#### AN ABSTRACT OF THE THESIS OF

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The purpose of this project was to explore health and nutrition concerns and priorities of parents and caregivers of children enrolled in Kids and Company (KidCo) Head Start using Community Based Participatory Research (CBPR). The project examined the feasibility of conducting CBPR with Head Start in the relatively short timeframe of one school year and identified action steps to address the community's concerns.

The first phase of this project used key informant interviews and participant observation to build relationships with Head Start administrators, staff, parents and caregivers. From these initial relationship-building activities, two Head Start centers chose to participate. A series of meetings were held with the two groups to identify community resources and concerns related to health and nutrition. Through a process of participatory issue selection, the groups selected a topic of concern and developed actions to address the issue.

The results of this project illustrate that CBPR is a feasible approach to identifying and addressing health and nutrition concerns with Head Start parents and caregivers. The methods used here adhered to CBPR principles and involved community members in all phases of the project. Both groups identified issues of importance and developed action steps to address their concerns. The project also resulted in an innovative approach to working with the Oregon State University Institutional Review Board to obtain approval for an evolving CBPR process. The timeframe presented challenges, however, and it was not possible to conduct the project in one school year because of the time required to build relationships and identify key members of the community. Additional challenges included recruiting and retaining parents and caregivers, conflicting research interests, and organizational capacity.

The actions that resulted from this project included development and implementation of a nutrition education program to augment existing Head Start nutrition education efforts, a partnership between Head Start and Oregon State University Extension, and a proposal to examine food security and develop a communication network between community members and local health departments.

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# Initiating Health and Nutrition Programs in Rural Oregon Using Community Based Participatory Research

by Elizabeth McCulley

#### A THESIS

submitted to

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in partial fulfillment of the requirements for the degree of

Master of Science

Presented May 29, 2007 Commencement June 2008

Elizabeth McCulley, Author
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# Initiating Health and Nutrition Programs in Rural Oregon Using Community Based Participatory Research

#### INTRODUCTION

Nutrition research takes many forms and addresses diet-related health issues on multiple levels, from the examination of nutrient interactions at the molecular level to the socioeconomic factors that affect food choices at the community level. When examining the relative success of nutrition research, it is important to evaluate the goals and outcomes of the different types of programs. Some programs measure direct health outcomes, such as reduction of disease or increase in nutrient intake. For example, enrichment of grain and cereal products led to a significant reduction in certain micronutrient deficiencies (1). Vitamin D fortification in milk products, orange juice, and other foods, has dramatically reduced the incidence of rickets in children and likely contributed to a reduced risk of osteopenia and osteoporosis in adults (2). Clinical trials and research at the molecular and cellular level have drastically increased the understanding of nutrient interactions in the body. The contributions these types of research and intervention programs have made in understanding and improving health cannot be underestimated.

Where nutrition research and interventions have been less successful, however, has been in health promotion and behavior modification. In light of the current focus on obesity, weight management provides a relevant example of the inability of health promotion programs to lead to long-term

behavior changes that result in maintenance of weight loss. It is well documented that rates of overweight and obesity in the United States, along with associated diseases such as type two diabetes mellitus and cardiovascular disease, are on the rise across all ages, ethnic groups, and socioeconomic levels (3, 4). Trends in Oregon show similar increases. In 2005, 59% of adults were overweight or obese, a 118% increase since 1990 (5).

These upward trends in overweight and obesity continue despite millions of dollars spent annually on obesity, nutrition, and diet-related disease prevention education and interventions (6). Controlling the "obesity epidemic" has become a priority of the U.S. government (7); however, effective long-term weight management and physical activity have yet to be developed. For example, in 2003, the majority of overweight and obese Oregonians reported trying to lose weight (5), yet rates of overweight and obesity continue to increase.

Many nutrition interventions seek to increase the public's knowledge about healthy eating. However, a study of people's perceptions about, and understanding of, healthy eating in the United Kingdom revealed that the lay understanding of healthy eating generally conforms to dietary guidelines (8). It is likely that a similar study conducted in the United States would have similar findings. Thus, increasing general knowledge about healthy eating may not be the most appropriate or effective goal of nutrition interventions. Rather, a more relevant focus might be on understanding and overcoming

physical and psychological barriers to healthy eating and identifying the resources, needs, and priorities of a given population so that they might set and achieve their own goals for health (9).

#### Fruit and Vegetable Intake

While the current focus of much nutrition research is on overweight and obesity, there are many other important diet-related health issues in the United States. For example, nutrition research has effectively demonstrated a positive correlation between intake of fruits and vegetables and a reduced risk of certain types of cancers (10, 11). However, most Americans do not meet the old recommended daily intake of five servings of fruits and vegetables (10) and even fewer meet the latest recommendations of nine servings per day for men and seven servings per day for women (12). In an effort to increase fruit and vegetable intake, the National Cancer Institute established the 5-a-Day for Better Health Campaign, which included a large nation-wide study targeted at adults and children. Despite this push to increase fruit and vegetable consumption among Americans, the most recent data from the National Cancer Institute, collected in 2003, show that only 46% of men and 40% of women consumed five servings of fruits and vegetables a day (12). The most recent data on fruit and vegetable consumption in Oregon shows that intake was well below the national average. In 2005, only 25.9% of adults in Oregon met the recommended intake of fruits and vegetables (13).

#### **Health Disparities**

Another important aspect of nutrition research is in the field of health disparities. For example, African Americans are disproportionately affected by incidence of, and mortality from, diet-related cancers (14). In addition, a study examining cholesterol screening and treatment among African American, Mexican American, and Caucasian populations in the United States found that African Americans and Mexican Americans were less likely to undergo serum cholesterol screening than Caucasians (15). The same study found that even when an individual was identified as having high cholesterol that required medication, African Americans and Mexican Americans were less likely than Caucasians to be taking cholesterol-lowering agents. In another study, an examination of NHANES III data revealed that Mexican American females were two times more likely to experience iron deficiency anemia than were Caucasian females (16). Data from the Behavioral Risk Factor Surveillance System (BRFSS) in 2000 revealed that African-Americans and Latinos were significantly more likely to be obese and have diabetes than Caucasians (17). The BRFSS data report that the national average for obesity in 2000 was 19.8%, while 29.3% of blacks, 23.4% of Latinos, and 18.5% of Caucasians were obese. With regard to diabetes, BRFSS data show that in 2000, 7.3% of all Americans had diabetes, while 11.1% of Blacks, 8.9% of Latinos and 6.6% of Caucasians had been diagnosed with the disease (17). The prevalence of diabetes-related complications, such as diabetic retinopathy, end-stage renal disease, and

peripheral vascular disease, has also been found to be higher in African Americans than in Caucasians (18).

The BRFSS data also demonstrate disparities in the prevalence of obesity and diabetes in people by years of education. For example, 26.1% of individuals with an education level of "less than high school" were obese and 12.9% were diabetic, while only 15.2% of individuals with a "college degree or higher" were obese and only 5.2% had diabetes (17).

Statistics from 2005 illustrate the health disparities that exist in Oregon. For example, a greater percentage of adults with a household income of less than \$15,000 per year were overweight or obese compared to adults with a household income of \$50,000 or more (13). Similarly, 27% of Oregon adults who did not finish high school were obese compared to 18% of college graduates (13).

#### **Role of Community Based Participatory Research (CBPR)**

Because of the complex factors associated with health and nutrition, researchers are continually seeking to establish nutrition interventions that will have lasting impacts on individual, community, and population levels (18-23). Community-Based Participatory Research (CBPR) is one type of research that is increasingly being turned to as a means of addressing persistent health problems such as health disparities, weight management, and others (18-24). In CBPR, researchers establish an egalitarian relationship with community partners and recognize the importance of local knowledge,

skills, and resources in informing the research process (24). Through the development of such community-academic partnerships, CBPR seeks to build community capacity and increase commitment among the partners by examining social and behavioral determinants of health and developing innovative, long-term solutions that take into account the priorities and needs of the target communities (20). An important emphasis of CBPR that is not always present in other types of health research is the focus on gaining knowledge for *action* rather than simply for understanding (25). According to Wallerstein and Duran, "participatory research involves the interconnected goals of research, action, and education" (26). Thus researchers commit to a process that will benefit both their research partners (the community) and themselves.

Important results of CBPR projects include the evaluation of both process and health outcomes. The ultimate goal of CBPR activities is to "improve the health and well-being of members of the community, however defined for a given research project, by means of taking actions that bring about intended change and minimize unintended negative consequences of such change" (27). As the Agency for Healthcare Research and Quality (AHRQ) report, "Community-based Participatory Research: Assessing the Evidence," points out, it is very difficult to compare the quality and impact of CBPR projects to projects using more traditional methods. Often CBPR projects use process evaluation to measure a project's impact on community capacity, empowerment, and level of satisfaction with the process. For

example, a randomized, controlled trial seeking to reduce cancer risk through African-American churches measured not only health outcomes of the intervention but also the development of trust and perceived benefit of satisfaction with the research process (20). While not traditionally used as a program metric, process evaluation is increasingly used as a means of assessing health interventions because it allows for greater understanding of whether a program works, why, and under what circumstances (28). Therefore, improving health outcomes is just one goal of CBPR. Other, equally important, goals that can be used to measure a program's success include increasing empowerment, building community capacity, and initiating social change to reduce health disparities.

#### **Project Objectives**

The purpose of this project was to engage KidCo Head Start staff, administrators, and parents and caregivers of children enrolled in KidCo Head Start in a CBPR project to identify health and nutrition priorities, barriers, and concerns as well as community resources and needs. The project sought to use a process of participatory issue selection to prioritize health and nutrition concerns and identify action steps to address these concerns. Finally, the goals of project evaluation were to determine whether a CBPR approach was a feasible method for developing health and nutrition programs with Head Start parents and caregivers and what action steps resulted from the process.

# RESEARCH QUESTIONS

- 1. Can a CBPR process be implemented with KidCo Head Start parents and caregivers within the timeframe of a sc hool year?
- 2. What specific action steps result from a CBPR project with KidCo Head Start parents and caregivers?

#### **REVIEW OF LITERATURE**

#### **Community Based Participatory Research Defined**

CBPR literature spans many disciplines, from anthropology and sociology to public health, nutrition, and even organizational theory.

Because of this broad theoretical foundation, CBPR practitioners have developed a variety of definitions for participatory research. The Agency for Healthcare Research and Quality (AHRQ) and the Community Health Scholars Program at the University of Michigan Department of Public Health have developed two widely accepted definitions that explicitly outline the key principles of CBPR practice.

The AHRQ defines CBPR as:

A collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change (27).

The Community Health Scholars Program (CHSP) definition builds on the AHRQ definition by emphasizing the importance of leveraging community knowledge in the research process. This second definition describes CBPR as:

A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities (29).

This emphasis on identifying and utilizing a community's expertise is important to the community empowerment process and allows for the development of locally relevant programs and actions. Acknowledging the skills community members possess is also a way of breaking down the teacher/learner relationship between the researcher and the community. Recognition of the value of expertise developed through the lived experience allows for the development of a more egalitarian, co-learner relationship that is important in CBPR partnerships.

Both of these definitions illustrate central features of CBPR, which Israel et al. (30) outline as nine principles:

- 1. Recognizing community as a unit of identity
- 2. Building on the resources within the community
- 3. Facilitating equitable partnerships throughout the research process
- 4. Promoting knowledge sharing between community and researchers as a process of co-learning
- 5. Integrating a balance between research and action that benefits all partners
- 6. Emphasizing local needs, values, and priorities in public health problems and recognizing the complex dimensions of these problems
- 7. Utilizing a cyclic approach, known as praxis, which promotes learning, action, and reflection
- 8. Developing and implementing a process such that all partners actively participate in the dissemination of the knowledge gained through research
- 9. Establishing a long-term commitment to the process.

Despite the diversity of disciplines in which the CBPR paradigm is applied, these principles, which have been described in a variety of ways by additional authors, provide the framework for effective and valuable community research.

#### A Theoretical Framework for CBPR in Health

Applications of CBPR in the health and nutrition disciplines draw on a variety of theoretical and health behavior models. For example, key concepts of Motivational Interviewing, a client-centered approach to behavior change, are relevant to issues related to motivation in CBPR. In addition, intrapersonal health behavior models such as the Health Belief Model (HBM) and the Transtheoretical Model (TTM), while generally used to describe individual health behaviors, are useful in understanding how existing health programs have developed. Examination of intrapersonal health models also allows for the identification of the strengths and weaknesses of these programs and their underlying theoretical frameworks. Several interpersonal health behavior models, including the social ecological model, social support and social network theory, community organization theory, and empowerment education theory, can be used to understand CBPR applications in health.

#### **Motivational Interviewing**

Motivational interviewing (MI) is an approach to behavior change that draws on a supportive and empathic, but consciously directive, counseling style to help clients overcome ambivalence and commit to change (31). MI is an evolution of Carl Rogers' client-centered counseling which is based on the following six conditions necessary for constructive personality change to occur:

- 1. There must be a psychological relationship between two people (the client and the therapist)
- 2. One individual (the client) must be in a state of discrepancy between the perceived or desired experience and the actual one
- 3. The therapist must be genuinely present in the relationship with the client
- 4. The therapist must have unconditional positive regard for the client
- 5. The therapist must experience an accurate, empathic understanding of the client's experiences
- 6. The client must be able to perceive the therapist's empathy (32). These conditions are central to MI, in which the counselor seeks to elicit "change talk" from the client, thus allowing clients to hear for themselves their own motivations for change (33). MI counselors then use reflective listening to allow clients an opportunity to hear their motivations again as expressed by the counselor (31).

The relationship between the counselor and the client in MI is similar to that of the academic researcher and the community in CBPR. For example, the MI counselor is not seen as the expert just as the academic researcher is not seen as the expert in CBPR (33). Rather, MI recognizes the client as the expert and as the owner of his or her knowledge based on the person's values, goals, and experiences (33). Similarly, the principles of CBPR

recognize the expertise of the community and CBPR researchers seek to establish equitable relationships, based on trust and respect, with community members (34). Just as there is an emphasis on genuineness within the relationship between the MI counselor and the client, CBPR practitioners should be genuine in their approach to working with the community (32, 35, 36). Thus, CBPR and MI share many of the same principles related to relationship dynamics, egalitarianism, and participation in the development of interventions based on the values and priorities of either the community or the client.

#### **The Health Belief Model**

The Health Belief Model (HBM), which is based on cognitive social theory and explains health behavior as a value-expectancy paradigm, continues to be one of the most frequently utilized health intervention models (37). The HBM assumes that people will take action to improve their health or avoid disease if they view themselves as susceptible, if they perceive that the severity of contracting the illness or not seeking treatment is high, and if the benefits of acting outweigh the costs. Essentially, the HBM describes health behavior in terms of the desire to avoid negative consequences. While many interventions based on the HBM have had positive results initially, the long-term efficacy of such programs is not well documented (38). For instance, does an individual's motivation to maintain a certain behavior continue even after the threat of disease has passed (for

example, are weight-management techniques maintained once weight-loss has occurred and risk of cardiovascular disease has been reduced)? The focus of the HBM, then, remains on what the Motivational Interviewing (MI) literature describes as an external locus of control – avoidance of the negative consequences – rather than an internal one (33). One of the basic principles of MI is that an individual must make the shift from the external locus of control to an internal one in order to affect lasting behavior change. Acting out of fear of adverse consequences at a future date is unlikely to be a sustainable means of dietary behavior change.

Several studies have shown that objective susceptibility to negative health consequences does not result in perceived susceptibility or behavior change. For example, Strychar et al. found that individuals who received the results of blood cholesterol screening as part of a nutrition intervention program were no more likely to change their diets than individuals who did not receive their screening results (39). Even those individuals with elevated blood cholesterol did not change their diets more than individuals with normal blood cholesterol. In another study, young adults with a family member who experienced a heart attack or stroke, indicating a significant risk factor, were not more likely to lose weight or alter physical activity behaviors (40). These examples illustrate that an individual who is susceptible to disease does not necessarily change behavior despite the fact that he or she is aware of specific risk factors.

Self-efficacy is a central construct of several health behavior models, including the HBM. Defined by Bandura as "the conviction that one can successfully execute the behavior required to produce the outcomes" (37), self-efficacy is the primary resource for change in the HBM (38). Self-efficacy is fundamental in CBPR as well and is manifested through participation, empowerment, and action in the research project. As MI has shown, people are more likely to modify their behavior if they perceive they have had a part in development of the behavior changes and that they are able to choose their course of action rather than having the changes imposed on them (33). CBPR takes this concept to the community level, assuming that if people have a part in identifying goals and developing interventions, they will be more likely to act on them and feel empowered to maintain their behavior.

#### The Transtheoretical Model

The Transtheoretical Model (TTM) is the other commonly used health behavior theory (41). The TTM describes individual health behavior change in a temporal context as a series of stages through which an individual passes, from precontemplation through contemplation, action, and into maintenance. As with the HBM, interventions based on the TTM are often successful in the short term, but are less effective in the long term. For example, one study that provided a six-month program utilizing a TTM-based clinical intervention found that participants lost approximately six

percent of their original body weight (42). As with most weight loss interventions, however, participants began to gain the weight back, and at one-year had maintained 61% of the weight lost and at two years had maintained only about 48% of weight loss.

While TTM-based interventions may not always be successful in terms of long-term health outcomes, they do allow for the understanding of important health behaviors. For example, the Riebe et al. study found that an individual's weight loss success was related to confidence and self-efficacy. Individuals who expressed greater confidence and self-efficacy were significantly more likely to maintain behavior changes than people with low confidence and self-efficacy.

The concept of individual confidence and self-efficacy is useful in considering community empowerment. For example, the Adolescent Social Action Program (ASAP) implemented a program to reduce morbidity and mortality among adolescents living in high-risk environments by encouraging them to make healthier choices in their own lives and using empowerment education to increase active engagement in social action in their own communities (43). Students in the program interviewed patients and jail residents who had problems related to drug or alcohol use, interpersonal violence, or other risky behaviors. The students learned how to conduct interviews and participated in exercises to teach them skills in decision-making, conflict mediation, communication, problem posing, and resistance to peer pressure. The project resulted in the development of a

three-stage model of change that included the development of an individual orientation of caring, followed by a sense of individual responsibility to act, and subsequently a sense of responsibility with regard to social action on a community scale. The first stage, characterized by the students' development of an orientation toward caring about their community, led to the second stage in which the students made individual changes and expressed an ability to help those around them. By helping others, the students developed an increased sense of self-efficacy and empowered self-identity. The ASAP example is particularly useful in demonstrating the relationship of individual self-efficacy and community empowerment. The relationship appears to be reciprocal: as an individual's self-efficacy increases, so does his/her commitment to community, while involvement in community empowerment activities seems to increase an individual's self-efficacy (43).

# Social-Ecological, Social Support, and Community Organization Models

While the HBM and TTM are generally used to describe intrapersonal behavior change, the social-ecological, social support, and community organization theories can be used as frameworks for understanding interpersonal behaviors as they relate to health. In particular, CBPR utilizes an ecological perspective by considering not only the individual but also both the immediate contexts within which the individual lives (family or social network), as well as the larger contexts of community, culture, and

society (30). Because of the importance of the ecological point-of-view, which focuses on both social networks and community organization, it is important to understand the theoretical background of these models to appreciate the theory and application of CBPR.

#### **Social-Ecological Model**

Sallis and Owen define ecological models of health behavior as those "proposing that behaviors are influenced by intrapersonal, sociocultural, political, and physical-environmental factors; these variables are likely to interact, and multiple levels of environmental variables are described that are relevant for understanding and changing health behaviors" (44). The authors go on to define social ecology as "the study of the influence of the social context on behavior, including institutional and cultural variables." Fawcette uses the ecological model to describe the difference between CBPR and most conventional research (45). In most traditional research paradigms, the researcher has control over the experimental conditions with the goal of illustrating large and immediate results in a small number of people. According to Fawcette, this research standard has made it difficult to examine broader contextual variables and to develop prevention programs that often have delayed results (45).

By utilizing an ecological perspective, CBPR programs take a different approach, seeking community-level results that are frequently realized in small, often delayed, increments but that incorporate a large number of people (45). Furthermore, academic researchers using a CBPR approach

often have much less control over their projects than they would if they were developing health interventions using traditional methods. In participatory research, the academic researcher shares control of the project with community partners, or co-researchers. Relinquishing control of the experimental conditions under the ecological approach allows community problems to be examined at not just the level of individuals and their proximate environments but also by taking into account broader environmental contexts (45). To illustrate the difference, Fawcette uses the example of a welfare client to describe individual changes and changes to the proximal environment. In this case, the client is provided with training for job interviews and gains skills in budgeting, which changes the individual and his/her proximal environment. Without changes to the broader context of increased job opportunities and adequate financial resources for the family, however, the client's situation is unlikely to change. The use of an ecological perspective allows CBPR practitioners to address both the individuals' proximal environment as well as broader sociocultural factors that affect health.

