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The Anatomy of CBPR: A Case Study of CBPR Implementation for Health Promotion with the Peer Community

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

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#### Abstract

THE ANATOMY OF CBPR: A CASE STUDY OF CBPR IMPLEMENTATION FOR HEALTH PROMOTION WITH THE PEER COMMUNITY

By Cory R. Cumming, Ph.D.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Social Work at Virginia Commonwealth University.

Virginia Commonwealth University, 2017

Major Director: Kia J. Bentley, Ph.D, LCSW. Professor, School of Social Work

This case study is a qualitative examination of a health promotion project conducted in collaboration with members of the mental health peer community. More specifically, it explores the community based participatory research (CBPR) implementation process used to conduct this health promotion project to gain a deeper understanding of the mechanisms at work in the implementation process. While there has been considerable attention to the principles that guide CBPR (Braun et al., 2012; Israel et al., 2008; LaVeaux & Christopher, 2009), there remains important work to be done in bridging

these principles to implementation; what processes or mechanisms translate these principles to action. Four mechanisms were initially proposed by this writer, derived from extant literature in this area (Wallerstein & Duran, 2003). These provided the initial framework for analyzing the data gathered throughout the case study. The case report discusses the findings of how these initially proposed mechanisms have been transformed and redefined in the context of this case. The resultant mechanisms, knowledge sharing, power sharing, task sharing, resource sharing, and shared purpose (there are five, as one additional new mechanism emerged in the analysis), are described with examples of how they were reflected in this case. Implications for these findings for CBPR research, collaborative health promotion with the mental health peer community, and the social work profession are shared.

#### **Chapter One: Introduction**

#### **Purpose of this study**

The aim of this study was to develop a deeper understanding of key mechanisms that drive community based participatory research (CBPR) to aid researchers in the planning and delivery of this approach to research and community collaboration. To develop this understanding, a case study design was utilized to investigate the implementation of CBPR in a community project. While principles and values of CBPR have been extrapolated from researcher and participant experience with CBPR (Braun et al., 2012; Israel et al., 2008; LaVeaux & Christopher, 2009), there remains a need continue to translate this knowledge into an evolving dialogue surrounding CBPR implementation. When effective, participatory research, such as CBPR, becomes a transformational process, an intervention unto itself. A central focus of this research is to better understand this transformational process and those mechanisms through which it is facilitated.

By focusing on the implementation of CBPR, it is hoped that a clearer understanding of "how" CBPR operates as a process between academic and community research partners will emerge. While there is a fairly robust literature that suggests "what" CBPR is, which serves to define key principles, structures, and values

(Blumenthal, Hopkins, & Yancey, 2013; Israel, Eng, Schulz, & Parker, 2013; Israel et al., 2008), there remains a need to further develop knowledge surrounding "how" these elements come together to produce effective actions for research and change (O'Brien & Whitaker, 2011; Rhodes, Malow, & Jolly, 2010). By understanding the dynamics or mechanisms of how CBPR operates, communities and academic researchers may be better able to: anticipate and plan for these areas as they are forming joint proposals, conceptualize dynamics as they emerge during the research process, and explain both expected and unexpected outcomes at the conclusion of CBPR projects.

To guide and focus this inquiry, four mechanisms related to the practice of CBPR have been proposed, based on the work of Wallerstein and Duran (2003). These include knowledge sharing, power sharing, resource sharing, and shared action for change. They are used as a priori propositions to guide the initial coding of the data gathered for this case study and are further defined and discussed in chapter three.

The project that was the focus of this study identified and targeted a community defined challenge to health and wellness for local mental health peers, and employed a collaborative CBPR process to develop a health promoting intervention to address this issue. The project sought to support an overarching agenda of, "integrating education and social action to improve health and reduce health disparities" (Wallerstein & Duran, 2006, p.312). By researching this project, the goal of this study was to contribute to the burgeoning literature on CBPR by offering insights into proposed mechanisms that are endemic to a CBPR process.

Community Based Participatory Research (CBPR) is an important tool for social science researchers seeking to address the social determinants of health and promote health and wellness in a way that empowers disadvantaged groups (Bogart & Uyeda, 2009; Krieger et al., 2002; Wallerstein & Duran, 2006, 2010). CBPR is a specific methodological approach to research that incorporates participation by community members in the research process. Community members are engaged in varying capacities, across a wide range of activities including planning research design, implementation, evaluation, and dissemination of results.

The Agency for Healthcare Research and Quality (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" (Viswanathan et al., 2004, p.3). CBPR served as the framework for the project that was examined in this study, and as such, the implementation of CBPR was the focal point of this inquiry.

The focus of the project for this study, promoting health and wellness for the peer community, was intentionally chosen to address mounting concerns that many people with serious mental illness don't have the same opportunities to experience health and wellness as the general population (De Hert et al., 2011; Robson & Gray, 2007; Thornicroft, 2011). While the symptoms of mental illness are distressing in their own right, people with serious mental illness also experience physical health problems at disturbing rates. Conditions such as diabetes, cardiovascular disease, high blood

pressure, certain viral diseases, and respiratory issues are all more prevalent in people with serious mental illness when compared to the general population (DeHert et al., 2011; Robson & Gray, 2007; Scott et al., 2012). These conditions contribute significantly to a deeply disturbing shortened life expectancy for people with serious mental illness, ranging from estimates of 8-30 years (De Hert et al., 2011a; Happell, Scott, & Platania-Phung, 2012; Thornicroft, 2011; Robson & Gray, 2007), a phenomenon that has been documented for nearly a century (Malzberg, 1932). The compounded effects of poor physical health and mental illness significantly compromise the ability of people with serious mental illness to lead long, fulfilling lives.

The project situated health promotion as a vital opportunity to address health disparities for people who have experienced serious mental illness. The aim of the project is to develop a health promoting intervention by engaging peers in a (CBPR) process that encourages them to change their environment in a way that better supports health and wellness. Health promotion is a process of empowering individuals, groups, or communities to increase control of and improve their health (WHO, 1986a) and has emerged as an alternative or supplement to the traditional medical model. One of the virtues of health promotion is that it broadens the scope of interventions from the individual to their surroundings. These surroundings include broad social, political, and environmental influences, also known as the social determinants of health. The social determinants of health Organization (WHO) defines the social determinants of health and social justice. The World Health Organization (WHO) defines the social determinants of health as my first and the social determinants of health offer an important connection between health and social justice.

wider set of forces and systems shaping the conditions of daily life" (WHO, n.d., Social determinants of health, para. 1). These include the economic and educational opportunities that are available, access to and quality of health care services, the quality of the natural and built environment in which we exist, and the sense of community and social context of our daily interactions (Office of Disease Prevention and Health Promotion, n.d). These social determinants have guided the work of the health promotion project.

The remainder of this chapter will begin by providing an introduction to some key terms that are recurrently used throughout this dissertation. Next, the conceptualization of the research project is discussed. This will end with a section that addresses the context of the study as a qualitative investigation of CBPR implementation and another section that provides the context for the actual project that was the focus of the CBPR implementation. Finally, the significance of this study will be examined, closing with a section exploring the relevance of this study for the social work profession.

#### **Definition of key terms**

**Peer.** For the purposes of this study, a peer is someone who identifies as having personally experienced the effects of mental illness and who engages in peer support activities. Peer support is defined by Mead, Hilton, and Curtis (2001) as the mutual transaction of giving and receiving help based on shared experiences, respect, responsibility and agreement about what is helpful.

**Health.** Popular definitions have included the biomedical definition of health as the absence of disease, the systems-based concept of health as a state of homeostasis, and the diagnostic notion of health as an ability to function (Blaxter, 2010). The World Health Organization (WHO) has taken a more encompassing approach to defining health, describing it as, "a state of complete physical, mental and social well-being" (WHO, 1946, p.100). Health has also frequently been described as a social construction, that is to say that we attribute meaning and value to health based on our interpersonal interactions with others along with our interaction with broader social influences (e.g. social media, organizations and institutions, influential groups). However, for the purposes of this study, health is defined through the lens of an ecosocial perspective as a dynamic expression of biology, place, time, and status that is uniquely experienced by an individual (Krieger, 2011). This definition situates health as a subjective experience that is susceptible to and composed of many influences. This research sought to better understand and potentially shape these influences.

**Wellness.** For the purposes of this research, wellness is defined as a multidimensional concept that encompasses a person's sense of connection to both internal and external experiences, one's ability to actively develop and participate in a personalized approach to recovery (from mental illness), and an integration of intra-, inter-, and extra-personal experiences (Cummings & Bentley, 2017).

**Health Disparities.** This research defines health disparities according to the definition offered by the Center for Disease Control and Prevention as "preventable difference in health outcomes and opportunities to achieve optimal health that are

experienced by oppressed and socially disadvantaged groups of people" (Center for Disease Control and Prevention, n.d., Adolescent and school health). At the core of health disparities lies disadvantage or the barriers and challenges that inhibit healthy growth and development, inequities evident through unequal access to resources and opportunities to be healthy, and oppression or systemic acts that disempower a group's ability to pursue wellness. Research on health disparities strongly suggests that not all people have the same opportunity to experience health and wellness in their lives. Braveman and colleagues (2011) explains that health disparities are, "particularly relevant to social justice because they may arise from intentional or unintentional discrimination or marginalization and, in any case, are likely to reinforce social disadvantage and vulnerability" (Braveman et al., p.S150). The disproportionality high prevalence of preventable (physical) health problems and threat of premature mortality for people with serious mental illness (DeHert et al. 2011; Druss et al., 2011; Thornicroft, 2011), makes a compelling case for understanding and addressing the health disparities experienced by this population.

**Environment.** This study defines the environment broadly, using Baranowski, Perry, and Parcel's (2002) definition of environment as those factors that are external to the individual. McLeroy and colleagues (1988) ecological model is helpful for demonstrating these environmental influences (see Figure 1). According to Baranowski and colleagues' definition and within the context of this model, all levels of social structure and interaction extending beyond the intrapersonal would constitute the environment. This definition incorporates aspects of physical, social, economic, and

political surroundings that converge to shape behavior. To further clarify, examples of environmental influences that may shape a health behavior, such as intake of food with a high nutritional value and healthy eating behaviors, are provided along each of the levels outlined in McLeroy's model.

*Interpersonal.* Social modeling surrounding food preferences and eating habits from reference groups such as family and peers; Social support for healthy eating behaviors, such as a healthy eating support group.

*Organizational/Institutional.* Local food environment and availability (workplace, school, retail); Institutional policies and practices that encourage/discourage healthy eating.

*Community.* Social norms surrounding eating and body images (especially for target groups), Cultural food preferences.

**Policy.** Policies and regulations surrounding advertising, zoning (for stores and markets), sales tax rates and pricing guidelines, health insurance provision, food quality regulations.

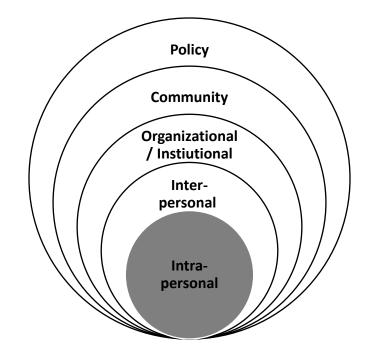


Figure 1. McLeroy, Bibeau, Steckler, & Glanz (1988) Ecological Model

**Community.** Historically, communities may have been sufficiently defined by geographic parameters. However, in modern society, a definition of "community" based solely on location is far too restrictive. We have experienced advances in transportation, communications, and other technologies that have forever changed the way we interact with others and shaped our patterns of social exchange. Consequently, we also need to consider a broader definition of community. Fellin (2001) offers a conceptualization of community that encompasses people brought together across a number of different commonalities, including: physical location, interests, culture, and other aspects of their identities. In the context of this research, community most closely resembles Fellin's dimension of community embodying a symbolic identification and sense of identity, that is community formed through the association with a certain group or organization related to one's sense of personal identity. The community

involved in this study was the mental health peer community. Members of this community may identify as consumers, community advocates, or peers, but regardless of title, share a common experience of being affected by mental health symptoms.

#### Conceptualizing this Research: An Interpretive Inquiry of a CBPR Project

The ultimate aim of this study is to enhance the understanding of how CBPR functions and more specifically, to gain insight into the mechanisms which impel or drive the process of CBPR. To investigate this process a qualitative case study was used to examine the implementation of CBPR for a collaborative health promoting project. To further clarify the approach to this research, both the context of the (qualitative) study itself and the context of the CBPR project (which was the focus of the qualitative study) will be discussed in greater detail below.

This study examined CBPR within an interpretive framework. As an interpretive inquiry, this study drew on the words, experiences, and observations of people directly involved in the work of CBPR through their participation in this project, exploring and interpreting the meaning and understanding that they attached to this experience.

However, this interpretive approach is tempered with postpositivist assumptions, evidenced foremost in the overarching aim of identifying mechanisms at work in this process. While a positivist would seek to remove (or at the very least control for) the influence of the researcher in the research process, research in a postpositivist tradition acknowledges that the researcher is likely to influence the research process and findings and will attempt to account for this influence. However, like positivism, a postpositivist inquiry will still seek to understand observable or identifiable truths

through the research process, but acknowledge that researcher and context both play a role in understanding these truths. This study started from a basic assumption that these mechanisms exist and that they can be discerned by the researcher; contrasting with an approach more closely following constructivism, which would suggest that these mechanisms can only be understood through social construction. Furthermore, the utilization of proposed mechanisms as a priori propositions to guide this case study suggests that the findings of other (authoritative) sources can inform and influence what has been learned here (as opposed to allowing findings to emerge independent from such influences). The rationale for the use of these a priori propositions is further discussed in chapter three.

Postmodern assumptions also played an important role in this study. Postmodernism assumes that knowledge or 'truths' are bound to the context in which they exist (Creswell, 2013). That is, researchers need to acknowledge the context in which their research takes place and consider how this context influences their findings. This requires the postmodern researcher to provide a rich description of the circumstances surrounding the research, including the role of that the researcher played in the research findings. Furthermore, research in a postmodern tradition requires that the research *consumer* needs to actively reflect on the relevance and applicability of study findings, comparing the rich description that is provided in the research report to their own working knowledge of the context and population with which they work (i.e. what are the similarities and differences, and how might these influence outcomes). As will be evidenced in the methodology (chapter 3) and findings (chapter 4), context

plays a very prominent role in this study and is considered across many levels (personal, organizational, community). This writer has attempted to account for the role of context in this study through the use of qualitative tools such as reflexive journaling and a positioning statement (attempting to account for the role and influence of the researcher on the research process and findings), and integrating descriptive information regarding the people and the place involved in the project of study in the final case report (i.e.) the synthesized results of the qualitative case analysis.

By adopting an interpretive approach to this study, the author hoped to gain insights into the experiences of participants that are involved in this CBPR project, and from these experiences derive a richer understanding of key mechanisms that are at work. Intentional efforts were made to combine: the perspectives of numerous participants; contextual information that is captured surrounding the circumstances in which this project is takes place; and an accounting of the subjective contributions of the researcher to the process. As CBPR represents an approach to research that relies on participant involvement, attention to (community, political, cultural, social) context, and involvement and conscious awareness on the part of the researcher and the role that they play (Israel et al., 2013; Wallerstein & Duran, 2003), CBPR as a research process is potentially well situated as a subject for this approach.

## The Subject of the Investigation: A CBPR Project Based on an Empowered Approach to Health Promotion with a Critical Lens

Empowerment and critical perspectives were combined to inform this project. A critical perspective frames health, at least in part, as a consequence of social structures

and the forces that influence them. By targeting these social structures as a source of change and transformation, an empowerment approach seeks to enhance the individual and collective efficacy to exert an (positive) influence on one's surrounding.

A critical approach often seeks to engage vulnerable and oppressed groups in consciousness raising, developing their insight and awareness surrounding power structures, how they operate, and how they influence the distribution of resources in society. Accordingly, this project involved people who identify as mental health peers in an effort to foster a better understanding of what local threats to health and wellness exist for people who experience persistent mental health problems, and what might be done to improve these circumstances. This process helps to develop participants' awareness and ability to exercise their own agency to challenge the dominant discourse (e.g. the voice of those who advocate for maintaining the current systems of oppression), with an ultimate goal of redistributing power and resources more justly throughout society.

Wallerstein (2002) specifically frames powerlessness as a risk factor for poor health. She provides a convincing argument that a number of environmental concerns such as low socioeconomic status, poor working conditions, living in neighborhoods of concentrated disadvantage and substandard housing conditions, and high unemployment are subsumed under powerlessness as a "core" social determinant. The project examined in this study explicitly utilized an empowerment perspective in the development of a health promoting intervention in hopes of addressing powerlessness by engaging the skills, knowledge and actions of peers for this initiative. Three specific

paradigm shifts that are supportive of an empowerment approach towards health promotion are discussed. The first is a shift from treating disease to promoting wellness. The second is the transition from focusing on individuals towards a dual focus on the individual and their environment. The final shift involves the evolution from patient to consumer.

Health promotion itself represents a significant shift from the disease treatment paradigm that has dominated our national health care environment through much of the twentieth century. This shift represents a significant transfer of power, agency, and responsibility from professionals to the general public. Focusing on the diagnosis and treatment of specific illnesses and diseases requires specialized expert knowledge and often access to specific resources such as medical equipment, medications, hospitals, and clinics. As an authority and gatekeeper to health services, the provider inherently has considerably more power when compared to people receiving services; thus maintaining a position of responsibility and control over health. However, health promotion challenges the power dynamics of a disease treatment paradigm in that it recognizes: the (environmental) context in which health occurs; the value of actively engaging people in a process of understanding and pursuing health, as opposed to passively treating an illness; and the integrated nature of human beings as biopsychosocial-spiritual creatures. Recognizing these shifts potentially empowers lay persons to take a much more active role in advocating for their own health and the health of their community. While health promotion has the potential to support empowered approaches to intervention that involve communities coming together to

transform environments in ways that encourage and support health and wellness, many health promotion efforts remain disproportionately focused on individual change. Next, shifting attention from the individual to the environment as a source of change and a resource for health is discussed as an important step towards empowered health promotion for this project.

Situating health as a transaction between a person and their surroundings offers an alternative to narrowly focusing on internal physiological and psychological processes. When health is attributed to a person's individual behaviors, health problems can be blamed on a lack of personal responsibility or weak moral character (e.g. not having the 'will power' to change a certain 'lifestyle' or health-related behavior). An understanding of poor health that is restricted to individual causes can often serve to segregate, label, disempower and even vilify those who may be affected by a disease or risk factor. Turning attention to both the physical (built and natural) and social environments is an important advancement in health care and health promotion efforts, and again, provides an opportunity to empower individuals and communities. A shifting focus to the environment helps to illuminate the connection between our surroundings (e.g. neighborhoods, service systems, political agendas) and their contribution to the production of health, and consequently the perpetuation of health disparities (Israel et al., 2006; Marmot, 2005; Schulz et al., 2005).

However, people can exert a transformational force on their environment. Despite the threats to health that environments may pose (e.g. unequal access to resources and opportunities, exposure to toxins, stresses and hazards, substandard

living conditions), there are numerous instances where CBPR initiatives have been implemented to empower communities to change their local environments in pursuit of better health (Krieger et al., 2002; Mendes, Plaza, & Wallerstein, 2014; Minkler, Vásquez, Tajik, & Petersen, 2008; Vásquez et al., 2007). This project sought to harness the transformational energy of the peer community in assessing a health need and developing a corresponding health promoting intervention which will target a local environmental change.

