Published in final edited form as:

Prog Community Health Partnersh. 2015 ; 9(2): 289–298. doi:10.1353/cpr.2015.0047.

Challenges of Data Dissemination Efforts Within a Community-Based Participatory Project About Persistent Racial Disparities in Excess Weight

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Abstract

Background—Despite universal environmental and policy-focused initiatives that resulted in declines in obesity among children in Cambridge, Massachusetts, disparities persist among racial/ethnic groups. In response, a community coalition formed the Healthy Eating and Living Project (HELP), to investigate and disseminate findings regarding disparities in excess weight among Cambridge Black youth (ages 6–14), with the aim of facilitating reciprocal learning and community mobilization to ultimately increase community engagement and inform prevention efforts.

Objectives—This paper details the theoretical framework, methods, and results of disseminating HELP findings to various sectors of the Cambridge Black/African American (Black) community.

Methods—First, using a community-based participatory research (CBPR) approach, the HELP coalition analyzed existing data and conducted qualitative studies with Cambridge Black families to better understand the sociocultural and familial determinants of excess weight. We then developed presentation and print materials and used different dissemination approaches. We solicited feedback to inform the dissemination process and mobilization of obesity prevention efforts.

Results—We disseminated information through six community groups (parents, students, pastors, men's health group, community leaders, and a health coalition), email lists, and websites. Reciprocal learning among and between HELP and community members yielded data presentation challenges, as well as prevention effort ideas and barriers.

Conclusion—Dissemination of local health data should be considered both as a strategy to increase community engagement and as an intervention to promote collective efficacy and

community change. Careful attention should be dedicated to the language used when communicating racial disparities in excess weight to various community groups.

Keywords

Data dissemination; racial/ethnic disparities; community-based participatory research; childhood obesity prevention

American childhood obesity rates remain unacceptably high.¹ Furthermore, there are stark racial/ethnic and sociodemographic disparities in childhood obesity.² Through Michelle Obama's Let's Move campaign, childhood obesity prevention has been nationally prioritized. However, there is a dearth of evidence regarding the determinants of racial and ethnic disparities in excess weight³ and effective intervention strategies to reduce racial/ethnic disparities in excess weight among youth.⁴ This article details the theoretical framework and methods of our dissemination efforts of local health data to our priority community embedded within a CBPR project dedicated to understanding the persistent disparities in excess weight among African American school-aged children in Cambridge, Massachusetts.

THEORETICAL FRAMEWORK: COMMUNITY DISSEMINATION TO FACILITATE COMMUNITY MOBILIZATION

The dissemination of local data to facilitate reciprocal learning, referring to the transfer and sharing of knowledge between academic and community groups,⁵ and increase community engagement are central components of CBPR and have been effective in mobilizing communities to reduce violence and health disparities.^{6,7} *Community mobilization* is an umbrella term that encompasses several frameworks of community engagement, including CBPR. Broadly defined as individuals or groups coming together to address a social issue, community mobilization initiatives are fundamental to address health disparities.⁸ Community mobilization assumes that community participation will lead to greater efficiency and effectiveness in addressing a social issue.⁹ Additionally, previous community-based efforts have demonstrated that an increase in collective efficacy, which is a community's "shared beliefs in their collective power to produce desired results," can lead to greater community mobilization and engagement.^{6,10–12}

The proposed relationships among community dissemination, mobilization, and collective efficacy within the context of a CBPR project, are depicted in Figure 1. This theoretical framework is an adaption of the CBPR Conceptual Logic Model proposed by Wallerstein and Duran¹³ with our unique contribution highlighting the role of data dissemination and reciprocal learning within a CPBR project dedicated to reducing health disparities. Specifically, it details the process through which our data dissemination efforts were hypothesized to mobilize our priority community to address excess weight among Cambridge Black and African-American youth, drawing on existing models of community engagement and collective efficacy.