#### **Social Support**

Social support theory uses the ecological model's emphasis on broad contextual influences on health behavior but narrows the focus to interpersonal interaction. Social support takes many forms and is perceived in many different ways. House proposes four broad types of social support:

(1) emotional support, which involves the provision of empathy, caring,

love, and trust; (2) instrumental support, which consists of behaviors that directly help the person in need such as helping the person do their work or supporting them financially; (3) informational support, in which a person provides information that can be used in coping with problems; and (4) appraisal support, which is relevant in self-evaluation and social comparison (46). For example, a supervisor telling an employee that he/she is doing good work is considered appraisal support (46).

House proposes two categories for evaluating a support network: perceived support and objective support (46). These categories have also been distinguished as functional support and structural support, respectively (47). While structural, or objective, support refers to the availability of support-givers in an individual's network, functional (perceived) support addresses the individual's perception of support (46, 47). An individual may have a network of support-givers who believe they are supporting the person (high structural support), but the individual may not perceive that he/she is being supported (low functional support). In many cases, interventions offer structural support, often in the form of peer groups; however, functional support may be lacking in these situations. Functional support has been found to have a stronger correlation with health, which illustrates the need to address both the quantity and quality of support that health interventions provide (47). Furthermore, Heaney and Israel point out that it is unlikely that one type of social network intervention will be applicable in all situations (48). Rather, they call for a participatory

framework for developing social network interventions to ensure that the programs are optimally effective. Using a participatory evaluation process allows for the establishment of programs that meet both the structural and functional needs of intervention participants.

Heaney and Israel propose five pathways in which social support and social networks influence health behaviors and outcomes: (1) meeting basic needs such as intimacy and companionship, (2) increasing coping resources (3) reducing an individual's exposure to stressors (4) increasing community capacity, resources and problem solving which leads to an increased ability to cope, and (5) providing support for health behavior changes (48).

#### **Social Network Mapping**

The social support framework serves as a useful foundation for the process of social network mapping, which can be used to clarify interpersonal relationships, uncover hidden members of the network, and identify strengths and weaknesses in the support system (49). Social network mapping came about as the result of Moreno's work on the relationship between psychological well-being and the structural features of social configuration (50). Moreno defined these configurations as the concrete patterns of interpersonal choice, attraction, repulsion, friendship and other relations in which people were involved (50). To illustrate these relationships, Moreno developed the sociogram, a diagram based on spatial geometry, in which individuals are represented by points and connected by lines to represent social relationships. Since Moreno, many other sociologists

have developed a variety of mathematical models for explaining social relationships (50). While these models can become quite complex, the basic objective is the documentation of the relationships among individuals in a system through graphic illustration.

Partners in a CBPR project can use social network mapping to identify relationships, sources of support, resources, and strengths within the research group. The graphic illustration of the network reveals reciprocal relationships among participants and demonstrates the group's reliance on one another (51). Identification of these reciprocal relationships is a powerful tool in the collaborative process as it allows all members of the network to perceive one another as legitimate contributors to the process. From this foundation of mutual respect and sense of legitimacy, knowledge flows more freely and trust develops among members of the group (51). Furthermore, a process of collaboration and social learning promotes empowerment within the network though identification of individual strengths and contributions to the system. According to a participant in Sandow and Allen's action research project at Hewlett-Packard, social network mapping revealed that networks were much larger than anticipated and were too complex to manage with traditional techniques (51). Thus, a collaborative social network was developed that allowed information to flow freely, which led to more efficient and effective business (52).

## **Community Organizing**

CBPR derives many of its key concepts from community organizing and community building theory. These core principles include: (1) empowerment, or the social action process through which people take control over their own lives and the lives of their community; (2) critical consciousness, which is based on the continuous cycle of reflection and action in making change; (3) community capacity which affects the ability of a community to identify, mobilize, and address problems; (4) social capital, or community relationships and structures that promote cooperation for mutual benefit; (5) participatory issue selection focusing on specific, achievable targets that build community cohesion and strength; and (6) participation and relevance, which emphasizes research that "starts where the people are" and engages community members as equals (53, 54).

Community organizing employs a number of strategies including grassroots organizing, organizing coalitions, employment of lay health workers, building community identity, political and legislative actions, developing critical awareness (as described above), and leadership development (54). As Minkler and Wallerstein point out, community organization is a dynamic process and may utilize a number of different strategies depending on the needs and priorities of the community (54).

The Treatwell 5-a-Day Study incorporated community organizing strategies into a worksite intervention that sought to increase fruit and vegetable intake (10). This project assigned 22 worksites to three groups – a

minimal intervention control group, a worksite intervention, and a worksiteplus-family intervention. Using a socioecological theoretical framework, the intervention targeted nutrition behaviors at multiple levels of influence. The study found that the interventions that included both the worksite and family were significantly more effective at influencing behavior change than were the worksite-only interventions. Controlling for gender, education, occupation, living situation, and worksite, the study found that the worksiteplus-family group increased fruit and vegetable consumption by 19% while the worksite-only intervention group increased fruit and vegetable intake by 7% and the control group saw no change in fruit and vegetable intake. As the authors point out, while the change in intake between the worksite-plusfamily group and the control group represented only approximately half a serving a fruits and vegetables, the change in consumption patterns are likely to have meaningful benefits at the population level. Furthermore, the results provide a compelling argument for the use of a community model that targets multiple levels of behavior influence when developing nutrition interventions.

# **Empowerment Education**

Paulo Freire's philosophy of empowerment education is instrumental in the application of CBPR to health research. Empowerment education involves groups of people, usually those in positions of powerlessness or perceived powerlessness, working together to identify their own problems,

analyze the roots of those problems, and develop strategies to generate positive changes in their communities (55).

Empowerment education has important implications with regard to the ability of research to address the root causes of health problems. As described previously, many disease risk factors, such as lack of access to healthy foods, unemployment, occupational stress, poor education, and powerlessness, are beyond the ability of one individual to control or change (56). Rather, the underlying social structure in which these health issues occur must be examined to truly understand and affect the root causes of these problems. As an example of the importance of this approach, the World Health Organization in 1991 identified community participation and empowerment as critical factors in promoting healthier individuals and environments (57).

Empowerment education occurs in three phases: first, listening to identify key community issues; second, promoting participatory dialogue about the issues identified; and third, taking action to address the community's concerns (55). This pattern does not occur in a linear fashion; rather, it is an iterative, cyclic process of listening, discussing, acting, and reflecting on those actions through another process of listening and dialogue. The emphasis in empowerment education is on sharing of knowledge and human liberation (58).

Empowerment occurs at three levels; individual, organizational, and community (56). Individual empowerment is similar to self-efficacy in that it

focuses on the development of personal competence and a sense of control over one's situation. The concept of individual empowerment, however, goes a step further and also addresses participation in actions to affect change at the institutional and community level (56).

Organizational empowerment refers to processes that enable individual control within the organization and that allow the organization to have influence on the larger community (56). Empowered organizations promote knowledge-sharing and cooperative decision-making, which results in empowerment at the individual level as well.

Community empowerment is the central focus in CBPR. At this level, empowerment efforts work toward the collaboration of individuals and organizations to improve the quality of life for the community (56).

Community empowerment seeks to increase community capacity and affect change within the larger social system.

Israel et al. point out that these levels of empowerment are not distinct from one another (56). Rather, efforts to empower communities result in individual empowerment as members of the community take control over their lives. Similarly, individual empowerment leads to community empowerment as individuals take action and increase social support. For example, the ASAP program described above, which uses an empowerment education model, resulted in personal empowerment as youths say they have developed more confidence and made changes in their own behaviors (59). While impacts from the ASAP program on the school

and community levels have been more difficult to measure, researchers have found that the community has responded to student requests to take action to address drug and alcohol problems.

In summary, both intrapersonal and interpersonal models of health behavior are relevant to the theoretical framework of CBPR. Motivational Interviewing's approach to the client-counselor relationship is useful in examining the relationship between the researcher and the community. The concept of self-efficacy is central to Motivational Interviewing as well as the Health Belief Model and the Transtheoretical Model. The Transtheoretical Model is also relevant to CBPR as community members may be at the precontemplation stage at the initiation of a CBPR project but move toward contemplation and ultimately action as a result of their participation. The social ecological model's explanation of health influences that extend beyond the individual and take into account sociocultural and environmental factors provides the foundation for CBPR's multi-level approach to health issues. CBPR's emphasis on strengthening interpersonal relationships within the community has its roots in social support theory, which illustrates the health benefits of strong social networks. Community organizing theory shares several core principles with CBPR, including empowerment, building community capacity, participation and cooperation for mutual benefit, and an emphasis on interventions that result in relevant processes and outcomes for the community. Finally, the concept of

empowerment education provides a model of the cyclic process of listening, dialogue, and action used in CBPR and illustrates the importance of an underlying belief in social justice and equality relevant to CBPR projects.

### **CBPR** as an Orientation to Intervention Research

Within the historical roots of CBPR, there is a fundamental commitment to social change that enables local people to seek their own solutions according to their priorities (25). Furthermore, CBPR consists of a process of mutual learning and analysis that occurs throughout the research rather than at distinct stages. Through this process, community members share in the research as owners of their own knowledge (25, 60-62) and dependence on "experts" to solve problems transforms into self-reliance (63).

Contemporary applications of CBPR are the result of multidisciplinary approaches to community action and social change (26). Practitioners generally point to two separate, but in many ways similar, research orientations as the foundation for CPRB. The Northern Tradition, based on Lewin's action research model, sought to develop collaborative strategies to undertake a participatory research cycle that involved three key components: planning, action, and assessment (26). The Southern Tradition, so named because it was initially practiced with oppressed populations in South American and Africa in the 1970s, originated in Marxist social theory with a goal of emancipation through education, knowledge-sharing, and community empowerment (26)

### **Action Research: The Northern Tradition**

Lewin coined the term "action research" in 1940, and defined it as "comparative research on the conditions and effects of various forms of social action, and research leading to social action" (64). Reason and Bradbury further describe action research as uniting action and reflection, and theory and practice, through collaborative participation that seeks to improve individuals and communities by solving practical problems (65). Action research is about both practical outcomes and the process of creating new forms of understanding, not about the development of new academic theories. As Reason and Bradbury describe it, the fundamental purpose of action research is "to liberate the human body, mind and spirit in the search for a better, freer world" (65).

Barrett presents an example of action research applied in a Midwives' Action Research Group (MARG) to improve midwifery practice, enhance women's satisfaction with their early mothering experiences, and facilitate women's access to informed choices (66). The project was a collaboration with midwives to identify women's experiences during the early mothering period, prioritize concerns, develop a plan of critically informed action, observe the effects of the action, and reflect on the effects to establish future actions. Through this iterative process, the MARG determined that the most beneficial course of action for new mothers and mothers-to-be was a space where they could go to learn from one another, establish supportive networks, and share and reflect on experiences. The project resulted in the

establishment of the Early Mothering Group, where women could go to be with one another during their hospital stay. As Barrett describes, "the findings are not only useful, but meaningful to those for and with whom the research is being conducted" (66).

Lewin's commitment to action through research is reflect in his statement, "research that produces nothing but books will not suffice" (64). Instead, Lewin, who pioneered the experimental study of complex social phenomena, called for a new type social research that could better integrate science and practice (67). To do this, he argued that research must take a multidisciplinary approach and examine socioeconomic structures, political leadership, and inter-group as well as intra-group relationships from the family level to the state, national, and international levels. Lewin also acknowledged that research could not seek to address one aspect of this interconnected network without also examining the whole. Furthermore, social action research acknowledged that simply diagnosing a problem is not sufficient. Rather, researchers must also implement actions to improve the quality of the social systems they were examining and evaluate these actions through an iterative process that ensured maximum positive outcomes.

Action research rejects the concept that knowledge is static (68). Instead, it calls for a constant cycle of planning, action, and evaluation throughout the research process (64). Further, the evaluation step, or what Lewin refers to as fact-finding about the result of the action, informs the

next step in the process (64). This continual cycle allows researchers to ensure effective research outcomes and processes before moving on to the next phase of planning and action.

The development of action research brought about the shift in researcher orientation for objective observer to subjective participant in the research process (26, 69). According to Lincoln, the objective detachment exhibited by social scientists led to disenchantment with academic "elites" who were perceived as unable to solve social problems. The lack of consultation with the targets of policies that resulted from social science research furthered the sense of dissatisfaction with social scientists. From this dissatisfaction and disenfranchisement came new modes of inquiry in which the objective distance previously held by the researcher developed into an egalitarian relationship between researcher and participants. This shift is also broke down the concept that "academics" and "subjects" existed in two distinct communities (69). The result has been a research paradigm that recognizes the interconnectedness of human life and respect for others and in which researchers not only learn about the subjects being researched but also commit to the welfare of the community. However, while many of Lewin's concepts of evaluation and participation have been integrated into contemporary social research, the close connection between research and action he envisioned has not yet been achieved (67).

Thus, action research introduced the fundamental CBPR principles of participation, action, collaboration, and a commitment by the researcher to the community to promote social change through knowledge.

# **Participatory Action Research: The Southern Tradition**

The core of the Southern Tradition of participatory action research (PAR) is similar in many ways to action research. A subtle difference between the paradigms is action researchers' utilitarian approach to problem solving through experimental study, understanding and action, usually at the small group or systems level, and PAR practitioners' commitment to radical, structural social and cultural change, and ultimately emancipation of the oppressed, through participation and education (26). The original PAR practitioners were less concerned with understanding the world than with changing it (65). Researchers in the PAR tradition take an explicitly political stance in their work by focusing on empowering disenfranchised and marginalized communities (25). As Fals-Borda describes this orientation,

there are two types of animators or agents of change [in PAR]: those who are external and those who are internal to the exploited classes. Both types are unified in one sole purpose – that of achieving the shared goals of social transformation (60).

The author goes on to explain how both the external and internal agents, and the unique knowledge each possesses, are required to create an accurate picture of the reality being transformed.

A fundamental construct of both PAR and CBPR is what Freire termed praxis, which, similar to Lewin's cycle of planning, action, and evaluation,

involves a cycle of actions toward individual and social changes, consciousness of those actions (also called conscientization), and reflection on the actions (26). This notion of praxis is the foundation for the participatory evaluation process that is essential in effective CBPR.

PAR acknowledges that people are the owners of their own knowledge and recognizes this knowledge as powerful (61). Because the people own their knowledge, it is they, not the researcher or academia, who must benefit from research which utilizes their knowledge. As Freire put it, "We have to be very clear about the objective of this work: it is the people themselves, not the advancement of science. If, however, the people are silent, then we have to provoke them, because we are not neutral." Thus PAR, like action research, recognizes the role of researcher as a facilitator or catalyst of change who supports rather than dominates the process (62).

While some might view PAR as a radical method of research and action, practitioners would argue that a revolutionary attitude toward knowledge is needed to empower the oppressed and address the root causes of social inequalities and unequal distributions of knowledge and education. PAR and CBPR are intentionally revolutionary, breaking the current power monopoly over science and culture by increasing community capacity and grassroots control over the production and ownership of knowledge (70).

## Challenges and Limitations in CBPR

While CBPR offers a unique and promising alternative to more traditional health interventions, it is not without challenges and limitations. This approach requires a significant investment, both in terms of time and funds, on the part of researchers and the community (25, 71, 72). Issues that often arise include challenges related to identification and inclusion of the community, definition of the issue, and control over the research and results.

## Who is "The Community?"

One of the first steps in the initiation of a CBPR project is determining who the community is and who should represent the community's interests. What is defined as a "community" is often a highly heterogeneous group of people with distinct values and priorities (25, 36). Therefore, it is critical for the outside researcher to understand how the community defines itself rather than relying on traditional definitions such as zip codes or census tracts (36).

Further challenges are presented by the fact that it is often easier to engage existing local leaders in a research project while overlooking marginalized members of the community (25). Stoecker defines community as "the people with the problem" who are usually not those involved with government agencies, foundations, or even the nonprofits working to address the problems (73). For example, the Brazilian Reproductive Health Project sought to involve the most marginalized and vulnerable groups but

found that these were the people who were the least able to participate (74). In some cases, it is possible to remove barriers and enable participation by providing food, transportation, and child care at meetings and research activities (36). However, there are many other barriers to participation that are more difficult to address including feelings of ambivalence and powerlessness that lead to passivity (75).

Gaining a genuine understanding for who the community is takes a great deal of time and energy on the part of the researcher and sometimes involves activities seemingly unrelated to research (36, 73). Stoecker describes his first community encounter in which he was assigned to cleaning out the community-based organization's storeroom (73). While not directly related to the research, efforts such as these demonstrate commitment to the community and provide deeper understanding of the community. Thus, it is important for potential CBPR practitioners to recognize that CBPR is not an easy solution to difficult research problems. Rather, the initial groundwork required to initiate a CBPR project is time-consuming, labor intensive, and often difficult and uncomfortable but it is also critical to the success of any partnership (25, 72, 73, 76).

### **Identification of the Issue**

Issue identification is a key component of CBPR and one that can be particularly challenging. When an outside researcher is the initiator of a potential CBPR project, he or she may have an idea of the problem that is

different from the issue that is of the highest priority for the community (72). For example, Mosavel et al. initiated a CBPR project in South Africa that sought to establish a cervical cancer primary prevention program (77). However, through the CBPR process and engagement of local people, researchers found that cervical cancer was not the most relevant concern for women in South Africa. Rather, the larger concept of cervical health, which included other reproductive diseases, HIV-AIDS, sexual violence and other factors, was a more pressing issue for the community. Furthermore, the researchers found that any intervention must consider the daily challenges of living with many health issues related to crime, poverty, violence, and unemployment. Thus, involvement of the community reshaped the research from a concept that seemed important to outside researchers into one that was important to the people for whom the research, and intervention, was intended.

The process of participatory issue selection requires the CBPR researcher to take the position of learner rather than teacher and to accept community members as co-researchers rather than passive recipients of services (45, 74). This approach, which challenges the traditional roles of "researcher" and "subject" in conventional research, may not be appropriate for all researchers or research situations. Therefore, it is important for researchers and communities to reflect critically on their capacity to conduct participatory research and take on the challenges it inherently presents (36).

An additional challenge relates to the fact that communities are often deeply divided on issues of importance to them (72, 76). For example, Fadem et al. describe the conflicts related to exploring attitudes of people with disabilities about death with dignity (physician-assisted suicide) in a community that was highly polarized about the issue (76). In this study, the researchers found that some leaders in the disability community were strongly opposed to the project and that others thought it was important to conduct open dialogue on the issue. Because of the controversial nature of the subject, the research group had to constantly ask difficult questions and reflect on the importance of the issue throughout the course of the project. Despite the challenges resulting from the divisiveness of the subject, the authors theorize that dealing with such dilemmas by actively engaging community members in all aspects of the research can contribute to the building of stronger, more competent communities.

### **Control Over Research and Results**

Unlike conventional research, in which the researcher and academic institution are owners of project findings, results of CBPR projects are, in principle, owned by the community (25, 71, 76). As Minkler describes, this leads to challenges on several levels, including issues related to dissemination of findings and implementation of actions resulting from the research (72).

# **Dissemination of Findings**

In CBPR, community partners are involved in decisions and actions related to the dissemination of research results (30, 34). This collaborative approach to sharing and use of findings can lead to conflicts between researchers and the community and among community members. In the death with dignity project described above, serious issues arose related to the use of project findings (76). For example, many study participants thought sharing the issues revealed in the study was essential while others felt, for a variety of different reasons, that the findings should not be disseminated to the community. Presentations to community groups found similar divisions related to the findings. Some welcomed the initiation of dialogue regarding death with dignity while others desired to suppress discussion that might conflict with the disability community's dominant public opinion on the issue. Thus, while involvement of community members in dissemination activities can increase the relevance of the ways in which information is distributed, it also requires constant negotiation related to how findings will be shared, who will share them, and to whom they should be presented.

Collaborative dissemination efforts can also be time consuming and resource intensive. It is important to budget adequate resources to compensate both the academic and community partners for their efforts in all aspects of dissemination; however, many funders and institutions value academic methods of dissemination, such as peer-reviewed publications and

conference presentations, over community methods such as fact-sheets and community presentations (78). Furthermore, some community members may not be interested in participating in certain activities such as the development of a manuscript or academic presentation (73, 78). Academic partners may find that they do not have time to write manuscripts when community presentations are the focus of dissemination efforts (78). Thus, Parker et al. point out the importance of working with funders and institutions to elevate the importance of community dissemination efforts, balancing community and academic presentations, and developing specific guidelines related to dissemination to provide direction when issues arise (78).

# **Implementation of Actions**

There are many issues that affect the action component of a CBPR project. For example, Minkler points out that conflict may arise when community members wish to move ahead with action while academic partners may want to wait until findings have been published (72). Funding issues can also constrain action when the desired actions are discouraged or prohibited by the funding agency (72). Furthermore, actions that challenge powerful corporations or institutions can have negative consequences for both the academic and community partners (72). For example, Diaz and Simmons found that women involved in the Reproductive Health Project described above did not want to be involved in actions that might appear to be politically charged (74). Therefore, the collaborative nature of CBPR may

hinder the implementation of action steps identified as a result of research activities. Managing these challenges requires a skilled community organizer who can help the partners make strategic decisions about appropriate actions that will benefit all group members and benefit the community (73).