Finally, the transition from 'treating patients who are mentally ill' to 'serving people who are mental health consumers' is an important shift in the evolution of mental health care and is a crucial transition to the empowerment perspective adopted for this project. By identifying people with serious mental illness as consumers, they are recognized as being capable of participating in their health and making health care decisions. A period marked by principles of empowerment and recovery for people who experience mental health problems has emerged, coalescing around the 1980s and 90s (Corrigan, 2002; Jacobson, & Greenley, 2001; Nelson, Lord, & Ochocka, 2001). This period represents a transition towards a more active and involved role for mental health consumers in the delivery of their health care, which also needs to be reflected in how health promotion services are designed. It is hoped that this project will address this area by actively involving (empowering) mental health peers in the creation of a local health promotion intervention. In the proceeding sections, the significance of this study is explored, as well as this research's relevance to the social work profession.

A critical perspective framed the understanding of health disparities for the project, and guided the change process. By intentionally targeting the involvement of the peer community as active participants in this project, part of the goal was to develop both a heightened awareness and understanding of the socio-political context of local/regional health issues affecting local peers, and to develop the collective efficacy, resources, and capacity for this group to set and pursue a health change agenda.

#### Significance of this Study

The significance of this study can be considered both in its contribution to developing a more nuanced understanding of CBPR and its implications for empowered health promotion for people with serious mental illness. First, by elucidating the mechanisms through which CBPR operates, this study seeks to augment the existing implementation literature on CBPR. Additionally, by focusing this study on a project that involves peers in research efforts related to health promotion, the intent is to combine the momentum of the wellness, recovery and consumer advocacy movements with health promotion to engender a commitment to empowerment, self-determination, and a more active and inclusive role for peers in health promotion activities and the general health and wellbeing of their community. Finally, this study seeks to draw attention to health differences as health disparities for people with serious mental illness to raise awareness surrounding the pressing social justice issue that these disparities represent.

#### Adding to the implementation literature on participatory health

**promotion.** Community based participatory research (CBPR) and other participatory research approaches such as action research and participatory action research are specifically identified as methodological tools for researchers to conduct inquiry in a way that addresses the power imbalances that are often experienced by socially disadvantaged groups. By engaging community members, important insights are gained into the needs and resources of the community, the present and historical context in which interventions take place, and specific obstacles and strengths that may be encountered by intervention efforts. A more thorough understanding of the mechanics of CBPR can help to ensure that these valuable benefits are realized.

Some scholars argue that communities and local organizations are most capable of and best situated to inform meaningful, relevant, and sustainable interventions as they are applied to local contexts (Hacker et al., 2012; Hawe, Noort, King, & Jordens, 1997; Kim-Ju, Mark, Cohen, Garcia-Santiago, & Nguyen, 2008; Tobias, Richmond, & Luginaah, 2013). Engaging community members in participatory research practices provides a platform for capacity building and community empowerment, ideally leading to high levels of investment and ownership. Developing an enriched understanding of how CBPR operates can aid both academic researchers and community members in anticipating and responding to the dynamics of community partnerships and increasing transparency in these processes.

**Promoting health: Combing wellness + recovery + consumer advocacy.** To examine how CBPR functions, the project that was investigated incorporated an

approach to health promotion that encourages wellness, recovery and consumer advocacy. Throughout the study, consideration was given to how these traditions or perspectives were evident in or influenced the CBPR process. Each of them is discussed briefly to provide some insight into their relationship to this project.

Both in the wider healthcare environment and specific to the mental health service sector, the concept of *wellness* is becoming increasingly prevalent. A wellness orientation builds on the values, preferences, strengths, and goals to treat the integrated parts of a whole being, attending to emotional, environmental, financial, intellectual, occupational, physical, social, and spiritual dimensions of their life (Swarbrick, 2006). A philosophy of wellness and concern for the health of the whole person guides the CBPR work that is carried out in this health promotion project.

A *recovery* philosophy highlights the potential for growth, resilience, and transformation in the lives of people affected by serious mental illness. The Substance Abuse and Mental Health Services Administration (SAMHSA) has delineated four key dimensions that support a recovery oriented lifestyle. Each of these dimensions is wellaligned with the critical, empowerment-oriented approach adopted by the project under study. Table 1 offers an examination of how different aspects of the project are aligned with SAMHSA's dimensions of recovery.

Table 1

Aspects of Study Aligned with SAMHSA Dimensions of Recovery

<b>Recovery Dimension</b>	Study Approach
Making healthy choices to	Taking a health promotion approach that does
support physical and emotional wellbeing	endorse the healthy choices, but also creating an

	environment that supports and reinforce these
	choices
Having a safe and secure	Examining how the social determinants of health
home	(such as housing) influence health and wellbeing of
	local mental health peers
The capability to participate	Targeting interventions that encourage the active
in meaningful activities	involvement of affected consumers in shaping their
	environment in meaningful and responsive ways
Sense of community and	Engaging community members (mental health peers)
supportive social network	directly with interventions that target changes in the
	community

The *consumer advocacy* movement is a strong force in the transformation of the mental health services system, the rights of people who experience mental illness, and societal perceptions of mental health. Consumer advocates and their families play an important role in shaping governments and policy agendas and organizational practices around issues that affect the mental health community (Funk et al., 2006; Goldstrom et al., 2006; National Mental Health Consumers' Self-Help Clearinghouse, 1999; Stylianos & Kehyayan, 2012). As the voice of consumers continues to shape the mental health policy and practice arenas, it is also a valuable resource for informing health promotion efforts.

All of these movements, wellness, recovery, and consumer advocacy consistently elevate the value and the potential of the peer community for producing meaningful change. The unique perspective of peers is grounded in the life experience of people who have suffered from mental illness and accompanying experiences of stigma, prejudice, discrimination, and their strengths and skills. Accumulating evidence suggests that health promotion interventions that incorporate the lay knowledge, skills, and resources of affected communities are responsive, contextually relevant, and effective (Minkler, 2000; Wallerstein & Duran, 2006; Whitehead, Taket, & Smith, 2003). There is a need to pursue research that actively engages peers in designing and implementing health promoting and wellness interventions that are grounded in local consumer knowledge and responsive to local consumer needs. The position of the project (being studied) is that peers are a necessary component of change efforts in the field of mental health research and health promotion. To promote improvements for the health and wellness of people that experience serious mental illness, research needs to involve people from the peer community as integral consultants to:

- Identify barriers to health and wellness for the people with serious mental illness
- Design and implement interventions that are responsive to the needs and the strengths of the mental health community
- Help determine appropriate outcomes measures and methods of evaluation that can assess changes that support health at multiple levels (i.e. individual, community, organizational, systemic)

Through the examination of dynamics in this CBPR project, it is hoped that insights are gained for both peers and academic researchers seeking to support greater integration of the peer community in the development of meaningful and effective interventions that promote health, wellness, and recovery.

# **Conceptualizing health differences for people with serious mental illness as disparities.** This study also seeks to support the position that poor health outcomes experienced by people with serious mental illness are avoidable disparities,

not just differences, and as such, are a social justice issue that urgently needs to be addressed. Poor health outcomes for people who experience serious mental illness have been well documented (DeHert et al., 2011; Druss et al., 2011). However, these health differences are not consistently described as health disparities. By failing to locate poor health outcomes for people with serious mental illness within the broader health disparities literature, researchers and advocates miss an opportunity to address the structural inequities and social disadvantages such as poverty, institutionalized stigma, and restricted access to resources that contribute to the poor health outcomes for this population. This research is focused on developing our understanding of CBPR as a methodological tool for researchers seeking to address the systems of disadvantage faced by people with serious mental illness.

#### **Relevance for Social Work**

CBPR and social work have many shared ideals. Some of these include: recognizing the value in working with communities; focusing on developing the strengths, resources, and inherent capacity of participants (or clients) to create change; building collaborative partnerships for transformation; a commitment to understanding the role of the environment and the importance of context; and honoring the power of human relationships through building rapport and sustaining commitments (Bisman, 2004; Israel et al., 2013; Israel et al., 2008; NASW, 2008; Reamer, 2013; Wallerstein & Duran, 2006). CBPR has been lauded by some social work scholars as a methodological tool that allows social workers to conduct research in a way that contributes to knowledge building, but also upholds a focus on tangible, practical and collaborative

efforts for social change (Baffour, 2011; Branom, 2012; Jacobson & Rugeley, 2007). By developing a better understanding of how CBPR operates and those mechanisms through which it is carried out, this study hopes to provide social workers with information that will aid them in conducting CBPR initiatives, but also in honoring a number of professional commitments. Examples of these commitments relevant to the specific health promotion project that is the focus of this study are shared below.

A commitment to social action: Addressing disparities by changing the environment. Part of social work's unique identity as a profession is its commitment to pursuing justice and equity through social action (Charles & Bentley, 2016; Kam, 2014; O'Brien, 2010; Thompson, 2002). Research that addresses health disparities is well suited for this mission (Braveman, et al., 2011; Marmot et al., 2008). The pursuit of eliminating disparities draws on the conceptualization of health as a basic human right, a fundamental idea that health and wellbeing should be accessible to all people, not just those who have access to power and privilege.

The connection between health and social determinants is congruous with social work's orientation to recognizing the link between people and their (social, political, economic, physical) environment (Andrews, Darnell, McBride, & Gehlert, 2013; Gehlert, Murray, Sohmer, McClintock, Conzen, & Olopade, 2010; Hernandez, Montana, & Clarke, 2010; Marshall et al., 2011; Mitchell, 2012; Moniz, 2010). The aim of this project is to utilize an approach to health promotion that is focused on creating change in the environment to support health and wellness for people with serious mental illness. This approach is offered as a counterpoise to the current attention that is being given to

health lifestyle and illness self-management interventions that are overtly focused on individual behaviors. Additionally, this study sought to contribute a clearer understanding of the change process within CBPR that promotes social change and environmental transformation.

Working with oppressed groups: A participatory approach to health **promotion.** A participatory approach to work with disadvantaged communities that experience health disparities allows social work researchers an opportunity to honor our professional charge to serve those who are vulnerable and oppressed. By actively engaging affected groups in a participatory process, it gives social work professionals an opportunity to join with people around health concerns in ways that challenge the traditional medical hierarchy that has often limited and strictly defined the role of the 'patient' and relinguished it to docile complacency. Griffith and colleagues (2010) exemplify this approach in their work partnering with faith-based communities to reduce the risk of HIV/AIDS for local African American residents. The authors describe a central commitment to social work values in their approach to health promotion, including self-determination, autonomy, dignity, and self-worth. Collaboration and engagement of people who are mental health peers is especially important in helping to overcome the historical legacy of forced treatment and depravation of human rights. As an example of social workers using a partnering approach for health promotion research, Cabassa et al. (2013) engaged a group of people with serious mental illness in a qualitative research project surrounding their experiences of health, particularly as it related to the place that they live. This was used to inform health promotion and

health care interventions to better support the residents of a group of supportive housing agencies that serve people with serious mental illness.

When working with disadvantaged groups, attention to responsibility and accountability of researchers throughout the research process is particularly important in participatory research traditions. This commitment parallels social work's professional attention to the use of self in practice. Developing a richer understanding of the mechanisms that drive CBPR can be an asset to support community engaged researchers in developing self-reflective research practices and aiding them in evaluating the participatory nature of their projects. By adopting a participatory approach to health promotion intervention, social work researchers are better positioned to engage with potentially vulnerable groups in a way that is attentive to the effects of the research process on participants and sensitive to the power imbalances that may be present when working with these communities. A better understanding of the CBPR research process can help researchers as they engage in health promotion work.

#### Supporting self-determination: Capacity building and collective

**efficacy.** Social work's commitment to honoring the dignity, worth, and selfdetermination of individuals (and groups), as well as social work's emphasis on the transformative power of human relationships is also well-aligned with this project's community based participatory approach to health promotion. This approach not only

relies on the engagement of community members, but it also takes the development of the community as a core objective.

Social workers have much to contribute and many reasons to support health promotion research that focuses on developing community capacity and enhancing the collective efficacy of disadvantaged groups through CBPR. There is a long history in social work of identifying and developing the strengths, skills, and resources of communities; bringing services into areas where they are most needed; and encouraging potential for hope and change through the transformative power of collective action (Palmer, 2011; Parton, 1996; Rothman, Erlich, & Teresa, 1976; Saleebey, 2012). For instance, Baffour (2011) highlights the valuable role of CBPR for social work researchers seeking to address health and social disparities in rural communities. By demonstrating a commitment to learning and developing the unique strengths of these locations, researchers are more likely to achieve a sense of "community buy-in" and participation. Additionally, Jacobson and Rugeley (2007) emphasize the implications that CBPR has for combining social work's commitment to work with groups and work towards social change and social justice. They assert that CBPR can be especially helpful in working with groups to question and address issues of power, difference, and inequity. Along with their skills as researchers, social workers posses skills that are grounded in traditional social work roles of advocate, mediator, service broker, and community change agent. Enriching an understanding of how potential mechanisms such as knowledge sharing, power sharing, resource sharing and shared action for change operate within CBPR also has the potential to aid social work

practitioners in better understanding how these mechanisms may apply to these vital professional roles (i.e. advocate, mediator, service broker, and community change agent).

## **Overview of the dissertation**

This first chapter is meant to provide an overview of the conceptualization of this research, both the context of this study as a qualitative inquiry and the context of the CBPR project that will be the focus of that qualitative inquiry. A general introduction to the problem of health disparities for people who experience serious mental illness is offered, as understood from a critical perspective. Further, an empowered approach to health promotion (using CBPR) has been suggested as a means of addressing the issue of health disparities, exemplified in the project being studied. Chapter two reviews current literature on health promotion, with explicit attention given to the current implementation of community based participatory research efforts, which target health promotion. In this chapter, the reader will be introduced to the Ottawa Charter and the five overarching strategies that are intended to guide international health promotion efforts. These five areas are used as a framework to explore different approaches to health promotion and have been instrumental in guiding the emergent design of the project. Chapter two closes with a summary of CBPR research related to implementation, providing the foundation for this inquiry. Chapter three goes on to outline the methodology for this case study, with attention given to design, rigor, and a more detailed discussion of the mechanisms used for the investigation (i.e. knowledge sharing, power sharing, resource sharing, shared action for change) and their origin.

The results of this study are shared in Chapter four in the form of a case report. Chapter five provides the reader with a discussion of the findings including a synopsis of the study; an exploration of relevant findings and implications for CBPR research, health promotion, and social work; and concludes with an examination of study strengths, limitations, and directions for future research.

### **Chapter Two: Review of the Literature**

#### Purpose of the review of the literature

The focus of this case study was to examine the implementation of a CBPR project that engages members of the local mental health peer community in designing a health promoting intervention. To better understand how implementation was being approached for this project, this chapter offers the reader a survey of the health promotion literature, with an intentional focus on those interventions targeting the health and wellness of people with serious mental illness and a discussion of how CBPR methods are being utilized to advance health promotion efforts for vulnerable populations. This literature has guided the work of the co-researcher team involved in this project. As the health promotion literature offers a vast diversity of approaches and strategies for intervention, this review is organized using the five areas of health promotion enumerated in the Ottawa Charter (WHO, 1986a, 1986b), a seminal document that helped to formalize the modern international health promotion movement (Kickbusch, 2003; Potvin & Jones, 2011; Wallerstein, Mendes, Minkler, & Akerman, 2011). These five areas of health intervention are:

 The development of personal skills to make informed choices about health

- The creation of environments that support opportunities to live healthy lives
- The reorientation of health services that are effective and responsive to the health needs of communities
- The creation of healthy public policy that recognizes and addresses the interactive effects of the determinants of health
- The empowerment of communities to become more active agents of change for health and wellness

Examples of current interventions and innovations in these areas are reviewed along with prominent theoretical frameworks that support them, when appropriate. When possible, health promotion interventions that target people with serious mental illness are discussed. After each area of the Ottawa Charter is reviewed, it is followed by a section that summarizes health promotion intervention efforts that utilize community based participatory research methods in that area. These are methods that integrate community members, to varying degrees, to: identify and prioritize threats to health and wellness; design health promoting interventions to implement in local contexts; and evaluate the effectiveness of these interventions. Research suggests that efforts to engage community members in these affected groups results in the design of health promoting interventions that are: (1) more individually tailored and responsive to the needs of the neighborhoods in which they occur; (2) better integrated into the context of the communities where they take place and consequently more sustainable; and (3) more effective and efficient in actively engaging community members around

issues of health and wellness in meaningful ways (Navarro, Voetsch, Liburd, Giles, & Gollins, 2007; Rhodes, Malow, & Jolly, 2010; Schulz et al., 2011; Viswanathan et al., 2004; Wallerstein & Duran, 2010). The focus of this study was to explore how CBPR functions within this project, not the topic of the health promotion project itself. However, the information provided here is meant to offer important details that have guided both the context and the content of the project that is being implemented. This chapter will conclude with a brief examination of CBPR researcher related to implementation.

# Promoting Health: The Influence of The Ottawa Charter and a Role for Communities

The Ottawa Charter represents an international call by the World Health Organization (WHO) and member countries for a more balanced approach to health care. Signed at the inaugural International Conference on Health Promotion held in 1986, this international agreement drew public attention to the monopolizing effects of the medical and disease treatment models, and offered a more balanced perspective that acknowledges the critical role of health promotion, wellness, and prevention. The Charter identifies health promotion as a tool for developing the capacity of individuals and communities to live healthier lives and encourages social action as a necessary intervention for improving population health (Mittelmark, 1999; Wallerstein, Mendes, Minkler, & Ackerman, 2011). In addition, the Ottawa Charter has challenged policy makers, researchers, and providers to take greater accountability for the role that the environment and structural issues play in (re)producing health and illness.

Acting collectively, communities can produce profound changes that support the health and wellness of their members. CBPR can be an important tool to join community groups and academic researchers together in support of such transformative change efforts. As noted earlier, community based participatory research is steeped in traditions of developing critical thought and consciousness raising; addressing power relations between different segments in society; the redistribution of resources to address inequity; and emancipatory or liberation-oriented goals for oppressed groups (Wallerstein & Duran, 2008). These aims can be focused on health promotion efforts in attempts to address health disparities and respond to inequities related to health and wellness. The principles of CBPR support an approach to scientific inquiry that is not only empirically sound, but also accountable to and actively shaped by research participants (Balazs & Morello-Frosch, 2013; Bogart & Uyeda, 2009). In the proceeding sections, each area of the Ottawa Charter is introduced and discussed, first in general terms related to health promotion efforts, and then a more focused look at community based participatory research intervention efforts in that particular area.

**Developing personal skills to make informed choices.** Developing individual skills to make informed choices about health and wellness is the first health promotion strategy outlined by the Ottawa Charter. With a focus on individual transformation, many health promotion efforts reflect a commitment to developing the specific personal skills of people as a strategy to promote health and wellness. These can include activities related to physical activity, eating habits, stress management, and

ongoing medical care. As we advance our knowledge of the human body, diseases, and treatments, the management of one's health is becoming an increasingly sophisticated task. Addressing health-related issues can require changing ingrained behaviors, deliberating over complex choices, and navigating complex systems of care. Health interventions that emphasize personal development and awareness as a means of promoting health and wellness draw on a number of theories of individual health behavior change. Three prevalent theories in this area include the health belief model (Rosenstock, 1974; Rosenstock, Strecher, & Becker, 1988), the theory of reasoned action/theory of planned behavior (Ajzen, 1991; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975), and social cognitive theory (Bandura, 1986; 1998).