COMMUNITY CONTEXT

The City of Cambridge

The sociopolitical setting for this project is Cambridge, a racially and economically diverse dense urban city of 108,000 near Boston, Massachusetts.¹⁴ Almost one-half of Cambridge public school (CPS) students (44.9%) are eligible for free or reduced school lunches (2004–2008)¹⁵ and 14.7% of all families with children under 18 years old had incomes below the poverty line in 2008.¹⁶ The African-American/Black community in Cambridge makes up 12% of the total population and 37% of CPS students. Black families with children under 18 have disproportionately higher rates of poverty (42.7%) compared with other racial groups in Cambridge.¹⁶

History of the Body Mass Index Disparities Initiative

The current CBPR project builds on a decade of community-based partnerships in Cambridge dedicated to promoting child health through nutrition and physical activity promotion.^{17,18} Universal and school-based environmental and policy-focused prevention initiatives, including farm-to-school programs, schoolyard gardens, cafeteria-based nutrition education, citywide social marketing campaigns, training of school staff and school food service members, and updated physical education curriculum, resulted in declines in obesity among Cambridge school children.¹⁸ However, disparities persist among racial and ethnic groups. In 2007, Black students (in kindergarten through eighth grade) were still twice as likely to be obese (24.1%) compared with White students (11.3%), despite universal prevention efforts.¹⁸

A coalition of researchers, local public health practitioners, and key community stakeholders from the Cambridge Black community came together to better understand weight disparities among Black youth. The impetus for the coalition formation was an opportunity to apply for a community-based pilot grant from Harvard Catalyst, a newly formed transdisciplinary clinical and translational research initiative. The coalition branded itself the HELP, successfully received the pilot grant and generated a mission statement and goals in 2009.

The HELP coalition decided to focus its research efforts at the Fletcher Maynard Academy (FMA), which is a neighborhood Kindergarten through eighth-grade school located in a geographic area within Cambridge known as Area IV. A large portion of Black Cambridge youth reside in the school's catchment area and the HELP coalition had established connections to this school and its parent community. After several discussions, the HELP coalition collectively decided to use the term "Black" exclusively to describe the priority community as opposed to using both "Black" and "African American" in any HELP written materials or communications because the term Black was deemed the most inclusive. Thus the term Black is used throughout the remainder of this article.

METHODS

Organizational Structure of the HELP coalition

Our dedication to community participation and engagement are highlighted by the organizational structure and work process of HELP that was directly informed by the African American Collaborative Obesity Research Network (AACORN)'s Expanded Obesity Research Paradigm, that underscores the importance of including community insight and collaborations with African American researchers to stimulate research that will effect obesity-related health problems in the African American community.^{3,19} The AACORN model, integrated with our CBPR approach, guided how we constructed our research team and work process to represent appropriately our priority community and ensure equitable relationships between African-American community members and academics. The HELP coalition was racially diverse with membership of prominent African-American community leaders from our priority community that would increase the likelihood of community ownership. HELP's community researchers, deemed "community investigators," were recruited based on past relationships, mutually expressed interest and community clout. All were Black, lived or worked in Cambridge for most of their lives, and were well-respected within the community. They included the principal of the FMA, the conflict mediator from the Cambridge Public Schools, the Area IV Coordinator, and the manager for the Men's Health League of the Cambridge Public Health Department. Consistent with a CBPR approach, the community investigators were compensated for their time and were involved in every step of data collection and dissemination to ensure transparency, data ownership, and shared decision making, and to reduce perceived or actual power differentials among the HELP coalition members. Specifically, community investigators were expected to engage in a variety of tasks that were detailed in written contracts:

1. Help refine research questions;
2. Review research protocols;
3. Organize and facilitate community workshops;
4. Facilitate recruitment for interviews, surveys, and community forums;
5. Participate in six research team meetings, and two advisory board meetings; and
6. Help to interpret results and identify/prioritize interventions.

The HELP coalition also consisted of several academic investigators, mainly White females, from the Cambridge Public Health Department, Tufts Medical School, Institute for Community Health, Harvard School of Public Health, and Brigham and Women's Hospital. Over the course of the project period, the HELP coalition met monthly and these meetings were generally located at FMA or the Cambridge Public Health department, which are both centrally located in Area IV, our priority community, and also represent spaces void of potential power differentials because two of our community investigators work in both of these spaces.

We also created a larger community advisory board, which met twice during our 12-month grant. We invited 22 key community stakeholders from various sectors of the Cambridge community, including the mayor's office, youth development agencies, faith-based organizations, health, public health, physical education, local food establishments, and other community-based organizations, to be a part of our community advisory board. The major responsibilities and expectations of the community advisory board, which were reviewed during the first meeting, included 1) participating in two meetings, and 2) reviewing project results and assisting in identifying and prioritizing interventions. Of the 22 individuals that we invited, a core group of 10 community members attended both advisory board meetings and actively participated in the discussions related to the research design and synthesis of our research findings. These 10 individuals represented various sectors of the community and were mainly Black Cambridge residents.

