PRISM: A Journal of Regional Engagement

Volume 1 | Issue 1 Article 1

May 2012

Engaging Rural and Urban Appalachians in Research using a Community-Based Participatory Research Approach

Laureen H. Smith
The Ohio State University, Columbus, OH, smith.5764@osu.edu

Jessica Valenzuela
Nova Southeastern University, jv637@nova.edu

Robert L. Ludke
University of Cincinnati, Robert.Ludke@uc.edu

Engaging Rural and Urban Appalachians in Research using a Community-Based Participatory Research Approach

Cover Page Footnote
The projects described were funded by NCRR Recovery Act Administrative Supplement for Collaborative Community Engagement Research – ULRR025755. The authors wish to acknowledge our community partners and research teams including Carol Smathers, Cindy Oliveri, Pike Healthy Lifestyles Initiative, Western High School, the Urban Appalachian Council, Lower Price Hill Residents, Demaree Bruck, Santa Maria Community Services, Cincinnati Diabetes and Obesity Center, and the Price Hill Health Clinic.

Our inaugural issue reflects disciplinary and methodological diversity in the context of an overarching theme of place: Appalachia. As the contributors demonstrate, this region, which is itself immense and diverse, has some unique challenges that offer opportunities for collaboration between universities and communities. At the same time, the initiatives described here, the models outlined, and the reflections offered, are not limited in their relevance to Appalachia as they offer broad lessons and guidance for engagement efforts.

Future spring issues of *PRISM* will explore other unifying themes including "The Current State of Engagement in American Universities" in 2013, and "Engaging Underserved Populations" in 2014. Fall issues are non-themed and will include works meeting the general aims and scopes of the journal. To be successful in promoting a culture of engagement between the university and region through the sharing of information, knowledge, and practices, *PRISM* depends heavily on support from the academic community. We call on faculty, staff, and administrators involved in engagement efforts to submit scholarly work on those efforts to the journal. We also encourage you to spread word of *PRISM* to colleagues and to community partners.

The launch of *PRISM* has been possible only through the assistance of many individuals. Eastern Kentucky University has been instrumental in the endeavor through institutional support. Inspired by President Doug Whitlock, the campus is demonstrating an enhanced commitment to service and outreach. In particular, *PRISM* has received generous support from Dr. Sara Zeigler, Dean of University Programs, as part of her unit's efforts through the Office of Regional Stewardship. University personnel have also played important roles as support staff, editorial board members, and manuscript reviewer. Of course, reviewers and board members are also drawn from other institutions and we express our gratitude to them as well and encourage interested individuals to contact us regarding opportunities to serve on the editorial board and/or review manuscripts. Finally, we thank our nineteen contributing authors for their diligence and patience in preparing their pieces for inclusion in *PRISM*'s inaugural issue. We are thrilled to present this issue to you and we look forward to future issues as we collaborate to advance the scholarship and practice of engagement.

©PRISM: A Journal of Regional Engagement, Vol 1, Number 1, p. x, (2012)

Engaging Rural and Urban Appalachians in Research using a Community-Based Participatory Research Approach

Laureen H. Smith *Ohio State University*
Jessica Valenzuela *Nova Southeastern University*
Robert L. Ludke *University of Cincinnati*

Appalachians are particularly vulnerable to chronic diseases as documented by recent national studies that have identified disproportionally higher rates of cancer, diabetes, heart disease and premature mortality for this population. Evidence-based interventions to reduce rates of diabetes and obesity among adults and children have been ineffective among Appalachians where multiple factors including poor living conditions, limited health information, lifestyle behaviors, and lack of access to health care interact to increase the prevalence of these problems. However, there is growing evidence that Community-Based Participatory Research (CBPR) conducted through community-academic partnerships can lead to significant health and social impact in communities faced with seemingly intractable health disparities. Framed in the guiding principles of the CBPR approach, this paper describes the development of two academic-community partnerships that took root in Appalachian communities, one urban and one rural. Both partnerships aimed to identify community health needs, develop a community-led intervention to promote positive health outcomes, and evaluate that work iteratively. Although the initial focus for each community was to address obesity and diabetes risk, adherence to the CBPR approach led to different community identified prioritized needs and different pilot projects. The CBPR approach resulted in strong partnerships, each with improved capacity to address Appalachian health disparities in their communities.

Stressors in the social environment are associated with poor health outcomes, contributing to the gaps in health status between socio-economic groups and ethnic or racial groups (Israel et al., 2010). Although much attention has been paid to health disparities in the past decades, efforts to ameliorate disparities have been largely unsuccessful (Gehlert & Coleman, 2010). One reason is that these efforts have not been tailored to the communities whose problems they are meant to address (Gehlert & Coleman, 2010). There is growing evidence that Community-Based Participatory Research (CBPR) conducted through community-academic partnerships can lead to significant health and social impact in racial/ethnic minority communities faced with seemingly intractable health disparities (Wallerstein & Duran, 2010). To date, CBPR has primarily been carried out in predominately low-income communities and communities of color (Israel, Eng, Schultz, & Parker, 2005; Minkler, 2004). Emphasizing collaboration, engagement, capacity-building, and mutual co-learning (Baiardi, Brush, & Lapides, 2010), CBPR efforts have addressed numerous community identified health concerns including breast cancer (Gehlert & Coleman, 2010), nutritional health (Kennedy et al., 2011), policy advocacy (Israel et al., 2010), rehabilitation (Hergenrather, Geishecker, McGuire-Kuletz, Gitlin, & Rhodes, 2010), teen tobacco use (Horn, McCracken, Dino, & Brayboy, 2008), depression among latinos (Michael, Farquhar, Wiggins, & Green, 2008), and youth living with HIV (Flicker, 2008).