Despite the challenges CBPR presents, it continues to show promise as a means of empowering communities and improving health. However, it is important to continually reflect on the issues presented here to ensure that the community is effectively engaged, the issue being addressed is relevant to the community, and the goals and objectives of project participants are being achieved (36, 77).

### **Fundamental Methods in CBPR**

It is important to recognize that CBPR is not itself a research methodology with a set of steps to follow but rather an *orientation* to research (24). This approach is similar to Motivational Interviewing (MI), which is not a counseling method but *a way of being with people* (33). As described above, the "expert" in both MI and CBPR is actually the client or community, respectively, rather than the interviewer or researcher. As Miller and Rollnick point out, when an interviewer assumes the role of expert, the client takes on a passive role rather than an active one (33). The same can be said for a researcher who acts as expert and places the community in the passive role of subject. It is important to note that in CBPR, researchers are

not simply passive observers either. Rather, they have an agenda at the outset of their work: to improve the lives of the people with whom they are working. Where the role of the CBPR researcher differs from traditional researcher roles, however, is in the fact that they relinquish control over the process and share power with community members. Thus it is important to establish an equal relationship, in which both community members and researchers are active members, to achieve a motivating, empowering process.

Instead of dictating the steps taken in research, CBPR defines the context in which the research occurs (25). The actual research methods employed in the CBPR project are decided on collaboratively and based on community priorities. Qualitative research methods such as focus groups, key informant interviews, community assessments, surveys, and participant observation are all frequently utilized (79-83). The applications of participant observation, key informant interviews, focus groups and participatory evaluation and dissemination within the context of CBPR are described below.

# **Participant Observation**

Participant observation is a primary data-collection technique in which the researcher engages with the community as an active member rather than a passive spectator (84, 85). As Patton points out, in participant observation there is no separation between observing and interviewing (84).

Rather, the participant observer is fully engaged in experiencing the community while maintaining an observational vantage point (84). The degree to which a researcher can participate in a community is often dictated by factors such as race, gender, sociocultural issues, and the type of community being observed. For example, Patton uses the example of a chemical dependency program to illustrate a situation in which a researcher, who is not chemically dependent, could never be a full participant. Instead, the goal is to find a balance of participation that will result in the most meaningful observation for the type of research being done (84).

Participant observation is frequently used in CBPR as a means to build relationships and trust, demonstrate a commitment to the community, and establish reciprocity with the community. For example, a CBPR project in North Carolina used participant observation as an initial step to learn about the community and gain access to key community members and organizations (85). The first step in participant observation was to conduct a *windshield tour* of the community and surrounding area. In addition, the research group attended the annual Octoberfest celebration, volunteered at local community groups, and observed activities at a senior center, the local health department waiting room, meetings of local leaders, and PTA meetings. These opportunities allowed researchers to get to know community members and identify key people in the community. Each group member systematically recorded field notes to document the observations and any reactions, thoughts, and feelings about these initial activities.

### **Key Informant Interviews**

Key informant interviews are often used in the initial phases of CBPR projects to help define who is "the community" and to identify issues of importance (85). Key informants are generally members of the community who have been in the community long enough to have developed relationships with other community members and knowledge about the history and culture of the community. As Hancock and Minkler point out, it is important in an empowering process that key informant interviews focus on community strengths as well as needs (86). Asking questions that enable residents to reflect on resources within the community builds capacity and provides valuable information related to the research process (86).

As an example, Corbie-Smith used a series of key informant interviews to examine the sociocultural context of HIV/AIDS risk and service use among Latino men living with HIV/AIDS (20). Interviews were conducted with both health service providers and Latino men living with HIV, which revealed themes related to cultural and social influences on sexual risk behavior. The interviews also identified barriers and facilitators to service use among Latino men living with HIV/AIDS. The results of the interviews provide useful information that can be used to inform efforts to improve access to health services for this population.

# **Focus Groups**

Focus groups are used in CBPR to enable community members and researchers to explore issues, exchange ideas, express opinions, and understand the collective experience of the community (81). This method also allows participants the opportunity to share their knowledge using their own language, which serves to validate their expertise. While focus groups have traditionally been used to conduct formal group interviews, with structured questions and focused discussions, they can also be used in collaborative research efforts to empower groups through collective dialogue (84).

The advantages of focus groups are that they allow for the observation of interactions among participants, reveal rich content about the group being studied through verbal expression of opinions and perceptions about the subject, can be used over a short period of time, can sample from relatively large populations at a low cost, and tend to produce a safe space for participants to reveal information they might not share in a one-on-one situation (84, 87). Disadvantages of the focus group method include the need for a skilled facilitator who can manage the group process and encourage dialogue among members and the fact that the number of questions that can be asked in a group setting is often restricted due to time constraints (84). In addition, people with a conflicting or minority opinion may be afraid to share their beliefs in a group setting and it is difficult to ensure confidentiality in a group setting (84).

# **Natural Groups**

An alternative to the focus group approach, in which participants tend not to know one another prior to the meeting, is the natural group process (88). Natural groups consist of individuals who know each other already and provide access to shared group culture and an understanding of how social knowledge within the group is generated. These groups can be either informal, which often occurs spontaneously in the field, or formal interviews in which the group is invited to come together for the purpose of research. Informal natural groups tend not to be audio taped and occur in such a way that, as researchers begin to ask questions, more people engage in the dialogue and come and go throughout the course of the discussion. This method requires flexibility and adaptation of formal protocols as the group changes (88, 89).

## **Participatory Evaluation and Dissemination**

Finally, evaluation and dissemination of results must also be a collaborative process. This process is critical to CBPR because of its commitment to using knowledge generate through research to inform action (78). Results may be used by the partnership to affect change at the individual, organizational, community, and policy levels depending on priorities. Methods for disseminating findings to broader audiences may include development of fact sheets, community forums, journal publications (on which community members serve as co-authors with researchers) and

others. Photovoice, a process in which community members use photographs to communicate elements of their lived experiences, can also be used to communicate research findings (90). Regardless of the methods used for communicating findings, the dissemination plan should be developed in the same collaborative manner used in conducting the research to ensure a truly participatory process from beginning to end.

In summary, CBPR does not prescribe a particular set of methods. Rather, it presents an ideological approach to research in which the researcher and community act as equals in an active, co-learning relationship based on mutual trust and respect. Regardless of the methods chosen, all members of the research group must have a commitment to participation from initial question development through dissemination and evaluation. Qualitative methods that are frequently used in CBPR include participant observation, key informant interviews, and focus groups.

#### **METHODOLOGY**

The purpose of this project was to examine health and nutrition resources and needs among Head Start families using CBPR. In accordance with CBPR principles, the project sought to balance research with action and implement participatory methods at every stage from recruitment to dissemination.

## **Participants**

Parents and caregivers of children enrolled in the Kids and Company (KidCo) Head Start program were the initial project targets. This Head Start pre-kindergarten program serves approximately 400 low-income children and families in the Western Oregon communities of Albany, Corvallis, and surrounding rural areas of Linn and Benton counties. Enrollment in Head Start is limited to three and four-year old children from families at or below the federal Office of Management and Budget poverty guideline (91).

KidCo staff and administrators, including the Executive Director (E.D.), the Health and Nutrition Services Coordinator, and family advocates, were also project participants. CBPR partnerships often benefit from prior positive working relationships between partners (36). KidCo Head Start was chosen because of an existing relationship between the OSU partners and KidCo administration. The OSU faculty member had served as the Health and Nutrition Services Coordinator for several years prior to project initiation

and had a positive working relationship with the E.D. and some members of the staff and administration.

KidCo is organized into an administration office and nine centers throughout Linn and Benton counties. The organization is governed by a board of directors and a policy council comprised of parent representatives from each center. Individual centers are served by at least one family advocate, a site supervisor, teachers and teacher aides, and administrative staff. Family advocates are direct service providers at Head Start and serve as liaisons between the Head Start administration and families. They also enroll children in the program each year, conduct home visits, and help families connect with community resources and health care providers.

Residents of Brownsville, Oregon, were also project participants.

Brownsville is located in Linn County and has a population of 1,500.

Participants were primarily regular customers of a locally owned coffee shop in downtown Brownsville.

### **Development of Initial Research Questions**

Initial research questions were developed to be broad enough to accommodate a CBPR approach. In particular, the questions were designed to avoid imposing a research agenda on the community. Rather, the questions sought to understand the health and nutrition priorities of the KidCo Head Start community and to explore the possibility of conducting a CBPR project within the short timeframe of a nine-month school year.

## Participant Observation and Partnership Building

Initial meetings were held with KidCo's E.D. and Health and Nutrition Services Coordinator to establish trust and respect, ensure that KidCo would benefit from the research conducted, outline a framework for the project that met the needs of both researchers and participants, and identify strategies for involving parents and caregivers. The KidCo administrators suggested that the next step in project development would be to attend a family services meeting to meet family advocates from each of the centers. A second meeting was held between KidCo's Executive Director and the author to discuss recruitment materials. In particular, the language to be used in the recruitment flyer was addressed. The administrators suggested that the language be non-technical so that parents and caregivers could understand it. Language that emphasized parents and caregivers as experts was discussed and agreed upon. These meetings also established a framework for research methodologies and the protocol to be used in the IRB application.

## **Family Services Meetings**

As suggested by the KidCo administrators, a family services meeting was attended in November, 2005. At this meeting, the OSU partners were introduced by the Executive Director. The OSU faculty member outlined the intent of the research and asked for input from family advocates. In addition, family advocates were asked about existing nutrition messages and

programs and whether they were meeting the needs of Head Start families. Questions about existing programs were asked using the illustrative example format, with the Food Guide Pyramid and other programs used as examples to initiate discussion about existing health programs and invite suggestions of programs that might work for the KidCo community (84).

The purpose of this meeting was to establish a framework for the partnership and build relationships, not to conduct recruitment or formal research. In addition, the family advocates were asked to evaluate the recruitment flyer to ensure the appropriateness of the language. The family advocates who were potentially interested in having parents and caregivers participate in the project suggested that attendance at family nights would be an appropriate next step. Contact information was collected from these family advocates and this information was used to schedule attendance at family nights. The family advocates also suggested that attendance at policy council would be a good way to meet parents who were leaders within KidCo and to further establish relationships. The OSU partners continued to attend family services meetings to maintain contact with family advocates and provide updates on IRB submission.

## **Policy Council Meetings**

The December, 2005, policy council meeting was the first opportunity to meet parents and caregivers. The introductory discussion at this meeting was similar to the family services meeting. The E.D. introduced the OSU

partners and the faculty member described the goals of the project. She again asked open-ended, illustrative example questions about existing nutrition programs to engage the meeting participants in a dialogue about health and nutrition and generate interest in further pursuing these issues. The recruitment flyer was passed out to meeting participants and feedback about recruitment methods was discussed. Policy Council members approved the initial recruitment flyer, which was used in subsequent recruitment efforts (Appendix A). The OSU partners continued to attend policy council meetings through February, 2006, to provide updates on project development and IRB approval.

## **Family Nights**

Family nights at five centers were attended beginning in January, 2006. Family nights are federally mandated parent meetings held monthly at each center. Childcare is provided and dinner is served, followed by a presentation of a federally mandated education topic. While the program is required to hold family nights each month, it is important to note that parents are encouraged but not required to attend.

Centers were chosen based on the interest of family advocates who provided contact information at the family services meeting. Attendance at meetings was scheduled with family advocates by phone or email. The OSU partners introduced themselves at the meetings using language that was agreed upon in advance (85). The introductions let community members

know that the researchers were from OSU and gave a brief introduction to CBPR. These efforts were considered pre-research partnership-building as IRB approval had not yet been obtained. Recruitment did not begin until after IRB approval was received. To remain true to the principles of participant observation, the researchers engaged fully in family night activities (84, 85)

## **Institutional Review Board Approval**

An application to work with human subjects was submitted to the Oregon State University Institutional Review Board (IRB) in December, 2005, and full approval was received on February 8, 2006. Recruitment began upon receipt of IRB approval.

CBPR is an ever-evolving process guided by participants in partnership with researchers; therefore, it does not lend itself well to the traditional IRB approval process. An agreement was developed with the OSU IRB that an evolving approval process would facilitate the changing procedures of a CBPR project. Because of this, several project revisions were submitted and approved as additional materials and methods were developed.

### Recruitment

Methods for recruiting parents and caregivers were developed with direct input from KidCo administrators, staff, and family advocates. Parents and caregivers assisted with recruitment through input at policy council and family night meetings.

Once IRB approval was obtained, recruitment began with attendance at policy council. At the February meeting a sign-up sheet (Appendix F) was passed around to gather names and contact information of parents and caregivers on policy council who were interested in participating in the project. Policy council members and family advocates were also given copies of the recruitment flyer to display at their centers.

Recruitment was also conducted at family nights. On these occasions, the project was described in detail with language that put particular emphasis on the parents as co-researchers rather than subjects. Interested parents were invited to provide their contact information on a sign-up sheet (Appendix F). The project was also discussed informally with parents during meals served at family nights.

## **Informational Meetings**

After consultation with family advocates at two of the participating centers, Central Linn and Lebanon, the next step was to hold an informational meeting at these centers. Flyers were sent home to parents and caregivers at both centers advertising the meetings. In addition, parents and caregivers who had indicated interest by providing contact information during a family night were called or emailed. Meeting dates and times were

scheduled based on the input family night participants gave on the sign up sheet.

The first meeting was held in April, 2006, at the Central Linn Center, which had seventeen children enrolled. This meeting functioned as a key informant interview and was conducted using in-depth interview techniques (85, 88). The interview followed a semi-structured format in which the facilitator asked open-ended questions (Appendix A) to explore health and nutrition in the Brownsville community and allowed the responses of the participants to guide the direction of the discussion (88). The facilitator also asked probing questions and used reflective listening techniques as a means to encourage discussion and reflection and ensure accuracy of meeting notes (33, 85). Meeting attendees provided input on methods for recruiting additional participants and appropriate incentives that would benefit both participants and the local community. Meeting notes were maintained by a note taker.

The second meeting was held at the Lebanon Center in May 2006. Of the twelve parents and caregivers who indicated interest in attending a meeting, three confirmed over the phone that they would attend but no parents attended the meeting. Neither of the center's two family advocates was present at the time of the meeting.

The third informational meeting was arranged differently. The Riverside Center was selected because of its year-round classroom, which meant that parents and caregivers could potentially participate in a project over the summer. One of the center's family advocates was consulted at a policy council meeting to inform recruitment efforts. The meeting was held in June 2006, and followed a semi-structured interview format similar to the Brownsville meeting. The meeting facilitator used existing nutrition program materials to as illustrative examples (84). Meeting notes were maintained by a note taker.

## **Meeting Facilitation**

The OSU faculty member was an experienced facilitator and moderated the initial meetings. Subsequent meetings were facilitated either by the faculty member or the author, both of whom had training in Motivational Interviewing and focus group techniques (33, 92)

The goals of meeting facilitation were to achieve the following:

- No single person dominates the discussion and all participants are heard from.
- Consensus is reached around topics to discuss, methods with which to proceed, and action steps to take.
- Once the group has identified a topic, that topic will be pursued unless the group decides to change it, realizing this action will lead to inefficient use of time but also allow for thought progression.
- Conflicts of interest are managed to facilitate the greatest comfort
- Meetings will start and stop on time to ensure respectful use of participants' time.

### **Field Notes**

A note taker recorded responses and meeting proceedings using the field note template from McQuiston et al (93) (Appendix G). The notes recorded meeting proceedings, participant responses, observations related to the meeting place and participants, comments on the methods and theoretical perspectives, and personal feelings during the meetings. As the work progressed, a simplified field note template was used in which methodological and theoretical notes were combined within the body of the meeting proceedings and personal notes were documented at the end of the document (Appendix H).

### **Brownsville Project**

At the Central Linn Center informational meeting, the parent suggested that future meetings be held at the local coffee shop to engage local community members and support local business. Because this meant expanding the scope of the project beyond Head Start parents and caregivers to the broader Brownsville community, a project revision was submitted to IRB. Once IRB approval was obtained, a meeting was arranged for the last week of June 2006.

An initial meeting with the Head Start parent was held at the coffee shop. The parent served as a liaison between OSU partners and the community and conducted introductions with community residents who used the coffee shop as an informal meeting place. In particular, the parent

linked the researchers to members of the self-named "geezer" table at the coffee shop where several key community leaders met informally on a regular basis.

At this initial meeting, members of the "geezer" table were invited to participate in a project to examine health and nutrition in Brownsville. Several members of the "geezer" table verbally agreed to attend weekly meetings on Wednesday mornings at the coffee shop. After two meetings, a core working group of six community members was formed. The working group was informal but members did make a verbal agreement to meet weekly. In addition to the core working group, a number of Brownsville residents, who were regular customers at the coffee shop, attended meetings sporadically and informally provided their input.

Formal focus groups were initially planned for meetings with parents and caregivers; however, the guiding principle of "starting where the people are" led to holding meetings at the coffee shop in a much more informal setting (94). The meetings took on the structure of natural groups rather than formal focus groups (88). Despite the informal nature of the meetings, the focus group facilitation techniques described above were used to encourage discussion, ensure participation, and move the group toward action.

As the work progressed, attempts were made to hold more organized, formal meetings. At the seventh meeting, the working group agreed that it would be useful to have an agenda to focus the discussion. An agenda was

brought to two subsequent meetings but not to the final, informal wrap-up meeting.

Meetings were recorded using field notes. Audio recording was not used in order to facilitate approval by IRB and encourage open, honest dialogue that might have been suppressed due to tape recording.

# **Project Development**

The work conducted in Brownsville followed a project-based research model, which involves a cyclic approach of diagnosis, prescription, implementation, and evaluation (73). Initial working group meetings sought to diagnose, or identify, a problem of importance to the community. This was achieved through facilitated discussion about issues related to health and nutrition in the community. The facilitator began by asking the question, "If you wanted to know about health and nutrition in Brownsville, what would you ask?" By repeating this question, the working group came up with a questionnaire of six questions that sought to identify health and nutrition issues of importance to the community. The note taker read the questions back to the group to ensure accuracy. The facilitator then suggested that the questions be typed by the note taker and distributed to working group members who would ask the questions of three to four Brownsville residents. The group came to verbal agreement that the questionnaires would be distributed at the next meeting and returned the

following week. The results of the questionnaires were used to guide subsequent discussion about health and nutrition in the community.

After several meetings, themes related to health and nutrition concerns began to emerge. Meeting notes were used to compile salient themes, which were then presented to the working group. There was agreement that the themes reflected the discussion to date and this document was used to develop ideas for addressing community concerns.

While the group was working to identify a problem to work on, one member, the director of the local Sharing Hands food bank, introduced a project idea related to food security. The food bank wanted to partner with Oregon State University to conduct a survey of residents in the Central Linn service area to determine the number of residents eligible for food bank services, the number of eligible residents who access the services, and what barriers exist for eligible residents not accessing the services. The diagnosis for this project was that food bank services were underutilized and that Sharing Hands did not have a way to accurately track eligibility. Further, Sharing Hands did not have a mechanism to identify barriers people encountered to accessing food bank services. The working group considered the concept of the food bank survey along with other issues that had been addressed, including researching potentially increased rates of certain diseases in the area, and participation in a formal resource identification process within the Brownsville area.

The decision to work on a particular project centered on a request for proposals (RFP) issued by the Northwest Health Foundation to fund Community Based Participatory Research projects looking at chronic disease. The RFP was distributed to working group members and other community participants at a regular meeting and discussed the following week. The working group agreed that it would be most beneficial to work with an existing organization with the capacity to administer funds and manage a project. Sharing Hands, the parent organization of the local food bank, was identified as a willing partner with the capacity to administer the grant. The working group agreed that the food bank survey would be the best project for which to use the Northwest Health Foundation funds.

The OSU representatives planned to meet with the Executive Director of Sharing Hands to begin a planning process, which led to the second step of project-based research of prescription or planning (73). The working group approved the meeting and a process was agreed upon in which the OSU partners and the Sharing Hands Director would work together to develop a grant application for submission to the Northwest Health Foundation. To ensure working group support of the food bank project, three working group meetings were spent discussing the development of the survey instrument and procedures. At a subsequent meeting, the Executive Director of Sharing Hands and OSU partners gave a verbal update on the progress of the grant application. Working group members gave

verbal agreement that they would play an active role in developing and conducting the survey once grant funds were secured.

# **Project Follow-up**

The grant writing group consisted of the director of the Central Linn Food Bank and faculty and graduate students from the Department of Nutrition and Exercise Sciences and the Department of Public Health. This group worked to develop a grant proposal that would carry out the goals of the community organization, the food bank, OSU researchers and funders. A grant proposal was prepared but ultimately the group agreed that it would not be submitted.

Follow-up with community members was conducted in an informal meeting at the coffee shop. Three of the community members were present and given a copy of the grant proposal. The group discussed the circumstances that led to the decision not to submit the grant. All working group members were provided with a letter describing the project and its outcomes (Appendix I).