Overview of HELP: Timeline of Research and Dissemination Activities

The timeline of our research and dissemination activities are detailed in Figure 2. We followed a systematic program planning model, "Intervention Mapping," to structure our research and dissemination efforts.²⁰ Briefly, the first phase of the project was dedicated to mixed-methods formative research, which included analysis of existing data and primary qualitative data collection among FMA's families and parents. In phase 2, The HELP coalition continued qualitative data collection and started to disseminate preliminary findings of the formative research through community forums. The purpose of these community forums was to solicit feedback and reactions to the data, facilitate reciprocal learning between community members and the HELP coalition, and identify next steps for intervention work.

Phase 3 focused on synthesizing the data collected, incorporating the community feedback, and identifying next steps. The community advisory board participated in this analytic phase through a group consensus building model.²¹ Phase 4, focused on intervention design and selection, continues to be the most difficult as sustaining community interest and engagement without continuous funding and integrating disparate opinions regarding intervention next steps from key community stakeholders is challenging. Phases 3 and 4 will not be discussed in the remainder of the text because the focus of this article is the process of data dissemination as a strategy to mobilize a community within a CBPR project.

Description of the Formative Research in Phase 1: Quantitative and Qualitative Data

This CBPR project resulted in a compilation of existing data sets, including 1) a longitudinal dataset about student body mass index (BMI) collected among CPS students in grades K–8, from a partnership with CPS; 2) the Cambridge Youth Risk Behavior Surveillance (YRBSS), which is a biennial self-reported survey of CPS middle school students about various health behaviors, with the triangulation of newly collected data by the HELP coalition including 3) 176 Cambridge FMA parent surveys about perceptions of health, perceived control of their child's health, and social support to make and maintain healthy lifestyle choices; 4) 10 parent/child dyad interviews with Area IV Cambridge Black families regarding family food practices, and cultural influences on health and weight; and 5) interviews and a focus group with community positive deviants. Table 1 provides a detailed account of the multiple

methods through which HELP aimed to understand the persistent racial disparities in excess weight among Cambridge Black youth.

For the primary data collection activities conducted by the HELP coalition, the parent survey participants and the parent/child dyad interview participants, were recruited directly through FMA, because we focused our recruitment on our priority community, the Area IV Cambridge Black community. Specifics on the qualitative data collections methods and analysis are detailed elsewhere.²² Briefly, the qualitative data gleaned from the parent/child dyad interviews were analyzed using grounded theory and the major themes, along with the results from the parent surveys, helped inform the sociocultural and familial determinants for excess weight, which was lacking from the quantitative datasets.

Objectives of Community Dissemination Efforts

Specifically, our community dissemination efforts sought to:

1. Disseminate formative research findings to facilitate reciprocal learning;
2. Translate research findings into community accessible information; and
3. Increase community mobilization to reduce excess weight in Black Cambridge youth by:
 - a. obtaining community input about the determinants and solutions to excess weight among Cambridge Black youth; and
 - b. emphasizing community collective efficacy by focusing on existing community strengths and partnerships.

Community Dissemination Forums

Our primary data dissemination efforts were in the form of informal facilitated group conversations (community forums) with diverse cross-sections of the community in hopes of mobilizing people across ages, physical spaces, and professional domains. The community investigators contacted existing community groups to assess their interest and arrange for HELP members to address groups during existing meetings. The community groups included FMA parents ($n = 12$), FMA middle school students in grades 6, 7, and 8 ($n = 30$), high school students from Cambridge Rindge and Latin ($n = 10$), members of the Cambridge Black Pastors Association ($n = 5$), members of the Cambridge Public Health Department's Men of Color Health Initiative ($n = 10$), and members of the Cambridge Healthy Children Task Force ($n = 15$). Across the six community forums, we engaged a total 82 individuals (Table 1).