Framed in the guiding principles of the CBPR approach, this paper describes the development of two community-academic partnerships, one urban and one rural, which focused on the health disparities faced by Appalachians. Both partnerships aimed to develop and evaluate a community-led intervention to promote positive health outcomes in their respective community. While critical to the CBPR approach, the evaluation of programs and analysis of outcomes are not the focus of this paper. Rather, a complete analysis of outcomes resulting from both partnerships is being drafted for future publication. The paper first describes the vulnerability and health disparities prevalent in Appalachia then provides details and examples of how each partnership applied the seven principles of community-based research described by Israel, Schulz, Parker, Becker, Allen, & Guzman (2003). The paper concludes with a discussion of recommendations regarding the use of CBPR.

Appalachia is the 205,000-square mile federally-designated region that follows the spine of the Appalachian Mountains from southern New York to northern Mississippi. It includes all of West Virginia and parts of twelve other states including Ohio. Forty-two percent of the region's population is rural. Mirroring the health disparities found in ethnic minority groups, residents of Appalachia are particularly vulnerable to chronic diseases compared to other regions within the United States. Recent national studies have identified higher rates of cancer, diabetes, heart disease and premature mortality among adult residents residing within this region compared to other geographic regions (Centers for Disease Control and Prevention, 2002; Halveson, Barnett, & Casper, 2002; Kluhsman, Bencivenga, Ward, Lehman, & Lengerich, 2006; Zullig & Hendryz, 2010). For example, more than 140,000 adults, 12.4% of Appalachian residents, have a diagnosis of diabetes; a prevalence that is significantly higher than national rates (Centers for Disease Control and Prevention, 2011). Furthermore, rates of childhood and adult obesity are higher in Appalachia compared to rural, national and state-level rates (State of Ohio, 2009a), with the proportion of obesity among Appalachian children fast approaching 25% (Mongtomery-Reagan, Bianco, Heh, Rettos, & Huston, 2010; Oza-Frank, Norton, Scarpitti, Wapner, & Conrey, 2011). Differences in socioeconomic and environmental stressors likely contribute to these health disparities (Brulle, & Pellow, 2006; Morrone, 2008). Persons living in Appalachia generally have lower income, poorer educational achievement and lack access to health care (Behringer & Friedell, 2006; DeNavas-Walt, Proctor, & Smith, 2010; Morrone, 2008). Consequently, economic deprivation is a serious problem in the region; Appalachia contains some of the poorest geographical areas nationwide (DeNavas-Walt et al., 2010).

In addition, there are large numbers of Appalachian migrants and their descendants living within cities outside of the region. Often referred to as "urban Appalachians" because of their concentrations in large Northeastern and Midwestern cities, many of these individuals participated in the Great Migration out of the Appalachian region during the 20th century (Obermiller, Wagner, & Tucker, 2000). Although there are fewer facts, mostly outdated, about the health of the millions of these urban Appalachian migrants and their descendents, many are experiencing the same socioeconomic and health concerns as do their counterparts in the Appalachian region (Obermiller et al., 2000). For example, the urban Appalachian community highlighted in this paper has some of the lowest levels of educational achievement, employment, and economic prosperity in the area. These factors are coupled with poor health status and the high rates of chronic disease and poor health status (e.g., diabetes). One neighborhood has a prevalence rate of diabetes exceeding 21%, more than double the rate for the city.

With a population of approximately 27,000 residents, the rural county lies in the heart of Appalachia Ohio. Compared to other counties within Ohio and Appalachia Ohio, the rural county is disproportionately burdened with high unemployment, poverty, and low educational attainment (State of Ohio, 2009b). The county ranks 80th out of Ohio's 88 counties on health outcomes [a composite of premature death and years of potential life lost prior to age 75 years] and 50th out of Ohio's 88 counties on health behaviors [a composite of tobacco use, obesity, alcohol use, and high risk sexual behavior] (University of Wisconsin Population Health Institute, 2010). Recent analyses suggest that children in the rural county may be at high risk for nutritionally related weight problems, as more than 71% of adults and 44% of children are overweight or obese (State of Ohio, 2009a). Home to 230 students of which 52% are economically disadvantaged, the participating school is located in the remote western area of the county. The urban project was conducted in a small, disadvantaged neighborhood in Cincinnati, Ohio. Its approximately 750 residents are predominantly low-income Caucasians of Appalachian descent. The neighborhood is characterized by high rates of poverty, unemployment, high school dropout, illiteracy, and food insecurity as well as rates of poor self-reported health status, obesity, and diabetes that are almost twice those of the city as a whole.

In both urban and rural Appalachian communities, poor living conditions, lack of access to healthcare, and limited health information may result in unhealthy lifestyle behaviors, including limited preventive care and unhealthy dietary and activity patterns. Health disparities research focused on racial/ethnic minority communities, both urban and rural, have identified these lifestyle factors as important contributors to poorer health status (Bai, Hillemeier, & Lengerich, 2007; Behringer & Friedell, 2006; Brulle & Pellow, 2006). These factors are relevant in considering disparate rates of obesity and diabetes found in Appalachian communities, as they have been important contributors in other racial/ethnic minority communities (Adams & Lammon, 2007; Haverson, Ma, & Harner, 2004).