#### **Incentives**

At the initial informational meeting, the Head Start parent was asked what she would recommend as an incentive for participation in the project. She suggested gift certificates to local businesses, including the local coffee shop where meetings would be held. Therefore, core working group members were given a five-dollar gift certificate to the coffee shop for each

meeting they attended. Additional community members who were not members of the working group but who provided informal input were given one five-dollar gift certificate. In addition, refreshments from the coffee shop were provided to participants at each meeting.

# **Riverside Project**

At the initial Riverside Center meeting, the parent agreed to subsequent meetings to examine health and nutrition in the community. In addition, he agreed to assist with recruitment of additional parents and caregivers at the center. The family advocate also supported subsequent efforts, although she was unsure of her ability to attend meetings due to her busy summer schedule. The original parent recruited the other member of the 2005-06 Riverside parent planning committee, who participated throughout the duration of the project.

#### **Meeting Facilitation and Data Collection**

A total of fourteen meetings were held over the summer and into the fall with parents from Riverside. In general, both parents attended most of the meetings. One of the parents had scheduling conflicts that prevented her from attending all meetings. The meetings were facilitated using techniques similar to those used in the Brownsville project. For the majority of the Riverside meetings, the author served as both facilitator and note taker. Field notes were recorded at each meeting.

As with the Brownsville project, the Riverside project was very informal and did not lend itself to written evaluation measures. Rather, informal check-ins were used to assess whether or not the participants felt the work was meaningful and participatory. Check-ins were recorded in meeting notes.

# **Project Development**

The Riverside Project also used a project-based research model to understand the nutrition needs of Head Start parents. Initial meetings focused on the identification of community needs and resources related to nutrition and health. Subsequent discussions over the summer focused on action steps to address concerns and recruitment of additional parents once the 2006-07 school year started.

#### **Nutrition Education Program**

The group focused initially on community resources, particularly sources of fresh fruits and vegetables. A list of local farm stands, farmers markets, and u-pick farms was developed to help parents and caregivers identify sources of affordable fresh produce. In addition, a poster was developed that listed seasonal availability of local produce.

Through a series of facilitated discussions, the group identified a lack of nutrition education as the problem they wanted to work on for this project. To do this, the group identified nutrition topics that were important to them. The group also brainstormed the ways they would like to see the

information presented, which included a nutrition program at every family night.

Once the list of topics was developed, the group developed a handout describing the program and discussed it with the KidCo E.D. While the E.D. supported the topics and the idea of increased nutrition education, she was concerned that it would be infeasible to present the information at family nights each month. Rather, she suggested the group discuss the notion of a "cluster" program, which involved meetings during the day with childcare and transportation provided, with the family advocates and site supervisor at the center. The E.D. also gave suggestions for editing the handout to make the program more participatory.

The group then met with the site supervisor to introduce the nutrition education program to her and to discuss the idea of clusters. The site supervisor was supportive of the project, but felt that buy-in from incoming parents was important before the project proceeded. The group agreed with this, and focused on recruiting incoming parents and gaining approval from the parent planning committee and parent group.

#### Recruitment of 2006-07 Parents and Caregivers

To recruit additional parents and caregivers, the group handed out information and talked with incoming parents and caregivers at the Riverside parent orientation in August 2006. Participants were given invitations the group developed and had printed in English or Spanish describing the project and inviting them to participate (See Appendix B).

The group also handed out nutrition education materials such as recipes, the list of local sources of produce, and OSU Extension handouts on stretching the food dollar and healthy eating. The group agreed on the content of the materials to be handed out and discussed them with the E.D. and the site supervisor who agreed that the language was appropriate. OSU IRB also approved the invitations. A sign-up sheet was used to gather contact information of interested parents and caregivers. Interested parents were invited to provide their contact information to receive updates about the project.

# **Approval Process**

Because work was conducted with parents from the previous year's parent planning committee, the site supervisor and family advocates recommended that the 2006-07 parent planning committee and parent group approve a partnership between the Riverside Center and OSU before work continued. It was agreed that the parents currently involved in the project would first present the work to the parent planning committee for approval. Representatives from OSU would not be present at either the parent planning committee or the family night so that parents and caregivers would not feel pressured to approve the partnership. The parent planning committee approved the partnership at its first meeting in October 2006. The full parent group approved the partnership at its November family night meeting.

# **Project Implementation**

To facilitate presentation of the nutrition topics and to bring additional resources to the project, the group agreed to invite an OSU Extension agent to partner with them. An Extension agent with an interest in CBPR was identified and invited to meet with the group to discuss her involvement. The group agreed that she would be a valuable addition to the group and approved adding her as a partner.

The group had initially planned to meet with the parent planning committee at the December meeting; however, it was cancelled due to inclement weather. Thus, the OSU representative did not meet with the parent planning committee until January 2007. The parent present and the family advocates discussed the project and the best way to proceed given the lack of parent involvement at the parent planning committee. It was agreed that the group would list the topics on sheets of butcher paper to allow parents present at subsequent family night to choose the topic they wished to learn about at the next family night.

The Extension partner presented the chosen topic at the nutrition family night in February. The group continued to present nutrition information at subsequent family nights based on the chosen topics and input from parents and caregivers. The March family night presentation consisted of a table with recipe testing and handouts. Attendance at the April family night was arranged with the family advocates; however, the meeting was cancelled at the last minute.

#### **Incentives**

Project participants were given a \$5 Safeway gift card at each meeting. This incentive was agreed upon by the group to ensure that it was appropriate and meaningful to participants.

# **Data Analysis**

All field notes were transcribed into Microsoft Word and analyzed using the MAXqda text analysis software program. The text was then analyzed using an iterative content analysis process (84). First, all of the data was reviewed and an inductive analysis process was used to develop a coding scheme (84). Codes were developed to identify major themes and sections of text relevant to the research questions. For example, the code "project value" was developed to categorize sections of text in which group members described the benefits of the project. Codes were also developed to allow for process evaluation. For example, "Understanding researcher roles" was selected to identify text segments related to participants' evolving understanding of the role researchers play in the CBPR process. The text was then reviewed a second time and sections of text were assigned to specific codes. In a third review, coded text was examined to ensure that the analysis accurately represented themes from the data. Quotations and sections of text that represented salient themes were selected to illustrate key points.

#### RESULTS

This project examined both the feasibility of implementing a CBPR project with KidCo Head Start parents and caregivers and the actions that result from initiation of such a project. The results of the project are examined in three separate yet inter-related phases: recruitment and project development, the project initiated at the Riverside Center, and the project initiated in Brownsville.

# **Feasibility**

This section explores the feasibility of implementing a CBPR project with KidCo Head Start parents and caregivers. Components of feasibility include participation, retention, initiation of a project using participatory methods and successful group process, development of a sustainable project with tangible outcomes, participants' perceptions about the value of the project, and implementation of a process for obtaining IRB approval.

# **Participants**

#### **Recruitment and Project Development Phase Participants**

The recruitment and project development phase involved the greatest number of participants. KidCo staff and administrators who were involved included the Executive Director, the Health and Nutrition Services

Coordinator, family advocates from all nine of the centers, members of the

policy council representing all nine centers, and KidCo parents and caregivers at large from five centers.

#### **Head Start Staff and Administrators**

KidCo Head Start staff and administrators, including the Executive Director (E.D.), the Health and Nutrition Services Coordinator, and family advocates, were the initial project participants. The E.D. and Health and Nutrition Services Coordinator guided project development and agreed to allow recruitment efforts to proceed. Family advocates were involved in project development and recruitment once the project received the approval of the E.D. and the Health and Nutrition Services Coordinator. Family advocates from five of the nine KidCo centers indicated interest in introducing the project to parents and caregivers.

Family advocates at the five centers helped to schedule attendance at family nights and inform recruitment methods and partnership building. The family advocate at the Central Linn center participated in the initial informational meeting held at her center. One family advocate at the Riverside center attended the initial informational meeting held at her center. Four family advocates participated in a subsequent meeting held as part of the usual Riverside parent planning committee meeting. In addition, all four Riverside family advocates provided feedback, input, and support at various stages of the project. The site supervisor at the Riverside Center assisted with project implementation to ensure that it was consistent with KidCo's goals and policies.

# **Policy Council Members**

Policy council members from each of the nine centers were the first parents and caregivers involved in the project. Approximately 20 policy council members attended these meetings. They gave feedback on recruitment materials and methods and were involved in initial partnership building efforts. In addition, one member of the policy council indicated interest in further participation in the project during recruitment; however, he ultimately was not involved.

# **Parents and Caregivers**

Parents and caregivers engaged in initial project development by attending family nights at the five participating centers. At the Lebanon Center, 13 parents and caregivers indicated initial interest in the project; however, none of them attended the informational meeting at the center. At the Central Linn Center, all parents and caregivers who attended family nights indicated interest and two provided contact information to pursue further engagement. One parent was present at each of the informational meetings held at Riverside and Central Linn.

#### **Selected Centers**

Participation in this project followed a funnel-like pattern (Figure 1) in which the initial focus was on engaging the maximum number of participants in recruitment and project development activities. With invitations to attend family nights from family advocates and policy council members, participation narrowed to the five centers that were interested in

further project engagement. Of the five centers' family advocates who expressed interest in initial participation, parents and family advocates from two centers agreed to participate in distinct projects. The Riverside and Central Linn centers were chosen based on substantial family advocate support and parent and caregiver interest. It was hoped that initiation of projects with Riverside and Central Linn would develop a template for use of CBPR with Head Start that other centers could follow.

Initial Participants:

KidCo staff and administrators, family advocates (9 centers), policy council (9 centers)

Family nights at five centers:
parents and caregivers, family advocates

Riverside project:
Parents and family advocates

Brownsville project:

Figure 1: Schematic of Project participation

#### **Riverside Project Participants**

Participants in the Riverside Project research group included two parents, four family advocates, and the OSU researchers. The two parents were members of the policy council and active members of Riverside's

parent planning committee, which provided input about center programs, such as family nights, for both the 2005-06 and 2006-07 school years. Other people who participated in this aspect of the project included the E.D. and the Riverside site supervisor.

One family advocate attended the informational meeting at Riverside; however subsequent summer meetings were held with the parents only. Family advocates became more involved once the school year started and they became active partners in the group as the nutrition education project got underway.

The site supervisor informed project implementation and ensured that action steps were consistent with KidCo's goals and policies.

# **Demographics**

Demographic information related to the participants at the Riverside Center was collected orally and through observations. The two parents were residents of Albany, Oregon, and met the income qualifications for inclusion in the Head Start program. Both were married and had three children.

# **Brownsville Project Participants**

Initial participants in the Brownsville project were the parent who attended the informational meeting, the Central Linn Center family advocate, and the OSU researchers. Based on the suggestion of the Head Start parent to meet at the local coffee shop and include Brownsville residents in the project, a core working group of six residents formed and met weekly. Approximately ten other Brownsville residents participated in informal

dialogue and provided input throughout the partnership building, research, and action phases.

# **Demographics**

Demographic information related to participants in Brownsville was also collected orally and through observations. Five of the six core group members were male and one was female. One group member was the parent of a child enrolled in Head Start and met the low-income requirements of the program. Income information was not collected for the other five members; however, one mentioned receiving aid from federal food assistance programs and another received a pension from the Veterans Administration. Three core group members were retired, two were employed in Brownsville, and one was not currently employed.

### **Retention**

Retention was examined to determine how many of the initial participants dropped out and why they chose not to continue participating.

#### **Recruitment and Project Development Phase Retention**

As described above, family advocates and policy council members from all nine centers were invited to participate in the project. Informational meetings were held at three of the five centers where participant observation was conducted. While 13 parents at the Lebanon Center indicated interest in the project, none of them attended the informational

meeting or returned phone calls regarding their participation. Therefore, it is unclear why they chose not to participate.

The family advocates from the centers that indicated initial interest said they supported the project for a variety of reasons. For example, one family advocate said she supported any project that sought to empower parents. Participants in this phase generally agreed that addressing health and nutrition issues in this community was a valuable effort.

#### **Riverside Project Retention**

At the Riverside Center, both parents who were initially involved participated throughout the duration of the project. The family advocate who participated in the informational meeting could not participate over the summer due to scheduling conflicts. This family advocate re-engaged with the project once the school year started. The other three family advocates became more involved once the 2006-07 school year started and remained involved throughout the year.

#### **Brownsville Project Retention**

Three parents at the Central Linn Center indicated interest in the project. One was a member of the policy council who indicated interest at the original policy council meeting but did not return phone calls or attend meetings and ultimately did not participate; the second acknowledged that she would not have time to meet because of her work and home schedule; and the third was initially involved but dropped out after three meetings due to time constraints and scheduling conflicts. The five other Brownsville

resident working group members attended weekly meetings throughout the duration of the project.

# **Participatory Process**

A participatory process was used throughout the project, from initial question development through evaluation. Table 1 illustrates the differences between traditional research and CBPR research and provides examples of participatory aspects of this project.

# Recruitment and Project Development Phase Participatory Process

In its initial phases, the project used a participatory process to develop recruitment materials and methods. KidCo staff, administrators, parents, and caregivers participated in this process by giving feedback on language on printed materials and guiding the development of a process to build relationships. Two KidCo administrators served as key informants and invited the OSU partners to attend subsequent family services meetings.

Family advocates were invited to participate in the project and asked if they were interested in having the OSU partners visit their centers. They also supplied feedback on recruitment materials and methods at a family services meeting. To facilitate trust and acceptance of the OSU partners, KidCo's E.D. introduced them at initial meetings. In particular, family advocates supported the concept of empowering parents and including them as co-researchers in a project to explore health in the community.

Table 1: Comparison of the process in CBPR and conventional research

(Adapted from Cornwall & Jewkes, 1995)

Process	Cornwall & Jewk CBPR	Conventional	Example
Trocess		Research	Lample
What is the research for?	Specific action steps aimed at correcting a condition	Knowledge, perhaps with action later	Nutrition issues were identified, which led to implementation of action steps (nutrition education program, dev. of survey project
Who is the research for?	The community as well as the researcher and the discipline	The researcher/discipline	Community evaluated the project and assisted with analysis, benefited from action steps
Who is the expert?	Both the community members and the researcher	The researcher	Both Riverside and Brownsville groups used local knowledge to identify resources and concerns and develop action steps
Who selects issue?	The community together with researcher	The researcher	Both Riverside and Brownsville used participatory issue selection to identify relevant health issue
Who conducts recruitment?	The community together with the researcher	The researcher	Head Start staff, administration, and parents and caregivers directed recruitment efforts & developed recruitment materials
Who presents findings?	The community together with the researcher	The researcher	Riverside parents presented at NWHF CBPR workshop

The third layer of participation involved policy council members.

These parents and caregivers were approached with the permission of the administration and family services staff. Policy council members gave input about recruitment and partnership building and expressed their support for the project.

Discussions were facilitated to maximize participation. In particular, use of open-ended questions and reflective listening allowed participants to identify for themselves important health and nutrition issues and to identify the difference between a participatory approach to intervention research and existing programs. Emphasis was placed on the egalitarian, co-researcher relationship to highlight the contrast between the conventional expert-subject research relationship. In addition, discussions emphasized the knowledge parents and caregivers possess about their community and what they need to keep their families healthy.

Both the administrators and the family advocates expressed support for the project because it sought to empower parents and caregivers and increase participation. Policy council members also expressed support for the project; however, as described previously, only one policy council member signed up to participate further during these initial meetings.

# **Riverside Project Participatory Process**

The research group, comprised of parents, family advocates, Therese Waterhous and Libby McCulley, all participated in the identification of

concerns and priorities and development and implementation of action steps. The group collaboratively defined the problem, a need for more nutrition education that met the parents' specific needs, and developed an education program to provide more nutrition information to parents. The group also developed additional recruitment materials to increase parent participation. The site supervisor and the E.D., while not specifically involved in the group, also participated by providing feedback about aspects of the research such as recruitment materials and project feasibility.

The family advocates, site supervisor, and E.D. provided guidance about the feasibility and appropriateness of the nutrition education program. As described previously, the E.D. gave suggestions to make the nutrition education program more participatory, and these were reflected in revisions of printed materials. In particular, she felt the original format of the handout presenting the education topics was too restrictive and would cause new parents and caregivers to feel excluded from project development. Thus, the months for the topics to be presented were removed so new group members would have input in the organization of the education program. In addition, the introduction on the handout was changed to emphasize that parents from the 2005-06 school year had identified the topics and that they were suggestions but not set in stone. The purpose of the handout was to give incoming parents an idea of the issues the original group had discussed and identified as important. The E.D. also supported the concept of knowledge sharing among parents and caregivers, in the form of recipe

sharing, a newsletter, and parents and caregivers participating in presentations of the nutrition education topics.

The group agreed to identify themselves on printed materials as the following: "Brought to you by the Riverside Parent Group in partnership with the Department of Nutrition and Exercise Sciences at Oregon State University." Once the project was further developed with the new parents, the group agreed this representation would need to be revisited and approved.

The results of the oral check-ins illustrated that the parents were satisfied with the participatory process. At first the parents were skeptical of the project and were unsure of how it differed from other types of research. It took several meetings for the parents to truly understand the difference between CBPR and traditional research. Eventually, however, one parent said that the project was "really different" because the parents felt as though they were listened to and their opinions were valued. The parents also said that part of the significance of the project was that they felt "respected" and that they had developed a "friendship" with the OSU partners.

#### **Brownsville Project Participatory Process**

The Central Linn Center parent's knowledge of the local community guided the development of the Brownsville project. Based on her local expertise, the parent suggested inclusion of Brownsville residents for a more effective discussion about health in the community. In addition, her familiarity with local meeting spaces led her to suggest holding subsequent

meetings at the coffee shop. She also provided a local connection to the community and facilitated the OSU partners' acceptance at the geezer table.

The Brownsville working group members used their expertise to identify local health concerns, community resources, and action steps that would be appropriate in the context of their community. The concept of the food bank survey was introduced by a community member and discussed and supported by the core working group.

The group also had a strong focus on community strengths and resources. For example, the decision to use neighborhood representatives to conduct the survey was based on the identification of Brownsville as a tight-knit community. The partners agreed that there would be a more favorable response from residents if a familiar face was conducting the survey. In addition, the survey project was intended to build on an existing community resource, the food bank, to enhance its ability to provide services to residents.

The result of the informal oral check-ins conducted at the end of meetings revealed that, while community members were satisfied with the participatory process, they wanted more people to be involved. The group agreed that it was likely more people would get involved once the project had a focus on a certain action such as the survey project.

# **Group Process**

The group process used in this project was different during the project development and recruitment phase as compared to the Riverside and Brownsville projects; however, in all phases of the project the group process focused on open communication and participation.

#### **Recruitment and Project Development Phase Group Process**

In this phase of the project, group process was based on the process already in place at the Head Start meetings where recruitment took place. For example, the OSU researchers' participation in the family services and policy council meetings was at the invitation of Head Start staff and administrators. These meetings were facilitated by the ED and a member of the policy council, respectively.

#### **Riverside Project Group Process**

The Riverside meetings followed natural group method in that the parents knew one another prior to the meetings and were leaders at the Center and in the KidCo organization. The initial parent, who served as a key informant at the informational meeting, recruited the second parent to participate based on her involvement with the parent planning committee and policy council.

A formal group process was not established in the Riverside project, primarily because the group wanted to avoid development of a strict protocol without input from additional parents. While the process was not explicitly formalized, decisions were made by oral consensus. Both parents

participated actively in discussions, though one parent tended to be more outspoken than the other. Both parents were equally active in development of program ideas, methods, and materials.

The parent partners introduced the nutrition education project to the parent planning committee and parent group. The parent partners decided on this process with input from the site supervisor. The purpose of excluding the OSU member from the project introduction was to alleviate any pressure parents and caregivers might have felt to approve the group if she had been present.

In the Riverside project, the author, who also served as the note taker, facilitated the meetings. The small group size and focused discussions simplified meeting facilitation.

#### **Brownsville Project Group Process**

In Brownsville, the Head Start parent served as a key informant and used her connections within the community to build relationships between residents and the OSU partners. Because of their connection to the parent, the OSU partners were invited to sit at the "geezer table" at the first coffee shop meeting. Through the informal, natural group process, the core working group of five members was established.

Throughout the project, the group functioned informally. Meetings were always held at the geezer table, which often meant that people who did not actively participate in the project were part of the discussion. In some cases this made it difficult to lead a facilitated discussion because not

all geezer table regulars were interested in participating in a formal process. These peripheral participants did voice their opinions about the health topics being discussed and provided valuable insight into community health concerns; however, this often led to a less focused discussion. In general, peripheral participants attended the beginning of the meeting and the core group held more focused discussions toward the end of the meeting.

Working group members were generally satisfied with the group process, though they expressed frustration with the lack of participation and would have liked to see a broader cross section of the Brownsville community involved. Group members agreed it was likely that more people would get involved when there was a concrete project, such as the survey, to organize around.

Another theme related to group process that emerged from the informal check-ins was that the group was frequently unfocused and interrupted by individuals both within and outside of the core group. For example, one group member said, "They are difficult to keep on track, aren't they?" The partners agreed that a more formal group process could be established once the grant was submitted and a concrete project was established.