During the community forums, usually two members of the HELP coalition would provide a short overview presentation using PowerPoint displaying some of the major findings from our quantitative and qualitative data. The quantitative data presented came from 1) longitudinal CPS BMI dataset (2003–2008), collected annually as part of BMI measurements, and 2) the Cambridge YRBSS (2007). We presented data on various obesity-related health behaviors of CPS students, including sugar sweetened beverage consumption, screen time, and physical activity patterns, as well as information on obesity rates among

CPS students. After the data presentation, we engaged the groups in a discussion regarding the relevance of the data, applicability to their own lives, and potential solutions to reduce disparities in excess weight among Cambridge Black youth. The Cambridge Health Alliance Institutional Review Board approved all research activities, including the community dissemination forums.

Because HELP investigators (both community and academic) presented to a wide variety of community members in the six community forums, we tailored each presentation so that the information was presented in an age-appropriate manner. The PowerPoint presentation generally lasted 30 minutes with another 30 minutes left for discussion, feedback, and reciprocal learning with the community members. During the data dissemination forums, HELP coalition members brought large chart paper to the meetings and took notes as community members reflected on the presentation. The chart paper notes served as physical documentation of the discussion and visibly represented the various ideas that the group generated during the forum, allowing community members to build on previous comments. The notes from the chart paper along with detailed “memoing” from the HELP coalition presentation members served as the documentation that led to the generation of the theme analysis across the community groups.

The project manager of the HELP coalition primarily drafted the presentations, but the HELP coalition, including all community and academic investigators, reviewed all materials before each of the community forums. As the process evolved, a major disagreement surfaced among HELP coalition members. Some HELP community investigators wanted to show the obesity rates comparing the CPS Black and White students only, therefore leaving out the Latino and Asian CPS students, to make the weight disparity message stronger, more abrupt, and stark. However, some HELP investigators felt that this was a misrepresentation of the data and that we should present the obesity rates across all represented racial/ethnic groups to avoid the Black versus White comparison. Furthermore, the HELP coalition did not want to present data or facilitate a conversation that equated being Black with being “unhealthy” or doing “worse” in comparison with White students.

These tensions resurfaced numerous times throughout the project as we discussed this issue at each generation of an additional community product. Finally, the group decided that we would present the data both ways, comparing the obesity rates first across all racial/ethnic groups to contextualize that excess weight is an issue for everyone, and then present the prevalence just among CPS Black and White students to underscore why HELP was specifically focusing on this disparity. Additionally, we presented disparities from the YRBSS in a series of health-related behaviors, including physical activity, television viewing (TV), family meals, and sugar-sweetened beverage consumption, between CPS Black and White students only because that is how we analyzed the data. Additionally, we intentionally tried to use the term “excess weight” during our dissemination efforts and in print material, to refer to both overweight and obesity, to avoid the social stigma associated with obesity and to align our project with language that is preferred by parents.^{23,24}

RESULTS

Briefly, based on our secondary data analysis of the longitudinal BMI dataset and of the Cambridge YRBSS, we found disparities between Black and White Cambridge youth on a number of obesogenic health indicators consistent with national research. Generally, obesogenic health behaviors were more common among Black middle school students. For example, Black students were more likely to report low weekly vigorous activity, greater consumption of sugar-sweetened beverages, and greater daily screen time.²⁵ With regard to the longitudinal BMI data set, we found that over the course of a 5-year period (2003–2008), Black students were at baseline less likely to be of a healthy weight (53.5% vs. 70.7%), and less likely to maintain a healthy weight at follow-up, 5 years later, (88.8% vs. 91.7%) compared with their White peers.²⁶

Our main goal of the community dissemination efforts was to increase community mobilization around the disparities in excess weight among Cambridge Black youth via candid discussions that explicitly discussed race through the facilitation of reciprocal learning between the scientific community and the priority community. As detailed in Table 1, we engaged more than 80 Cambridge youth and adults regarding the persistent disparities in excess weight among Cambridge Black youth. We created several tangible community and scientific products containing the results from our formative quantitative and qualitative research as well as the common themes and reactions across the community dissemination forums.