The health belief model focuses on the cognitions that people have about adopting and maintaining behaviors that affect their health and how they develop these cognitions. Interventions that are grounded in the health belief model often rely on education and raising awareness as a means of shaping or modifying expectations surrounding health conditions (e.g. diabetes, heart disease, depression) or specific health behaviors (e.g. monitoring blood glucose level, engaging in routine physical activity, obtaining routine preventive health screenings); with the anticipated effect that modifying these expectations will change health-related behaviors.

Druss and colleagues (2010) provide an example of such an intervention in their Health and Recovery Peer Program (HARP). This is a health promotion intervention that is a peer-delivered adaptation of a chronic disease self-management model. It focuses on developing the knowledge and skills of participants utilizing strategies including,

"regular action planning and feedback, modeling of behaviors and problem-solving by participants, reinterpretation of symptoms, and training in specific disease management techniques" (p.265). The health belief model has made important contributions to the health promotion literature by way of specifying constructs that are linked with health behaviors. However, it offers limited guidance for changing behaviors (Bartholomew, Parcel, Kok, & Gottlieb, 2006).

The theory of reasoned action and theory of planned behavior provide a framework for exploring people's motivations and internal drives connected with the performance of behaviors like smoking cessation and health service utilization. The theory of reasoned action and the theory of planned behavior contend that our adoption of a particular behavior is based on our intention or motivation to engage in that behavior, and our intention develops from a number of sources. These sources include our perceived beliefs about how others view the behavior (i.e. subjective norms), our own attitudes and beliefs about the behavior and how much we value the outcome, and how much control we think we have over any given condition and our own ability to make changes (i.e. perceived behavioral control).

Brunettte and colleagues (2011), developed and tested a web-based computer decision support system, targeted and tailored for people with serious mental illness to assist them with smoking cessation. This intervention was heavily influenced by the theory of reasoned action and theory of planned behavior in that it provided participants with assessments, information, feedback, modeling of skills, problemsolving activities, planning tasks, resource sharing and direct opportunities to support

linkage; all in support of developing the motivation and behavioral intention to develop cessation behaviors.

The health belief model and the theories of reasoned action and planned behavior do acknowledge that the environment has some impact on health behavior; however, this impact is largely indirect and poorly accounted for within the model. For instance, environmental influences such as health care policies, neighborhood safety, and cultural norms may indirectly shape people's attitudes, norms, and perceived control over a health behavior, but these models have little ability to account for this indirect influence. Consequently, since environmental factors are not conceptualized to have direct influence, the focus of interventions within this framework is on modifying individual factors, such as self-efficacy beliefs (i.e. the belief in one's ability to carry out a health behavior) or providing education to shape the attitudes or norms surrounding a health behavior.

Finally, social cognitive theory centers on the concept of reciprocal determinism, or the idea that we both shape, and are shaped by our surroundings through the experiences that we have, particularly social experiences. These social experiences provide opportunities for modeling and receiving feedback and reinforcement for behaviors. These processes form our expectations regarding the outcome of the particular behavior, as well as our belief in our capability to perform the behavior (selfefficacy). Thus, our interactions shape our thinking and perception of the world and, consequently, our behaviors. Kilbourne and colleagues (2014) draw heavily from social cognitive theory in their development of their health promotion intervention, Life Goals

Collaborative Care (LG-CC). Experiences are created where participants can modify their health-related expectations through semi-structured social interactions with facilitators, peers, and other health professionals; providing them a forum for observing, practicing, and sharing feedback on new health behaviors. Social cognitive theory has made important strides towards highlighting the importance of interaction between person and their (social) environment; and the implications that this interaction has for shaping behavior.

Across all of these theoretical models and intervention examples primacy is given to the individual responsibility for health change efforts. As these theories continue to drive many health promotion efforts, it is perhaps not surprising that health promotion remains heavily focused on modifying individual health behaviors and 'lifestyle choices' (Richard, Gauvin, & Raine, 2011). There is also a very limited ability within these models to account for the structural inequities such as unequal access to health-related services, limited health-specific knowledge and expertise, and restricted or non-existent allocations of health promoting resources; or the broader social determinants of health such as educational and vocational opportunities, substandard housing conditions, or restricted social supports, that may be significantly shaping individual health experiences.

# CBPR and the development of personal skills to make informed choices.

CBPR research efforts have been involved in numerous interventions that target the development of personal skills to aid people in making informed choices about their health. By accessing community knowledge, researchers can develop insight into how

health problems (and treatments) are perceived, popular lay beliefs and messages that may contribute to the prevalence of health risk behaviors, and valuable clues as to how interventions might be targeted in ways that are most likely to resonate with the community members. A good demonstration of this is a grounded theory study, conducted by Rhodes and colleagues (2010), which utilized CBPR practices to develop a richer understanding of perceptions and beliefs of gay men and men who have sex with other men surrounding HIV risk-related behaviors and meaningful strategies to help counter many of these inaccurate perceptions and beliefs. Beyond providing useful knowledge to inform future intervention, CBPR methods are also involved as a strategy to actively engage community members in designing interventions that target health promotion. Chomitz et al. (2010) discusses a study that involved a community task force in the design of a multicomponent health intervention that included: new city policies, awareness campaigns, new school requirements, innovative nutrition programs, and outcome tracking (and disseminating) strategies; all in support of improving children's weight and overall fitness level within the community. Finally, CBPR strategies can also be instrumental in recruiting community members to participate in health promotion interventions and are often involved in the direct delivery of the interventions, themselves. For example, DeHaven et al. (2011) describes a community-based intervention where a number of local African-American churches were recruited, trained, and invested with the delivery of a health maintenance intervention aimed at reducing risk factors for cardiovascular disease among ethnic minorities. In another instance, peer mentors were trained as 'participant

leaders' and 'primary motivators' to deliver a community-based healthy lifestyle intervention to adults with developmental disabilities (Bazzano et al., 2009).

**Creating supportive environments.** The Ottawa Charter identifies the intentional creation of supportive environments as vital for health promotion efforts. As highlighted throughout this document, there is a steadily evolving more nuanced understanding of the role that the environment plays in producing (and reproducing) health. The interaction between physiological processes that take place within the person and exposure to external influences continues to gain increasing attention as we learn more about the complexities of gene expression and "gene x environment" interactions (Belsky, Moffitt, & Caspi, 2013; Manuck, & McCaffery, 2014) and the cumulative effects of environmental stressors on neurobiology and overall health (Stults-Kolehmainen, Tuit, & Sinha, 2014; Seo et al., 2014). Alongside individually oriented health promotion interventions, projects that target transforming the environment or surroundings in which people live are becoming an essential component of a comprehensive response to health promotion (Taylor, O'Hara, & Barnes, 2014).

Environmental health interventions are largely based on ecological models of health promotion. Applied to health behavior and health promotion, ecological models are concerned with how the various systems that constitute our environment (e.g. family, peer group, neighborhood, government, cultural institutions, and service organizations) support or encourage health decisions and health behaviors. Rimmer and Rowland (2008) discuss the importance of creating 'enabling environments' to help support health promotion efforts, particularly for people with disabilities. For example,

Glanz and colleagues (2005) describe efforts to understand and foster 'healthy nutrition environments' as a means of combating our national epidemic of obesity. Interventions that target the creation of health supporting environments can take many different forms. Campbell and colleagues (2007), for example, explore the use of church-based health promotion (CBHP) interventions as a means of targeting health change from a socioecological perspective and addressing environmental transformation for wellness that is both spiritually and culturally responsive. In another instance, Goetzel and Ozminkowski (2008) discuss work site based health promotion programs, which focus on modifying employment environments to improve wellness.

While many health promotion interventions target modification of the physical (e.g. built and natural) environment, others address the social aspects of the environment. Addressing the social environment may involve efforts to challenge stigma, which can serve to segregate and disenfranchise individuals and groups from pursuing health and wellness goals. In addition, these interventions may address social isolation and efforts to build supportive groups and communities that reinforce and encourage wellness. Cattan, White, Bond, and Learmouth (2005) provide a systematic review of health promotion interventions that specifically address social isolation and loneliness among older adults. These authors found a range of effectiveness across these studies, but generally found greater support for educational and social activity groups interventions that intentionally target defined populations. Unfortunately, this review was limited to measures of loneliness and social isolation, failing to connect these social strategies with other outcomes of health and wellbeing such as physical

functioning, vocational and educational satisfaction, or spiritual connection. While environmentally focused health promotion interventions do encourage the modification of surroundings to better support health and wellness, they may do little (explicitly) to change the structural arrangements and power dynamics that have fostered these environmental conditions in the first place.

**CBPR and the creation of supportive environments.** CBPR has been very useful for the purposes of creating or modifying environments to be more supportive of the health and wellness of community members. Researchers using CBPR methods can access community wisdom to develop their understanding of environmental threats to health and wellness. Information from community participants may help to validate previously suspected environmental threats, to modify or refute currently accepted information based on contextual experiences, and may suggest novel or previously uninvestigated influences to consider (Israel et al., 2006).

In addition, CBPR methods can be instrumental in bringing together multiple stakeholders to create a milieu that is more supportive of health promotion efforts. Fisher and colleagues (1998) discuss a study where they strategically used community organizing to involve local community members in neighborhood activity planning to promote not smoking and to help change the local culture around smoking behaviors. In another example, Krieger and colleagues (2002), describe multiple 'environmentally focused' efforts of the Seattle Partners for Healthy Communities, a multidisciplinary task force involving community agencies, activists, public health workers, academic

researchers, and health providers, with a unified goal of improving the health of socioeconomically disadvantaged communities in Seattle.

Health promoting interventions that attend to changes in the physical environment may involve the removal of certain caustic influences such as pollutants and toxins, dilapidated buildings and roads in disrepair, and poor quality drink water; or the additions of beneficent ones such as bike lanes or sidewalks, fresh food markets, and safe, quality, affordable housing. Examples of such projects include:

- Community clean air 'brigades' that take air quality samples and use this data to effect changes through legislation and modified business practices surrounding air pollution from oil refineries (Minkler, 2000).
- A pilot program to incentivize owners of local corner stores to improve their stock of nutritious foods (Vasquez et al., 2007) .
- The formation of community led walking groups that are supported by local municipalities and changes to neighborhoods to create safer walking areas (Schulz et al., 2011).
- A citizen group working with county commissioners to craft legislation to limit the expansion of livestock processing factories in local African American communities (Minkler, Vasquez, Tijik, & Peterson, 2008).

Additionally, CBPR efforts targeting health promotion may focus on the changing the social environment through changes to interpersonal relationships, social organizations and groups, and broad sociocultural norms, values, customs and practices. Examples of interventions which target the social environment include:

- Developing social support networks to help enhance the social resources of vulnerable groups (Krieger et al., 2002).
- Vocational, educational, and supplemental income programs to create or enhance the social capital of disadvantaged groups (Williams, Costa, Odunlami, & Mohammed, 2008).
- Anti-stigma campaigns to promote awareness and advocate for social change (Kondrat & Teater, 2009).

In an example specific to people with serious mental illness, Cabassa and colleagues (2013) utilized Photovoice®, a tool frequently used with CBPR research, to allow residents in (mental health) supportive housing agencies to describe their health and preferences related to their health services. This project elicited preferences (peer-based over clinician driven models), priorities (learning practical skills through hands-on activities, increasing physical activities), and perceptions (neighborhood food environment was strongly associated with eating habits and available options). This information was specifically sought in preparation for the development of future health and wellness programming across these supportive housing agencies.

**Reorienting health services.** Another area outlined in the Ottawa Charter is the reorientation of health services, "beyond its (current) responsibility for providing clinical and curative services," towards the promotion of health (WHO, Reorient health services, para.2). The health service sector can play a significant role in creating and sustaining a health promoting environment. However, focused attention needs to be given to both the processes through which services are delivered and the scope of

those services. Recent advances in both of these areas have provided important opportunities to better promote the health and wellness of people with serious mental illness. Three areas that represent promising changes in health care services that support health promotion efforts for people with serious mental illness include the movement towards what are called "integrated care" models, the incorporation of wellness and recovery principles into routine health care practices, and the incorporation of peers into the delivery and management of care in the health service sector. These areas represent broad, structural changes in the service-related environment for people who experience mental illness. Consequently, they also represent opportunities for health promotion research and intervention efforts.

Integrated care represents an important emerging trend in health service delivery, which directly corresponds to the redundancies, lack of coordination, limited communication, inaccessibility and other inefficiencies that have come to be the hallmark of a fragmented health care service system in the United States. By correcting these inefficiencies, collaborative efforts to meet the comprehensive health needs of health care consumers is emphasized. Carey and colleagues (2013) engaged in a systematic review of the literature evaluating the integration of mental health and substance abuse treatment with primary care. They then combined the review with feedback from a representative stakeholder panel (i.e. researchers, funders, health care providers, clients, families) to guide them in identifying the future research needs of care integration in this area. Their work suggests that there is a need to explore specific strategies to support care integration; what are the most effective uses of

program components, personnel, information technologies, supervision arrangements, billing structures. In addition, they found that increased emphasis needs to be placed on research that evaluates integration effects across multiple health diagnoses or multiple morbidities, as opposed to evaluation efforts that examine integration effects on discrete diagnostic categories, such as depression (Breland, Mignogna, Kiefer, & Marsh, 2015), or schizophrenia (Schöttle, Karow, Schimmelmann, & Lambert, 2013). By better understanding the health needs and health care experiences of people who experience serious mental illness, researchers in the area of health promotion can make significant contributions to the current dialogue on integrated care.

Another shift in the health service environment has been a focus on services that explicitly adopt a focus on wellness and recovery. Wellness and recovery programs may encompass many components and span a variety of treatment settings. Bond and colleagues (2004) identify a number of evidence-based mental health practices that are well aligned with a wellness and recovery orientation including: supported employment, assertive community treatment, family psychoeducation, illness management and recovery, integrated dual disorders treatment, and appropriate medication management. All of these practices are unified by a commitment to community integration for people who experience serious mental illness and supporting the development and pursuit of meaningful life goals for this population.

The evidence base for wellness and recovery services continues to develop. Certain strategies and components, such as the use of Wellness and Recovery Action Planning are better established and have begun to move towards more rigorous

randomized controlled trials (Cook et al., 2009; Cook et al., 2012; Jonikas et al., 2013), while other strategies remain in earlier stages of development and testing, such as community/peer navigation (Reed et al., 2014). Programs are being evaluated that center around a designated health topic such as smoking cessation (Lee et al., 2011) or weight reduction (Temmingh et al., 2013); and more comprehensive programs addressing wellness, quality of life, and illness self-management are also being examined (Bartholomew, & Zechner, 2014; Tierney, & Kane, 2011). As intervention models and specific strategies continue to emerge that are philosophically grounded in a wellness and recovery orientation, one consistent trend that deserves further discussion is the use of peers as providers in the health service delivery environment.

Innovations surrounding the integration of peer services into the health care system have made a substantial contribution to health promotion for people with mental illness. Since the 1990s peer support services for people with mental illness have been gaining popularity in areas including mutual support groups, consumer-run service organizations, and consumer/peer positions within clinical service settings (Davidson, Chinman, Sells, & Rowe, 2006; Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999). Aligned with an empowerment philosophy, peer services offer an opportunity for health systems to acknowledge the valuable experiences of peers and create services that reflect a peer's perspective. Well aligned with social cognitive theory, peer services also rely on strategies such as modeling health promoting behaviors, creating opportunities for sharing both direct and vicarious learning on a

variety of health and wellness topics, and shared support and encouragement towards wellness goals.

One particular facet of peer services that has been gaining attention has been the use of "patient navigators" to assist clients in accessing and negotiating systems of care (e.g. obtaining referrals and authorizations, locating and navigating physical locations, interpreting and responding to policies and procedures, following up with care recommendations) (Lorhan et al., 2013; Parker & Lemak, 2011; Wells et al., 2008). An example of peer navigation interventions specifically targeted for people with serious mental illness is the Bridge, a peer care-linkage model (Brekke et al., 2013; Kelly et al, 2014). The Bridge focuses on peers assisting other mental health consumers to develop connections (e.g. care providers, insurance and financial resources, social supports) and skills (e.g. help-seeking, understanding and utilizing health information, developing exercise and self-care habits) to more effectively engage with physical health services and healthcare activities. In a similar vein, research is currently being done to better understand the health care needs of African Americans who experience mental illness and homelessness to inform the design of a peer health navigator intervention for one community in Chicago (Corrigan et al., 2015). The specific use of peers as an intentional and integral part of health care service delivery reflects an increasing understanding that the experience and knowledge of peers is a potentially important resource for improving client engagement with health care systems.

Across these three areas (i.e. integrated care, wellness and recovery programming, and the infusion of peer providers into the health care service sector)

one begins to sense the varied and rapidly expanding approaches that are presently being taken to reform and re-orient health care services to better promote health and wellness. Some of the changes that have been discussed across these areas begin to address structural barriers to health and wellness that are embedded in our current health care service environment. However, many of these efforts continue to be in the formative stages of research development and our understanding of which components are most effective at promoting health and wellness is limited. As research in this area progresses, researchers and service providers will need to especially consider facilitators and barriers that exist to successfully translating evidenced informed practices across these areas into different contexts and across a variety of service environments (inpatient, outpatient, community-integrated).

This study specifically be drew on the wisdom and experience of peers, including their knowledge related to health care systems. Shaping and modifying the health service environment may be one area that is particularly relevant or salient for this group. In a pre-research focus group conducted by this writer and a co-facilitator, numerous participants highlighted their negative interactions with health care systems as a significant barrier to enhanced health and wellness.

**CBPR and the reorientation of health services.** Health care services are delivered by institutions and providers that are governed by policies, have hierarchal power structures, and experience competition over finite resources. These dynamics can create very inequitable and unfriendly health care experiences. CBPR as a methodology can be particularly helpful in gaining insight into these experiences and

can also be instrumental in shaping health promoting interventions aimed at addressing the structural influence that contribute to these inequities.

Large health care institutions are beginning to access the wisdom of the people they serve to deliver services that are more responsive to local needs. For instance, Johns Hopkins University created the Johns Hopkins Urban Health Institute. The institute has relied on a CBPR approach to develop partnerships and ongoing relationships with community organizations and leaders to help prioritize needs (e.g. health care, economic, social support) within local communities and design programs supported by the institution that are directly responsive to these needs. It has developed specifically targeted programming for grandmothers who are caregiving for children whose parents are absent or incapacitated by substance abuse (Fox, Morford, Fine, & Gibbons, 2004). Additionally, CBRP methods have helped to create alternative points of service delivery for health care services. Challenging the notion that health services should only be provided in hospitals or clinic-based settings, community preferences have led health researchers to consider settings that may be more meaningful, accessible, or inviting to service users. For example, Campbell and colleagues (2007) discuss health promotion efforts that were designed/adapted through collaborative efforts with predominantly African American church congregations. This intervention process relied on research teams developing ongoing relationships with church members to understand the values and beliefs of congregants to help tailor health promotion efforts that would resonate with them. Additionally, Bogart and Uyeda (2009) discuss a CBPR process that involved multiple stakeholders across a

school district, including students, parents, district staff, local health department officials, members of community organizations, to help translate a district-wide obesity prevention policy into practice across school settings. CBPR has proven to be a useful tool in helping to translate health promoting interventions into more familiar settings, helping to make health promotion a more integrated part of peoples' lives and hopefully to become a more meaningful experience for oppressed groups.