The core working group also agreed to the use of an agenda to better organize the meetings and felt that the agenda was helpful in moving the discussions forward. This was implemented for the last three meetings.

The group agreed that future meetings should be held in the back room of

the coffee shop to allow for more focused meetings among project participants and not impose on community members who were not interested in participating.

# **Project Outcomes**

Tangible project outcomes included the participatory development of recruitment and project methods, identification of health and nutrition concerns of importance to the community, development and implementation of a sustainable nutrition education program that significantly increased the amount of nutrition education delivered to Riverside parents and caregivers, and development of a viable food security survey project in Brownsville.

### **Recruitment and Project Development Outcomes**

The recruitment and project development process resulted in the establishment of relationships between the OSU researchers and KidCo staff, administrators, and policy council members. In addition, KidCo administration, staff, and policy council members expressed support for the project concept and representatives from five centers invited the OSU researchers to work with families at their centers. This phase of the project also resulted in the development of a process for recruitment and entrance into the community through family nights at participating centers.

#### **Riverside Project Outcomes**

Outcomes of the Riverside project included identification of nutrition concerns, the development of a parent-driven nutrition education program,

recruitment of incoming parents for the 2006-07 school year, and identification of community resources.

#### **Identification of Nutrition Concerns**

Group discussions led to the identification of a number of nutrition concerns. In particular, barriers to healthy eating, problems with existing nutrition programs, and limitations of current nutrition messages, both within Head Start nutrition programs and beyond, were major themes.

# • Barriers to Healthy Eating

Barriers to healthy eating were identified as limited income, lack of practical knowledge regarding the incorporation of healthy eating behaviors, lack of information on more healthful preparation of usual foods, confusion about the meaning of "healthy" and how it translates into information on food labels, lack of knowledge about how to prepare healthful foods, particularly fruits and vegetables, homelessness, health issues, and child feeding issues.

The following quotes illustrate the parents' comments about barriers to healthy eating:

"People don't know how to improve their diets or prepare their usual foods in a healthier way."

"Most families don't have the means to change what they eat because of limited incomes."

"Everyone eats at home because it is less expensive. When people do go out, it is to McDonald's or pizza because that is what they can afford."

# • Existing Nutrition Programs and Messages

The parents' impressions of existing nutrition programs were primarily negative. Existing programs were perceived as boring, "the same old same old," a one-size-fits-all approach that does not meet the needs of the diverse target audiences. Conflicting opinions also arose, including the negative perception that the programs are telling people what to eat, but also that the programs tell people what they should *not* eat rather than what they should be eating. The parents also expressed the feeling that people are tired of being told what to do when no one asks them what they want to know about nutrition.

The following quotes illustrate parents' comments about existing nutrition messages:

"We need someone to tell us what we can do, not what we can't do."

"People are tired of being told how to eat."

"No one asks us what we want to know about nutrition."

Perceptions about messages related to overweight and obesity were also negative. In particular, the group felt that people struggling with overweight and obesity perceived ideal weight goals as unattainable and unreasonable. In general, the group agreed that obesity messages were more discouraging than helpful.

The following quotes illustrate parents' comments about messages related to overweight and obesity:

"People get uncomfortable when talking about 'obesity'... So far all the media coverage and discussion about the obesity epidemic has not been helpful."

"What healthcare providers think is the ideal weight is unreasonable... How on earth am I supposed to get to that weight?"

"There are conflicting messages about obesity and eating disorders."

#### • Head Start Nutrition Education

According to the parents, Head Start nutrition programs did not meet their needs, which were identified as practical, realistic, and simple methods for incorporating healthy eating habits into their lives. The parents identified the nutrition family night, which occurred once per school year, as the primary source of nutrition information at Head Start. They agreed that the information presented at the previous years' nutrition night, which included a trivia game and demonstration of the length of the small intestine, was interesting but not useful. They also felt that one hour of nutrition information per year was not enough.

In addition, the parents felt that Head Start staff and administrators were not always able to communicate information in a way that parents could easily understand. They felt that the staff and administrators often spoke in language that was "over the heads" of parents and caregivers. They agreed it would be beneficial for parents to be involved in the development

of health and nutrition messages to ensure that language was appropriate and non-technical.

The following quotes illustrate the parents' comments about Head Start nutrition programs:

"Information from KidCo is not always at a level parents can understand."

"The information at nutrition family night is not always that useful."

"One family night is not enough to answer all the parents' questions."

#### • Other Nutrition Programs

Existing programs outside Head Start were perceived differently between parents and KidCo staff and administrators. While Head Start staff tended to view programs such as WIC and Extension positively, the parents viewed the programs, particularly WIC and food stamps, as helpful but not always run well. One of the parents saw that an unemployed relative received more money in food assistance than his family with working adults in the household. To him, this appeared to discourage people from working if it meant they got less food assistance. Both Head Start staff and the parent partners felt that many people did not know programs like Extension existed. Lack of knowledge about existing programs and lack of time were cited as the two most significant barriers to participation.

The following quotes represent a family advocate's and parents' comments about existing nutrition programs outside Head Start:

"People are busy and don't have time to go to classes even though they are interested."

"The programs [specifically WIC] work, but they are not run well."

"No one really knows these resources [specifically Extension] are out there. It would be helpful if they did because it is good information."

#### **Selection of Priorities**

Through facilitated discussion and a process of participatory issue selection, the group chose to identify community food resources and develop and implement nutrition programs at the Riverside Center that would better meet the needs of Head Start parents and caregivers. Topics for the nutrition education program were identified through a brainstorming process. The E.D. and Riverside Center family advocates also provided input and feedback on the selected topics.

### **Nutrition Education Programming**

The Riverside Center partnership resulted in the development of additional nutrition education programming through the cooperation of KidCo Head Start and OSU Extension. The group was concerned that existing nutrition messages and programs, both through Head Start and other programs, were not meeting their need for "practical tools that can be applied easily" about "how to prepare usual foods in healthier ways" and how to eat healthfully "at a good cost." Because the primary opportunity for nutrition education at Head Start was the nutrition family night, they agreed

that more opportunities to learn about nutrition would be helpful. Therefore, a plan to deliver nutrition information at each monthly family night meeting was developed. The parents chose topics that were of interest to them, as illustrated in Table 2.

**Table 2: Riverside Center Family Night Nutrition Topics** 

Topic 1: Creative Ways to Stretch Your Food Dollar	
Topic 2: Affordable and Healthy Holiday Cooking	
Topic 3: Activities You Can Do Around the House to get Exercise! No special equipment necessary!	
Topic 4: Affordable and Healthy Everyday Meals	
Topic 5: Affordable and Romantic Dinners for Your Valentine	
Topic 6: Preserving Food	
Topic 7: Get Answers to All Your Nutrition Questions: An Informal Q&A	

The list of topics was discussed with the E.D. and revised based on her feedback. In particular, she was concerned that a nutrition presentation at every family night was not feasible because the federal Head Start program mandates specific topics to be presented at these events. The parents did not have the option of choosing to attend different, unrelated, presentations at family nights. Rather, the E.D. suggested a program called a "cluster," which occurred during the day but could also include childcare and transportation.

In addition, the E.D. was concerned that parents be given the opportunity to participate in the development of the topic ideas. She suggested that the way the ideas were presented by month on the handout made them appear set in stone, which would discourage parents from

feeling as though they truly participated in the program development. She suggested that making the topics more general and emphasizing participatory activities such as recipe-sharing in the introduction to make the handout more inclusive.

Both the E.D. and the Riverside family advocates participated in the development, and supported the idea, of a parent-driven nutrition education program. On several occasions the family advocates said they were happy that parents were involved in an empowering process and that additional nutrition information was available to them.

# **Recruitment of Incoming Parents**

Another primary focus of the summer work was recruitment of incoming parents for the 2006-07 school year. Initial recruitment of new parents took place at the center's orientation. Approximately 100 people attended the orientation, all of who passed by the table that was set up at the Center where group members passed out information about the program. This was an opportunity for the two parents who had been involved over the summer to describe the project and introduce themselves to incoming parents. The project was represented as a partnership between OSU and the parent planning committee. Thirteen people signed up as interested in finding out more information about the project and receiving additional nutrition information.

#### **Project Presentation: Northwest Health Foundation Workshop**

The OSU partners were invited to participate as panelists at the Northwest Health Foundation's CBPR Technical Assistance Workshop held in Corvallis, Oregon, in August, 2006 (95). The partners also served on the working group that planned the workshop.

To ensure that OSU's presentation maintained the spirit of CBPR, both members of the Brownsville working group and the Riverside parents were invited to attend. Both Riverside parents attended the workshop and one of them delivered a brief presentation about their perceptions of participation in a CBPR project. In particular, the presentation highlighted the parents' original skepticism about being involved in a research project and how that view had changed over the course of the partnership. The parent also described his nervousness at presenting to a room full of "doctors and lawyers" but that he had been made to feel welcome and that his opinions were valued by the workshop participants. In the evaluations of the workshop, several people noted that it was beneficial to hear the community perspective.

Because the parents were presenters at the workshop, they were asked to develop biographical sketches to include in workshop materials. The process of developing these sketches was also beneficial for the parents. This served as an opportunity for them to explore and explicitly state their expertise as parents and validate the knowledge they brought to the partnership.

# **Project Sustainability: Partnership with OSU Extension**

The Riverside group agreed that the OSU partners would work with the parent planning committee to further develop the topics and determine a method for presenting the information. Because OSU Extension programs were already providing much of the information the parents were asking for, it seemed natural to bring the parents together with this existing resource. To do this, an Extension agent with an interest in CBPR was identified based on her participation in the NWHF workshop. An initial meeting was held between the OSU partner and the Extension agent to describe the project and work out the details of funding and overlap of federal agencies. A Memorandum of Understanding (MOU) between OSU Extension and KidCo Head Start was signed to formalize the partnership and determine the roles and responsibilities of the two agencies. After the MOU was signed, a meeting was held with the parent partners to introduce them to the Extension representative and discuss next steps. All partners were enthusiastic about the relationship with Extension and the opportunities and resources that the agency could bring to the project.

Involvement of the Extension agent ensured project sustainability for subsequent school years. Her participation also brought additional resources to the partnership, including existing nutrition programming and materials, and enhanced Extension's ability to achieve their goal of providing community-based nutrition education that meets the needs of the target audience.

# **Brownsville Outcomes**

Outcomes of the Brownsville project included identification of health concerns, participatory issue selection, identification of community resources, and development of the food bank survey project.

#### **Identification of Health Concerns**

In Brownsville, residents chose to focus on health issues that were important to the community. Table 3 illustrates the health-related themes that emerged from the discussions. These themes focused on both community strengths and needs and were used to guide the identification of health priorities.

Working group members identified the loss of a "local touch" in healthcare as another health concern. Participants voiced strong apprehension about the role of corporations in the healthcare process and cited an example in which the local health care corporation had attempted to close one of the two doctors' offices in Brownsville. The partners felt that as corporations grew, they lost touch with the local community. There was a sense of distrust of, and disenfranchisement from, these health care organizations.

The group also expressed frustration with existing health messages and programs. One participant said he felt "beaten up about health and nutrition" by the government. When this idea was introduced to the rest of the group, they agreed that the messages were often inconsistent and not

useful. One participant responded that he felt beaten up because he felt "guilty" for not following the messages' recommendations.

#### **Selection of Priorities**

Through facilitated discussions and a process of participatory issue selection, two priorities emerged: the issue of cancer rates in teenage boys and the need to survey residents regarding eligibility and use of the local food bank.

One member of the working group, who was affiliated with the local food bank, introduced the survey idea to the OSU partners, who then brought the idea to the rest of the group. The group member had attempted to conduct a similar survey with OSU researchers in the past, but, because of different research priorities and

methodologies, the projected had not been completed. The group member felt that the community-driven focus of this project would be a good fit for his door-to-door

survey idea. The decision to work toward development of the survey was facilitated by the introduction of a request for proposals (RFP) from the Northwest Health Foundation to support a community-campus partnership working on a CBPR project. The RFP required that the primary applicant be a community-based organization and a partnership with the local food bank was a natural fit. The working group verbally agreed to support the submission of a grant to fund the survey.

**Table 3: Brownsville Themes** 

Table 3: Brownsville	
General Theme	Sub-themes
General Brownsville	o Many people don't have health insurance in
Community	Brownsville.
	o Many retired/older residents.
	o Tight-knit community.
	o There is no grocery store – limited access to healthy
	foods.
	o Different sub-groups in Brownsville – people who
	work in Corvallis/Eugene, people who live and work in Brownville, retired residents – who have different needs.
	o People who live in town versus out of town might
	also have different needs.
Health	o There is no emergency care in Brownsville. It takes 30
Needs/Concerns	minutes to get to the hospital. There is no locally
Treedo, Goriceirio	based emergency transportation.
	o There is a need for a retirement facility.
	o There seems to be a high incidence of certain types of
	disease – cancer in teenagers, ALS.
Health Resources	o Local gym
	o A safe park with a playground for kids
	o Food Bank
	o Two doctors
	o Co-op and community garden (in the planning
	stages)
	o New farmers market
Reasons people are	o People don't know how to cook or garden
less healthy	anymore. No home economics in schools.
	o People don't have time, or think they don't have
	time, to care for their health.
	o We live in a fast food world – people want results
	fast or they give up.
	o Kids want immediate gratification.
	o Physical activity is no longer a required part of the daily routine.
	o Soft drinks.
	o People feel disenfranchised from the political
	system.
	o Food is available everywhere, all the time.
	o People don't eat together anymore. Not eating together/thinking about food has led to overeating.
	o People don't know how to translate health and nutrition information into everyday life.
Important Aspects of	o Personal touch, local connection between health
Health Care	care providers and patients.
	o The sense that someone cares.
	o Getting to see the same doctor, continuity of care.
Community	o The newspaper
Organizations/Groups	o Churches
	o Chamber of Commerce
	o School system

## Participants' Perceptions of Project Value

According to comments made during group meetings, both the Brownsville and Riverside projects resulted in meaningful outcomes for participants. Both groups also saw value in their participation.

## **Riverside Project**

The Riverside parents said that the most valuable aspect of the project was that they felt listened to and respected. Because they had a role in the development of the nutrition education program, they said that the information was relevant to their community and delivered in a way that parents could understand.

The family advocates saw value in the addition of monthly nutrition presentations at the Center. One family advocate thought the opportunity for parents to taste the recipes was particularly important and she commented on the way in which parents and caregivers gathered around the table and discussed nutrition with one another. All the family advocates thought having additional nutrition resources was valuable and one said she handed out some of the information during her home visits.

## **Brownsville Project**

The value of the Brownsville project was reflected in comments made by both working group members and members of the Sharing Hands Board of Directors. Working group members said it was valuable to have "someone to bounce ideas off" and that they appreciated the opportunity to have conversations about health with people they might not otherwise discuss these issues with. At the wrap-up meeting, the working group members agreed that their participation in the project had been valuable and that the outcome of the survey project would be beneficial to the Brownsville community.

The Sharing Hands Board of Directors also saw the outcomes of the project as meaningful. They agreed that the project, through a partnership with Linn County Health Department, Sharing Hands, and Oregon State University, would help both Linn County and Sharing Hands build capacity. The outcomes of the survey would provide Sharing Hands with information that would result in improved service delivery and future funding opportunities. One board member said, "This will be a great contribution to the community because it is more than just feeding people."

## **Implementation of "Rolling" IRB Process**

Application to IRB was complicated by the participatory nature of this project. For example, specific methods could not be established until after meetings with community members began; however, in order to record and report on such meetings IRB approval was required. Thus, a "rolling" IRB process was established in which project revisions were submitted as methods were developed or changed throughout the project.

## **Specific Action Steps**

This section examines the specific actions that resulted from the three project components: recruitment and project development; the Riverside project, and the Brownsville project.

## **Recruitment and Project Development Action Steps**

Action steps that resulted from the recruitment and project development phase included attendance at family services and policy council meetings, participation in family nights and other center activities, and implementation of recruitment and relationship building efforts.

## **Riverside Project Action Steps**

Specific action steps that occurred at Riverside included the involvement of the parent planning committee and parent group, implementation of the nutrition education program, and community food resource identification.

#### **Involvement of Parent Planning Committee and Parent Group**

The parent partners presented the project at the first parent planning committee meeting in October. At a debriefing session, the parents said that the new parent planning committee was enthusiastic about continuing to work with OSU and expressed interest in the topics that had been developed.

A similar process was followed to gain approval from the parent group. The parent partners were given a few minutes at a Family Night to introduce the project, and the parent group agreed that work should continue. According to a debriefing session with the group, the parent group was also enthusiastic about the ideas for additional nutrition education at Head Start.

## **Implementation of Nutrition Education**

The January parent planning committee meeting was intended to be an opportunity to introduce the OSU partners to committee members and begin further development of the nutrition education program. All group members, with the exclusion of one parent, attended the meeting. In addition, four family advocates and one member of the parent planning committee were present. Although it was difficult to further develop the project with only one parent present, the group identified and discussed issues related to nutrition concerns and parent involvement and participation.

Themes that resulted from this meeting were consistent with those from group discussions held over the summer, including: many people have information about nutrition but that bridging the gap between knowledge and action is difficult; emphasizing small changes people can make is important so they are not overwhelmed; getting parents involved in Head Start activities, including parent planning committee, is very difficult; and it is unclear exactly why parents don't get involved, aside from a lack of time. The family advocates were very supportive of the nutrition education project

and encouraged the partners to continue working. All meeting participants supported the idea that the topics be presented to the parent group at the family night held later that same day. This allowed parents who attended the family night to select the topic to be presented at the February nutrition family night.

Of the 31 people present at the family night, 13 voted on at least one of the topics. Based on the votes, Creative Ways to Stretch Your Food Dollar received was selected for presentation at the nutrition family night. Table 4 illustrates the results.

**Table 4: Outcome of Topic Selection for Riverside Nutrition Night** 

Topic	Number of Votes
Creative ways to stretch your food dollar	12
Activities to do around the house to get exercise	10
Affordable and healthy everyday meals	10
Affordable and romantic dinners for your valentine	10
Preserving food	8
Nutrition Q & A	2
Write ins: Food activities to do with kids, which food	ls are good for
children	

## **Nutrition Family Night**

When the Extension partner introduced the presentation at the February family night, she asked how many people present had voted on the topics last month and two parents indicated that they had. Therefore, very few of the parents who participated in the decision-making process at the previous family night were present for the actual presentation.

Attendance at the presentation was limited due to other activities, including ice cream making, occurring in the classrooms.

At the end of the presentation, the Extension partner asked the parent group if they would like to continue having nutrition information at family nights. The group did not respond positively or negatively to this question.

During the question and answer session, one parent asked how she could get her children to eat more fruits and vegetables. This was one of the most frequently asked questions during previous nutrition family nights and was often asked during other discussions about nutrition.

## **Subsequent Nutrition Education Activities**

Because a parent planning committee meeting was not held between the February and March family nights, the author and Extension agent group members selected the topic to present at the March family night. The topic that two parents had written in, "Nutrition activities parents can do with their kids," was chosen to support the parents who suggested the subject. The presentation also incorporated the question of how parents could increase their children's vegetable consumption.

At the March family night, a different format was used in which a variety of activities were held in the Center's classrooms rather than the standard format of a single presentation. The nutrition program was held in a central location in the breezeway and consisted of a fruit salad recipe testing and handouts on child-friendly cooking activities and information related to increasing children's fruit and vegetable consumption.

Approximately 40 people, about half adults and half children, sampled the fruit salad. All the adults who tried the fruit salad took a recipe. Many of the parents also took the information on helping kids eat more fruits and vegetables, particularly when they were informed that the brochures contained recipes.

Children and parents both responded favorably to the fruit salad. Parents said they appreciated a new way of incorporating fruits into their, and their children's, diets. Several parents asked questions and engaged in discussion about getting their kids to eat more healthfully. A number of parents shared stories of foods their kids liked or disliked and techniques they used to get their children to eat more fruits and vegetables.

Several parents said they were grateful to have the additional nutrition information and supported the continuation of the nutrition education programming. The family advocates were also supportive of the program. One family advocate said she had been using the recipes provided

as part of the program on home visits to provide her families with additional nutrition information.

A nutrition topic was planned for the April family night but the meeting was cancelled. At the April parent planning committee meeting, the family advocates asked the author to present a topic at the final year end celebration in May. The author was also asked for assistance with healthy recipes for the menu items planned for dinner at the year-end event.

# **Community Food Resource Identification**

One of the priority areas identified by the parents was the identification of community food resources, particularly related to local sources of fresh fruits and vegetables. This resulted in the compilation of a list of local farmers markets, farm stands, and U-Pick farms in the community. This list was intended to assist parents with locating more affordable sources of fresh produce. The list was distributed to parents at the parent orientation and remaining copies were displayed in the parent lounge for parents to pick up.