Table 2 presents the major cross-cutting themes from our community dissemination forums organized by three central questions that framed our conversations: 1) reactions to the data, 2) barriers to healthy eating and active living, and 3) ideas for programs and policies that would successfully promote healthy living among Cambridge Black and African-American youth. As we engaged several different sectors of the community including, youth, parents and members of the Cambridge Black Pastors Associations, there were both similarities and divergences in the results of the dissemination forums among these groups. For example, across all five community groups, the cost of healthier food was identified as a barrier, as were several mentions of parental and cultural factors that might influence the diet and physical activity patterns of Cambridge Black families. Additionally, the increased rates of screen time, specifically television viewing, among Black youth was mentioned as a major barrier to healthy living across all five groups, with youth specifically mentioning that Black youth are “spoiled” as many of their White friends and peers did not have TV’s in their bedrooms or had stricter rules about screen time enforced by their parents. Not surprisingly, youth had different reactions to the data compared with the adult groups and were interested in the reliability of our findings and survey methodology, because many of them remembered completing the YRBSS surveys in school. Finally, most of the community groups mentioned the importance of engaging families in healthy weight promotion as a potential intervention target and the parent group, specifically, stressed the importance of sharing these data with the community, because they thought it was a powerful message and potentially could serve as a catalyst for change.

CONCLUSION

The objectives of our community dissemination efforts were to disseminate local data that presented racial/ethnic disparities on childhood obesity/health indicators to members of the Cambridge Black community to facilitate reciprocal learning, community mobilization and increase community collective efficacy to address demonstrated disparities in excess weight and other health behaviors. Owing to the organizational structure of HELP and our commitment to CBPR, the involvement of the four well-respected individuals as HELP community investigators enabled the rest of the “academic” investigators to engage with the Cambridge Black community in ways that would not have been feasible without the trust and collaboration of community partners. As a result of our community engagement efforts, the HELP coalition engaged diverse cross-sections of the Cambridge community, including youth, and increased partnerships among existing community based organizations and local community leaders to help understand the determinants for the persistent weight disparities among Cambridge Black youth.

Lessons Learned from Our Community Dissemination Methods

Given that we discussed this issue with different segments of the population, trying to synthesize the solicited feedback about determinants and potential solutions to reduce disparities in excess weight among Cambridge youth was challenging. Because a community is not singular, an equitable process to prioritize community voices and ideas to identify a concrete intervention strategy remains elusive.

The youth in the community dissemination forums questioned the purpose of comparing two seemingly different groups (CPS Black and White students) on a variety of different health indicators, and at times, seemed offended by the dichotomy of our data presentation. Although all HELP members vetted the presentations for the two youth forums, the community investigators do not represent and cannot speak for the entire Cambridge Black community. Additionally, it is possible that, because of repeat exposure of the data on local disparities, the community investigators were desensitized to the potential pejorative effect of presenting the data in such a manner. The process of communicating disparities to the priority community with the goals of empowering and mobilizing is difficult and requires a focus on collective efficacy and recognition of the multiplicity of a community in order to avoid isolation and community paralysis. Because disparities in excess weight are structured socially, economically, and racially, attempting to increase a communities’ collective efficacy through community dissemination forums alone, though an important first step, was inadequate. Among the HELP coalition members, there was a constant tension about the most effective strategy to communicate racial disparities to different segments of the Cambridge Black community during the community dissemination forums. Communicating racial disparities to youth and adults may require different strategies and having a youth advisory board would have helped to avoid some of the unintentional effects of presenting the data in the manner described.

Community-level interest in health disparities among minority populations is strong in Cambridge. To reduce health disparities, public health planners should collaborate with communities to increase community engagement to ensure program saliency and

sustainability. The public health collaboration in Cambridge is a working model of participatory research activities with dual goals of disseminating information and facilitating reciprocal learning among academic and community audiences. Dissemination of local health data should be considered a strategy to increase community engagement and to promote collective efficacy and community change.

Acknowledgments

This research was conducted with the support of a pilot grant from Harvard Catalyst | The Harvard Clinical and Translational Science Center (NIH Grant #1 UL1 RR 025758-02 and financial contributions from participating institutions). The authors acknowledge the Institute for Community Health for support of this research project, specifically Dr. Justeen Hyde and Dr. Lisa Arsenaault. Finally, the authors acknowledge and thank the Cambridge community for their willingness to participate in various aims of this research project and for their dedication to promoting the health and well-being of all Cambridge youth.