CBPR can be especially important as a tool for bridging health-related scientific advancements and policy initiatives with culturally receptive health care practices. Felix, Burdine, Wendel, & Alaniz (2010) discuss the importance of a community health development approach as being critical for successful health care reform in the United States. They share an example where a large academic institution partnered with a number of community groups to reform a large health care system at a regional level. This included efforts to assess the perceived health needs of the community and action planning at the community level to reduce health disparities by improving local health care service delivery. From a scientific standpoint, Tapp and Dulin (2010) have suggested that CBPR is an important tool for the academic health researcher as it relates to the dissemination of evidenced based practices. In support of translational research efforts, these authors suggest that community members can enhance virtually all aspects of research due to their intimate knowledge of community characteristics including shared beliefs, important resources, formal and informal resources, and cultural practices.

Examples of CBPR methods targeting people with serious mental illness around issues of health services have mainly focused on the reorientation of the mental health service sector. Most of these studies focus on partnering with racial or ethnic minority groups to better understand the experiences and mental health needs of these populations. For instance, Conner and colleagues (2010) utilized focus groups that were developed and executed within a CBPR framework to gain insights into the experiences of African Americans who had experienced a major depressive episode. This study garnered information related to perceptions of depression, treatment-seeking experiences, myths about treatment, and culturally-related stigmas and coping strategies connected to mental illness. Cabassa, Druss, Wang, and Lewis-Fernandez (2011) present a study where CBPR methods were combined with intervention mapping to assist in modifying and targeting a healthcare manager intervention, aimed at better serving the physical health needs of people with serious mental illness who are Hispanic.

**Building healthy public policy.** The Ottawa Charter identifies policy as a vital tool for supporting the creation of social, organizational, and economic conditions that promote health and wellness (Breton et al., 2008; Golden et al., 2015; Jackson et al., 2006; Rütten et al., 2011). Rather than considering health as a discrete area of policy, health promotion is connected with policy implications for health across public sectors. For instance, how do property zoning regulations affect the ability of community residents to access green space or secure safe housing that is in close proximity to resources and services? As another example, how do international trade agreements

affect vocational opportunities in both countries; what does it mean for the economic well-being of citizens; how will these factors impact the stress experienced by workers and their families? The Robert Wood Johnson Foundation (2014), has emphasized the importance of building a national 'culture of health', describing a culture that "empowers everyone to live the healthiest lives that they can" (para.6). Mockenhaupt and Woodrum (2015) have suggested that such a cultural shift requires the alignment of policy, environmental, and financial factors to support a national health and wellness agenda for all people.

Policies can foster community interactions, organizational activity, and even the formation of interpersonal relationships that support individuals and groups in their pursuit of health and wellness. As an example of policy intervention for health promotion, Cheezum and colleagues (2013) describe an intervention where CBPR methods were utilized to engage and train community members in policy advocacy techniques. Their study documented positive outcomes not only related to participants developing policy advocacy skills (e.g. letter writing, speaking and presenting in public and board meetings, organizing rallies and protests, networking with policy makers), but also process outcomes, with community members describing an increased sense of cohesion and empowerment with their neighbors. The advocacy efforts of trainees went on to positively effect a range of policy issues including affordable housing, school safety, immigration reform, and unemployment. This study is a good example of how community members can be incorporated into the policy change process, using CBPR methods to develop and assess an educational advocacy intervention.

**CBPR and the building of healthy public policy.** Policy related initiatives related to health and wellness may be perceived as controlling or as a challenge to personal autonomy (Lieberman, Golden, & Earp, 2013); however, community engaged methods can be strategically employed to address this concern. Shulz and colleagues (2011) argue that building the capacity of communities to craft more equitable and just social and economic policies is essential for eliminating health inequities.

CBPR policy projects have outcomes that span local, municipal, state, and federal levels of government. In one example, a CBPR project addressing food insecurity in San Francisco began with data collection efforts by local youth. These data helped to provide information to support a local policy partnership agreement and incentive program amongst community merchants to encourage them to carry greater quantities of fresh foods. The success of this project was recognized by state legislative members, and has informed policy changes at the state level and led to discussion of replication projects across the state (Vásquez et al., 2007). Another project involved an environmentally focused clean-air CBPR project in New York City that resulted in local air quality testing and conversion to cleaner burning fuels by local industries, but also had important implications for emissions standards legislation and other policy changes within the EPA (Minkler, Vásquez, Tajik, & Petersen, 2008). However, it is important to realize that not all efforts are so broad and far reaching. Many projects are focused and intentionally narrow to address a specific change, such as efforts to maintain a system of trails or authorization for a neighborhood playground (Minkler, Vásquez, Warner, Steussey, & Facente, 2006). These examples highlight how local policies, such

as city ordinances and zoning, may overlap with other areas of health promotion (i.e. creating environments that promote health and wellness), evidencing the interconnection or intersection of the five areas of health promotion.

There are a number of strategies employed by CBPR research teams in affecting policy change and building community capacity for change. These include: assessment and evidence gathering, report writing, public awareness campaigns, media advocacy, legal proceedings, and lobbying efforts (Minkler, Vasquez, & Shepard, 2006; Minkler, Vásquez, Tajik, & Petersen, 2008). However, policy change can require high levels of visibility for participants, potentially making them exposed and vulnerable. Mendes, Plaza, and Wallerstein (2014) emphasize the importance of adequately assessing the power context (i.e. the policy environment and power base of involved stakeholders) and pairing this with appropriate change strategies to support effective and sustainable community engaged policy change interventions, providing an example of how this might be done in a CBPR case study. Minkler, Vasquez, and Shepard (2006) also identify the need for adequate attention and resources devoted to relationship building throughout the policy change process, along with ongoing efforts to effectively negotiate and clarify roles and commitments with community members.

While community based policy change efforts may require substantial planning, coordination, and long-term commitments, they offer the potential to effect significant environmental changes to support the health and wellness for large groups of people. Furthermore, the collaborative relationships and networks that engage in this type of

advocacy work often spawn future projects and efforts that extend the potential for positive health-related changes for communities involved in these projects.

**Empowering communities.** The final area of the health promotion outlined by the Ottawa Charter involves empowering communities. Wallerstein, Mendes, Minkler, and Akerman (2011) propose that an empowerment approach to promoting health and wellness in communities is grounded in ideals of, "agency, equality, autonomy and solidarity" (p.ii234). Again, while the Ottawa Charter specifically delineates the five areas of health promotion, empowerment of communities demonstrates considerable overlap with other areas such as building health public policy and creating health supporting environments. Strategies such as education, advocacy work, coalition building, and oversight functions (i.e. community members holding organizations and political groups accountable) (Bigby, 2011) are instrumental in many efforts to change policy and shape the environment, as well as empowering people; however, what differentiates these different areas is the outcome or aim of the health promoting intervention (e.g. adoption of "healthy" public policy, creation of health-supporting environments, the empowerment of individuals and groups to pursue health and wellness). Empowerment, as endorsed by health promotion activities, supports citizens developing a sense of efficacy (individual and collective) as they redress structural influences that limit their potential to be healthy and well, and encouraging capacity building for sustainability and future change.

Empowering communities entails building capacity by developing the strengths, resources, and skills within communities to address their own needs and concerns.

Cheezum and colleagues (2013) explored the development of community capacity as a result of a workshop intervention aimed at developing community members' skills for community change. Capacity was demonstrated as: community members developed their "voice" or ability to effectively raise concerns in the public sphere and have issues addressed; coalitions, alliances, and networks were formed; community leaders emerged and shared their skills and talents for collective change; and resources to support policy change efforts, such as training materials and educational activities were developed.

A rather obvious, yet significant benefit of focusing on community empowered approaches to health promotion and wellness is that successful outcomes extend beyond an individual or a particular service setting, potentially impacting entire communities and, in fact, increasing the future potential capacity for change efforts. Through their work with a number of community partnerships aimed at addressing local health inequities, Slater, Knowles, and Lyon (2008) identified both individual benefits such as feeling valued, connected, informed; and community benefits, such as stronger social ties, social capital, and collective efficacy. These benefits were in addition to direct program outcomes and accompanying improvements in other health indicators.

*CBPR and empowering communities.* Griffith, Pichon, Campbell and Allen (2010) assert that health promotion interventions that focus on community empowerment are more likely to be culturally sensitive and ecologically responsive because they are built on the assets and the resources that are unique to a specific

community. Examples of health promotion projects that focused on community empowerment and CBPR strategies include:

- A project that involved Latino and African American youth in Los Angeles in data collection activities and used this information to support the formation of a citywide youth coalition that addressed environmental and child labor laws that affected youth in the area (Delp, Brown, & Domenzain, 2005).
- A pilot study of an intervention working to empower faith leaders and congregations in Flint, Michigan to address issues related to HIV/AIDS in the local African American community (Griffith et al., 2010).
- Ongoing city-wide community empowerment initiatives and forums for community representation and participation in civic affairs throughout Europe connected with the Healthy Cities Movement (Heritage & Dooris, 2009).

These activities range from smaller grass roots projects to larger, city-wide multipronged initiatives involving public-private sector coordination. A number of empowerment outcomes have been associated with health promotion interventions using CBPR designs (Laverack, 2006; Raeburn, Akerman, Chuengsatiansup, Mejia, & Oladepo, 2006; Wiggins, 2011; Wilson, Minkler, Dasho, Wallerstein, & Martin, 2008). These include:

• Improving group problem-solving abilities to secure resources, such as medical supplies or clean drinking water.

- Involvement in social action activities, such as educational campaigns and lobbying efforts.
- Improving civic participation rates.
- Increasing self-esteem and self-confidence.
- Developing critical consciousness around new threats to community health.
- Enhancing perceived sense of community.
- Growing capacity for visionary goals to help realize new community projects.
- Enhancing leadership skills, both formal (e.g. boards and coalition groups) and informal (e.g. amongst social groups, families, peers, as a lay leader).
- Expanding social networks and opportunities for mutual aid and support.
- Developing an enhanced sense of ownership over community resources and potential.

A current need in this area of the literature is to more clearly connect empowerment with other health-related outcomes. As an example, Wiggins (2011) found a number of broad ranging improvements to health associated with community empowerment programs, including: specific changes to health risk behaviors, improvements in health knowledge and health literacy, measurable physical indicators of improved health, and improved food security.

There are no specific studies identified that explicitly focus on utilizing a CBPR approach to community empowerment for health promotion for people with serious mental illness at the time of this review of the literature. That is, no specific instances where the focus was on people with serious mental illness or peers explicitly being

empowered to actively design community focused interventions to promote health and wellness, indicating an important niche for this research. Thus, the project that was examined in this case study presented a unique opportunity to gain understanding and appreciation for such an approach.

### Summary discussion on interventions to promote health and wellness

While this has by no means been an exhaustive review of health promotion literature, it hopefully has provided some demonstration of the range and variation that exists across interventions and strategies that are presently being explored, adapted, and adopted to promote health and wellness. By utilizing the five areas outlined in the Ottawa Charter, many spheres of influence, including personal, environmental, health services, policy, and community, have been highlighted as potential targets for promoting and supporting health change efforts. As we continue to advance our understanding across these strategies, we can begin to create interventions that situate human wellness as an achievable, but complex goal. A goal that recognizes health as a response to intra-, inter-, and extra-personal processes and interactions; and thus demands interventions that are adaptable and responsive to the needs of individuals and groups.

A number of interventions specifically targeting people with serious mental illness have been discussed. The majority of these interventions continue to be focused largely on strategies to shape individual health behaviors and modify lifestyles to support 'healthier choices.' Many of these interventions are making efforts to incorporate peers. However, these approaches still place the impetus for change

squarely on the individual and offer very limited potential to address structural changes that impede health. There are also a number of health services initiatives, many driven by policy changes. These changes have begun to acknowledge that the current structures of our health service environment need to be modified to better support the whole health needs of people with serious mental illness. Reorienting health services, alone, is insufficient in addressing the broader social determinants of health that effect people with serious mental illness. Interventions that create health promoting environments and seek to empower the mental health community to make changes to support health and wellness are the least developed areas outlined in the Ottawa Charter. However, they offer great potential for focused attention on the redistribution of power and resources for people with serious mental illness as they pursue a path to health and wellness.

In the search for more effective, sustainable, and contextually responsive health promoting interventions, researchers are often turning to community engaged methodologies, such as CBPR, as a means of merging researcher expertise with lay health knowledge and experience. CBPR efforts span the different health promotion areas outlined in the Ottawa Charter. While community involvement in these projects varies widely, a consistent emphasis is placed on a reciprocal exchange of information between community members and researchers, co-involvement in the research process, and co-investment in research outcomes. The focus of this dissertation was to further our understanding of *how* collaborative CBPR relationships produce change. By

exploring the mechanisms through which CBPR work takes place, a more detailed description of key elements that facilitate collaboration is offered.

The majority of health promoting CBPR studies presently appear to be connected to racial or ethnic communities, particularly those that have been identified as experiencing pronounced health disparities. While there are some instances of CBPR methods being employed with people who experience serious mental illness, these are largely connected with efforts to transform mental health services, rather than being connected with broader goals of health promotion and wellness for this population. This presents a significant opportunity for further research in this area.

### Implementation research

Implementation research is concerned with "the scientific study of processes used in the implementation of initiatives as well as the contextual factors that affect these processes" (Peters, Tran, & Adam, 2013, p. 27). That is to say, implementation science involves developing a richer understanding of "how" interventions are applied in real world settings. By tracking implementation efforts, valuable information is gleaned regarding facilitators and barriers to the implementation process, perspectives from a variety of stakeholders that may be involved, and capturing both intended and unintended changes throughout intervention initiatives.

Implementation research serves as a key methodological link between scientific advancement and the practical application of these advancements in communities that they are meant to serve. Studying implementation efforts related to health promotion and disease prevention efforts can be particularly important for the successful

translation of these advancements into disadvantaged, marginalized, or oppressed communities, as these populations have often been underrepresented in initial health intervention design and development (Nápoles, Santoyo-Olsson, & Stewart, 2013). Furthermore, as a means of achieving and sustaining health changes in communities, Woolf et al. (2015) suggest that implementation research is necessary to help design and adapt interventions that are responsive to community needs, cognizant of the decision-making environment in which interventions take place, effective at engaging key stakeholders, and skilled at adopting an approach to communication that resonates with the intervention audience.

Implementation research has already figured prominently in many community based research projects, and conversely, CBPR principles have aided implementation efforts. CBPR strategies have been adopted to form implementation research partnerships (Blevins, Farmer, Edlund, Sullivan, & Kirchner, 2010; Brown et al., 2012; Lindamer et al., 2009), to better understand the dynamics within these partnerships (Ammerman et al., 2003), and to help target and tailor intervention efforts that are more culturally acceptable and responsive (Cabassa & Baumann, 2013). Implementation science has aided CBPR projects to improve the integration and sustainability of interventions that are embedded in communities (Yip, Chun, Edelson, Feng, & Tu, 2015) and to better understand the extent of collaboration in these projects (Belansky, Cutforth, Chavez, Waters, & Bartlett-Horch, 2009; Khodyakov et al., 2014).

**Examining the implementation of CBPR.** CBPR, as a research approach, assumes that the act of research, in and of itself, is an intervention for change, or that there is a balance between the research aims of producing knowledge and producing change (Minkler & Wallerstein, 2008). This change takes place in the context of communities and through the active involvement of community members in the intervention process. Community members are involved, not as traditional research subjects, who are studied by objective and detached researchers, but as co-researchers who actively engage, shape, and are shaped by the research process. There is evidence that CBPR has potential benefits across a number of domains, including: enhanced recruitment efforts and community involvement, improved integrity of the research design and/or research capacity (e.g. rigor, reach, and relevance), improved community capacity and potential for future change efforts (e.g. acquisition of resources, skills, networks), and specific health-related outcomes (e.g. changes in health behaviors, policies, services) (Balazs & Morello-Frosch, 2013; Cook, 2008; Horowitz, Robinson, & Seifer, 2009; Viswanathan et al., 2004). However, not all CBPR projects recognize these benefits. Understanding what the facilitators and barriers to successful CBPR projects; what aspects, mechanisms, strategies, and circumstances help to promote CBPR effectiveness (however defined), lies in developing a more detailed understanding of how CBPR is implemented.

Implementation research is concerned with understanding how evidenceinformed practices or advancements are translated into 'real world' contexts (Peters, Tran, & Adam, 2013; Proctor et al., 2009; Schillinger, 2010). This vein of research has

largely arisen out of the realization that the successful application of scientific advancements outside of carefully controlled experimental conditions and laboratory settings are often largely dependent on understanding the dynamics that take place between an intervention and the circumstances in which they are delivered. Nápoles, Santoyo-Olsson, and Stewart (2013) suggest a number of critical areas for implementation research to address, including:

- Understating the nature of the relationship between the intervention site (e.g. organization, community, system) and the intervention researchers, and contexts that influence both parties.
- Considering how intervention information is conveyed between stakeholders and how communication exchanges take place.
- Understanding the processes, adaptations, and evaluation strategies that are integral to the intervention itself.
- A clear conceptualization of the delivery system and infrastructure that is required for an intervention.

Beyond the value of more effectively introducing interventions to wider audiences and more diverse settings (and consequently utilizing resources more wisely when doing so), implementation research also helps to develop the capacity of research teams and the capacity of communities and organizations (Peters et al., 2013). Research teams are provided with valuable knowledge about how real-world practice can enhance intervention. Communities and organization have the potential to gain infrastructure

and knowledge that will assist them in implementing, adapting, and evaluating current and future change efforts.

Applying an implementation focus to CBPR is beginning to extend our understanding of CBPR in many ways. For instance, some implementation research efforts are considering how to integrate CBPR practices into specific research arenas, such as randomized controlled trials (Leykum, Pugh, Lanham, Harmon, & McDaniel Jr, 2009) and culturally adapting existing evidence-informed interventions (Cabassa & Baumann, 2013). Other researchers are considering specific aspects of CBPR, such as developing an understanding of specific facilitators and barriers that influence collaborative partnerships (Hicks et al., 2012), or exploring strategies for maintaining scientific integrity within CBPR initiatives (Diaz, Johnson, & Arcury, 2015). Finally, some implementation studies have explicitly begun to focus on capturing the experiences of community members participating in CBPR projects (Amendola, 2013; Ammerman et al., 2003; Doyle & Timonen, 2009; Foster, Chiang, Hillard, Hall, & Heath, 2010). These studies offer important information regarding the perspective of community researchers on a variety of topics, including: what motivates their participation (e.g. helping their community, developing social contacts), how they perceive their role (e.g. as community educators), what they value about CBPR (e.g. creating health changes, bring community together), and expectations that they have regarding partnerships (e.g. that projects would 'give back to the community'). Taken collectively, these studies represent a growing body of literature that is constructing what it means to conduct CBPR in rigorous, effective, and meaningful ways. This study aims to

contribute to this growing body of implementation literature surrounding CBPR by examine the mechanisms through which it operates. Essentially, exploring the question, what components or processes are essential to CBPR projects and how do they interact? The proceeding section will discuss the context of the health promotion project (facilitated by CBPR), which was examined as the focus of this study.

The examination of a community based participatory project. The project that was the focus of this study has sought to combine CBPR methods with the targeted health promoting aims of (a) empowering communities and (b) the creation of environments that support health and wellness for people with serious mental illness. By studying this process, the researcher hopes to provide a better understanding of those elements or mechanisms that are required to produce a transformative milieu that promotes health and wellness. Developing insights into these mechanisms may help CBPR researchers to support goals of community empowerment and developing the capacity of community members to identify, target, and address threats to health and wellness that are personally meaningful.