The high burden of health disparities in Appalachian communities cannot be externally solved. To have a meaningful and sustainable impact on health and healthy lifestyles, Appalachian communities must be active partners with researchers and health care providers to address self-identified health needs. Community participation in the identification of their health needs, the design of solutions to disparate health outcomes, and the implementation of those solutions is an empowering approach to the challenges faced by Appalachians. Although written from the perspective of the researchers, the input of community partners was invaluable in the paper's completion.

Applying the Principles of Community-Based Participatory Research in Appalachia

CBPR is a collaborative approach that equally involves and recognizes the unique strengths of all partners (Horn et al., 2008). The CBPR approach includes: a) building trust with community stakeholders, b) using co-learning and empowerment as a means of defining research questions important to the community, c) employing culturally appropriate research methods, and d) using a community-driven process to disseminate findings (Israel et al., 2005; Williams, Bray, Shapiro-Mendoza, Reisz, & Peranteau, 2009). The potential strength of CBPR in addressing health concerns and disparities within communities comes from combining scientific rigor with community wisdom, reality, and action for change (Gehlert & Coleman, 2010). The CBPR principles that guided the projects in the urban

and rural Appalachian communities and each partnership's efforts to make the principles a reality are outlined below (Israel et al., 2003).

Principle 1: Recognizing Community as a Unit of Identity

Community identity is a central foundation of CBPR (Israel et al., 2003). While it is impossible to describe one culture for all Appalachia, Appalachian communities may identify themselves locally by geographic place (i.e., by neighborhood) or by other factors such as place of origin, shared values, or shared experiences. In both urban and rural Appalachia, 67% of project participants considered themselves Appalachian or of Appalachian descent.

Urban Appalachian residents in metropolitan areas may live outside of the geographically-defined Appalachian regions, but share a history of migration into industrial areas of the Northeast and Midwest as well as shared kinship networks, ties to faith or religion, and living in urban poverty with housing, education, and health concerns (Obermiller et al., 2000). Similar shared experiences exist within rural Appalachian communities. However, many rural community members report longer generational residency in the same geographic locale and strong ties to place.

At the start of the project, the rural Appalachian community was forming a wellness coalition made up of community residents and stakeholders. The coalition's goal as defined by its members was to improve community health by promoting healthy lifestyle behaviors. Although the coalition meetings were held in the largest town, coalition members defined their community to include both local towns and the more remote regions of the county; i.e., all residents of the entire county.

In the urban Appalachian community, the overarching goal was to empower community residents about diabetes through advocacy programs and to directly benefit neighborhood residents through improved diabetes outcomes. To achieve the goal, researchers sought partnership with an established community-based service and advocacy agency, the Urban Appalachian Council (UAC), as well as directly with community residents targeted through UAC programs and services. Through early discussions among community and academic partners, the community of interest was defined as a small geographic neighborhood within the greater metropolitan area. This largely Appalachian neighborhood included smaller groups of African-American and Latino residents. Given awareness that other racial/ethnic groups in their community have similar barriers to positive health, there was unanimous agreement among community residents and stakeholders that the project be inclusive of all neighborhood residents. Community resident and stakeholder input made it clear to research partners that including only residents of Appalachian heritage would not be representative or in the best interest of the project or community.

Principle 2: Building on Community Strengths and Resources

CBPR requires reaching out to potential partners for collaboration in identifying and addressing the community's health concerns (Israel et al., 2003). In both selecting partners and designing community-based efforts, CBPR requires building on existing strengths including skills, social networks and support systems (Israel et al., 2003). Assets previously identified as protective factors for positive health have been identified in Appalachian communities. These assets include strong family ties, spiritual beliefs, and a sense of place (Coyne, Demian-Popescu, & Friend, 2006). However, each community also had unique partnership opportunities and resource assets.

Although a community interest in wellness was identified among a core group of residents and agencies in the rural Appalachian community, key organizational and individual stakeholders were only beginning to become engaged in the work of building a community health coalition. The structure, mission goals, and leadership structure of the coalition were not yet established and strong partnerships were not yet recognized or effectively engaged in health promotion. Given the fledging nature of the coalition, researchers in rural Appalachia were welcomed to join coalition members in identifying and prioritizing health concerns and working collaboratively to improve health outcomes. Consequently, from its inception, academic partners have been a key organizational coalition partner. Researchers attended and contributed to every coalition meeting providing input on a conducting a health needs assessment, understanding health concerns, and developing a pilot research project.

Strengths and resources of the urban Appalachian community partners included strong social networks, a sense of urgency around improving health, and prior experience with CBPR. Residents working as long-term employees of the UAC and those who frequently volunteered at local service agencies had a wealth of information and experience with previously successful and failed community initiatives. For example, an understanding that community fliers and mailings were often ineffective recruitment strategies and that door-to-door communication was necessary in the community. In addition, the existence of a local meeting place, a hall in a former neighborhood church where residents frequently gather for events as a community, was a significant strength. Because of it, the project's advisory board, consisting of UAC staff, neighborhood residents, and academic partners, was able to conduct part of the community needs assessment using a "town hall meeting" methodology that actively engaged residents in the process.

The urban community's sense of urgency about community health and strong drive to advocate for each other were also significant strengths. Several residents who provided feedback to the partnership were disabled, had difficulty accessing care, or recently had someone close to them fall ill or die. These experiences were paired with community volunteerism and work in local social service agencies. Therefore, the strong drive to make a difference coupled with a solid foundation permitted residents and local agencies to steer a successful CBPR effort.