The group also thought that not all families realized that it was more affordable to purchase produce in season. To emphasize this, a poster was developed and printed at OSU Media Services that listed the growing seasons for various fruits and vegetables grown in Oregon. Space was left on the poster to highlight a different fruit and vegetable each month. The group agreed that it was important to provide parents with information on selecting, preparing, and storing various types of produce. Both the parents

and the site supervisor thought the poster would assist the center in their goal of bringing more parents into the parent lounge and encouraging parent involvement. Although the site supervisor and E.D. approved the poster and it was supported by the family advocates and was intended to hang in the parent lounge, it had not been hung up to date.

## **Brownsville Project Action Steps**

Specific action steps that occurred as a result of the Brownsville project included development and administration of a community questionnaire, identification of community resources, and development of the food security and communication project.

## **Development of Community Questionnaire**

The Brownsville working group developed a series of questions to better understand health in the community. The goal was for each working group member to ask three to four other community members to answer the questions; however, only six sets of questions were returned with answers. One person orally answered the questions during a meeting. The responses revealed that respondents did not understand Medicare/Medicaid policies and have a sense of distrust and frustration toward the government, that they felt responsible for their own health and that they took time to take care of their health. Responses to a question about whether or not there was enough preventive information were mixed. Some respondents said they had enough information while others wanted more. One person said there

was enough information but the problem was that people don't take steps to protect their health.

## **Identification of Community Resources**

Like the Riverside group, the Brownsville working group undertook an informal process to identify community resources related to health. Primary resources identified included the local gym, a safe park where children could play, the food bank, two local doctors, the development of a co-op and community garden, and the new farmers market. Other community resources that were identified over the course of the project included social organizations such as churches, women's groups, the Chamber of Commerce, the school district, and the senior center. Because most members of the working group were older adults, they were particularly concerned about resources for seniors.

# **Table 5: Selected Responses to Brownsville Community Questionnaire**

# How do you decipher Medicare/Medicaid policies?

- "Medicare and AARP publications."
- "Don't know."
- "Don't know."
- "Yes, how do you? Medicine policies structured by lawyers."

## Are you responsible for your health?

- "I am the only person responsible for my own health."
- "Yes, nobody else is responsible. Period. Take care of your family. It is simple."

# Do you have time to take care of your health?

- "I take time."
- "Yes. I walk 2 miles each day, assuring at least 10,000 steps a day or much more. I also often spend half an hour on a stationery bike."
- "I take time."
- "It is my responsibility to prioritize the time."
- "A lifetime. Do we have the knowledge and interest required to take care of our health?"

## Do you have enough preventive information?

- "Can usually find it."
- "Not always."
- "Yes. The pharmacy in Brownsville is also very helpful on health and other issues on meds."
- "Yes, there is a lot of stuff out there. The trouble is we don't do it."

# What do you get from your doctor during your 15-20 minute visit? Do you get what you need?

- "Good information. I have an exceptional doctor who communicates well and gives me all the data I need to make decisions."
- "I need my doctor to listen to me fully before taking action. 15-20 minutes is usually not enough. My local doctor will take the time when I need it so I am very lucky."
- "Not really. They listen but each appointment feels like 'try this or call or come back.' Weeks in between. Very discouraging."
- "I get conversation and understanding. There is always room for improvement."
- "He gives me plenty of time so I don't feel he is ignoring me or is too busy for me. I am lucky!"

The newspaper was also cited as a community resource that had been leveraged in the past to address health concerns such as the proposed closure of one of the local doctor's offices. Through letters to the editor, editorials, and news stories, the local newspaper helped mobilize community support to prevent the local hospital corporation from closing the office.

As evidenced by the answers to the community questionnaire, the local doctors were of significant value to the members of the working group and provided both the "local touch" and a resource for information and care.

Food and nutrition resources included Meals on Wheels, meals at the senior center and local churches, the new farmers market, the incoming food co-op, the community garden, the local food bank, and the Dairy Mart convenience store. The Dairy Mart was the only local source for groceries and the nearest supermarket was located in Lebanon.

## **Development of Food Security and Communication Project**

The Brownsville project culminated in the working group's agreement to support the development and implementation of the food bank survey. Members of the working group reviewed the Northwest Health Foundation RFP and agreed that the best use of the funds would be to partner with Sharing Hands on the project.

The initial OSU partners collaborated with a faculty member and doctoral candidate from the OSU Department of Public Health and the Executive Director of Sharing Hands to develop the grant proposal. The proposed project would have resulted in the development of a communication network comprised of Brownsville residents and Linn County Health Department staff. The purpose of the communication

network was to train community members to disseminate health information and to provide feedback from the community to the Health Department to improve programs and service delivery. Another purpose of the network was to establish a group of neighborhood representatives who could assist with development of a survey instrument, door-to-door data collection and analysis.

The OSU researchers met with the Sharing Hands board of directors to introduce the project and support the Executive Director as he sought approval for the project. While the board members had concerns about the scope of the project, they said that it would result in increased capacity for Sharing Hands and Linn County, provide a benefit to the community beyond Sharing Hands' food bank function, meet the need for better communication between the community and the local health department. The board also felt that the establishment of neighborhood representatives to administer the survey was appropriate given the tight-knit community and the fact that many rural residents might be distrustful of, and reluctant to speak to, strangers who approached them.

The target funder for the grant application was the Northwest Health Foundation through their "Preventing and Managing Chronic Diseases through Community Based Participatory Research" program. While the grant proposal was developed and letters of support were secured from both Linn and Benton County health departments, it was not submitted due to funding

constraints and time restrictions for both the Sharing Hands and OSU partners who would ultimately implement the project.

#### DISCUSSION

Community based participatory research (CBPR) has the potential to improve relationships between academic researchers and community members, increase the relevance of health interventions, and motivate and empower individuals and communities to improve their own health and life situations (24, 45). While many health interventions target one aspect of health, such as individual behavior, CBPR seeks to address complex determinants of health by involving community members in all aspects of program development and implementation (24, 45, 96). The purpose of this project was to examine the feasibility of the use of CBPR to address the health and nutrition concerns of KidCo Head Start parents and caregivers and to explore the action steps that result from this process.

## **Feasibility of CBPR Approach**

A key objective of this project was to work directly with parents and caregivers, as opposed to Head Start staff and administrators, to identify and implement actions that address the issues parents and caregivers recognize as important within the relatively short time of a school year. Aspects of this project that suggest that it is possible to conduct CBPR under these circumstances include the involvement of individual community members, a process that started "where the people are," the project's focus on empowerment and language of equality, the use of participatory issue

selection, and the development of a sustainable nutrition education program.

While many aspects of this project were successful, others presented challenges that made it difficult to implement the project, particularly within such a short timeframe. Limited parent participation, conflicting research interests, organizational capacity and funding requirements, and the short timeframe were challenges faced during this project. In addition, while a method for working with IRB was established, the ethics review process continues to present challenges to the implementation of research that is truly participatory and regards community members as co-researchers rather than subjects.

## **Involvement of Individuals and Community Based Organizations**

An important aspect of CBPR is the definition of "community" and the determination of who will represent members of a given community. A variety of models have been used that involve either representatives of community based organizations (CBOs), individuals from within the community, or a combination of both (30). Many projects work with members of community based organizations that are seen as representing the community's interests (30). For example, the Detroit Community-Academic Urban Research Center, a leader in the field of CBPR, chose representatives of community- based organizations that were well respected in the community to serve as board members (30). Thus, while board

members worked in the community of interest, not all members lived within the community. However, the concept behind the selection of CBOs was that they were seen as representing the community and thus could adequately provide community perspective.

In another approach, the Community Action Against Asthma project chose both representatives from CBOs and an individual, in this case the parent of a child with asthma, to serve on the steering committee (30). In this model, Israel et al. point out that, just as no one CBO can adequately represent the community, no one individual can adequately represent a specific group (30). When involving individuals in CBPR projects, it is important to ensure adequate representation of community perceptions and values.

This project sought to work directly with individuals from within a community rather than with specific community based organizations. This decision was made based on the notion that individuals within a community are not always given a voice within CBOs and are not always represented by community leaders (25). For example, the Riverside parents felt that Head Start did not always represent them or understand their points of view. Thus, to adequately capture the views of parents and caregivers, it was important to work directly with them. As one of the parents pointed out at the Northwest Health Foundation workshop, the direct involvement of individual parents added value to the project for them and "gave a voice" to people who often do not have one. The importance of directly involving

community members in CBPR projects was evident in the evaluations of the Northwest Health Foundation workshop as well. Several participants commented that it was unfortunate that only two members of the community were present and that more community perspective would have been beneficial.

While the original intent of this project was to work with parents and caregivers, it became important to also involve representatives of CBOs in both Riverside and Brownsville. For example, the Northwest Health Foundation CBPR grant required that a CBO, rather than a university, serve as the primary applicant. In addition, the Sharing Hands director provided valuable input on community needs and resources that individual community members were not necessarily aware of. Involvement of CBO representatives also provides valuable perspective about the feasibility of community-driven projects, and, in the case of Brownsville, the ability to conduct the food security survey.

Partnering with individuals rather than CBOs presents specific challenges to participation. In particular, it is often much easier to get service providers, professionals, and government representatives to participate in projects and attend meetings than individuals such as parents, low-wage workers, or the elderly (36). This problem was evident in the Riverside project. For example, family advocates were always in attendance at Riverside parent planning committee meetings, even when only one or two parents were present. However, involvement of the family advocates

allowed for valuable feedback on the nutrition education program when parents were not available. Furthermore, involvement of both family advocates and OSU Extension led to increased project sustainability because, although there will be a new parent group during the next school year, the Extension agent and family advocates will be able to continue the program.

The results of this project illustrate the importance of finding a balance between CBO and individual participation in CBPR projects. While it is important to include individuals in the project to ensure representation of often under-represented community members, it is also important to include CBOs to take advantage of, and build upon, existing organizational capacity within the community and the unique expertise that both groups bring to a partnership.

## **Developing Trust: Start Where the People Are**

An important principle of CBPR work is the concept of "starting where the people are" (94). Put another way, this means starting from the problems identified by the community rather than those identified by the outside researcher (59). Engaging in a process of listening and dialogue allows community members and academic researchers to work together to identify local priorities and solutions, which fosters trust and addresses the immediate concerns of the community (97). In addition, following this principle increases the likelihood that the community will feel true program ownership (54).

Starting where the people were in this project had the benefit of establishing relationships and trust and overcoming, within a relatively short period of time, the skepticism some participants felt at the beginning of the project. For example, the parents at Riverside were initially skeptical of the academic researchers and were concerned that their participation in the project would not result in meaningful outcomes. They also expressed concern on several occasions that it would be just another "boring" nutrition program that focused on telling people what to do. When the parents realized that the researchers were more interested in finding out what was important to them rather than telling them what to do, they found meaning and value in the project. This transformation of the parents' perceptions about the project and the researchers illustrates the importance of listening as the first stage of any CBPR process. Had the researchers approached the parents with a preconceived research agenda, it is unlikely that they would have participated in the project or found the value in it that they did.

An additional benefit of starting where the people are is that participants experience a direct benefit from their participation. In many cases, communities or individuals who feel powerless initially perceive that getting involved in an empowerment process is not worthwhile or significant (25, 56). Emphasizing local relevance and working within existing social structures, both formal and informal, can increase a community's willingness to participate. In this project, this was done by working directly with community members through the existing social networks at Head Start

and the Brownsville coffee shop. By continuing to participate in Head Start activities and meeting at the coffee shop, community members began to recognize the academic partners' commitment to a process that would ultimately benefit the community.

In a physical sense, starting where the people are meant going to the community and identifying local meeting places. As Wallerstein et al. point out, one way to demonstrate respect for, and commitment to, a community is to meet on their turf rather than asking community members to come to the university (36). This approach has been used in projects such as the North Carolina BEAUTY and Health Project which recognized beauty salons as community meeting places and potential venues for a cancer prevention education program (71). As Solomon et al. point out, the beauty salon is often a place where community members socialize and discuss issues of community importance. In the PRAISE! project, described previously, churches were identified as an important meeting place for the African-American participants and thus were chosen to host a nutrition education program (20). For the current project, the researchers went to the community and asked where the appropriate meeting places would be and, as a result, met in the parent lounge at Riverside and the coffee shop in Brownsville. This allowed the community to meet in a natural setting where they were comfortable and familiar and also demonstrated the researchers' commitment to equality and respect in the relationship. Furthermore, the

invitation to meet at the geezer table in Brownsville signaled the researchers' acceptance into the community.

## Trust, Benefit, and Satisfaction

Because of the community-driven approach used in CBPR, it is expected that participatory research projects will result in a high level of perceived trust, benefit, and satisfaction for both participants and researchers (20, 98). The PRAISE! project described above used a quantitative approach to support this assumption as a component of a CBPR-based nutrition education project (20). The study found that participants felt a high level of all three variables from their participation in the project. Consistent with these findings, participants in both the Riverside and Brownsville projects established trusting relationships with the researchers, which both groups referred to as friendships. Furthermore, both groups found benefit from their participation in the project and were satisfied with the process.

#### **Empowerment**

Unlike many nutrition intervention studies, the short-term goal of this project was not behavior change. As Wallerstein and Bernstein point out, an empowerment education process is often viewed as problem-posing rather than problem solving (59). Problem-posing recognizes that solving complex problems related to health and health disparities is complex and that the processes of identifying community needs and program planning are themselves an empowering process (59, 94). Instead of seeking immediate

solutions that will likely be unsuccessful in the long term, it is hoped that behavior change will evolve as people become empowered and have greater control over their lives and social situations (59).

#### **Power**

One of the primary goals of CBPR and empowerment education is to help marginalized people develop the skills and tools they need to overcome barriers such as lack of education, health disparities, and low wages and take control over their own lives (25, 45, 55, 59). These research ideologies recognize that the complex issues that affect health and access to health care are often related more to power than to individual behavior. For example, inequalities such as the disproportionate exposure of low income communities to water pollution and hazardous waste and reduced access to affordable, nutritious food illustrate risk factors beyond individual control (56). To overcome these issues, it is important to engage in a social action process that empowers community members to collectively work toward solutions (56).

An important component of power relations identified in the current project is language that either supports or undermines equality. This issue was explored in both the Riverside and Brownsville projects.

## Language

Language plays an influential role in the dynamics of human relationships. Laborate points out that "our language exerts considerable force in our world constructions" (99). As Baker and Motton found, even

when all partners speak the same language, they still may not be able to understand one another (100). It is of the utmost importance in CBPR to use language that promotes equality and empowerment for all partners.

Because a commitment to addressing inequalities in the researcher/subject relationship was important in this project, language that supports equality was used throughout the project. For example, emphasis was placed on shared ownership of the project. At the start of the partnership, community members referred to it as "your project;" however it was important that they recognized it as "our project." Placing emphasis on the difference between these two descriptions helped break down the researcher/subject relationship and establish a stronger partnership.

In both the Riverside and Brownsville projects, language was identified as a barrier to understanding and implementing health messages. The Riverside parents stated that the language used in existing nutrition education materials was often "boring" or over their heads, which caused them to feel unmotivated to follow the recommendations. It was important to the Riverside group that the language used on materials for the education program come from the parents and be appropriate for the targets of the messages. In addition, language was an important barrier to meaningful participation in Head Start. The parents felt that communication from Head Start staff was not always understandable, which prevented them from feeling empowered to make good decisions in their roles as policy council representatives.

In Brownsville, the group found that they had difficulty understanding Medicare and Medicaid policies because they were written by "doctors and lawyers" and not in lay language. This caused them to feel disenfranchised and disempowered from the health care system. An inability to understand the language of Medicare and Medicaid is not uncommon. A controlled experiment examining knowledge about Medicare benefits found that there was low understanding in the areas critical to making informed decisions about healthcare including differentiating between Original Medicare and Medicare managed care, understanding medigap eligibility, and familiarity with sources of Medicare information (101). These findings came after the survey respondents were mailed the handbook Medicare and You, which was meant to clarify issues related to Medicare knowledge. The ongoing confusion about Medicare suggests that, despite efforts to clarify program components, the program remains difficult to understand for most people. Engaging local people in a dialogue about what they need to better understand Medicare policies offers a potential solution to this issue. For example, county health departments could convene a local steering committee, similar to the one proposed in the Brownsville project, to oversee development of messages related to Medicare and Medicaid to ensure the target audiences understood them. Federal agencies could implement a similar program to engage Medicare and Medicaid recipients in a community-based effort to examine issues related to implementation of these programs.

One of the benefits of a CBPR approach is that it allows community members to develop health messages in their own words. For example, in the Los Angeles-based project that surveyed the availability of healthy foods in low income areas as compared to a contrasting, higher income area, referred to the community meetings to disseminate findings in Indabas, a Zulu word meaning "deep talk", because it reflected the language of the local community (22). In addition, the meetings were marketed as opportunities to discuss "brown bananas and bad meat," which puts important food security information in a context relevant to the community.

The language differences in this project were evident in the recruitment materials the groups developed. The original language, developed by the academic researchers, focused on the recruitment of "experts" to explore health messages (Appendix B). When the Riverside parents developed their own recruitment invitation (Appendix C), the heading was "Tired of being told what to feed your kids?", which reflected their frustration with existing health programs. The recruitment flyer the Brownsville participants came up with emphasized the community dialogue, which built on the tight-knit feeling Brownsville residents valued (Appendix D). It also highlighted the local issues the group had recognized as important to make the project relevant to other community members.

One of the challenges for the CBPR researcher is the need to relinquish control over the way ideas are expressed and the language used to express them (73). The benefit of stepping back and listening is that

community members have the opportunity to share their perspective and experiences in their own words (100). As one of the community partners said, the CBPR approach used in this project allowed people to have a voice and be heard and respected. Feeling listened to and respected is also an essential component of an effective decision-making process and has been shown to be at least as important as being agreed with (98). This respect for language and communication formed the foundation of the strong relationships that were built between the academic and community partners.

## Participatory Issue Selection and Program Development

The process of participatory issue selection was a key feature of this project. Both the Riverside and Brownsville groups worked together to identify an issue to work on; however, it took time and considerable discussion before the groups came to agreement. Minkler and Hancock refer to this process as "turning problems into issues" and identifying concerns that the community feels are important enough to warrant in-depth examination (102). In particular, the identification of an issue on which to work gives the partners a concrete idea around which to organize, recruit new members if necessary, and take action to make improvements that will benefit the community as a whole.

The importance of issue selection to partnership building should not be overlooked when a CBPR project is undertaken. The process of identifying a topic of community importance can serve to strengthen partnerships, attract new leaders, increase opportunities for participation, and motivate group members to take action (102, 103). For example, implementation of the food security survey and communication network project in Brownsville would have provided a concrete goal around which to organize community members, increased opportunities to participate, and built community capacity through the training of survey-takers and neighborhood representatives. However, it is important to find balance between recruiting partners to engage in project development and initiating a project to recruit more community members. In order to be truly participatory, the research questions and project design must still come from the community.

Furthermore, as Deering points out, "Those who have had a true part in making decisions will not see those decisions lightly set aside" (103). Allowing the community to identify the issues that are important to them avoids what is called "the expert trap" in the Motivational Interviewing literature (33). In the expert trap, the interviewer identifies and tries to "fix" the problem for the client, which places the client in a passive role. A key concept in Motivational Interviewing is the identification of a set of internal values that are important enough to participants to cause an individual to change. Through the CBPR process of participatory issue identification, the community establishes its own set of values and a course of action to make the changes necessary to overcome the problems it identifies.

## **Project Sustainability**

Project sustainability is an essential component of CBPR efforts (25, 30, 45). To ensure sustainability of the project at Riverside, a partnership was built between the Linn County office of OSU Extension and KidCo Head Start. This process was again facilitated through existing relationships between family advocates at Riverside and the Extension agent. In addition, the agent initially met with the parent partners to develop a relationship with them before moving forward with formalizing the partnership.

Another important component of sustainability in this project is the family advocates' commitment to the project. Because the parent group changes from year to year, family advocates provide a constant presence at the Center. If the family advocates are committed to the continuation of the project, it may be that the lengthy process of obtaining parent approval could be avoided in the following years. The project could be incorporated into the Center's usual programs; however, it is essential that the emphasis on parent participation and ownership remain a central feature of the nutrition education program. Thus, it proved important to foster relationships with family advocates who, at Riverside, were strongly supportive of parent ownership of the project.

#### **Head Start Parent Involvement**

It is well documented in the literature that engaging parents and caregivers in Head Start activities is challenging (Powell, 1989, (104). This

difficulty was supported in the challenges related to parent and caregiver recruitment encountered in this project. While no KidCo staff, administrators, or parents voiced opposition to the project and many expressed interest in further participation, actually attaining commitments from parents to continue engagement was a primary limitation.

The literature on parent involvement in Head Start illustrates that there is a tendency for some parents to participate more than others, as seen at the Riverside Center (105). For example, in the 2005-06 school year, only two of Riverside's nine seats on policy council were filled. These same two parents, who participated in this study, also comprised the parent planning committee. A review of a 1975 report issued by the U.S. Comptroller General examining parent involvement found that, while parents averaged a total of 32 volunteer hours per year, only 35% of parents accounted for 71% of the total volunteer time (105).