Mental health peers have coalesced as a knowledgeable, skillful, and talented community. This community has much to offer the field of health promotion research and the field of health promotion research has expertise that may support the ongoing pursuit of wellness within the mental health community. The project examined in this case study involved this researcher partnering with local mental health consumer advocacy organizations, jointly identifying a local 'felt-need' recognized as being important to the ongoing health and wellness of the local consumer community, and

designing a health promoting intervention to address this specific need. The examination of the process of coming together in collaboration to do this work was the focus of the case study design described in the next chapter, specifically focusing on the mechanisms or processes that underlie this work. It is hoped that a clearer understanding of how this collaboration takes place will enhance the ability of other CBPR research teams to continue the very important work of promoting health and wellness with disadvantaged and poorly served communities in empowering ways.

## **Chapter Three: Research Design**

# **Framing the Research Question**

The aim of this study was to systematically investigate the implementation of a community based participatory research (CBPR) process as a case study to develop a deeper understanding of key mechanisms for conducting CBPR research, that is to better appreciate "how" CBPR is accomplished by examining its innerworkings in a case application. To examine this process, a collaborative project between this researcher and members of the local (mental health) peer community was examined. This project involved the design of an environmentally focused health promotion intervention, meaning that this intervention addresses some aspect of the community's physical, social, economic, and/or political surroundings.

As discussed in chapter two, a community based participatory approach to health promotion with minority groups is increasingly being utilized and shows promise for actively engaging communities most affected by health disparities in shaping health intervention (Schulz et al., 2011; Nina Wallerstein & Duran, 2010; N. B. Wallerstein & Duran, 2006). However, while health disparities for people with serious mental illness have been well documented (De Hert et al., 2011; Robson & Gray, 2007; Thornicroft, 2011), only a few instances of engaging this population in a CBPR process towards

environmental change for improved health exist. Additionally, while there is growing evidence to support the use of CBPR in health promotion intervention efforts (Meredith Minkler, 2000; Navarro, Voetsch, Liburd, Giles, & Collins, 2007; Whitehead, Taket, & Smith, 2003), studies that specifically examine the process through which these projects are implemented are limited and influential mechanisms for facilitating this process remain obscured.

Said more specifically, while there is literature defining and outlining the key principles of CBPR (Blumenthal, Hopkins, & Yancey, 2013; Israel, Eng, Schulz, & Parker, 2013; Israel et al., 2008), there is a continued need for research that develops our understanding of the mechanisms through which CBPR operates (O'Brien & Whitaker, 2011; Rhodes, Malow, & Jolly, 2010). Four mechanisms derived from the literature are proposed in this study as foundational to CBPR efforts: knowledge sharing, power sharing, resource sharing, and shared action for change. The conceptualization of these mechanisms and their origins are described in more detail later in this chapter, but the focus of this research is to develop a richer understanding of these concepts and their relationship to CBPR through the examination of this case study. Enriching our understanding of these mechanisms will aid researchers, community partners, and other invested stakeholders in conceptualizing how CBPR projects might most effectively be employed to produce collaborative community change efforts and to critique existing efforts. The central question of the study being:

How are knowledge sharing, power sharing, resource sharing, and shared action for change reflected in the implementation of a community based participatory research process to develop an environmentally focused health promotion intervention with the local (mental health) peer community?

The purpose of this study was to explore implementation of CBPR through a case study design, outlined below, and more specifically to develop an understanding of how four proposed mechanisms may influence this process. The remainder of this chapter will outline the case study design that guided this inquiry.

#### Case Study Design

This research utilized a case study approach to examine the proposed CBPR mechanisms of knowledge sharing, power sharing, resources sharing, and shared action for change. Creswell (2013) describes a case study as an in-depth analysis of a case (which may be a process, such as CBPR) through the examination of detailed information, often across multiple sources of data. Rather than controlling for context, a common goal of experimental research, case studies seek to examine and understand the context in which a particular case (or multiple cases) takes place (Baxter & Jack, 2008; Hird, 2003). Indeed, case studies can be particularly beneficial for capturing the breadth and depth of human experiences and eliciting tacit knowledge, which may be challenging to capture with other methods (Flyvbjerg, 2006; Stake, 1978).

Because case studies are especially adept at gleaning information regarding context and gathering information from multiple perspectives and sources, it is wellsuited for the examination of community based participatory research, a process which

is heavily context dependent and often involving multiple stakeholder perspectives. Case studies have been used to examine a number of different aspects related to CBPR research efforts. These include studies that examine partnership development (Jones et al., 2006), how stakeholders benefit from CBPR (Flicker, 2008), the level of community involvement (Derose et al., 2011), how CBPR principles are applied in research (Savage et al., 2006), and a number of efforts that seek to capture emerging research designs and outcomes (Garcia, Minkler, Cardenas, Grills, & Porter, 2013; Jurkowski et al., 2013; Kreuter, Kegler, Joseph, Redwood, & Hooker, 2012; Meredith Minkler et al., 2008; Meredith Minkler, Vasquez, & Shepard, 2006).

**Case description and bounding.** Defining the case or the unit of analysis in a case study is a critical first step when using a case study as a methodological approach (Baxter & Jack, 2008; Yin, 2014). By clearly defining the case, the research efforts become more focused, cohesive, and manageable. Examples of units of analysis for case studies include individuals, small groups, organizations, programs, activities, events, partnerships, communities, relationships, processes, and special projects (Creswell, 2013; Hancock & Algozzine, 2011). Beyond defining the case, Yin (2014) emphasizes the importance of bounding a case, that is offering parameters that help to delineate what will be included in the inquiry. Defining and bounding the case helps to identify the scope of the research and aids the researcher in identifying what information may be relevant and what information is extraneous to the study.

For this research study, the unit of analysis was the CBPR process that is employed by a collaborative partnership for a project to design a health promoting

intervention for the local mental health peer community in a mid-Atlantic state. To aid in bounding this case, the various participants involved in this process are discussed, the model and stages that guided the intervention development are outlined, and a timeframe is offered.

**Participants.** CBPR relies heavily on the effectiveness of the collaborative relationships developed, often among a number of people who are invested in the wellbeing of the community. Participants in the process included an academic researcher, community partnering organization, a core work group, and a stakeholder advisory group. A brief description and discussion of primary tasks for each of these is provided below.

Academic Researcher (co-facilitator). As is frequently the case with CBPR research, in this study one of the primary functions of the academic researcher was to coordinate and facilitate many of the research functions. This writer functioned in this role and acted as a co-facilitator for the stakeholder advisory group and core work group, both described below. Core responsibilities included recruitment, facilitation, education, and communication. A positioning statement for this academic researcher will be shared in chapter four, with further discussion of his role within the project.

*Community Partner Organization:* There are two community partnering organizations involved with this project. They played slightly different roles in this project, but both provided a link to the peer community and assisted in formation and infrastructure for this project. These organizations will be referred to as State Organization and Regional Organization, based on their primary scope of service.

Further information regarding each organization's role and relevant aspects of their identity are discussed in chapter 4. The primary contact at one of the organizations, Cora (a pseudonym), has served as a co-facilitator throughout this project.

*Core Work Group:* The core work group was composed of 3 people who identify as local peers and two co-facilitators (this academic researcher and Cora). This team was ultimately responsible for carrying out the planning and design tasks in this study. The core work group was responsible for identifying and assessing a community health need, designing, and creating an implementation plan for a health promoting intervention. This group is also further discussed in chapter 4.

*Stakeholder Advisory Group:* The stakeholder advisory group included a health care practitioner, who is knowledgeable about mental illness, a person who is involved with peer services in a professional capacity locally (who is not a representative from the community partnering organizations), a person who has experience related to mental health consumer advocacy and the peer movement AND experience related to program sustainability. We had also hoped to have two additional peers participate, but had difficulty recruiting for this. Other members who do fit the criteria above do identify as peers, as well, and as such, there was peer representation in this group. This group provided guidance and feedback to the core work group. The constitution and function of this group is also further discussed in chapter 4.

*Stages.* To guide the CBPR implementation project for this study, a five-stage community model targeted for health promotion interventions in a participatory community context was utilized, as developed by Bracht, Kingsbury, & Rissel (1999). It

was selected to guide the health promoting intervention design for the project, as it offers a concise, stage-driven, community health promotion intervention model. This approach to health promotion is heavily influenced by the work of Alinsky, Friere, and Rothman and their contributions to the corpus of knowledge regarding community empowerment and its relationship to social action and change. The model presented by Bracht and colleagues was especially attractive for this project based on its explicit attention to health promotion and wellness intervention at the community level, its flexibility and adaptability across aims and objectives (corresponding well with the emergent design of the project), and its overt attention to community involvement in the intervention process.

A number of health promotion activities have been previously supported by this model, including specific applications such as increasing bike helmet use (Nolén & Lindqvist, 2002), increasing physical activity (Matsudo et al., 2002), decreasing adolescent alcohol consumption (Veblen-Mortenson et al., 1999), the development of community workshops and campaigns to promote positive mental health and coping (Barry, 2003), and decreasing loneliness and social isolation (de Vlaming, Haveman-Nies, van't Veer, & de Groot, 2010). While these studies represent a range of health promotion activities conducted with a variety of groups (e.g. the elderly, adolescents, disadvantaged neighborhoods, entire municipalities), there were no identified instances where Bracht, Kingsbury, and Rissel's model was specifically utilized with a group of people who are peers or people with serious mental illness. It is hoped that insights gleaned from this study will help to understanding what aids community researcher

teams in accomplishing these stages effectively and collaboratively progressing towards change.

As this study explicitly examined the process of <u>developing</u> a CBPR health promoting intervention and not the actual execution and evaluation of the intervention, a slightly modified version of the first two stages of this model was used (the final three stages are beyond the scope of this study). Table 2 provides an overview of all 5 stages with corresponding key tasks for each, and highlights the two stages that were the focus of this inquiry.

# Table 2

Five Stage Community Model for Promoting Health and Wellness with Key Tasks

	Stage	Key Tasks
<i>/</i>	Stage 1.	Define community
Focus of this Case Study	Community	<ul> <li>Collect data from community members for</li> </ul>
	Assessment	assessment
		<ul> <li>Assess community capacity (resources</li> </ul>
ů G		available for change efforts)
Cas		<ul> <li>Assess community barriers</li> </ul>
his		<ul> <li>Assess readiness for change</li> </ul>
of t		Synthesize data and set priorities
	Stage 2.	<ul> <li>Establish a core planning group and select a</li> </ul>
	Design &	local organizer or coordinator
	Initiation	Choose an organizational structure (citizen
		coalition, community board or task force,
		grassroots organization or network)
		<ul> <li>Identify and recruit organization members</li> </ul>
		<ul> <li>Define organization mission and goals</li> </ul>
	ς	<ul> <li>Clarify roles and responsibilities</li> </ul>
	· 	Provide training and recognition
	Stage 3.	<ul> <li>Determine priorities for intervention activities</li> </ul>
	Implementation	<ul> <li>Develop a sequential work plan</li> </ul>
		<ul> <li>Generate broad community participation</li> </ul>
		Obtain resource support
		Provide a system for monitoring and feedback
	Stage 4.	<ul> <li>Integrate intervention activities into</li> </ul>
	Maintenance &	community networks
	Consolidation	Establish and maintain a positive team climate
		<ul> <li>Establish an ongoing recruitment plan</li> </ul>
		Acknowledge the work of volunteers
	Stage 5.	Update the community analysis
	Dissemination &	<ul> <li>Assess the effectiveness of intervention</li> </ul>
	Reassessment	programs
		Summarize results and planning future
		directions

Stage 1. Community assessment requires the examination of values, beliefs, and customs within the community, prioritizing needs of members, and evaluating existing strengths and resources (Bracht, Kingsbury, & Rissel, 1999). Community assessments utilizing a CBPR framework may employ a host of techniques, which are often used in combination to assist in triangulating data. Methods of collecting assessment data might include focus groups, key informant interviews, community mapping, survey data, observational measures, and Photovoice® techniques (Cristancho, Garces, Peters, & Mueller, 2008; Hannay, Dudley, Milan, & Leibovitz, 2013; Mosavel, Simon, Van Stade, & Buchbinder, 2005; Schulz et al., 2011; Williams, Bray, Shapiro-Mendoza, Reisz, & Peranteau, 2009). A number of studies assess community needs or perceptions of people who experience serious mental illness (Cabassa et al., 2012; Suto, 2012; Townley, Kloos, & Wright, 2009). Regrettably, there seem to be few examples that translate this knowledge into actual CBPR health promoting interventions; that is to say, that while peers are involved in aiding researchers and providers in understanding problems that affect health and wellness, there are limited instances where they are also involved in changing these issues.

For this project, the core work group discussed the most effective ways for assessing the peer community needs surrounding health and wellness. The groupgathered data to support an assessment from the wider peer community. A preliminary focus group was conducted on the topic of threats to wellness for peers at a statewide mental health consumer advocacy conference in the spring of 2015. Themes from that focus group provided a preliminary source of information for the core work group

during this stage. Other tools, such as additional focus groups, key informant interviews, community forums, and surveys were also considered as strategies to collect additional data for this phase.

*Stage 2.* Design and initiation involves planning, preparation and mobilization. This involves establishing organizational structures, ranging from informal working agreements, to formal partnerships or collaboratives; clarifying roles and responsibilities; and specifying the direction and intent of the organizational relationships that emerge. The tasks in this stage lay a foundation for effectiveness and cohesiveness for the future work of the group. The work of designing the intervention may take place through a variety of forums and with an array of participants. These can include small co-researcher teams working closely with consultants and community leaders; large town hall meetings where the community has an open invitation to share input and advise the direction of the project; or structured workshops, where specific representative community members are invited to attend and participate in activities and exercises that will inform intervention development.

For this project, the core work group was responsible for the design and implementation planning of the health promoting intervention. This work has been guided by the assessment information gleaned from stage one, feedback from the stakeholder advisory group, and consultation with other key stakeholders. While still in development, strides have been made in engaging collaborators and gathering the data needed to tailor th intervention.

*Time frame.* The starting point for the case study is the point of initiation where the academic researcher and the community partnering organization began discussions regarding this project. While some information will be provided in the case report discussing the existing relationship between the community organization and the academic researcher as context for this study, data source gathering started with the notes from those initial meetings. The conclusion of the material covered in this case study was the completion of interviews with participants regarding their participation in the project. These interviews took place approximately 6-9 months after initiation.

**Case propositions.** Propositions in a case study help to further direct the attention of the researcher in their process of data collection and analysis toward evidence that is relevant and informative to the research question and to clarify the rationale for the study itself (Yin, 2014). When forming propositions, researchers may draw from existing literature and empirical support if available, theoretical or conceptual knowledge, or personal and professional experiences (Baxter & Jack, 2008). Propositions represent well-supported hypothetical statements regarding what the researcher anticipates finding during the research process. While propositions are not always included in case study design, they can serve as an important means of further refining the scope of the research and situating the study within the existing literature related to the topic.

The specific propositions for this study involve four mechanisms, proposed by this writer and derived from the work of Wallerstein and Duran (2003), who suggest a number of key elements as fundamental to the practice of CBPR. These elements

include joint participation by community members and (academic) researchers in the research process, understanding what kinds of knowledge is being produced and for what purposes, the context of power dynamics that influence the research process, and the goal of praxis in CBPR or a research process that is inherently change oriented. Based on the elements outlined by Wallerstein and Duran, this writer has proposed four key mechanisms for the CBPR process:

- Knowledge sharing
- Power sharing
- Resource sharing
- Shared action for change

O'Brien and Whitaker (2011) do offer alternate mechanisms specific to informing health policy through the use of CBPR. These include: direct community involvement and engagement in intervention, assessment and generation of local data to inform local problems, the collaborative interpretation of findings, and the building of a natural infrastructure for change. While O'Brien and Whitaker do provide some guidance in this area, these proposed mechanisms seem inadequate for capturing the processes employed in CBPR. For instance, a better understanding of these mechanisms would help us to understand how a natural infrastructure for change is built, or what it is about accessing and generating local data or jointly interpreting findings that is instrumental for the success of a CBPR initiative. Each of the mechanisms advanced by this writer might aid in a richer understanding of those suggested by O'Brien and Whitaker. For example, by exploring the dynamics of knowledge sharing, power

sharing, resource sharing, and shared participation in a change process, we might better conceive how a natural infrastructure for change is built during a CBPR initiative. Therefore, in hopes of furthering a more foundational understanding of this topic, the central proposition for this case study is that:

*Knowledge sharing, power sharing, resource sharing, and shared action for change are essential mechanisms for change in a CBPR process.* A brief description of each of these mechanisms is provided below.

**Knowledge sharing.** Knowledge sharing is concerned with the exchange of information that takes place between (academic) researchers and community members. This exchange of knowledge allows researchers to impart technical expertise that they may hold regarding the research process or theoretical explanations about health or human nature, while community members are able to contribute their intimate understanding of local context and subjective experiences of events and circumstances. This exchange potentially leads to a more complete understanding of the issue being studied and greater opportunities for envisioning solutions to these issues. Springett, Wright, and Roche (2011) suggest that this knowledge may take many forms in the context of CBPR, including experiential, presentational, propositional, and practical knowledge (see table 3 for a brief description of each of these types of knowledge derived from Heron and Reason (2008)). Kothari and Armstrong (2011) discuss the difficulty in accurately operationalizing and capturing the knowledge exchange that takes place between health researchers and community members. This complication largely stems from the various forms of knowledge that this may encompass and the

diversity of means by which this knowledge might be shared (e.g. formal trainings,

informal conversations, and cultural practices). It was hoped this case study would

provide valuable insights into what these different forms of knowledge look like and

how they manifest.

Table 3

Type of Knowledge	Description
Experiential	Knowledge that comes from direct participation in an experience or an event
Presentational	Knowledge that comes from and through the act of expression, such as through art
Propositional	Knowledge that seeks to describe or define what is 'real' or 'true'; Knowledge that is theoretical and conceptual
Practical	Knowledge of a particular technique or skill

Different Types of Knowledge as described by Heron and Reason (2008)

*Power sharing.* Power sharing is considered an instrumental component of CBPR and may be especially important in redressing the diminished sense of power and autonomy that can shape the experiences of disadvantaged and oppressed groups; group that are often most affected by health disparities (Chavez, Duran, Baker, Avila, & Wallerstein, 2008; M Minkler & Wallerstein, 2012). Power, in its most basic form, is the ability to make and enact decisions. In regards to CBPR, or more broadly to research in general, power involves decisions about research focus, design, and dissemination (Muhammad et al., 2015); or put another way, what gets studied, how it gets studied, and who gets to know about it (how it gets disseminated). Plumb, Collins, Cordeiro, and Kavanaugh-Lynch (2008) identify that power sharing can be a significant challenge for CBPR partnerships, and an important consideration for research teams to account

for. Further, in their case study of partnership development and functioning surrounding a health-related initiative, Jones et al. (2006) underscored the important implications that power and conflicts over power sharing had over: the scope and direction of the work targeted by the group, the relationship between group members, and the dynamics of trust within the group. A number of considerations related to power sharing in CBPR research initiatives are identified by Rhodes et al. (2010). These include the importance of:

- Acknowledging who has power over what within the collaborative research relationship.
- Open communication, transparency, and mutual understanding.
- Understanding that it is power sharing over the research process and the research products (e.g. ownership of data and dissemination of results).
- Considering what organizational structures are put in place to encourage shared decision making (an important indication of power sharing).
- Recognizing that it may be difficult for academic researchers to relinquish power, particularly based on their training to reduce threats to validity and efforts to maximize generalizability, which may be at odds with the priorities of community members.