Principle 3: Facilitating Collaborative Partnerships across All Phases of Research

CBPR requires that communities have the opportunity to name and define their own experience in a project. CBPR involves a power-sharing process that recognizes the marginalization of certain communities and reinforces mutual decision making in research (Israel et al., 2003). A number of methods and structures can be used to facilitate engagement of partners and active listening on the part of the researchers such as focus groups, town hall meetings, personal interviews, and participation with active coalitions or in board meetings.

Within six months of its inception, the rural Appalachian wellness coalition decided on its formal name, established an organizational structure, and formalized long-term and short term goals. It was agreed that attendees be offered a small meal during meeting times. At the same time, the coalition grew from 10 to 25 members. Community members of the rural wellness coalition continuously provided guidance to researchers on ways to collect

additional information and data, key stakeholders and organizations to contact, and a target aggregate to focus their initial project. For example, it was suggested that initial health data be collected at the local county fair. Focus group sessions with community residents, school staff, and high school aged teens as well as personal interviews with school cafeteria workers were also conducted. Following the findings from these efforts, coalition members agreed to focus their first community-academic partnered project on teenage lifestyle behaviors, specifically consumption of sugar-sweetened beverages. Researchers continued to attend scheduled coalition meetings and provided updates on the project status. Community coalition members provided continued input and guidance as the project progressed.

In the urban Appalachian community, bridging existing gaps between the community and academia required that advisory board composition be equitable. Board membership was balanced so that community residents who participated would not be outnumbered by academic partners or "health care experts" from outside the community. Urban residents, almost 50% of the board at the project's onset, were paid a small fee for board meeting participation. Agency stakeholders on the advisory board advocated for this fee because they felt it was important to recognize the value of residents' time and contribution.

All major decisions involved in the development of a health needs assessment and the designs of a pilot intervention were made by the advisory board via "majority rule" with the priority being to balance research and community goals. The equitable inclusion of community residents and the transparency of decision-making processes were critical to establishing a true partnership. Building trust in this manner was particularly salient in this community because residents had experienced previous disappointments with research and researchers not "keeping their word." In the end, prioritizing the principle of collaboration within each project, urban and rural, created the opportunity for building much needed trust. This trust made possible the important contributions of community partners to research including their input on translation into practice as well as protecting and engaging the communities.

Principle 4: Promoting Co-Learning and Capacity Building

By its nature, CBPR promotes co-learning and capacity building for both academic researchers and community partners. However, human and fiscal resources are critical requirements to support co-learning and capacity building (Horn et al., 2008). A key need of the rural Appalachian coalition was to identify and reach out to community leaders and individuals whom could provide needed information, feedback and resources for coalition efforts. Coalition members conducted brainstorming sessions to identify potential members. Academic partners assisted with organizing these efforts and contacting potential coalition members. Through these efforts, coalition membership (human resources) more than doubled within the first six months.

In an effort to build capacity for a school-based intervention, rural partners trained teens at a local school to serve on a teen advisory council (TAC) to develop and promote an intervention aimed at reducing sugar-sweetened beverage consumption. The TAC consisted of two teachers and ten students representing grades 9-12. By this approach, the coalition's goals of promoting health behaviors among younger residents and developing future health leaders were achieved. The TAC members, through weekly planning sessions, gained information and knowledge of health behaviors and became more empowered and active in promoting health within their school community. At the conclusion of the initial

school-based project, TAC members volunteered to serve in a leadership capacity on the TACs to be formed at the middle school as part of a follow-up project.

There were several ways in which the urban Appalachian community and academic partners sought to incorporate capacity building and co-learning. Initial surveys, town hall meetings, and focus groups provided opportunities for diverse advisory board members to learn from one another and from community residents. Examples of this co-learning included knowledge from UAC staff about existing community-level data and successful community engagement strategies, community knowledge about appropriate language and literacy levels, and researcher knowledge about designing surveys and analyzing data. Integrated data from the needs assessment provided continued opportunities for co-learning about community needs. Preliminary data from the needs assessment reflected family and lifestyle factors that placed residents at a high risk for diabetes as well as limited diabetes knowledge. Focus groups and town hall meeting data indicated a strong desire among community residents to be involved in efforts to empower residents and to take their community's health "into their own hands." Given these lessons about the local community, health advocacy and diabetes risk became the focal points of the urban community's project.

The initial project, aimed at improving diabetes awareness and screening, was developed utilizing a community health advocate (CHA) model. The goal of the CHA approach was to build capacity in the community by providing training, resources, and opportunities for residents to assist their neighbors in understanding diabetes prevention and accessing services. The advisory board worked with new partners, including local health centers, to design a training program to ensure the success of the CHAs outreach efforts. More than 25 hours of advocacy training were completed by CHAs.

Although our efforts were just beginning in the rural and urban Appalachian communities, one of the first steps to increase capacity was to secure funding to continue work after the completion of the initial projects. Academic partners led the technical aspects of the grant-writing process while community partners shaped project ideas and ensured community support for the proposed research projects. At the conclusion of the initial projects, both Appalachian community-academic partnerships secured follow-up funding to continue and expand each project.