These findings were supported by the results presented here, in which the parent partners at Riverside were both actively involved in the KidCo Head Start organization prior to participating in this project. Both served on policy council and on the Riverside parent planning committee and were invited to participate because of their close ties to the Center's family advocates and their previous engagement in Head Start. It was more difficult to engage parents and caregivers who were not already involved in Head Start activities as evidenced by the limited participation by additional parents. Because of this lack of participation, it is important to understand

the barriers that prevent other parents and caregivers from participating in Head Start activities.

An examination of barriers to parent involvement in Head Start found that the most significant impediment for mothers was scheduling conflicts (104). While many of the women surveyed reported having difficult life experiences, including depression, lack of heat, hot water, or electricity during part of the school year, and having one or more children with a special need, less than one-fourth of the women listed these as barriers to participation. Rather, the most significant life experience that prevented them from participating was having a baby or toddler at home.

Parent involvement is a primary goal of Head Start programs and has been shown to provide positive outcomes for both parents and caregivers and their families (106). For example, Lamb Parker et al. found that greater parent involvement has been associated with an improved parent-child relationship, an enhanced home learning environment, and an increased likelihood of the parent having paid employment (106).

Although the parent partners involved in this project were actively involved in KidCo's programs, including policy council, they experienced issues related to program management that were frustrating and that they believed led to a lack of motivation to participate. For example, although the parent planning committee was responsible for planning family night programming, the parents did not feel as though they had control over program development. Because the family night topics were federally

mandated, the parents felt that the programming and speakers were predetermined without their input.

Participation in the development of a parent-driven nutrition education program increased the parents' sense of program ownership and control. The program planning served as an opportunity for parents and family advocates to engage in a dialogue about health and nutrition issues of importance, which they might not otherwise have had. This dialogue also led all partners to reflect on why parent participation was low at Riverside and what the Center could do to actively engage more parents and caregivers.

One of the goals of the Riverside partnership was to enhance parent involvement at the Center through the development of a parent-driven program that addressed the nutrition concerns of parents and caregivers. Because of the short duration of this project and the limited parent participation at the Riverside Center during the 2006-07 school year, it is unknown whether or not the project would have resulted in increased participation. It may be that parent participation would have been greater if the program had been initiated earlier in the school year without having to undergo the parent planning committee and parent group approval process. As the program continues into next year, more information about parent participation could be gathered.

## **Conflicting Research Interests**

It is not uncommon for research partners to have conflicting research and participation goals in CBPR projects (107). Often, academic partners have an interest in knowledge production that clashes with community members' need for practical improvements to programs and services (107). In the case of the Brownsville project, the community based organization (CBO) wanted to conduct a simple door-to-door survey to understand issues related to food bank use and to improve service delivery. The academic and health department partners were interested in a larger project to develop an information network that would inform health department service delivery and programs and allow for improved communication with the community. While both projects were targeted at improving programs and services and ultimately would have benefited the community, the project expanded beyond the scope the CBO had anticipated or had the capacity to manage.

Managing these conflicts is critical in CBPR projects. As Wallerstein and Duran point out, it is important for communities to benefit from projects in the short term even when overall program implementation may be long term (107).. In this case, the CBO had the short-term goal of completing the survey, while the health department and the academic partners had a longer-term goal of enhancing community-health department relationships. The development of the communication network also served to make the grant proposal more competitive in the eyes of the funder. However, one of the primary barriers to consensus on project goals and design was the

timeline in which the grant proposal had to be submitted. The period from RFP announcement to the submission deadline was approximately two months, which did not allow adequate time for the partners to agree on project design and resolve conflicting interests. The results of this project illustrate that resolving conflicting research goals is a time-consuming process that requires significant dialogue and investment from the partners. Had the timeframe allowed for more partnership-building, including a meeting with all members of the group, it is likely that consensus on project design could have been reached.

## **Organizational Capacity**

A primary goal of CBPR is to increase community capacity and to support the resources that enhance community members' ability to work together to improve health (30). The Sharing Hands board of directors acknowledged that participation in the project would enhance the organization's capacity by going beyond its food bank function and collecting data that could be used in future grant proposals.

While capacity building is important, it is also essential to properly evaluate the existing capacity of the group to determine if the partnership has the ability to implement a program idea (36). In the case of Sharing Hands and Oregon State University, the grant writing group agreed that the capacity was not sufficient to successfully conduct the survey and communication network projects. This was due, in part, to the restrictions of

the grant that required the CBO to be the primary grant applicant, which limited the ability of the partnership to access the grant-writing resources at the University. It also severely limited the role the University was willing to take on in terms of grant administration. This left Sharing Hands responsible for all aspects of grant administration, including management of an additional staff person to oversee volunteers and data collection, which was beyond the scope of their desired involvement.

Organizational capacity also refers to the ability of the university partners to carry out the research. Because of graduate student turnover and a lack of time on the part of faculty researchers, the resources necessary to execute the project with Sharing Hands were not available. Because of these challenges, the grant writing group agreed that the grant should not be submitted until the issues of organizational capacity and program management could be resolved.

## **Funding Requirements**

As described above, the grant requirements limited the involvement of the University and shifted the bulk of grant administration to the CBO. While the intention of the funder, Northwest Health Foundation, was to empower the CBO by giving them control over the funds, in contrast to typical arrangements in which the University controls research monies, it also served to restrict the partnership's access to University resources. However, had the University administered the grant, a substantial amount of

the funds would have gone to indirect costs incurred by Oregon State rather than directly to the community and research effort.

The limited time for project development described above was an additional barrier to development of a successful proposal. To truly engage in CBPR, it is important to establish the researcher-community partnership before research begins (108). While relationships had been established with key community leaders, there was not enough time between the announcement of the proposal and the deadline to foster a true partnership engaged in project development. Ideally, there would have been opportunities for community members, health department representatives, and academic partners to meet and develop the proposal jointly. Therefore, it is important that funders seeking to support CBPR projects recognize the amount of time it takes to properly establish a partnership and develop a project proposal.

### **Institutional Review Boards**

This project resulted in an innovative approach to conducting CBPR within the Institutional Review Board (IRB) approval process. There is an inherent conflict between IRB review and participatory research in that IRB approval was required before recruitment could begin but, in order to stay true to the principles of CBPR, project development could not be initiated until after Head Start staff, administrators, and parents were involved. To resolve this conflict, an agreement was reached with IRB in which a general

project outline was be submitted initially with follow-up approval given as the project progressed and evolved. This provided the project with increased flexibility but still allowed for appropriate ethics review.

Despite this "rolling" IRB approval, the institutional structure of ethics review presented challenges to the spontaneous generation of ideas that results from CBPR. While the OSU IRB was very flexible and worked to accommodate the needs of the project, it was difficult to work within the constraints of the project revision process each time a new idea or method was generated. For example, at one meeting the parents had several ideas for recruitment materials that needed to be translated and reviewed for a meeting the following week. While IRB was able to review the materials in time, requesting reviews such as this on a regular basis would have placed an undue burden on IRB staff.

IRB and ethics review frequently presents a challenge to CBPR projects. Because the approach to program development and participants (as opposed to subjects) is fundamentally different from traditional research, IRB review boards are not typically equipped to effectively evaluate CBPR projects (109, 110). As Khanlou and Peter point out, "given the large variations in context, goals, and processes embedded in PAR-driven research, an itemized and list-oriented approach to evaluating ethical merits of a PAR proposal can be ineffective." The authors go on to suggest that ethics review boards implement overall ethics guidelines for participatory action research that would allow greater flexibility within the process.

The role of community members in the research is also challenging to traditional ethics review (109). Because the community acts as researchers rather than subjects, it is unclear how they should be treated within the context of an IRB proposal. By continuing to perceive community members as "subjects" rather than researchers, IRBs perpetuate existing power dynamics that marginalize segments of the population (109). In addition, the need to seek approval of community-generated ideas could be seen as invalidating, and disempowering, to the group that developed the ideas (109). Thus, ongoing dialogue with institutional ethics review boards is needed to examine ways in which community members can be better integrated into the research process.

# **Summary of Project Feasibility**

The outcomes of this project demonstrate that CBPR can be conducted with Head Start parents and caregivers to examine health and nutrition issues and priorities in the community. This was illustrated by the fact that both parents and Head Start staff and administrators participated and saw value in their participation and in the outcomes of project activities. The project used truly participatory methods, as evidenced by parents' participation in all aspects of the recruitment and project development phase and the Riverside project and Brownsville residents' participation in all aspects of the Brownsville project. Finally, the project resulted in tangible

outcomes and the introduction of an innovative process for working with IRB on a CBPR project.

One of the primary goals of this project was to work within the timeframe of one Head Start school year to determine the possibility for shorter-term CBPR projects. Completing this project within such a short timeline was not possible for several reasons. First, it took a significant amount of time to establish relationships with Head Start staff and policy council members before accessing parents and caregivers at large. Once contact was made with parents and caregivers at participating centers, there were only limited opportunities to meet with them and conduct recruitment. For example, because family nights were the primary opportunities to meet with parents and caregivers, these contacts were made only once a month. Furthermore, because parents and caregivers are not required to attend family nights, a different group attended each month. This complicated the continuous contact necessary to develop the strong relationships required to effectively implement a CBPR project, particularly within such a short time. Solutions to these issues are explored in the suggestions for future research section below.

In conclusion, this project was able to use participatory methods to implement CBPR with Head Start parents and caregivers; however, accomplishing this goal within a single school year was not possible. Thus, the project spanned two consecutive school years with meetings held over the summer as well. To ensure the success of a CBPR project with Head

Start, it is important to allow adequate time to develop relationships and establish project buy-in with staff and administrators before attempting to meet with parents and caregivers. Once these relationships have been established, meetings with parents and caregivers should be initiated at the beginning of a given school year when parent involvement is highest and to maximize the time available to project development and implementation of action steps.

# **Action Steps Resulting from the CBPR Process**

The health and nutrition issues and action steps that were identified as a result of this project varied significantly between the Riverside and Brownsville projects. Both groups identified barriers to health and nutrition as well as resources within their communities and developed unique action steps to address a topic chosen through a process of participatory issue selection.

# **Brownsville and Riverside: Community-specific Actions**

One of the unique features of this project is the fact that, despite the use of similar research methods in both Riverside and Brownsville, the two projects had distinctly different results. For example, the Riverside group chose to focus their efforts on development and implementation of a nutrition education program at their Head Start Center, while the Brownsville group selected food security in the broader community rather than focusing just on Head Start. In addition, while the Riverside discussions

primarily addressed nutrition, the Brownsville group discussions were broader in scope and examined general health issues as well as nutrition.

There are several reasons the two projects could have had such distinct outcomes. First, the demographics of the two groups were quite different. For example, both parents involved in the Riverside group were active parents both at the Center and in the broader KidCo Head Start organization. The parent from the Central Linn Center was relatively new to Head Start but had lived in Brownsville for several years. She had strong connections within the broader community and thus suggested meeting with Brownsville residents rather than just Head Start parents.

Another reason the Central Linn parent suggested meeting with Brownsville residents was likely the tight-knit nature of the community. The closeness of the Brownsville community was a major theme of the group discussions, while the dynamics of the broader Albany community was not mentioned during discussions at Riverside. This is potentially the result, in part, of the different sizes of the two communities. Brownsville has a population of 1,550 residents, while Albany is a much larger town of 44,030 residents. Thus, because Albany lacks the closeness of Brownsville, it is likely that the Riverside parents identified their community as the Center, while the Central Linn parent identified more with the broader Brownsville community than with just the Head Start center.

The topics addressed by the research groups in the two locations were also reflective of the differences in participant demographics. Because

the focus of the Riverside project was within the Center, the issue the group selected to work on arose out of the parents' desire for more nutrition education from Head Start. The broader focus of the Brownsville discussions, which revolved around several different health-related issues, reflected the involvement of community members from a variety of backgrounds. The common experience of the Riverside parents was their involvement at Head Start, while the common experience of the Brownsville members was their residence in the community. These different shared experiences, along with the different knowledge and priorities possessed by each group as a result of those experiences, guided the directions of the two projects.

The differences between these two projects, particularly the different issues identified by the two groups, illustrate the importance of tailoring health and nutrition programs to individual communities. Such community-specific interventions allow community members to address their own health priorities in a way that is meaningful for them (26, 30). For example, the issue of concern the community identified in the Los Angeles study described previously was the lack of access to fresh fruits and vegetables (22). The project used local expertise and selected a problem of local relevance, which resulted in the generation of data to support initiation of actions to improve the nutrition environment in the community. If similar methods were used in another community, it is likely that the results would be quite different based on variations in needs and priorities.

This emphasis on local needs and actions presents challenges related to measurement and generalizability of results (26). For example, in a comprehensive analysis of the quality of existing CBPR research, the Agency for Healthcare Research and Quality (AHRQ) was unable to complete a direct comparison of the studies due to the variation among outcomes and measurement strategies (27). Furthermore, the often unexpected outcomes of CBPR causes difficulties in predicting the potential benefits of CBPR (27). Because of this, the AHRQ calls for CBPR practitioners to work toward achieving the highest possible scientific standards in their research and for funders to provide guidelines for reviewers and applicants to strengthen the quality of community-based research.

In addition, it is important to recognize that locally relevant results may not be generalized to the broader community. What can be generalized, however, are the methods used to engage community members and apply the principles of CBPR. As Wallerstein and Duran point out, it is important to recognize the role community action plays in achieving social change. These actions may be different for individual communities but the ultimate goal is the same—to create knowledge and work toward a more just society (26).

## **Addressing Barriers to Health and Nutrition**

Both the Brownsville and Riverside groups identified barriers to health and nutrition that are important in their communities. While the issues identified are common among rural and low-income populations, the solutions that arose from these projects were unique and addressed each community's specific needs.

# Food Security and Health Communication in Brownsville

In Brownsville, the working group identified several barriers to health including lack of access to healthy foods, food security, confusion about health and nutrition messages, and a culture that is constantly on-the-go and too busy to allow people time to take care of their health.

Lack of access to fresh, healthy food is a common problem in rural areas (111). An examination of factors that result in poor diet quality in rural areas, including limited supermarket availability, limited food item availability, and higher food costs, found that fresh fruits and vegetables were limited in the small and medium-sized supermarkets more common in rural areas. The Dairy Mart in Brownsville was the only local retail source of food, and was, according to residents, both more expensive and limited in the amount of fresh produce available. However, one of the unique features of the Brownsville community was the grassroots effort already underway to address this issue. For example, there was an active community group that had already established a local farmers market and community garden and was working to develop a co-operative grocery store. This effort serves as an excellent example of the power a community has to overcome barriers to overcome these challenges. While healthy food choices are an individual

decision, complex factors that affect these decisions, such as food availability, cannot be resolved on the individual level. Rather, it requires a group of empowered citizens to address these socioeconomic issues.

The communication network project idea sought to address the group's confusion about health information by creating a formal mechanism for community members to dialogue directly with the health department about their health concerns and to work together to improve service delivery. Thus, while the barriers to health identified in this CBPR project were not new, the process of developing action steps to address the concerns resulted in the potential for creative solutions that would relevant to the community and met the needs of both Brownsville residents and the local health department.

## **Riverside Nutrition Education Program: A Process of Discovery**

A Freirian approach was used in the development of nutrition education program in the Riverside Project such that the research group collaboratively developed the curriculum (59). As Wallerstein and Bernstein point out, in a Freirian approach the health educator contributes information *after* the group has identified issues of importance. This method was challenging to the parents at first, particularly because many people are accustomed to looking to the researcher, or expert, for guidance (25). One of the Riverside parents pointed out that it was initially difficult for them to identify nutrition issues they wanted to learn about. In particular, it was difficult for them to make the shift from being instructed about nutrition to

discovering what they wanted to know on their own. The development of the nutrition education program was a process of discovery for the research group in which, through a process of listening, dialogue, and reflection, parents went from being told what they needed to know to identifying and asking for information that was relevant to their situations.

As with the Brownsville project, the nutrition education topics the Riverside parents identified are not new and are generally included in many existing nutrition education programs. The topics were similar to those already offered at KidCo through family night programs and written materials. The difference between the programming developed as part of this project and existing programs is that the parents, or targets of the nutrition messages, identified the issues they wanted to learn about. Furthermore, the parents participated in planning activities to inform the process by which the messages were delivered to ensure that the programs were presented in a way they could understand and that they were relevant and interesting to the target audience.

The importance of including the targets of nutrition messages in message development is clear from statements the parent partners made during the project. For example, the parents were frustrated that there was not enough information available that helped them make decisions about eating healthfully. At the same time, they felt that they were being told "what to eat" in a way that was not helpful or encouraging.

Knowledge about existing nutrition messages and programs was limited as well. For example, the parents were familiar with the Food Guide Pyramid and the importance of eating fruits and vegetables, but they were not aware of the emphasis on eating produce of different colors.

Incorporating colorful fruits and vegetables to increase antioxidant consumption is a major effort of nutrition education programs, yet these parents had not heard about it.

The parents emphasized the need for practical information that families could use to implement healthier eating behaviors. Where and how to buy healthier foods, methods of storage and preparation, and getting kids to eat fruits and vegetables were all important topics to the parents. The most frequently asked question at meetings and family nights was how parents and caregivers could increase their children's consumption of fruits and vegetables. While information on these topics already exists, it is either not reaching parents and caregivers or is not in a format that is useful to them. This speaks to the need to enhance understanding of exactly what types of nutrition information parents and caregivers find acceptable, useful, and relevant to keep their families healthy.

# **Including the Community in Development and Evaluation of Nutrition Programs**

Including the targets of nutrition messages in development and evaluation efforts is a valuable means of increasing this understanding; however, large-scale program evaluation rarely directly engages message

recipients in a meaningful way. As Fawcett (45) points out, most research focuses primarily on the "variables of interest to the discipline" and less on the benefits to the community at large. For example, in a review of national nutrition education efforts, the General Accounting Office interviewed officials from the USDA's food assistance programs, including the Food Stamp Program, WIC, the National School Lunch Program, and the Child and Adult Care Food Program, in five states to identify the components of a successful nutrition education program (112). The issues under consideration were the key actions officials can take to increase the success of nutrition education programs and whether or not the federal, state, and local officials undertake these actions in program design, delivery, and evaluation.

While the review resulted in valuable information from the perspective of service providers, the authors did not interview recipients of the services to understand whether the programs were actually meeting the needs of the target audience or if they felt motivated to make changes as a result of the education efforts. For example, one of the keys to program success was to accurately assess the needs of the target populations; however, the program audiences were not asked if this was done effectively. Including parents and caregivers in this process, as recipients of the nutrition education programs, would also enhance understanding of the reasons nutrition programs are not reaching, or being utilized by, the target audiences. For example, only one of the two parents had heard of OSU

Extension, which offers classes on many of the topics the parents asked for. Thus, it is likely that lack of participation in Extension's education programs is related to both a lack of time and also a lack of knowledge about the resources offered.

To truly understand the components of a successful nutrition education program, it important that recipients of the programs be included in monitoring and evaluation efforts such as the one described above. The report calls for stronger linkages among nutrition education efforts, which is important in conserving resources and maximizing the efficiency of the programs, but it fails to address the components of a successful nutrition education effort from the perspective of the target populations (112). While some programs measure behavior change related to participation in a nutrition education program, it remains unclear why people who participate do not change their behaviors and what participants need in order to make such changes. To encourage these connections, one of the results of this project was to link Extension directly with the research group to use participatory methods to inform implementation of the nutrition education program at Riverside, which can serve as a model for the ways in which nutrition education programs can link directly with communities to improve program outcomes and, ultimately, the health of the community.

# **Expansion of Nutrition Education Programming**

The implementation of the nutrition education program at Riverside significantly increased the exposure parents and caregivers had to nutrition

information. While both the Center's family advocates and parents identified the nutrition family night as the primary opportunity for nutrition education, other Head Start efforts included nutrition messages on monthly menus, information accompanying the nutrition screening of children enrolled in the program, and opportunities to meet with the Health and Nutrition Services Coordinator. The family advocates also indicated they had nutrition information available if parents asked for it but said that they rarely did.

Thus, initiation of nutrition programming at every family night resulted in an increase in the parents' opportunities to learn about nutrition. Instead of providing nutrition at only one of the family nights, parents could access printed nutrition materials and discuss nutrition issues with either an OSU Extension Agent or nutrition graduate student, or both, at five family nights. The ultimate goal was to increase not only the number of nutrition messages provided but also the relevance of the education materials and programs. Thus, the topics that were presented at family night were those the parents had asked for.

# Opportunity to try new foods

While many nutrition messages do give practical information about how to incorporate healthful foods into the diet, many parents and caregivers are unable to experiment with new foods the way nutrition programs recommend. For example, the message of incorporating a variety of fruits and vegetables was familiar to the parent partners, but the cost of trying new foods prohibited them from doing so. While it is true that healthy

foods are not necessarily more expensive than unhealthy alternatives, the parents said they could not afford to purchase foods their families might not eat. To make the most of their food dollars, parents and caregivers buy the foods they know their families will eat, which prevents them from trying new foods and incorporating a wider variety of fruits and vegetables into the diet.