As a final note on the topic of power and CBPR, Golob and Giles (2013) explore the importance of recognizing the constraining potential inherent within CBPR, describing the potential for CBPR to be a Foucauldian "technology of domination," or a tool with which community members are covertly recruited (through research

initiatives) to participate in and reinforce existing power structures (e.g. health services systems) which inhibit, constrain, and systemically disadvantage certain individuals and groups. These same authors challenge that CBPR also has the potential to empower and increase the agency of community members, particularly by enhancing their critical awareness thus improving their ability to challenge systems and structures that may constrain or limit them (Golob & Giles, 2013). Presented with these many challenges and opportunities related to the role of power in CBPR, this study hoped to develop a better understanding of the dynamics of power sharing within a CBPR process.

**Resource sharing.** Resource sharing in the context of this study, is concerned with how assets are divided and utilized to support health and wellness. Estape, Mays, Harrigan, and Mayberry (2014) underscore the important association between resource allocation and more specifically the unequal distribution of resources, and the existence of health disparities for disadvantaged groups. CBPR initiatives may involve partnerships sharing concrete or tangible resources, including funding, space (e.g. office), equipment, or staff (Wendel, Prochaska, Clark, Sackett, & Perkins, 2010). Intangible resources may prove equally as valuable to CBPR efforts, including examples such as social support, information, expertise, and skills (Barnidge et al., 2015). Using a strategy such as CBPR to engage disadvantaged groups to challenge these unequal systems of distribution may be particularly befitting. Simmons et al. (2015) explore the important implications that resource sharing has for a central aim of CBPR, capacity building, as resource sharing can enhance the skills and assets of a group in very practical ways. However, Khodyakov et al. (2009) highlights the potential for a high

degree of variability across perceptions of equity in resource sharing amongst different stakeholders involved in CBPR efforts, which may pose challenges to researchers attempting to assess this construct. This study sought to develop a better understanding of how resource sharing takes place and, like Khodyakov, how it is perceived by participants.

*Shared action for change.* Shared action for change, or the act of participating in a transformation process, is also considered a key ingredient in CBPR initiatives. Cook (2008) identifies that community-level action can significantly enhance initiatives targeting health and wellbeing, and can be particularly effective when a threat to health is identified by an affected community. Research by Malone, McGruder, Froelicher, and Yerger (2013) suggests that being part of a participatory change process can result in benefits to participants including new skills, changed behaviors, a sense of belonging, enhanced awareness of community assets, improved ability to confront power asymmetries, and expanded social networks.

However, measuring *shared* action can present challenges to CBPR researchers. Jivraj, Sacrey, Newton, Nicholas, and Zwaigenbaum (2014) discuss the complexity in effectively capturing dynamic concepts, such as community participation, as it involves questions regarding who is involved in the research process, when they are engaged, and what activities they are involved in. To reflect this complexity, a continuum of community participation has been suggested to help conceptualize 'how' community members may be involved in change efforts (Draper, Hewitt, & Rifkin, 2010; Khodyakov et al., 2013). When considering where particular initiative may fall along this

continuum, a number of indicators have been suggested for gauging community activity, including: recruitment/retention of new members, the role of participants in activities, number and type of events attended, amount of time spent in and outside of initiative activities, benefits and challenges of participation, satisfaction with the work or process of participation, and opportunities for decision-making (Butterfoss, 2006). Hoping to build on these ideas, this study investigated what shared action for change looked like for this project, and furthermore, how it may relate to other proposed mechanisms.

The case study examining these mechanisms evaluated data from the specified health promoting project that has been discussed. The next section will outline where data came from and how it was used.

**Data.** Case studies frequently involve the bringing together of data from a variety of sources in developing a detailed understanding of case. To do so, researchers need to thoughtfully consider a number of related topics, including: what data sources to include, how to organize and manage the data, and of course, a plan for how they will conduct the analysis of the data that has been gathered. This section will outline these elements as they pertain to this study.

*Sources.* Case studies often involve multiple data sources. Including a variety of relevant sources of information can serve to enrich the quality and credibility of the data and the findings (Creswell, 2013; Stake, 1995; Yin, 2014). Sources of data may include: field notes, archival records or artifacts, observations, interviews and focus

groups, and even survey information. For the purposes of this study, information was drawn from sources, including:

*Interviews.* Interviews were conducted with all stakeholder advisory group members, all core work group members, and with the executive director of Regional Organization. The director of State Organization was not interviewed, as she transitioned from her role early in the process of conducting this project and she was not as heavily involved, as Cora was also a staff member of this organization and kept their team abreast of project details at staff meetings. All but one interview was conducted in person (one was conducted via telephone due to scheduling and location conflicts), using a semi-structured interview guide, which was only very slightly altered between groups of interviewees (core work group member, stakeholder advisory group member, or community partnering organization member).

*Meeting transcripts.* Meeting transcripts from a number of core work group meetings and a stakeholder advisory group meeting were included in the analysis (the core work group met much more frequently compared to the stakeholder advisory group). These meetings were recorded (with participant permission) and transcribed by the (academic) researcher. These transcripts helped to document interactions within the group.

*Supporting documents.* Other supporting documents included communications, worksheets, handouts, agendas, survey tools, and other resources that were shared with participants and community members (e.g. training documents, recruitment materials). These were largely developed or disseminated by the academic researcher.

Some examples did have significant input from other group members, such as two surveys that were collaboratively developed through group interactions.

**Organization & management.** Due to the number of data sources that are often involved in a case study, it is advised that a system for organizing and managing the data that are compiled throughout the course of the research is established early on in the research process. Yin (2014) advocates for the creation of a case study database. This involves the cataloging of all data sources, either electronically or via hard copy, so that they are easily accessible for the researcher throughout the data collection and analysis process.

Data documents for this study were stored electronically, with any existing hard copies kept in a locked file. As documents were obtained, they received a unique code identifier, representing the type of document and date produced. After receiving a code, these documents were catalogued via Excel spreadsheet. Original documents that are in hard copy were scanned (for analysis) and stored electronically, as well. Electronic files were stored on an encrypted, password protected flash drive.

Finally, a qualitative data analysis software package was used to aid this researcher in the organization and management of data during the analysis process. NVivo®, version 11 (QSR International) was utilized to store, code, and compare data. Software packages, such as NVivo can be helpful to researchers seeking to code, categorize, and compare data across a variety of sources and can be helpful in storage, organization, and retrieval with large numbers of documents (Creswell, 2013). That being said, a software system only serves as a tool to aid the researcher in the data

analysis process and cannot take the place of the researcher developing and documenting a systematic and rigorous data analysis plan.

**Analysis plan.** Data analysis for the purposes of case study research, like most, if not all gualitative inquiry, involves the dismantling and reassembling of data to tell a story. Identifying a strategy to guide this process before data collection begins is especially important as a means of managing the potentially large volume of data and variety of data sources that may be contained in a case study. Yin (2014) suggests four general strategies for guiding this process: relying on a priori theoretical propositions, working with the data from the "ground up" to derive insights, developing a case description, and examining plausible rival explanations. For the purposes of this study, the researcher chose the first approach, relying on theoretical propositions, as a means of developing a better understanding of the four proposed mechanisms (knowledge sharing, power sharing, resource sharing, and shared action for change) in this project. That is not to say that the researcher did not seek to explore other alternative mechanisms in the data (in fact one was identified), but preliminary exploration of the data began with those four purposed a priori categories. Data analysis not only looked at themes (dimensions) within each mechanism, but will also examine relationships across mechanisms, including potential facilitators and barriers of the CBPR process.

In addition to this general strategy of using a priori categories to guide analysis, Creswell (2013) outlines an approach to data analysis in qualitative inquiry that follows the format of:

- 1. Reading and reviewing the data.
- Memoing to identify key phrases, ideas, or concepts and to document the researcher's initial thoughts and perceptions.
- 3. Coding to help reduce and label data into meaningful units or segments.
- 4. Classifying the data into themes or broad units or categories that bring together codes that share a similar meaning or common sentiment.
- Interpreting across themes by abstracting back out to the collective meaning of the data.
- 6. Representing this collective interpretation so that it tells the "story" within the data.

These general steps provide a useful format for organizing the approach to data analysis that guided this study. Table 4 provides a translation of these general steps into a more concrete description of what they entailed for this case study.

# Table 4

Description of Data Analysis Approach that was Adopted in this

Case Study, as Guided by Creswell's General Steps for Qualitative Inquiry

General	Application to this Case Study
Steps	
Reading &	Data was read, reviewed as it was obtained throughout the case study,
Reviewing	as opposed to waiting until data collection was complete (Creswell,
	2013; Hancock & Algozzine, 2011; Merriam, 1998). Once a piece of
	data was generated, it was catalogued, electronically saved, loaded into
	NVivo, and reviewed.

General Steps	Application to this Case Study
Memoing	Memoing took place in a separate excel sheet that captured the
	document, the category it was associated with, if there was one, and
	researcher thoughts/reactions to the particular item.
Coding	Consistent with the overarching strategy of this case study to rely on a
	priori theoretical propositions (Yin, 2014), the four proposed
	mechanisms of knowledge sharing, power sharing, resource sharing,
	and shared action for change guided the initial coding of the data,
	representing preliminary parent codes (NVivo terminology referring to
	broader, more encompassing groupings of ideas). As the analysis
	proceeded, additional child codes (more narrowly defined groupings,
	ideologically connected under a parent node) were generated for each
	parent code that helped to describe and redefine each of the
	mechanisms (parent codes).
Classifying	This step involves what Stake (1995) describes as categorical
	aggregation. Categorical aggregation involves the bringing together of
	individual instances to better make sense of a larger group. This
	involved examining the child codes under each parent code to better
	understand each of the mechanisms, and to determine if these
	mechanisms accurately reflected what was observed in the data from
Techanovski	this case, or if other mechanisms are suggested.
Interpreting	This step involves abstracting back out from the individual mechanisms
	to the case as a whole and interpreting the broadest meaning of the
	data. In this study, this involved consider the relationship between the
	mechanisms. It also involved refining dimensions within each
	mechanism as a means of deriving a richer understanding of how they
Doproconting	operated within the project.
Representing	Finally, the culmination of the analysis and collective findings is
	represented in the case report (chapter four). This case report will
	provide a clear description of the case, the role of the researcher, and
	an integrated discussion of themes (as opposed to a composite case).
	The aim of the case study is to provide a rich description of the case that integrates the findings, ideally in a meaningful, comprehensive,
	well-supported, and compelling manner (Yin, 2014). This representation should link directly back to the initial research question
	representation should link directly back to the initial research question
	(or its adaptation as it evolved throughout the research process).

**Rigor.** Dimensions outlined by Lincoln and Guba (1985) were used to frame the discussion of rigor in this study. These dimensions offer qualitative researchers a framework for accounting for their role in the research process and findings, recognizing and acknowledging the role of context in the inquiry, and enhancing the transparency with which the research process is conducted. These dimensions include: credibility, transferability, dependability, and confirmability. A brief description of each of these dimensions will be provided below with accompanying strategies that were utilized to help support rigor across each dimension.

*Credibility.* Credibility is concerned with the accuracy of the story that is being told with the data, or what Lincoln and Guba (1985) refer to as the "truth value" (p.294) of the version of reality that is being presented with the data. Have the multiple voices that are present in the data been represented honestly and fully? To help establish credibility, prolonged exposure, triangulation, and member checking were essential to this study. Prolonged exposure has to do with the researcher having sufficient and substantial contact with the topic of study (e.g. a community, organization, event, or process). This strategy helps to ensure the researcher has a reasonable understanding of the context and/or culture, and that they are better able to discern what information is most helpful and relevant in answering the questions of the study (Creswell, 2013). The demonstration of prolonged exposure related to this study is further discussed in chapter 4.

Stake (1995) details the importance of triangulation as a means of establishing credibility of case studies, thus minimizing the opportunities for misrepresentation and

misunderstanding of their findings. He outlines a number of types of triangulation including data source, investigator, theoretical, and methodological. For the purposes of this study, data source and methodological triangulation are used as tools to further support the credibility of the findings. Data source triangulation is a means of examining whether evidence is consistent across different contexts (Stake, 1995). Do the findings hold across different people, circumstances, or phases? To accomplish data source triangulation, data were gathered from a variety of sources (e.g. core work group members, stakeholder advisory group members, the researcher) and continuously throughout the process (e.g. planning, training, design). Closely related, methodological triangulation is concerned with utilizing multiple approaches to data collection in the design of the research study (Stake, 1995). For example, support for findings might come from a variety of methods, including interviews, direct observations, and review of records. In this study, methods for data gathering included interviews with different groups, direct observations by the academic researcher, and examination of a variety of documents (e.g. training materials, meeting minutes, reports and survey tools).

Finally, member checking involves, "the researcher soliciting participant views of the credibility of the findings and interpretation" (Creswell, 2013, p.252). Member checking was used in this study by soliciting feedback from participant members to confirm, refute, and/or refine findings. Participants were asked to consider and provide feedback as to whether the findings and the case report itself accurately reflects their experience of the CBPR process.

**Transferability.** Transferability refers to the applicability of the research findings to other cases or scenarios. The researcher has a responsibility to provide their audience with enough detail and context so that the reader can draw conclusions regarding how these findings may relate to topics and situations that are relevant to their own lives, practice, or line of inquiry (Lincoln & Guba, 1985). Transferability is best accomplished through a rich or "thick" description of the study. In case study research, this entails providing a detailed description of the case and a full discussion of themes and how they relate to the case as a whole (Creswell, 2013). Also specific to case studies, this thick description should be evident in the final case report, helping the reader to gain a comprehensive and holistic understanding of the case (Stake, 1995).

**Dependability.** Dependability is related to the positivist notion of replicability in research, or the ability of repetitions of the research process under similar conditions to produce similar results (Lincoln & Guba, 1985). Dependability is concerned with providing a detailed accounting of how the research was planned and conducted (Shenton, 2004). What transpired during the research process and how did the researcher respond to it? The concept of dependability is closely linked with the concept of transparency, both transparency of the research process and transparency of the researcher respond to reflexivity of the researcher (i.e. a conscious awareness on the part of the researcher of their perspective and how this perspective may shape or influence the research process). The dependability of this research process in this study was reflected in the memoing conducted during the data analysis and reflexive journaling conducted by this writer specific to this inquiry. This writer attempted to

regularly use reflexive journaling both before and after group meetings (core work groups and stakeholder advisory groups) to consider his contributions to the group process and the products that were being created. Additionally, this writer also attempted to routinely capture reflexive journal entries before and after interviews to help explore his role in and reflections on the qualitative process. Additionally, a positioning statement for this researcher is included in the case report in an effort to clarify the researcher's role and potential influence on the research process.

*Confirmability.* Confirmability is concerned with "the degree to which the results of a study could be confirmed or corroborated by others" (Trochim, 2006, Confirmability section, para.1). Could an independent researcher reasonably arrive at similar conclusions based on the process that was followed? Again, from an interpretivist standpoint, the unique perspective of each researcher would preclude any exact derivation of findings even if they were looking at the same data. However, has the research approached the data in a systematic, coherent, and convincing way; one that is clearly connected to the findings that have been revealed? The concept of confirmability is, of course, closely related to the previously described concept of dependability, however while dependability attests to a clear description of the mechanics or actions contained in the research process and the context in which they take place, confirmability helps to clarify the thought process and the judgments that are made as the researcher arrives at conclusions regarding the findings.

Memoing provided support for confirmability in this study, encouraging accountability in the data analysis process, illuminating how data units, codes, and

themes are interpreted and integrated into the final presentation of the case. Furthermore, a peer debriefer was also used as a more objective observer of the data analysis process. A colleague researcher, independent of this research project, met with this writer on a few occasions during the data analysis process to review documents, examine reflexive journaling, and to provide reflective questions to this writer related to process and findings. The peer debriefer also sampled a sub-set of findings related to each mechanism, the corresponding coded data, and any associated memos. This review was discussed with writer to help clarify and refine the categorization and discussion of findings.

**Protection of human subjects.** This study should present no more than minimal risk to participants and was approved as an expedited review by this university's institutional review board. Upon agreeing to participate in the CBPR health promoting intervention project, participants, including both core work group and stakeholder advisory group members were informed about the project itself and accompanying expectations, as well as the nature of this case study to examine the CBPR process that the groups will be taking part in. They were also informed that they may be asked to participate in interviews and focus groups related to their experience with the project and to aid in the member checking process to lend credibility to the findings. Participants were asked to sign an information and consent form to affirm their understanding and agreement with these expectations. To protect the identity of participants in this study, participants and organizations will not be referred to by name, with the exception of the co-facilitator, Cora, who was given a pseudonym. Electronic

data was maintained on a encrypted, password protected flash drive and hard copies of documents was kept in a locked file.

# **Chapter Four: Results**

## **Overview and Orientation to the Case Report**

This case study examined a community based participatory health promotion project, conducted as a collaboration between an academic researcher and community partners from the local peer (mental health) community. As described in the previous three chapters, the investigation was specifically focused on exploring the social processes involved in this project and the mechanisms that drive this work to gain insight into the implementation of CBPR. The remainder of this chapter will outline the findings of this study as a case report which will include:

- The **context** of the case, including the positioning of the academic researcher, an introduction to the organizations involved, an overview of the project structure, and some reference information related to the geographic location.
- The **process** that was engaged in by the project participants, outlining the phases of work that were conducted.
- A review of **findings related to each of the mechanisms** reflected in the data, providing a description of what was learned about that mechanism in relation to the work of CBPR in this study.

# **Demonstrating Quality in the Case**

A number of strategies were employed to improve the quality of this case report. These strategies were aimed at fostering researcher reflexivity and attempting to account for authenticity and credibility in research findings. While the purpose of this study is not to represent what is universally "true" or valid with respect to the conduct of all CBPR projects; it is hoped that these steps will help to ensure that what was learned from this study is accurately represented, authentically expressed, and conveyed in a way that is useful for other community based participatory researchers.

**Reflexivity in the research process.** Since this case study directly involved the researcher as an active participant in CBPR project that was being studied, it was important to account for his role in the research process. To accomplish this, reflexive journaling was a tool that was employed during the project to encourage researcher reflection as he engaged in research-related activities.

For this purpose, the researcher routinely recorded (and transcribed) his thoughts related to project work activities and group process before and after meetings of both the core work group and the stakeholder advisory group. These entries included content that helped the writer to reflect on how he conceived of his role as co-facilitator of these two groups. Some entries explored the decision-making process within the groups, the writer's expectations (as well as his perceptions regarding group member expectations), and consideration regarding collaboration and task-sharing with Cora (the other cofacilitator) and other group members. Furthermore, it gave the writer an opportunity to process reactions of group members and group dynamics, and explore

his own affective reactions to the work at hand. It was also a means of tracking progress, both towards the practical project(s) of the group, but also progress towards group formation and functioning. This writer was also able to begin to compare and contrast this work, with his role as a community researcher, and previous work a practitioner in the community. Finally, it was an opportunity to reflect on the context in which this project was taking place, an opportunity for this writer to gain some insights into what it means to be a part of this peer community. For instance, this writer captured a number of observations that he made while attending a recovery conference with other team members as part of the community assessment and data gathering work for the project, helping to develop his understanding or recovery and its significance in attendees' lives.

Journaling was also utilized to capture reflection before and after interviews conducted with participants for this inquiry. This aided the writer in processing what was being learned throughout the interviews and considering how this shaped the inquiry. For instance, initial interviews suggested that motivation for participation was an important topic to explore (a topic which was not reflected in the initial draft of questions). As such, this was included in the proceeding interviews and eventually these data figured prominently in defining one of the mechanism (shared purpose).