Principle 5: Integrating and Achieving Balance between Research and Action for Mutual Benefit

In CBPR, knowledge and social change efforts are integrated in a manner suitable to address community concerns and be of benefit for all partners (Israel et al., 2003). For research to translate into culturally effective interventions, it must address the prioritized needs of the community itself (Coyne et al., 2006). This principle was reflected in the development and testing of the pilot research projects.

In rural Appalachia, once the coalition identified a need to improve lifestyle behaviors, focus group sessions were conducted with adult and teen residents to gather additional information and gauge interest in lifestyle behaviors to improve health. Three initial focus group sessions were conducted with 8-10 participants at each session. Focus group sessions asked about the general health of community adults and children and the barriers they faced. All participants voiced a concern about diabetes and the need to work with "youngsters." When asked about nutritional barriers, all participants verbalized concern about teenagers' consumption of sugar-sweetened beverages. Based on the initial focus

group input, additional interviews and separate focus group sessions with school personnel and teenagers were conducted. Results from these sessions were compiled and reported back to the coalition and participating school. The results reinforced the coalition's identified health need of addressing teenagers' consumption of sugar-sweetened beverages.

The next step was to establish an effective community-academic partnership with a local high school identified by the coalition. Since the high school hosted two focus group sessions described above, school leaders, personnel and students welcomed the researchers as a partners to address the identified health need. Consequently, the TAC was formed at this local school. The academic partners organized the TAC's initial duties and assisted with generating ideas around interventions to impact sugar-sweetened beverages. The TAC adopted the idea of a "30-Day Challenge" asking students to refrain from consuming sugar-sweetened beverages for 30 days. Academic partners developed measurement tools including a Vending Machine Survey, Daily Beverage Log, and a Survey of Beverage Consumption. A pre-test/post-test design was developed. To track long term impact, measures were repeated 30 days post intervention. The academic partners attained IRB approval for the project.

TAC members organized a social marketing campaign aimed at promoting the "30 Day Challenge" and supporting students during the challenge itself. To recruit students, the TAC produced a video commercial about the Challenge that was shown during homeroom. TAC members were present during its airing to promote the Challenge and answer questions. A t-shirt designed by the group was worn during these recruitment times. The TAC designed posters displayed throughout the school and other media messages used during the month long challenge. For example, a "daily fact" about sugar-sweetened beverages was shared daily during school-wide announcements. Furthermore, the TAC developed and assembled a participant "kick off kit." Each kit contained a water bottle, flavorings, a rubberized wrist band and a knapsack with the slogan "What's in Your Cup?" Finally, the TAC planned a school-wide assembly marking the end of the Challenge. Although a full examination of the results in underway, preliminary results indicate that the TAC designed intervention was effective at reducing sugared-sweetened beverage consumption and improving water consumption at post-intervention and 30 days post intervention. Details of project results are discussed elsewhere. In the end, the CBPR approach allowed for the collection of accurate, reliable and complete data about the community's health while establishing effective and trusting relationships between the researchers and the rural Appalachian community. Most importantly, CBPR empowered the community residents to develop and deliver a sustainable health program to impact the health of community residents.

The urban Appalachian advisory board balanced the need to create new knowledge and impact the community's health by building opportunities for evaluation into the design of its project. In addition to collecting community needs assessment data, the advisory board agreed that it was beneficial to conduct process and summative assessments throughout the project. Board members recruited and interviewed community members for CHA positions. Once a final group of residents was selected, potential CHAs participated in CHA training sessions in their community. Sessions were led by UAC staff, academic partners, and health care providers in the community. At each session, CHAs completed "pre and post" tests to assess knowledge and skills gained during the session. While the board members, particularly academic partners, were interested in understanding the effectiveness of the CBPR-designed CHA training program at impacting knowledge and self-efficacy, the data were also used by trainers and the CHAs to understand areas where more training was needed or where CHAs were already proficient. Opportunities for CHA feedback at each training session allowed for modifications to the program as needed.

Similarly, data collection opportunities were built into the CHA outreach intervention. Upon completion of their training, the CHAs conducted a canvassing of 300 households to: a) provide information about diabetes prevention and lifestyle behaviors shown to reduce risk, b) identify persons at high risk, and 3) make appropriate recommendations for accessing screening services at a neighborhood wellness site established by community partners. As part of this effort, CHAs interviewed residents about their health status, diabetes knowledge, and risk for diabetes. CHAs made follow-up phone calls to those persons identified as high risk. These calls allowed for CHAs to provide additional support and guidance for accessing services pursuant to the CHA home visit. The data collected were agreed to by the advisory board if they contributed to improving the pilot project, enhancing decision-making about future CHA outreach, and/or securing future funding. Urban advisory board members worked to ensure efficiency and limited community burden during data collection.

In addition, the community-academic partnership worked in concert to advance community health by strengthening and connecting existing resources to the CHA program. For example, the advisory board worked closely with a local service agency to establish the wellness site where residents could obtain screening and triage by nurses and community volunteers. CHAs advocated for high-risk residents to obtain additional screening and referral. Connections for these services were developed with two local health clinics including one at the local health department and a free clinic for the uninsured operated by a community partner. Community and academic partners worked to develop these connections and ensure appropriate care provision for community residents.

