit, Department of International Health, The Johns Hopkins University

02/2013-05/2013 Research Assistant, Johns Hopkins Global Center for Childhood Obesity, Department of International Health, The Johns Hopkins University

05/2010-08/2010 Research Assistant, Department of Government, Franklin & Marshall College

Non-Profit Experience

07/2011-06/2012 Mobilization Specialist/Bike Tour Intern, She's My Sister, American Bible Society, Chantilly, VA

- Supported volunteers and donors with regular letter/email communications and reports.
- Oversaw data content, updates, and quality control of social media sites for the She's My Sister Bike Tour
- Maintained and oversaw presentation scheduling for individuals from She's My Sister Speakers Bureau
- Developed and maintained the database of supporting volunteers, including churches, groups, and organizations
- Gathered and maintained important information related to Bike Tour follow-up: volunteer reviews and feedback, videos for official documentation
- Researched and provided summaries related to 2012 Lord's Resistance Army conflict
- Designed budgets and projected 5-year target numbers for She's My Sister
- Traveled to other organizations and groups to give presentations on the work and vision of She's My Sister

Academic Service

09/2010-05/2011 Member, Educational Policy Committee, Franklin & Marshall College
01/2009-12/2009

02/2011, 05/2011 Student Advisor to Trustee Committee on Advancement, Franklin &

Marshall College

02/2009, 05/2009, 10/2009 — Student Advisor to Trustee Committee on Academic Investments, Franklin & Marshall College

03/2009-05/2011 — Student Co-Chair, Human Rights Awareness Week Planning Committee, Franklin & Marshall College

Volunteer Service

05/2011-07/2011 — Volunteer Logistical Coordinator, She's My Sister Bike Tour 2011, American Bible Society

Student Extracurricular Leadership

12/2009-05/2011 — Co-Founder and Treasurer, The Human Rights Initiative (THRI)
02/2009-12/2009 — President, Ware College House Parliament, Franklin & Marshall College
08/2007-05/2011 — Staff Writer (News), *The College Reporter*, Franklin & Marshall College

Professional Development

Language Skills: Fluent English, Conversational French, Reading Comprehension of Attic and Koine Greek
Computer Skills: Proficient in MS Office (Word, Excel, Powerpoint), STATA, Social Media (Facebook, Twitter)
Leadership: Project management (logistical planning), Customer Service, Public Speaking