This information was shared with a peer debriefer. The role of this peer debrier was to act as a more objective observer of the research process and to aid the researcher in accounting for his role. The peer debriefer was not introduced until most of the data had been collected. They reviewed the reflexive journal entries, research

proposal plan, initial findings, and did some independent examination, tracing findings back to data sources. These activities were used to provide feedback to the researcher to help guide the analysis of the data and the representation of results. Finally, a positioning statement has been included in the results of this study as a means for helping to account for and acknowledge the potential bias that the researcher introduces to this inquiry and the influence it may have on the interpretation of these findings.

**Creating an authentic representation.** To help ensure that there is an accurate representation of findings for this study (accurate in that they truly represent the collective experiences of those involved), the researcher has employed two primary strategies, prolonged exposure and member checking. To support prolonged exposure, or extensive involvement of the research within the community, the researcher has had an ongoing relationship with local peer community for a number of years. He has worked with State Organization for past research activities and attended social gatherings hosted by State Organization, participated in state-wide peer conferences as an invited presenter, and consulted with peer providers on other topics and ideas germane to their work. Furthermore, this project has entailed many meetings with the groups involved, helping to foster relationships with community members. Findings from this case study have also been shared with participants that have been directly involved in this work to ensure that the results encompass an accurate representation of their experience, or in other words, to confirm that they can 'hear their voice' within the data.

**Credibility of the findings.** In support of the credibility of these findings, the researcher has attempted to provide a thick description within this case report. By supplying the reader with detailed information regarding the context, content, and process of the project; along with findings specific to each of the mechanisms involved, it is hoped that a cohesive narrative is well represented. To further solidify the relevance of these findings, the researcher has also attempted to triangulate themes across multiple sources (i.e. interviewing all involved participants and a variety of documents).

## **Case Report**

**Context.** A number of elements help to provide a contextual understanding for this case study, across organizational, social, and geographical levels. First, the identity or the positionality of the academic researcher is offered to help encourage transparency regarding his perspective as a researcher and the influence (and potential bias) that he may bring to the execution of this case study. As this was a project that involved partnering with community organizations, the identity of the organizations involved and the function they serve within the community is also provided. This will help the reader to consider how institutional identity may inform this process, as well. The organizational structure of the project will also be discussed, to provide an introduction to the sub-groups involved and the function(s) they served. This section will close with a brief orientation to the geographic location and the associated regional context within which the project takes place. It is hoped that this will provide the reader with some exposure to the broader socio-political environment.

**Positioning the academic researcher.** This writer played an influential role in the study, as the academic researcher and co-facilitator involved in the CBPR project being examined, and as the investigator for this qualitative inquiry. To encourage reflexive transparency, this section provides some insights into his background, experience, values and aims. These will be discussed in relation to various aspects of the writer's identity (i.e. social work practitioner, graduate student, human being) that have a bearing on this study.

As a practicing social worker, this writer has worked in the field of community mental health for over a decade in various capacities. He is committed to strengthsbased, person-centered care, and has increasingly become interested in the liberation health model of clinical practice as a means of acknowledging and incorporating systemic forces of oppression in micro intervention. Furthermore, he has witnessed how environmental factors (housing, transportation, access to services, education and vocational opportunities) influence the lives of his clients, their symptoms, and the outcomes they achieve. It is through this work that he became interested in the overall health and wellbeing of the mental health community, and in particular, how greater attention to health promotion is needed. Relying solely on 'symptom-focused' treatment has left him feeling professionally unsatisfied and at times, ineffective.

As a graduate student, the focus of his scholarship is addressing health disparities and building health equity for people who experience persistent mental health problems. During the course of his graduate education, he has developed a collaborative working relationship with members of the peer community for other

projects and has come to greatly appreciate their focus on empowerment, organizational skills, genuine support and appreciation for one another, and conveyance of hope. He has come to see them as an important ally in his research and as such, finds CBPR a useful tool for this work; combining community involvement, research, and intervention. Both as a researcher and practitioner, he values non-hierarchal, power-sharing arrangements when possible. This inquiry is being conducted as the writer's dissertation research, and as such, it is directly connected to his successful completion of his studies.

As a human being, this writer highly values, but continues to struggle with pursuing and maintaining a sense of health and wellness in his own life. He has had a number of health-related experiences (cancer survivor, broken neck, heart surgery), that have come to shape his view of health as dynamic, sometimes elusive or even precarious, yet a desirable pursuit. These experiences have also caused this writer to reflect on what it is like to be a "patient," having many interactions with healthcare systems and healthcare professionals. Some of these experiences, more traditionally, reflected a narrow focus on diagnosis and treatment; while others did encourage more encompassing aims of health and wellness. Furthermore, this writer's environment has often shaped his own sense of wellness. This has been reflected in his level of access and engagement with friends, family and social groups; financial resources availability; and physical surroundings. Identifying as a gay man, this writer also finds seeking out and participating in queer-centered spaces (i.e. environments) as important, affirming, and wellness-promoting. He finds a strong sense of purpose in serving others. He is

curious about the nature of social relationships, how they operate, and how they influence our lives. He tends to be reflective, attentive to social cues, a frequent provider of validation, support, and encouragement. However, he is also privileged in his role as an able-bodied, white man, and likely experiences and exerts power and influence in social interactions that he is naïve to (including in this project).

This writer views the CBPR project that is being studied as an opportunity to collaboratively work towards change with and for the peer community. He also views it as an opportunity to learn about the peer movement, the local peer community, and the organizations that are involved. He also desires to share information regarding research and its potential for change. His hope is that the project will be able to create a helpful intervention and that participation is a meaningful experience for people that are involved. He also hopes that by studying this project, he can come to better understand how CBPR functions to aid in bringing mindful awareness to this process, and to share this with other researchers and the peer community.

*Identity of organizations.* Two community organizations have been directly involved in the project. For the purposes of confidentiality, these organizations are referred to as State Organization and Regional Organization. Both are non-profit organizations. Additionally, both organizations are peer-run, peer-serving, and grounded in values consistent with peer support and recovery models. They are both located in the same mid-Atlantic US state.

State Organization offers a number of services statewide, including (but not limited to) training of peers and other providers around recovery-based topics, offering

groups and networking opportunities, and coordinating advocacy efforts. They have an extensive communication network with local peers (individuals and groups) throughout the state, and they are well connected to other allies of the peer community (e.g. community service boards, city council members, local mental health providers, business owners, etc.). They have a small number (<10) of paid staff members, a volunteer board of directors, and a wide-reaching membership (which is free and open to any person that identifies as a peer). State Organization served as the initial point of community involvement for this project (described further in the section below, *Forming relationships*), and has been an intimately involved throughout this venture.

Regional Organization also provides a range of services to peers, however, these services are more localized to a regional area within the state. Many of these services center around personal advocacy coaching and peer-facilitated groups that run throughout the week. Groups focus on a host of recovery and wellness topics including setting personal goals, recovery-oriented book and movie clubs, walking groups, anger management, and addiction. Additionally, staff and volunteers coordinate with many local services organizations (e.g. hospitals, social service agencies) to assist other members as liaisons and navigators as they pursue their recovery. Similar to State Organization, Regional Organization also has a small paid staff and is overseen by a board of directors. However, Regional Organization also has a number of members who are trained as peer advocates (a volunteer position) that work directly with other members around issues related to recovery coaching. Regional Organization became

involved with this project at an early phase (again, further described in *Forming relationships*) and has been instrumental to the functioning of the core work group.

*Structure of our project.* The project structure consisted of four primary components. Two co-facilitators, a core work group, a stakeholder advisory group, and the involvement of community partnering organizations (i.e. State Organization and Regional Organization). A brief overview of 'who' these components were composed of and their functioning within the project is provided below.

*Co-facilitators.* This writer functioned as one of the co-facilitators, functioning as an academic research partner and fulfilling many of the organizational/administrative roles within the group (e.g. coordinating group communications, setting agendas). The other co-facilitator, Cora, is a representative from State Organization (paid staff), a peer, a social worker, and a previous acquaintance of this writer. She has worked professionally, both as a (social work) practitioner and as a peer, has experience in medical and community-based settings, and has practice experience in community organizing, advocacy work, and administration. She is a long-standing resident of the area where the project is taking place and is well-known within the local recovery community. Her connection to the peer community stems from her own firsthand experiences, her family of origin, and perspective that she has gained in the field. She is a mother, "empty-nester", and semi-retired. She was instrumental in networking within the peer community, recruitment, liaisoning (especially with State Organization), and attending to process elements of meeting facilitation. Both co-facilitators actively participated in the core work group and the stakeholder advisory group.

*Core work group*. The core work group consisted of two co-facilitators and three other peers. These three peers were members of Regional Organization (see details regarding their recruitment below, *Forming relationships*). The peers had varying levels of association with Regional Organization (current and past paid staff, trained volunteers, members), diverse experiences in their path toward recovery, reflected a range of expertise and skills sets, and had a variety of connections within the peer community. Members had entrepreneurial experience, culinary expertise, administration and practice experience with nonprofits, and professional peer experience. Some members were currently employed, one was a student, some were active volunteers, and mothers. Most group members were Caucasian, with one member identifying as Hispanic, and ranged in age from 20's to 60's. We were composed of two women and three men. This group was responsible for the majority of work within the project including planning and design, collection and analysis of community assessment information and other data, intervention planning, and (eventually) dissemination of results.

*Stakeholder advisory group.* The stakeholder advisory group was composed of the two-cofacilitators and three other members who were associated with the peer community in various capacities. One person had previously (many years ago) served as the director of a mental health consumer advocacy and education organization, and has substantial experience related to grants procurement, organizational leadership, and nonprofit management. Another person works as a nurse on an inpatient psychiatric unit and serves on the board of Regional Organization. The final member of

this group has an administrative role related to recovery services throughout the state, has worked in peer services for several years, and has previous experience in health systems administration. All members were Caucasian, and outside of this writer, members were aged 60 and above (this writer is 37). We were composed of three women and two men. The function of this group was to provide suggestions, guidance, and feedback for the core work group regarding project planning and direction.

*Community partnering organizations.* The community partnering organizations, State Organization and Regional Organization, have been described above. Contact through State Organization was primarily through Cora, as a representative of that organization and a liaison for the project. She conveyed information regarding the project status at staff meetings. Contact with Regional Organization was conducted through meetings and emails between project co-facilitators and the executive director of Regional Organization, and through conversations between core work group participants (members of Regional Organization) and the same executive director, who routinely saw one another. The executive director of Regional Organization was also included as an interviewee for this study based on her connection to the project being tied closely to this organization (e.g. meeting space, recruitment of core work group members, data gathering). She is a Caucasian female in her 40s and has been involved in peer work professionally for a number of years, both as a practitioner, administrator, organizer, and educator. She is a also a mom and identifies as feminist and organizer for women's events. Conceptually, State Organization acted as collaborator for the project as a whole (from inception), and Regional Organization acted as a host

organization for the core work group activities, and as such, was closely associated with the planning and functioning of the project within the peer community.

*Geographical: A community within a community.* While the broad community of interest for this project is the (mental health) peer community, it is also important to note that the focus of the project's efforts are localized to peers in a specific region (in an effort to keep the scale and scope of the project manageable). Because of this, it is also important to consider the local geographical context for this project. The project is set in a smaller sized urban center in a mid-Atlantic US state. This is also the location of Regional Organization, and hence, the home of the three, peer core work group members. It also happens to be where Cora, the co-facilitator for this project, resides. The city hosts a prominent university and accordingly, it's population is skewed towards a younger median age, progressive policies, higher educational attainment, and liberal leaning politics. Both due to the location of the university and the size of the city, there is a fair sized social service sector, including a continuum of mental health services that does encompass peer support, evidenced by Regional Organization.

**Process.** The process elements or stages that this project focused on two broad areas: forming relationships; finding directions and engaging in work. A brief discussion of each of these will be provided to help describe and represent that activity involved in the project. As previously discussed, the five-stage community model for promoting health and wellness (Bracht, Kingsbury, & Rissel, 1999) was utilized as a framework for guiding the work for this project.

*Forming relationships.* The project has centered on forming and accessing collaborative relationships. Initially, this focus was on this writer seeking community organization involvement, and from this involvement forming project teams (stakeholder advisory group and core work group). This process involved drawing on existing connections, fostering new ones, and tapping into the passion and interests of community members.

This writer has had contact with State Organization, for a few years. They have assisted in the recruitment of peers for some other projects, and have been gracious in sharing information regarding peer services and the local peer community. This writer is acquainted with several of their staff and State Organization has provided vital support to the project. First, through their initial willingness to partner, including Cora's tremendous work as a co-facilitator, but also in their sharing of resources, such as meeting space for the stakeholder advisory group meetings, and access to contacts and their communication network.

The co-facilitators met first and began planning to assemble project related groups. Initially, the stakeholder advisory group was formed. Early discussions were used to identify desired areas of representation for this group (e.g. peer, service provider, sustainability in peer services, recovery model expertise), and potential candidates for these areas. Cora's knowledge and connections with community members proved invaluable for this phase of work. Once prospective members were identified, co-facilitators reached out to them and shared recruitment information

regarding the project and expectation regarding stakeholder advisory group participation.

In meetings with the newly formed stakeholder advisory group, thoughts on recruiting peer participants into the core work group for the project were solicited. One of the members of the stakeholder advisory group was well acquainted with Regional Organization (serving as a board member), and suggested that we might consider discussing this opportunity with them, as they have a very active membership and are quite involved in the community. The stakeholder group discussed this and decided this might be a good option, especially having access to a group with established relationships. Cora made the initial outreach to the director of Regional Organization, who then met with both co-facilitators to discuss the project. This director then suggested that the proposed project be presented at a group meeting of peers at Regional Organization, a forum where they often invite guests. After this presentation, interest among attendees was surveyed, and interested attendees formed the core work group (along with the co-facilitators). Regional Organization has proved instrumental to the project in providing a pool of participants, allowing the use of space for core work group meetings, and helping to provide information, contacts, and assistance with coordination at times.

*Finding direction and engaging in our work.* The core work group has done the majority of planning, preparation, and project-related activities, with some guidance and input from the stakeholder advisory group. Activities for this group have included defining community, exploring interests and concerns as potential threats to health and

wellness, developing tools for data gathering, and collecting/analyzing/interpreting community assessment information. To accomplish these tasks, the core work group meets on a monthly basis with occasional between group assignments and communications. Meeting time and frequency has been dictated by group members' collective scheduling needs. The choice of location for meetings (Regional Organization) was also a collective decision and based on convenience for the majority of group members. Generally, this writer is the primary facilitator for these meetings (including setting the agenda), with Cora providing input on agendas and aiding the group process in maintaining focus and fidelity to purpose. Decisions regarding activities outlined above are arrived at through group collaboration and discussion at meetings. To aid project work, a range of tools including worksheets, websites (regarding community research tools), and videos have been used to help convey information.

The focus of the project is improving access to transportation for peers. This topic was selected first through discussion amongst core work group team members, seeking to elicit from peers on this team what their perceptions were of prominent threats to health and wellness for local peers. After a list was generated, two areas were prioritized by the team based on the level of impact on peers' lives and the perceived prevalence of the concern within the community. To further assess this need and to aid in validating core work group perceptions, a preliminary convenience survey was conducted to assess community perspectives on this issue at a regional conference. This information was collectively gathered and analyzed by the core work group, and

based on results, was found to support access to reliable, acceptable transportation as an issue of need/concern within the community. The core work group continues to develop, refine, and work towards the distribution of another survey tool that will further help to gather data on this problem, which will be directly incorporated into intervention efforts.

The stakeholder advisory group played a very active role in helping to form the core work group, but has had a more indirect role since that time. As was commented on in interviews with stakeholder work group members, they feel somewhat on the "periphery" of the project, but feel "okay" with this, perceiving that this was likely by design. One member of this group even discussed the importance of authority figures or "outsiders" having limitations placed on their influence, so that the voices of peers are allowed to more intentionally guide the process. They have, however, helped us to reflect on topic selection and also provided feedback on preliminary survey information.

**Mechanisms as part of a living organism.** At the heart of this analysis is a desire to better understand and elucidate those mechanisms that propel the work of CBPR; hoping that by studying the process(es) involved in this project, it will provide a window of insight into this area. 'Mechanisms' is a word that the researcher had chosen at the outset of this study, primarily based on a conceptual unit that drives a process or system forward (i.e. CBPR implementation). However, through the learning that has taken place during this study, the researcher has come to appreciate CBPR in more complexity, perhaps more appropriately as a living organism – dynamic, transforming, evolving. As such, a central organizing metaphor of human biological

systems (nervous, circulatory, skeletal, muscular, and transcendental (non-biological))

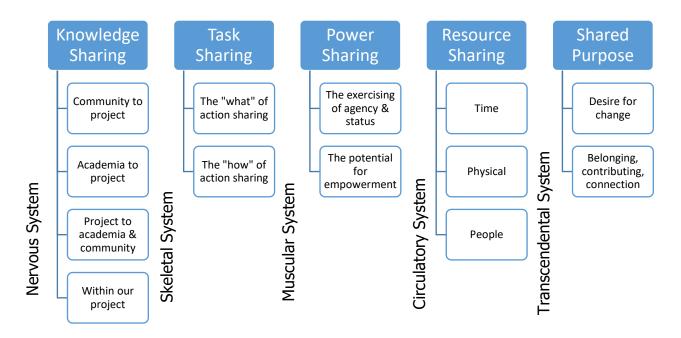


Figure 2. Findings Related to Mechanisms

has been chosen as a heuristic tool to discuss what has been learned about each of these mechanisms. This metaphor, fully developed and explained below, helps to recognize that none of these mechanisms act in isolation, they often have multiple, and overlapping duties. The original four proposed mechanisms, derived from the literature, included knowledge sharing, power sharing, resource sharing, and shared action for change. These mechanisms are discussed below based on this researcher's new understanding of them and in the context of the human biological systems metaphor. Figure 2 provides a visual representation of these mechanisms, their sub-themes or dimensions, and their corresponding biological system.

*Knowledge sharing: The nervous system.* Knowledge sharing is the nervous system of the project. Not simply based on equating knowledge with the brain; but

because the nervous system conveys information both within the body and coordinates the expression and interpretation of information external to self. As a category, knowledge sharing was extensively represented in the data. By volume, it represented the greatest number of codes and was present across many different types of documents and across all perspectives. Upon further examining the responses that were coded under this category, four dimensions emerged to help better define how knowledge was perceived in relation to this work. These dimensions were all connected to understanding how knowledge flowed throughout this project. Knowledge was transmitted: from the community to our project, from academia to our project, from our project back out to the community and academia, and exchanged within our group. Insights into each of these dimensions are shared below.

*Community to our project.* The flow of knowledge from the community to the project touched many areas of the work. By representing the perspective of community members, this knowledge helped to simultaneously expand the universe of what was possible, but also narrow efforts to what was essential. It was knowledge that helped explore, interpret, confirm, challenge, contextualize and critique what was being learned. It helped to understand the problem much more holistically, to transform the problem into a living reality. It helped to consider the scope of the problem within the community: who is affected, what types of issues are created by the problem, how prominent are these issues. Furthermore, community information was also vital in helping to prioritize efforts. A range of topics were initially identified by community members related to the topic of transportation. However, by combining community

survey data and experiential knowledge, direction and focus were brought to the project. For example, while it is perhaps easy to view a lack of transportation as a utilitarian issue, a means of getting from point A to point B, community knowledge helped to provide context and meaning to the vital role that transportation plays in people's lives (especially the lives of peers). This could be the emotional impact of losing a sense of independence, particularly after a recent hospitalization; or the constant strain and uncertainty of being able to provide for the upkeep of a vehicle on a rigidly fixed income – with asset caps and resource penalties. The project's evolving understanding of the problem at hand derived from community knowledge sharing. Ultimately this knowledge helped to understand what qualified as a valid research question from the community's perspective.