Principle 6: Using a Cyclical and Iterative Process to Address Health Concerns

Although the initial pilot projects focused on diabetes and teen nutrition, capacity-building efforts led to the identification of other health concerns in the communities. For example, in rural Appalachia, health concerns consistently voiced during the focus group sessions included: (a) difficulty in accessing health care, (b) financial assistance for the elderly to purchase medications, (c) food insecurity, (d) substance use/abuse among teenagers, (e) growing prevalence of diabetes among younger residents, and (f) meal preparation. Because of these concerns and the need to address them, we have learned in our projects that the iterative process does not always mean repeating the same process or re-addressing the same need. New issues may emerge and community-academic partners must decide to what extent they will deviate from the initially stated problem. The rural Appalachian coalition began to address some of these concerns through the invitation of additional key stakeholders. These new members collaborated with local extension officials to plan nutrition education classes. Building on the increased competencies and growth, expansion of the sweetened-beverage project into local middle and elementary schools is planned.

Within the urban Appalachian community, the CHA program was developed in phases through iterative cycles of feedback. First, community and academic partners on the advisory board used the needs assessment findings and the existing literature on "promotoras"

and "community health workers" to develop a list of goals for training CHAs including communication skills, diabetes risk and prevention, healthy lifestyle behaviors, safety, research ethics, and confidentiality. Next, sessions were designed and adapted by expert trainers in each area with continued feedback from the board. Community residents on the board were particularly helpful in providing input about existing myths about diabetes and information that residents-in-training would need to know in order to be successful. Finally, CHA feedback during training, data collection, and outreach was incorporated into the program. Changes made as a result of the feedback included: additional training on home visits, altering the ordering of events during home outreach visits, and rewording health status questions to better reflect the phrasing prevalent in the community.

While from a research perspective these are considerable challenges, both in terms of parity of data and amendments to research protocols, these changes and flexibility are a necessary component of community-based research. Levied by demonstrated initial success, the urban Appalachian community partners received funding to develop a second phase to the project. The second phase will allow the CHAs to function as "health navigators", further assisting high risk residents in accessing follow-up medical services. Pilot projects implemented in both urban and rural Appalachian settings were seen as iterative processes of addressing community concerns while gaining knowledge about successful implementation through planned action.

Principle 7: Disseminating Findings, Knowledge Gained, and Implications for Practice

An important feature of dissemination is using results to inform future action. As equal partners, credit is shared between the researchers and community partners. Through these initial projects, trust between academic and community partners was forged. To share our stories, we began disseminating the findings at local, state, and national levels.

It was initially important in the rural community to disseminate findings locally, beginning within the coalition during all phases of the project. From there, coalition members shared results with their respective agencies and other stakeholders. This dissemination approach provided many benefits. First, sharing results with others led to recognition and legitimacy of the coalition within the community. Second, this approach allowed the coalition to take ownership of the pilot project. Third, coalition members were able to discuss other concerns with residents and other stakeholders thus generating ideas for future initiatives. Coalition members quickly learned that the community craved knowledge about healthy lifestyle behaviors, nutrition, and diabetes. Consequently, the project dissemination triggered other initiatives in the rural community such as a faith-based walking program, community-based nutrition classes, and health events for diabetics. Academic partners were asked to remain active with coalition initiatives and help to determine the feasibility and evaluation of future projects. Finally, to reach the wider local rural community, the TAC invited local media to attend the school-wide assemble marking the end of the pilot project. As a result, the piloted research project was featured on the front page of the county-wide newspaper.

Findings were next presented at state, regional, and national conferences focusing on Appalachian health. Although the researchers were the primary presenters, the rural coalition was recognized as a prominent member of the team. These presentations were beneficial to other coalitions in attendance as they heard about how the community-academic

partners successfully engaged one another to conduct research on a topic of interest to the community. Finally, to more fully reach the research and scientific community, project results are being drafted for submission to submission to peer-reviewed journals.

Ongoing dissemination efforts were also conducted by the urban Appalachian advisory board to provide community residents with an understanding of the CHA program and the source of knowledge and skills available. This communication provided residents with an understanding that regardless of the lifespan of the research partnership or the uncertain nature of future funding, an accessible community resource had been developed. The first dissemination effort was a community-wide meeting where community residents were invited to hear about the community survey, town hall meeting results, and focus group findings. A presentation to community leaders, specifically health care professionals and agency directors, was also carried out. These initial dissemination efforts were led by the community resident members of the advisory board with feedback and support from academic partners. Community-based dissemination led to additional partnerships of value to the CHA program and the community such as the community wellness site previously described. In addition to these efforts, research partners presented the project and its findings at a regional meeting with other Appalachian health researchers and to the broader Appalachian research community through UAC's Research Committee and website. Ongoing dissemination in both community and academic venues is an important goal of community-academic partnerships.

Recommendations regarding the use of CBPR

It is our experience that CBPR is a promising approach for researchers and community members seeking to serve vulnerable communities, specifically within the Appalachian region (Israel et al., 2005; Minkler, 2004). Several recommendations emerged from our efforts. First, CBPR should begin by active listening and efforts to understand community-identified needs. While sometimes challenging for research partners, pre-conceived needs or project ideas cannot be solely adhered to and flexibility is needed to define and develop a truly community-based research project. Although our rural and urban projects were linked by a broad focus on obesity and diabetes prevalence, the rural and urban community partners identified vastly different perspectives and strategies to impact diabetes prevalence within their own communities. The rural Appalachian community stressed to need to focus on children and adolescents in school settings whereas the urban Appalachian community stressed the need to focus on adult empowerment. Efforts to stay true to CBPR principles cultivated trust, co-learning, and mutual respect between researchers and community residents; these cultivated outcomes were critical to the success of our projects (Baiardi, Brush, & Lapides, 2010). Keeping true to our word and delivering what was promised to the community fostered and solidified the partnerships.