This illustrates a need to not only educate families about ways of eating healthfully but also to increase opportunities for parents and children to try healthful, but unfamiliar, foods without having to buy them. Many programs offer these opportunities in a variety of formats. For example, Head Start's meals frequently include unfamiliar foods such as quinoa and sweet potatoes, providing children an opportunity to try them; however, parents and other siblings do not always have the opportunity to sample these foods. Extension offers cooking classes through a variety of programs; however, attendance continues to be a problem. As illustrated in the current project, community members are not always aware of Extension's programs and barriers exist that prevent them from attending.

The nutrition education program addresses this in several ways. It builds on the existing Head Start social structure of family nights so that parents and caregivers do not have to attend a separate program to receive the nutrition information. Parents already plan to attend family nights as part of their participation in Head Start and the program takes place in the familiar surroundings of the Center and with other Head Start parents and

caregivers. As part of the project, Extension offers a recipe testing at each family night to allow parents and caregivers and their children an opportunity to try healthful foods such as pumpkin cookies, carrot cookies, lentil soup, and fruit salad. In discussions with the author, the Extension agent, and the family advocates, family night participants responded favorably to the opportunity to try healthy foods and were more likely to prepare the recipes when they knew what they tasted like and that their children would eat them.

# **Increasing Communication Between Institutions and the Community**

One of the needs identified in the Brownsville project was improved communication between the health department and community members. This need was echoed during discussions at the Northwest Health Foundation workshop in which participants called for improved mechanisms for community members to approach research institutions or service agencies such as universities and health departments. While both the local health departments and Oregon State University conduct research that seeks to benefit the local community, there is currently no real mechanism in place through which community members can approach researchers and initiate a project idea.

The current project sought to overcome this challenge in two ways. In the Riverside project, parents were linked directly with an Extension agent to further develop and implement the nutrition education program.

Extension is the formal channel through which research conducted at OSU is disseminated to the public; however, the communication is largely unidirectional. While OSU communicates research findings to community members, there is no formal means through which community members can voice concerns or influence research goals. For Extension's projects to be truly "community-based" rather than "community-placed," it is important for them to offer an opportunity, such as that offered by the Riverside nutrition education program, for community members to communicate with researchers and participate in program development and delivery (96).

The Brownsville project developed ideas to improve communication with local health departments through the proposal to establish a two-way communication network that allowed the health department to disseminate information to the community and the community to bring health concerns to the department. The local health departments recognize the need for improved communication with the community and for greater community participation in program development. Both Linn and Benton county health departments supported the development of this community network and wrote strong letters of support for the grant proposal. Although the proposal was not submitted, the project remains viable and could fulfill an existing need in the community.

# **Summary of Action Steps**

The action steps that resulted from the Riverside Project were quite different those developed in the Brownsville project. The Riverside group chose to focus their efforts within Head Start to improve delivery of nutrition education at their center. In contrast, the Brownsville group examined broader health issues in the context of their community and chose to develop a grant proposal to conduct a food security survey and develop a health communication network. Both groups conducted an informal process of resource identification in their communities.

#### LIMITATIONS

There were two primary limitations identified in this study: the number of participants and the timeframe of the project.

# **Participation**

The most significant limitation of this project was the number of Head Start parents and caregivers and Brownsville residents who were involved. In particular, it is important to note that the parents who participated at the Riverside Center may not have been representative of the general population of parents and caregivers at the Center. For one, the majority of parents and caregivers at Riverside are Latino, while both participants were Caucasian. In addition, the parents who participated at Riverside were already actively involved in Head Start. Therefore, their opinions and perceptions may not accurately reflect those of parents and caregivers who were not actively involved in Head Start already.

Limited participation occurred for several reasons. As described previously, it is challenging to involve Head Start parents due to a variety of factors, including scheduling conflicts and having young children at home. Neither parent in this project had a toddler or infant at home and one of the parents was unemployed during most of the project. The other parent was a student at a local community college, which, once the school year began,

significantly limited her participation in the project. For parents and caregivers who did have a toddler or infant at home or who did have significant scheduling conflicts, participation in additional meetings above and beyond those already in place at Head Start would have added an additional burden.

To facilitate participation and achieve the CBPR goal of reciprocity, it was agreed that the nutrition education project would be a function of the parent planning committee. Because the group thought other parents and caregivers would want to participate in the project, the expectation was that combining the nutrition education program with the parent planning committee would achieve Head Start's goal of increasing parent participation. While both the parent planning committee and the larger parent group both voiced strong support for the project, efforts to engage the parent planning committee were largely ineffective due to factors beyond the control of the project participants. Two of the meetings the academic researchers attempted to attend were cancelled and only one other parent attended the other two. This was, in large part, due to the limited participation overall at the Center during the 2006-07 school year.

In Brownsville, the group was primarily representative of one segment of the Brownsville population: retired Anglo-Americans. While participants came from a range of socio-economic backgrounds, they did represent other facets of the Brownsville population. One of the primary goals of the group was to increase participation. Lack of knowledge about

the project was likely the most significant barrier to participation to be more representative. While the group came up with a flyer to advertise the meetings, which was posted in the coffee shop, this did not result in additional recruitment.

An additional barrier to participation in Brownsville was the time of the meetings. Meetings were held on Wednesdays at 9:30 a.m., which made it difficult for working residents to attend. It was agreed that, once the survey project was initiated, the meeting time would be addressed to allow for greater participation.

# **Timeframe and Partnership Building**

One of the primary goals of this project was to examine the possibility of conducting a CBPR project within the limited timeframe of a nine-month school year. One of the principal reasons for this is the difficulty in establishing long-term relationships with Head Start parents and caregivers because they are usually involved with the organization for one, or at most two, years. However, the limited timeframe also proved challenging because it did not allow for adequate time to establish partnerships with key participants at Head Start and in the Brownsville project.

As described above, the strong relationships that were established with Riverside family advocates toward the end of the project were beneficial to implementation of the project. It is likely that, given additional

time, the support of the family advocates would assist with recruiting additional parents and caregivers and formalizing a process for the nutrition education program. However, because of the limitation of the school year, time ran out before additional contacts could be made with parents and caregivers during the 2006-07 school year.

In Brownsville, the most significant timeframe issue was related to the amount of time to for the development of a grant proposal for submission to the Northwest Health Foundation. As described above, only two months were available from the time the RFP was announced to the grant deadline, which did not allow enough time to establish relationships between the Brownsville group and the Health Department. Ideally, a meeting would have been held to introduce the two groups and collaboratively develop the grant proposal.

#### **CONCLUSIONS**

## **Summary**

There is increasing emphasis on the role of community based participatory research (CBPR) as a means of addressing the complex causes of health problems. This project employed participatory methods in all stages to explore health and nutrition concerns and priorities of Head Start parents and caregivers and develop and implement actions to address the issues identified. Because the parents and caregivers directed the project, it resulted in several unexpected outcomes. For example, the parent in Brownsville suggested meeting at the local coffee shop and expanding the project to include residents of Brownsville. Both projects resulted in the initiation of actions to address concerns identified by the community.

At Riverside, the group initiated a nutrition education program with topics selected by the parents to address their nutrition concerns. A partnership was established with OSU Extension to assist with the implementation of the project and delivery of the education program. The parents had the opportunity to share their perceptions about the partnership and the project at a Northwest Health Foundation-sponsored CBPR workshop held in Corvallis. The Riverside project resulted in a strong partnership based on respect, trust, and friendship and, due to the support

of the family advocates and Extension, in a nutrition education program that will continue into the following year.

In Brownsville, the group collaborated to select an issue of importance that was identified by a local community-based organization. The food security survey was developed based on the needs of community members and the desire of the local CBO to better understand food bank use and to improve service delivery. The group agreed that the OSU researchers and a representative of the CBO would develop and submit the grant proposal. If the funds were received, the group agreed to reconvene and collaborate to recruit neighborhood representatives, develop survey questions, and implement the project. Because of a lack of time to adequately develop the partnership and issues related to organizational capacity, the grant was not submitted. The project did, however, result in a viable project that would provide direct benefits to the community in terms of increasing communication with the health department, empowering the community to address health issues of concern to them, and building upon the tight-knit community in Brownsville.

This project illustrates the importance of trust and respect in a CBPR project. Had the time not been spent on building relationships, listening to community concerns, and reflecting on community strengths and needs, the project would not have been successful.

While many studies focus solely on the participation of CBO representatives, this project highlights the importance of balancing

participation between CBO members and individual community members. In the case of Head Start, the parents did not feel that the staff and administration represented them or always adequately understood their needs. Therefore, including both parents and Head Start staff in the project allowed the two groups to dialogue, better understand one another, and build stronger relationships. In addition, inclusion of family advocates in the partnership facilitated program implementation and sustainability.

Because CBPR projects are inherently different from other types of research, IRB approval remains challenging. For this project, an innovative approach to IRB approval was devised in which pieces of the project design were submitted as they were completed. This resulted in a rolling IRB process that facilitated project approval. Despite this improved process, however, IRB approval continued to pose challenges in terms of inhibiting implementation of ideas generated for upcoming events and undermining the role of participants as researchers rather than subjects.

Finally, the project resulted in a partnership between Head Start and OSU Extension that facilitates the sustainability of the Riverside nutrition education program and helps Extension fulfill its mission to disseminate research from the University to the public. Extension's involvement also provides the resources necessary to use the Riverside and Brownsville projects as a model and expand the efforts to engage parents and caregivers in a CBPR process to other centers.

#### **Recommendations for Future Research**

Future studies with Head Start parents and caregivers would benefit from the establishment of a formal group to oversee project implementation and serve as a constant from year to year. For example, a steering committee could be established comprised of family advocates, former Head Start parents and caregivers, and current parents and caregivers. As one year ended, the individuals serving as "current parents and caregivers" could rotate into the role of "former parents and caregivers." This approach would allow recent Head Start participants to lend their expertise to incoming parents and caregivers and provide continuity, while the incoming parents and caregivers could take the lead on project development and implementation for their school year.

Additional studies should seek out methods to overcome barriers to participation for parents and caregivers. It is unclear why participation was low during this school year; however, it is important in the future to explore these issues to increase participation and ensure a more representative group of parents and caregivers. Working together with parents and caregivers to explore improved recruitment methods and incentives is also important to increasing parent participation.

A process of social network mapping with Head Start parents and caregivers would be a useful method to identify where social support resources and needs exist within the community. The outcomes of social network mapping could be used by Head Start staff, administrators, and

parents and caregivers to strengthen relationships and clarify roles and responsibilities within the organization. A social network map could also serve as a foundation for establishing a stronger social support system within the Head Start program.

The Brownsville project resulted in a viable project that was not implemented because the time needed to adequately establish a partnership between the Brownsville group and the health departments was not available. Therefore, it is important in future work to address these partnership issues before a project is developed. It is too difficult to develop a collaborative project without bringing the groups together to work out issues and concerns, establish roles and relationships, and build trust. In addition, it is important that funders acknowledge the time required to successfully develop a collaborative, community-base grant proposal and provide extended deadlines to facilitate these efforts.

Further work is needed to address the conflicts between ethics review and CBPR. The potential for including community members on IRB review boards should be explored, particularly for the review of community-based projects. A streamlined approach to IRB approval also needs to be developed that allows for the spontaneous generation of ideas inherent in the CBPR process and that does not invalidate, or give the appearance of invalidating, the knowledge of community participants or their role as co-researchers.

Finally, CBPR offers an exciting opportunity to address the complex causes of health problems. It is important that, as more funding becomes available and greater emphasis is placed on CBPR as a research methodology, future work in this area remains true to its theoretical roots. Practitioners of CBPR should follow the advice of Mary Northridge and "show up," be genuine, listen, pay as much attention to the process as the outcome, strive for the highest degree of scientific and professional standards, and conduct the work with joy, passion, and a commitment to social change (35).

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#### **APPENDICES**

#### **Appendix A: Interview Outline**

#### **Introductory Statements:**

"We are really happy that you are joining us in this project. We realize that nobody knows more than you do about your child's health. Thank you for your time. (allow time for small talk, introductions and informal discussion about the children)

#### **Questions:**

<ol> <li>Tell me about your child's he</li> </ol>
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- 2. What resources are available to parents to help you keep your kids healthy and meet their nutrition needs?
- 3. What are the challenges you face in meeting nutritional needs of your family?
- 4. How well are current nutrition programs working?
- 5. What do you want need/want in terms of nutrition information or programs?
- 6. Pretend it is your job to teach children about health...how would you do it? What would help your community take care of their families?

7. Any other thoughts about health and nutrition related to your family?

#### **Appendix B: Initial Recruitment Flyer**

# **WANTED: EXPERTS!**

IF YOU CARE FOR KIDS, YOU ARE AN EXPERT



Do you want to put your knowledge to use?

This is your chance to come up with health messages for children! What will you create?

Use your experience to create a plan for health.

Please be part of a creative program to explore health in your community

Want more information?

Sign up with your Family Advocate or call Libby at 541-737-9190



#### **Appendix C: Riverside Recruitment Invitation**

# You're invited!



Tired of people telling you what to feed your kids? As a parent, you know what's best for your family.

Share your ideas, opinions, and concerns and help plan programs around nutrition and health at Head Start!

### Too busy to come to a meeting?

Don't let that stop you from making your voice heard.

There are many ways to share your ideas, concerns, and needs.

Talk to your family advocate Send us an email at riverside\_parent\_group@yahoo.c om

Call us at 541 - 967 - 1044
Talk to us at a Family Night or fill out a suggestion form. We will use these forms to help create future programs!

#### This is a great opportunity to:

- o Meet other Riverside parents!
- o Develop nutrition programs that work for you!
- Share your ideas and concerns about nutrition and health in our community!
- o Make your voice heard!

Stay tuned for info on our first meeting date and time! Snacks and refreshments will be provided. Please come and help us make this a great year at Head Start!



# Riverside Parent Group: in partnership with Oregon State University

Riverside Center KidCo Head Start 35140 Meadow Road Southwest Albany OR 97321 Phone: 541 - 967 - 1044 Email: riverside\_parent\_group@yahoo.c

#### Appendix D: Brownsville Recruitment Flyer

# You are invited to participate in a community conversation about health!

Join Brownsville residents and people who work at OSU for coffee, pastries, and a discussion about health resources and needs in the community.

Topics we have been discussing include:

- Identification of local health resources and needs
- Incidence of certain diseases in Brownsville, particularly cancer in teens
- Need for a local retirement facility
- Quality of health and nutrition messages produced by local, state, and federal agencies. What's working and what's not? How can we improve them?

Together we can develop a plan for health and community action!



Where: Randy's Main Street Coffee, Brownsville

When: Wednesdays, 9:00 - 10:30 am

More info? Call Libby at OSU, 541.737.9190



#### **Appendix E: Informed Consent Form**



Dept. of Nutrition and Exercise Sciences Oregon State University, Langton Hall 214, Corvallis, OR 97331 Tel. 541-737-9192 E-mail-therese.waterhous@oregonstate.edu

#### INFORMED CONSENT DOCUMENT

Project Title:

Initiating Health and Dietary Changes in a Head Start Program Using

Community Based Participatory Research

Principal Investigator: Therese Waterhous, Nutrition and Exercise Sciences Co-Investigator(s): Therese Waterhous, Nutrition and Exercise Sciences

#### WHAT IS THE PURPOSE OF THIS STUDY?

You are being invited to take part in a program designed to examine health and nutrition in your community. The goals of this research are to:

Understand how you and your family stay healthy

- Identify what, if anything, gets in the way of you and your family's health and nutrition needs.
- O Determine what tools are available that help you keep your family healthy
- Come up with ideas and/or actions that will help make your job as a parent easier in terms of health and nutrition

You and other interested KidCo parents will guide the process and we will work as a group to set priorities that are important to you, your family, and the other KidCo families. We hope that together we can come up with ideas that address concerns you might have around health and nutrition. We are inviting you to participate with us because each person has unique knowledge that will be helpful in developing health messages and actions.

#### WHAT IS THE PURPOSE OF THIS FORM?

This consent form gives you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask any questions about the research, the possible risks and benefits, your rights as a volunteer, and anything else that is not clear. When all of your questions have been answered, you can decide if you want to be in this study or not.

#### WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY?

You are being invited to take part in this study because you are an expert about health and nutrition for your family. As a parent, you know what you need to keep your family healthy. We hope you will share your expertise with us.

# WHAT WILL HAPPEN DURING THIS STUDY AND HOW LONG WILL IT TAKE?

During the study, we will be having a series of one-on-one interviews and group meetings. You are invited to participate in both experiences or one or the other. There will be an introductory meeting to describe the process. Then we will have up to three additional group meetings that will each last about two hours. They will happen at Head Start sites and maybe community sites that are convenient for the group. We will provide childcare. Transportation will either be provided using the Kidco Head Start vans and drivers or we will arrange to meet a group of parents at a conveniently located community site such as a library or other meeting place that is easy to get to or we will reimburse for mileage. There will be approximately

OSU IRB Approval Date: 2/0/26 Approval Expiration Date: 2/7/07 The information you provide during this research study will be kept confidential to the extent permitted by law. To help protect your confidentiality, we will not share your name, the names of your family members, your address, or your phone number with anyone. We will make every effort to keep this information private. We will keep your information in locked file cabinets and use numbers to identify members of the group. Computer files will have passwords so only we can see them. This is to keep your information private so that you feel free to share your thoughts with us.

All written documents, including general meeting summaries (which will be used to describe important points and action items from the meetings), will be provided to the community in a timely manner. These summaries will not contain names or other information that would be linked to you) Minutes of meetings, which will include more specific information but no identifiers such as names, ages, addresses, and others, will be sent to meeting participants only to ensure accuracy. One-on-one interview participants will also be able to view their own interview responses for accuracy, but individual interview responses will be kept confidential and not shared with other members of the community.

We respect the fact that you are willing to share your time with us. We will honor your privacy to the best of our ability.

If the results of this project are published your identity will not be made public.

#### **DO I HAVE A CHOICE TO BE IN THE STUDY?**

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. Your participation is completely separate from your child's enrollment in Head Start. If you choose not to participate, it will in no way affect your child's experience with Head Start.

You will not be treated differently if you decide to stop taking part in the study. You are free to give us only the information you want to share. You do not have to answer any questions or share any information you don't want to. If you choose to withdraw from this project before it ends, the researchers may keep information collected about you and this information will be kept confidential but may be included in study reports.

#### WHAT IF I HAVE QUESTIONS?

If you have any questions about this research project, please contact: Therese Waterhous, 541-737-9192 or Libby McCulley, 503-312-2510.

If you have questions about your rights as a participant, please contact the Oregon State University Institutional Review Board (IRB) Human Protections Administrator, at (541) 737-3437 or by email at IRB@oregonstate.edu.

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

OSU IRB Approval Date:<u>みんん</u> Approval Expiration Date:<u>みんか</u>

		Page 5 of 5
Participant's Name (printed):		
(Signature of Participant)	(Date)	

OSU IRB Approval Date: 2/2/2/2 Approval Expiration Date: 2/7/27

### **Appendix F: Sign-Up Sheet**



# Want to share your ideas about health and nutrition with other Head Start parents and Oregon State? Sign up here for more information!

Name	Phone	Email Address	What days of
Traine		Lilian Addicss	w Hat days Of
	Number		the week/times
			work best for
			you to meet?

# **Appendix G: Field Note Outline**

Meeting Field Notes
Meeting Type: Meeting Attendants: Note Taker: Date: Location: Time:
Observational Notes: What do you notice about the group? The meeting place? The environment?
Methodological Notes: Comment on group process, participation, etc. Who facilitated the meeting?
Theoretical Notes:
Personal Notes: How did you feel during the meeting?

# **Appendix H: Simplified Field Note Outline**

Meeting	Field	Notes
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Meeting Type: Meeting Attendants: Note Taker: Date:

Location: Time:

Meeting Notes:

Personal Notes: How did you feel during the meeting?

#### Appendix I: Brownsville Participant Thank You Letter

Date		
Dear	,	

Thank you for being part of a group of Brownsville residents who worked with us this summer to come up with ideas and concerns about health and nutrition. This work actually did result in a grant being written and it will contribute to Libby's masters thesis. We also discussed the process of talking to community groups, like the Brownsville group, as part of a workshop this summer. While we ended up not being able to submit the grant, we had a good idea and a good team and maybe in the future we can use some of that grant effort. So, your expertise and hard work did result in something very worthwhile.

Some of the ideas we talked about and that you identified were the need for better access to healthy foods, a retirement facility and services for older adults, and better communication between health service providers and community residents. We also recognized the importance of understanding the role that the Sharing Hands Food Bank plays in meeting the emergency food needs of Brownsville residents. Another important topic we discussed was the many health and nutrition resources in Brownsville, which include the food bank, the local gym, safe parks where kids can play, local, well-respected doctors, and the new farmer's market and co-op. Many of you said it was just nice to get together and talk about these issues and we thought so too.

Libby is hoping to recognize you by mentioning your name in a acknowledgement page of her thesis unless you tell us not to do that. If you do not want this done please call 737-9190 and leave Libby a message. In addition we would like to give you a small gift as a token of our thanks.

Therese Waterhous

Libby McCulley