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Figure 1. Theoretical Framework of the Role of Data Dissemination Within in a CBPR Project Dedicated to Reducing Health Disparities

Adapted from CBPR Conceptual Logic Model.¹³

Figure 2.
Timeline of Healthy Eating and Living Project (HELP) Research and Dissemination Activities

Table 1

Triangulation of Data to Understand the Persistent Weight Disparities Among Cambridge Black Youth

Quantitative	Qualitative	Community Participation	Literature Review & Products
1 Cambridge YRBSS, 2007 ($N = 561$) Topic: Information on eating behaviors and physical activity patterns of Cambridge Public School middle and high school students	5 Community Nominated Positive Deviants ^a Topic: <ul style="list-style-type: none"> Successful strategies Barriers Recommendations 	HELP Community Advisory Board Topic/Purpose: <ul style="list-style-type: none"> Inform data analysis and recruitment procedures Identify community groups for dissemination efforts Synthesize feedback from community groups Emphasis on collective efficacy 	Intervention targets among community based efforts <ul style="list-style-type: none"> Behavioral targets Settings Culturally specific strategies for healthy weight promotion <ul style="list-style-type: none"> Strength-based approaches Social support Faith-based
2 CPS Longitudinal School BMI Data 2003–2008 ($N = 3,348$) Topic: School based BMI data collection for Cambridge public middle school and high school students from 2003–2008	10 Parent-Child Dyad Interviews Topic: <ul style="list-style-type: none"> Family food practices Parental modeling Socio-cultural influences Barriers Successful strategies 	6 Community Dissemination Forums (Community Groups): Total $N = 82$ <ul style="list-style-type: none"> Middle school students ($n = 30$) High school students ($n = 10$) FMA parents ($n = 12$) Men's Health League ($n = 10$) Cambridge Black Pastors Association ($n = 5$) Healthy Children Task Force ($n = 15$) 	Scientific Products: <ul style="list-style-type: none"> Conference presentations: <ol style="list-style-type: none"> 2010/13 American Public Health Association 2011 Society for African American Public Health Issues Manuscripts: <ol style="list-style-type: none"> Quantitative: BMI data Community Case Study Qualitative: parent/child dyad interviews
3 FMA Parent Surveys ($N = 176$) Topic: Parental attitudes about influencing child's eating/physical activity patterns	Positive Deviant Focus Group ($N = 8$) Topic: <ul style="list-style-type: none"> Review results Provide feedback on data 	HELP Community Investigators Topic/Purpose: <ul style="list-style-type: none"> Equitable research activities Building community capacity 	Community Products: <ul style="list-style-type: none"> HELP culminating report Powerpoint presentations One page HELP mission statement and introduction

^a“Positive deviants” refers to members of the community who had been identified as having made healthy changes to their lifestyle.

Table 2

Cross-Cutting Themes From Community Dissemination Efforts

	Reactions to Data	Barriers to Healthy Living	Ideas for Interventions
Men	Data makes sense – but do kids lie? Why are White kids less overweight? Why do Black kids not go to the gym?	Violence in the neighborhood Single parent households Healthy food is expensive Cambridge is territorial	Need to ensure that parks/playgrounds are safe: parent monitor Educate parents Have kids cook with parents Expose fast food industry Break cultural habits
Youth	Why is there a focus on Black kids? Why are Black kids more overweight if they are more active? White kids are underreporting their TV viewing	Black kids are “spoiled” – TV in bedroom, money to buy snacks White parents—more strict and stingy Healthy food is expensive	Community pool Water fountains at school More speakers and education for kids about nutrition Cooking classes Longer recess at school
Parents	Can families afford to eat healthy? Why do Black children have higher rates? How can we teach parents about the influence of the media?	Limited time for family meals Healthy food is expensive TV is a babysitter Cultural traditions of meals Habits Parents misperceive their children’s weight and diet	Show the data to the community Focus on one behavior at a time Educate children to read nutrition labels Get local stores involved More hands on activities/education Healthy cultural foods Alternative to TV
Black Pastors	How do we think about the diversity within the “Black” community? Have the disparities in excess weight between White and Black youth always been this dramatic? Childhood obesity is covered in the media, but no one explicitly talks about disparities The role of culture in health	Transitions in family structure Economics “Cutbacks” in schools Lack of family meals Reliance on TV People are drinking more soda Access to healthy foods	“It’s all about the home” Collaborate with churches Talk about the importance of general health Focus on loving yourselves Recognize and respect legacies Need to consider mental health “If I had a kitchen in my church, I would use it to teach kids how to cook”