Next, open communication was critical and partners in our projects devoted considerable time to coalition, advisory board and community-based meetings. Frank discussions about the partners' values in terms of Appalachian culture, community health, and academia's history with the community ensued. This process exposed some mistrust of research and academia within the Appalachian communities that needed to be addressed. In the end, this process recognized the unique strengths and concerns of community partners (Horn et al., 2008) that resulted in a shared understanding of unique community priorities (e.g., sweetened beverage consumption, community access to diabetes screening and

risk information). Consequently, the development of distinct approaches to addressing the problems of obesity and diabetes was undertaken.

Third, building capacity for future partnership efforts must begin early on (Baiardi et al., 2010). From the beginning, academic partners demonstrated a commitment to capacity building by working to ensure both financial and human resources for future efforts. Because of our early focus on building resources and follow up funding, academic and community partners demonstrated a commitment to long-term collaboration. Following the initial projects, both Appalachian community-academic partnerships successfully secured funding to continue and expand each project. In the rural Appalachian community, community partners and stakeholders have asked academic partners to assist with other identified health concerns. To this day, academic partners remain committed and actively engaged with the rural Appalachian and urban Appalachian communities. Academic partners are engaged in planning initiatives to offer a day camp to children living with diabetes in the rural Appalachian community.

Finally, ongoing dissemination of results and findings is essential. Early dissemination focused on the local Appalachian communities. These early efforts triggered other initiatives in the rural Appalachian community such as a faith-based walking program, community-based nutrition classes, and health events for diabetics. Local and regional presentations to community partners and stakeholders benefitted to other coalitions in attendance as they heard about how the community-academic partners successfully engaged one another to conduct research on a topic of interest to the community. For each audience, the dissemination efforts and messages were tailored to best meet the needs of those in attendance. As the word spread throughout the regional Appalachian community, community partners assumed more presentation responsibilities thus allowing for the true strength of the community-academic partnerships to become more evident. These communications provided communities and others with an understanding that regardless of the lifespan of a research partnership or the uncertain nature of future funding, accessible community resources can be developed and nurtured.

References

Adams, M., & Lammon, C. A. (2007). The presence of family history and the development of type 2 diabetes mellitus risk factors in rural children. *Journal of School Nursing*, *23*(5), 259-266.

Bai, Y., Hillemeier, M., & Lengerich, E. (2007). Racial/ethnic disparities in symptom severity among children hospitalized with asthma. *Journal for Health Care of the Poor and Underserved*, *18*(1), 54-61.

Baiardi, J. M., Brush, B. L., & Lapides, S. (2010). Common issues, different approaches: Strategies for community-academic partnership development. *Nursing Inquiry*, *17*(4), 289-296.

Behringer, B., & Friedell, G. (2006). Appalachia: Where place matters in health. *Preventing Chronic Disease, 3*(4), A113.

Brulle, R.J., & Pellow, D. N. (2006). Environmental justice: Human health and environmental inequalities. *Annual Review of Public Health*, *27*, 103-124.

Centers for Disease Control and Prevention. (2002). Cancer death rates- Appalachia, 1994-1998. *Morbidity and Mortality Weekly Report*, *51*(24), 527-529.

Centers for Disease Control and Prevention. (2011). National diabetes fact sheet: National estimates and general information on diabetes and pre-diabetes in the United States, 2011. Atlanta, GA: U.S. *Department of Health and Human Services, Centers for Disease Control and Prevention*.

Coyne, C. A., Demian-Popescu, C., & Friend, D. (2006). Social and cultural factors influencing health in southern West Virginia. *Preventing Chronic Disease*, *3*(4), A124.

DeNavas-Walt, C., Proctor, B., & Smith, J. C. (2010). U. S. Census Bureau: Current Population Reports, P60-238- Income, poverty, and health insurance. Washington DC: U.S. Government Printing Office.

Flicker,S. (2008). Who benefits from community-based participatory research? A case study of the Positive Youth Project. *Health Education & Behavior*, *35*(1), 70-86.

Gehlert, S., & Coleman, R. (2010). Using community-based participatory research to ameliorate cancer disparities. *Health and Social Work*, 35(4), 302-309.

Halverson, J., Barnett, E., & Casper, M. (2002). Geographic disparities in heart disease and stroke mortality among black and white populations in the Appalachian region. *Ethnicity and Disease*, *12*(4), S3-82-91.

Haverson, J., Ma, L., Harner, E. (2004). An Analysis of Disparities in Health Status and Access to Care in the Appalachian Region. Appalachian Regional Committee: Washington DC.

Hergenrather, K.G., Geishecker, S., McGuire-Kuletz, M., Gitlin D. J., & Rhodes, S. D. (2010). An introduction to community-based participatory research. *Rehabilitation Education*, *24*(3), 225-238.

Horn, K., McCracken, L., Dino, G., & Brayboy, M. (2008). Applying community-based participatory research principles to the development of a smoking-cessation program for American Indian teens: "Telling our story". *Health Education and Behavior*, *35*(1), 44-69.

Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, et al. (2010). Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities. (2010). *American Journal of Public Health*, *100* (11), 2094-2102.

Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (2005). Methods in community-based participatory research for health. San Francisco: Jossey-Bass.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A.B., Allen, A., & Guzman, J.R. (2003). In M. Minkler & N. Wallerstein (Eds.). Community-based Participatory Research for Health (pp. 56-73). San Francisco: Jossey-Bass.

Kennedy, B.M., Prewitt, E., McCabe-Sellers, B., Strickland, E., Yadrick, K., Threadgill, P., Champagne, C., Mcgee, B., McCabe Sellers, B., & Bogle, M. (2011). Academic partnerships and key leaders emerging from communities in the lower Mississippi Delta (LMD):A community-based participatory research model. *Journal of Cultural Diversity*, *18*(3), 90-94.

Kluhsman, B., Bencivenga, M., Ward, A., Lehman, E., & Lengerich, E. (2006). Initiatives of 11 rural Appalachian cancer coalitions in Pennsylvania and New York. *Preventing Chronic Disease, 3*(4), A122.

Michael, Y. L., Farquhar, S. A., Wiggins, N., & Green, M. K. (2008). Findings from a community-based participatory prevention research intervention designed to increase social capital in Latino and African-American communities. *Journal of Immigrant and Minority Health, 10*(3), 281-289.

Minkler, M. (2004). Ethical challenges for the "outside" researcher in community-based participatory research. *Health Education & Behavior, 31*(6), 684-697.

Montgomery-Reagan, K., Bianco, J. A., Heh, V., Rettos, J., & Huston, R.S. (2010). Prevalence and correlates of high body mass index in rural Appalachian children aged 6-11 years. *Rural and Remote Health, 10(1)*, 1408.

Morrone, M. (2008). Environmental justice and health disparities in Appalachia, Ohio: Local cases with global implications. In: P.H. Liotta, D.A. Mouat & W.G. Kepner, eds. *Enviromental change and human security: Recognizing and acting on hazard impacts* (pp.299-326). Dordrecht, Netherlands: Springer.

Obermiller, P.J., Wagner, T.E., & Tucker, E.B. (2000) *Appalachian Odyssey: Historical Perspectives on the Great Migration.* Westport: Praeger Publishers.

Oza-Frank, R., Norton, A., Scarpitti, H., Wapner, A., & Conrey, E. (2011). Executive summary: *The Body Mass Index of Ohio's Third Graders* 2004-2010. Columbus, OH: Ohio Department of Health.

State of Ohio: Department of Insurance, Department of Job and Family Services, Department of Health, and Department of Mental Health. (2009a). Ohio Family Health Survey, 2008-09 [Computer File]. Columbus, OH. Ohio State University, Ohio Colleges of Medicine Government Resource Center [distributer]. Retrieved from www.grc.osu.edu/ofhs.

State of Ohio: Department of Development, Office of Policy, Research and Strategic Planning. (2009b). *Ohio County Profiles:* Pike County- 2009. Columbus, Oh: Author.

University of Wisconsin Population Health Institute. (2010). *County Health Ratings: Mobile Action toward Community Health- Ohio 2010*. Retrieved from: http://www.countyhealth-ratings.org/ohio

Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*, *100* Suppl 1: S40-S46.

Williams, K. J., Bray, P. G., Shapiro-Mendoza, C. K., Reisz, I., & Peranteau, J. (2009). Modeling the principles of community-based participatory research in a community health assessment conducted by a health foundation. *Health Promotion Practice, 10*(1), 67-75.

Zullig, K. J., & Hendryz, M. (2010). A comparative analysis of health-related quality of life for residents of U. S. counties with and without coal mining. *Public Health Reports, 125* (4), 548-555.

About the Authors

• **Laureen H. Smith** is an assistant professor at The Ohio State University College of Nursing with over 25 years of nursing experience, specializing in public health and community health nursing. With a research specialty in health promotion and risk reduction nursing, Smith is activity involved in community and school-based research activities, specifically targeting children and youth in underserved areas. Most recently her work has focused on children residing in the rural Appalachian region. Smith serves on the *Editorial Boards of the Journal for Specialists in Pediatric Nursing* and the *Michigan Journal of Public Health*. Her work has been published in peer-reviewed interdisciplinary and nursing-focused journals.

• **Jessica Valenzuela** is an Assistant Professor at the Center for Psychological Studies at Nova Southeastern University. She received her PhD in Clinical Psychology with a specialization in pediatric health from the University of Miami. Prior to that, Dr. Valenzuela completed internship training at the Children's Hospital of Philadelphia and a two-year NIH-funded postdoctoral fellowship at the Cincinnati Children's Hospital Medical Center, and collaborated in the development of the University of Cincinnati's Clinical and Translational Science and Training (CCTST) Community Engagement Core. Dr. Valenzuela is a NIH NRSA minority fellowship recipient for her research examining prescription practices in minority youth with diabetes and her current research focuses on health disparities and community-based participatory research paradigms. Through her research, Dr. Valenzuela partners and consults with various community partners and service agencies to develop and expand community health promotion programs, increase cultural competency of providers, and improve the quality of care provided to children and families.

• **Robert L. Ludke** is professor of family and community medicine at the University of Cincinnati with over 30 years of senior management and research experience. Trained as a health systems engineer at the University of Wisconsin-Madison, he has been actively involved in community-based research activities, with a particular focus on health disparities among vulnerable populations. Ludke serves on the Board of the Urban Appalachian Council of Greater Cincinnati and chairs the Board's Research Committee. He serves on the editorial board of the *Journal of Appalachian Studies* and recently co-edited a book with Dr. Phillip J. Obermiller entitled *Appalachian Health and Well-Being* published by the University Press of Kentucky.