In addition to developing an understanding of the problem, community knowledge sharing with the project was also seen as helpful for conceiving of solutions. This knowledge included examples of what has already been tried and who has been involved with these efforts, such as ride service agreements post-hospitalization. Community knowledge was a source of information for envisioning what could be, ideas like peer ride sharing programs. This knowledge could also be helpful in keying the project into existing momentum in the community regarding change projects that are directly or indirectly related to transportation that may be potential points of connection and networking, indicating who is already passionate about this issue and what they are doing about it.

There was also a lot of general information that was shared about the community. This information helped to frame the community as a complex and dynamic organism. Discussions of both current and historical events, trends, and resources within the peer community, as well as, the sharing of diverse (and common) experiences helped to define community from an emic perspective. This was also important for understanding the variation that exists within the peer community. Procedural knowledge about how the community works (i.e. how to get things done) and insights into community norms and values were transmitted. Included in this was discussion about what community members' exposure to research had been like and how they have been involved in the past. Community input was also instrumental in identifying the key knowledge holders or wisdom keepers in the community. These might be people with official titles or informal contacts who hold a special status, passion for change, or interest in issues related to transportation. Knowledge about where to find people, how to connect with them (or alternatively, what offends or alienates peers) was also a very important contribution. This proved very helpful in contemplating where best to gather data and planning for where and how to disseminate results. Community knowledge also helped the project know how to talk about things in meaningful and relevant ways, knowing what words to use and knowing how things are defined (e.g. "street sheets").

Finally, related to the community of peers sharing information with the project, it also seems important to understand why community members share information and the value that is placed on knowledge sharing by the peer community. Based on

comments made during interviews and observations of peer events, sharing knowledge and wisdom seems to be a defining feature of the peer community; a community largely grounded in relating through common experiences. As an extension of this, by sharing information about mental health, recovery, and the community with the project, there was a desire that this would help to 'spread the word' about what peers have to offer others; research as advertisement for recovery, in a sense.

Academia to our project. There was also knowledge being transmitted from academia to the project. This was evidenced in documents such as the recruitment and training materials that were designed and shared, agendas from meetings, and content from interviews. Some of this information was germane to the substantive area(s) of the study, including health promotion and community based participatory research. This writer, as the academic researcher, attempted to deliver this knowledge through several mediums, including discussions, worksheets, videos, and handouts. Participants were receptive to this knowledge, and made general comments about the interest many of the topics held for them (e.g. creating 'good' surveys, data analysis)

Additionally, knowledge was communicated about how academia works, i.e. scientific inquiry and the empirical process, and rigor. Important functions of academia related to research were also discussed, such as institutional oversight, ownership of data, and the role of research (e.g. intervention, knowledge building, and professional advancement). Because this study is also part of a dissertation, the structure and function of a dissertation were also explored with participants. One of the core work

group members cited that learning more about research and the dissertation process was a main draw for his initial participation in the project.

*Project to community and academia.* Knowledge also emanated from the project out to community and academia. This category of knowledge focused largely on sharing information about the identity of the project and what it's work is about. Details about who was involved in the project were shared, including individuals and organizations that were affiliated. Information was also shared about what the focus of the project is, why it is seen as important, and what the general aims of the group are. Additionally, sharing information that is learned through the project with the community was also viewed as essential for many stakeholders.

Knowledge sharing from the project out to the community and academia served many purposes. Early in the process, information was often geared toward recruitment purposes; sharing information to help solidify agency involvement and engage participants in the core work group and stakeholder advisory group. However, as work progressed, knowledge sharing also became a part of engaging community members as assessment information was gathered and allies were sought. Participants also commented that by sharing the work that was accomplished, they hoped to extend the project's influence – providing a "model" for continuing change in the future within the local peer community. One participant discussed this being important work to be involved in, from an organizational perspective, because it felt "cutting edge." By having their organization represented and sharing information about the project with peers, it

becomes a way for them to maintain a reputation for keeping peers abreast and involved with what is new and innovative.

Participants were also hopeful that by sharing knowledge from the project with others in academia ("write it up in the journals!"), it is an important opportunity to share information about peer experiences, recovery, and the potential for collaborating with peers. This was framed as especially important in the training of future professionals. Finally, in very Freirean fashion, disseminating knowledge about the project was also discussed as having liberating potential. Specifically, the act of peers working to change the environment, rather than solely being responsible for changing themselves, was seen as an important value in the work and an important message to share, "Let's not put it all on ourselves."

To facilitate the sharing of knowledge from the project out to the community and to academia, a couple aspects seemed important to consider. First, it was important to know how to 'speak' in a way that was meaningful and impactful. This meant knowing the languages of peers, providers, academics, and other allies that might be involved (or at least where to find interpreters). The need for a variety of channels for relaying information was also discussed – newsletters, recovery conferences, academic journals, board meetings, community advisory groups.

*Exchanging information within our group*. Knowledge sharing also took place within the project. Information within the project was drawn from several sources. First hand experiences, observations, and shared stories within the peer community represented a substantial portion of this knowledge. For example, participants provided

examples of what it was like to be released after a hospitalization, and how frustrating it was to be dependent on others to meet their transportation needs. This often involved navigating systems that felt foreign and intimidating. Participants valued that information shared within the project consisted of a variety of perspectives, including first-hand knowledge of peers, more administrative professional peer knowledge, and outsider representation (i.e. academic researcher – "looking from the outside"). Having various degrees of exposure to the community was largely seen as a benefit.

Some important aspects related to how knowledge was shared within the project or factors that helped to facilitate this process, included: adopting a receptive and communicative environment, structuring opportunities for these exchanges to take place, and valuing autonomous and group thinking. A receptive, communicative environment seemed to involve clear communication, a willingness to share opinions and a receptivity to hear opposing views. For example, one participant commented that she felt it was important that in the core work group initial planning meetings, group members had arrived at independent ideas about how the group should proceed, but that the group was then collectively able to deliberate and decide how to move forward, helping to validate the direction of the project

Finally, participants also reflected on the benefits of knowledge sharing within the project. Some participants were excited to learn more about the process of conducting research, and that it may help them in their professional role and/or their personal pursuits (e.g. their success in school). Others expressed a hope that this knowledge sharing would help deepen their appreciation and understanding of the peer

community and how to create change. On a personal level, this writer hopes that this knowledge aids him in becoming a more responsive and effective practitioner and researcher in working with peers.

Task sharing: The skeletal system. Continuing with the biological systems metaphor, task sharing is likened to the skeletal system. It provides the framework through which the work of the project was accomplished, much like our skeletal system provides the structure for our functioning. While this mechanism was originally labeled shared action for change, it has been relabeled task sharing based on what was reflected in the data and as an effort to reduce redundancy and improve clarity in differentiating it from shared purpose (described below). This mechanism was initially conceptualized as an attempt to capture the act of participation in a CPBR project, the activity of involvement and what that means. However, reviewing data pertaining to 'what it means' to participate began to gain significance as an independent category, hence the emergence of shared purpose. This category was often most vividly reflected in the transcripts from project meetings. Coded units were grouped into two dimensions in helping to make sense of this information. The first dimension examines the tasks that were reflected in the work of the project, the "what" that transpired. The second dimension is anchored in understanding the "how" it took place, describing important elements and tools creating a collaborative and functional milieu where work could be accomplished.

*The "what" of action sharing.* In the initial phases of this project, the work focused on gathering a team and beginning to form an identity. This began by

discussing the concept for the project, purposive recruitment of contacts and interested parties, and arranging initial meetings. As work progressed, the team defined 'who' specifically was the community and what needs might be important to them. This required examination, synthesis and prioritization of existing team member knowledge with preliminary data gathered from the community. Here the integration of these mechanisms begins to become evident – knowledge sharing helped to provide a direction and focus that clearly informed how task sharing transpired.

Common goals and purpose were established, allowing for a consistent message that could then be shared with the community. This was viewed as instrumental by a number of participants, a need to network, gain access to a variety of audiences, and "grow our message." Task sharing involved attending to a number of logistics, including: determining the scope of the project, how best to approach the community, how to obtain the information needed to understand the problem, including what tools for data gathering would best meet project needs. Time was also spent in the act of gathering data from the community. After data were gathered, task sharing also involved a collaborative process of learning from the data, analyzing and interpreting the results. The results of these tasks have further informed intervention planning, as the tasks of the group turn to focus on how findings can be presented in a way that will speak to intended audience(s).

*The "how" of action sharing*. Beyond the specific tasks, various aspects of how action sharing took place were also reflected in the data. These aspects included both

qualities reflected in the work environment, as well as tools that helped to facilitate shared action.

The work process embodied several qualities. First, perhaps more implicitly stated in the data, was a general sense of willingness to do the work – to volunteer for specific tasks, to show up, to contribute ideas. This was also balanced with a receptivity to others taking an active role and voicing their opinions and idea. Convenience (of participation) was another theme, the perceived ease of participation and flexibility to meet unique needs (to attend remotely through phone conferencing). A sense of connection to the work being accomplished by the project was also evident, a desire to see work progress and to see it through to completion. Some members felt more intimately involved in the work (core work group), while others perceived themselves to be more on the periphery (stakeholder group members, executive director), however, these levels of involvement were generally perceived as matching expectations, which also seemed to help facilitate engagement.

In interviews, some participants described the progress as slow, but perhaps necessarily so, as the project engaged in a process that incorporated different perspectives, jointly deliberated on options, built consensus among participants, and sought to create an intervention for the "real world"; this was described as unique and important. Perhaps this writer's favorite quote, which also seemed to be particularly descriptive of the collaborative process, was described by one person as, "juggling Jell-o" – difficult to anticipate, intricate, maybe messy, quite possibly fun. To this last point, it was also evident in the data that the group enjoyed working together. While it may

not have been essential, this writer does suspect that enjoyment and the use of humor helped participants to feel excited about the work being done. Engaging in task sharing also seemed to require creativity and expansive thinking (i.e. what are the possibilities), with concurrent grounding in reality. Fostering a balance of this within the group environment emerged as important. Task sharing also required the group to stay anchored in purpose. For example, as conversations in the core work group meetings would begin extending to potentially tangential discussion, a group member would frequently redirect back to task.

The tools that aided this work included conceptual tools and logistical tools. Conceptual tools aided in envisioning the work of the project. These included items like worksheets (e.g. problem formulation, community defining), homework assignments, mission statements, and data gathering tools. Logistical tools included agendas, group emails (reminders, updates), set days/times for meetings, phone conferencing availability, computer/internet access, access to data analysis software. Logistical tools were often closely tied with administrative tasks that proved essential for structuring the group process.

Task sharing was conceptually very closely tied, as well, to resource sharing and power sharing. For instance, tasks were often related to categories of resources, such as 'expertise' or 'people' (discussed below). Furthermore, tasks were also connected to opportunities to gain skills and sometimes even visibility (in the community), potentially connecting to elevating a sense of empowerment and efficacy and likely closely associated with power sharing.

*Power sharing: The muscular system.* The muscular system is related to how we translate impulse to action, much like how power can be an instrumental catalyst for change. As discussed in chapter three, power sharing can present as a strength and even a defining characteristic of CBPR projects, but it can also be a formidable challenge. In reviewing the data for this project and considering if and how power sharing was evident and integral to functioning, two central dimensions emerged. The first examines how agency and status are exercised in relation to the project and the work being done. The second is related to the potential for empowerment within the project, or its (potential) ability to work towards redistribution of social power.

The exercising of agency and status. The concepts of agency and status were both significantly reflected in the data. Agency, or the capacity of an individual to act, first seems evident in the choice to participate. Participants made a commitment to the project and dedicated their time, often fitting the work of the project into very busy schedules and making sacrifices in other areas of their lives to be involved. Having the agency to freely participate was important. This also meant participants needed to have the agency to reduce (or discontinue) their involvement. For example, one participant in the core work group has recently let the group know that while she is still open to helping out with specific tasks, she feels she can no longer commit to regular attendance at meetings.

The concept of agency was also present in examining how the group functioned. For instance, who was involved in tasks related to structuring the group (demonstrating

a close connection between power sharing and task sharing): who set the agenda, who summarized notes, who oversaw group communications? In this project, this writer was responsible for many of these tasks, perhaps reducing the agency that other participants felt they could exercise within the project. However, during interviews, Cora (the other co-facilitator), did mention that she actually felt that she was able to more fully participate as a representative of the community because she did not have as many of these administrative responsibilities. It was also interesting to examine transcripts of meetings, reflecting on who introduced ideas and who challenged them, who tended to lead discussions, how were decisions negotiated, who was responsible for presenting information within the group and to outside parties. All of these aspects seem important to consider in relation to agency and how it may have been expressed and or experienced within the project.

Status was also present as an important concept related to power. The status, or the perceived power in relation to one's social, professional, or economic standing, was strongly connected to the concept of trust and was repeatedly cited as the reason why participants were willing to engage with this project in the first place. Most of the participants that were recruited suggested that their involvement was largely (at least initially) based on their affiliation with my co-facilitator – "she trusted you, I trust her,"; "what she spends time on is deemed to have worthiness and value." Lending her name and status within the peer community to this project was key to recruitment, in other words, who made the invitation mattered. This was also true for the status that the peer community attributes to the agencies involved in the project. During discussions,

these agencies were identified as well known, experienced, embedded and involved within the peer community. This was initially important for recruitment, but as work progressed, it also proved to be important for gaining allies and social networking. Other participants also mentioned that this writer's connection to a university and to a social work department were viewed as an important link, and consequently, part of the reason for their participation. Academia was seen as place that can create change, particularly in relation to shaping how (mental health) professionals are trained and this was viewed as an important connection to foster. Related to this writer's connection to academia and to clinical practice, this status was viewed as important and valid, but as one stakeholder group member identified, it should be "submerged" and that it was important for this writer to "take (his) lead from peers" (another participant). Considering how agency and status operate throughout various phases of this project has been a key in helping to reflect on how power operates.

*The potential for empowerment.* While this dimension is quite closely related to aspects of developing a shared purpose (discussed below), its explicit connection to power leads this writer to discuss it here as a strong motivating influence, propelling the work of the group. First, throughout interviews with all parties, the potential for this project to support the empowerment of peers was emphasized. Empowerment was discussed on many different levels. Specific to goals addressing transportation, core work group members shared how frustrating and disorienting it could be trying to navigate transportation systems, particularly after (or during) a crisis, "I just couldn't put the pieces together," also discussing a sense of fear and powerlessness that could

be triggered by transportation concerns. By addressing a transportation issues experienced by peers, there was hope that the project might effect change, in some way, for the peer community. More generally, having peers actively empowered to be involved in community change was seen as advantageous, helping community members to feel connected to the place that they live and capable of changing it, being able to participate fully as "citizens." Finally, the work of this project being connected with the Recovery movement (perhaps largely through organizational affiliations), was seen as having an inherent connection to advocacy and anti-stigma work within the community, ideologically being connected with the empowerment of all people who experience problems with mental health. As one stakeholder advisory group member described the impetus of the project as helping participants to, "transition from being objects of (mental health) service...to subjects who run their own lives." Research, conducted in this way was seen as a potential tool for helping to accomplish this transition.

As a sub-theme to this concept of empowerment, many references (both direct and indirect) were made for the potential of this project to foster and develop the power of having a voice or a means of being recognized. As one work group member put it, when asked to reflect on his reasons for participation, "...to have a voice. Even though it may be a very small voice, I still feel as if I participated." This voice was seen as important for battling ignorance (or challenging stigma), and also for speaking to power, "Increasing awareness among the powers and the systems that be that (transportation) problems exist." Related to this notion of voice, participants commented on the need to have many voices represented in the work that is done,

including opposing perspectives. Furthermore, it was important to be aware of forces that constrain or stifle peer voices; these forces needed to be anticipated and incorporated into the planning process. That is, the group needed to build awareness of who has a vested interest in conditions staying the way they were (i.e. opposed to change). To conclude this discussion on the mechanism of power, these data indicate that it is important to consider both how existing power is used and to seek out ways in which power can be shifted (empowerment). This mechanism has the potential to be a key defining feature for CBPR research; however, it is not easily captured and requires consistent and conscious attention.

**Resource sharing: The circulatory system.** By distributing nutrients throughout our bodies, the circulatory system is critical to sustaining life, much like how resource sharing has been instrumental to the functioning of this project. In outlining the a priori mechanisms at the outset of this dissertation, this writer had envisioned resource sharing as the way in which assets were obtained and utilized within CBPR projects. While both tangible and intangible resources were important for this project, this writer failed to anticipate the emphasis or value that would be attributed to intangible assets. Perhaps this is a manifestation of the more grassroots nature inherent in the design of this particular project. Whatever the reason, while physical resources were mentioned, most of the data for this project refers to resource sharing in terms of items like time, people, and expertise.

*Time*. Time was prominent as a resource in the findings from this project. It was evident in many different forms and in a variety of sources of data. The coordination of

times for participant groups to meet was a significant challenge and during interviews participants discussed the difficulty of finding, balancing, and designating time. Time (and energy) was perceived as a very valuable and often scarce resource, due to competing priorities (e.g. family, work, school, self-care), unexpected circumstances (e.g. car accidents, unanticipated events), and health issues (e.g. low energy levels, side effects of medications, symptoms). Because of this, some participants identified that making a commitment to a project like this could be quite intimidating for other peers. However, as a means of compensating for this, it was appreciated that there was flexibility in the ways that people could participate, and where and when meetings took place. As community researchers, participants also emphasized the importance of spending time in the community getting to understand the "root" of the problem by "going to the source" (i.e. asking community members directly). In this respect, it was important to look beyond the amount of time being spent, but to also consider other qualities, such as where it was being spent and how.

*People.* "People" were repeatedly identified by participants as a vital resource for the work of the project (as a response to direct questions about resources). Reflecting on how participants spoke about 'people' it became evident that people, at least as they are reflective of resources (for CBPR), are a representation of skills, talents, expertise, and hands to do the work at hand. Participants identified a range of skills and talents, such as being able to socially engage with others, being able to effectively utilize or navigate resource systems (like to secure and maintain benefits), and leadership skills.

Also, related to the category of people as a resource and also closely linked to knowledge sharing, expertise was also an important intangible resource. The mechanism of knowledge sharing, described above, is very closely linked to this notion of expertise. However, expertise was presented here, in connection with resource sharing, as it was discussed more as a form of applied knowledge, specific to accomplishing some discrete task or objective; whereas knowledge sharing more closely approximated the exchange of wisdom and ideas that generally shaped or informed the course of the project. This expertise took many different forms, including professional expertise, expertise in social change work, and community expertise.

One type of expertise was related to professional awareness across any number of categories related to the project. Examples of professional knowledge areas of expertise that were evidenced include:

- Peer services
- Health promotion and wellness
- Mental health services
- Transportation service sector
- Entrepreneurial and non-profit management
- Educational and understanding how people learn
- Research

These areas included information about how to access these services, how they operate, their organizational structure, and how they are regulated. Participants in the project did not necessarily possess expertise in all these areas (although many were well represented), but they were often connected with individuals who were well acquainted with these areas.

Expertise with social change work was also seen as highly valuable. This encompassed having a good grasp of how social systems operate and how they are changed. This knowledge consisted of areas such as:

- Community organizing knowledge
- Cross-organizational negotiation
- Advocacy (esp. mental health advocacy)
- Systems and structures, social networks
- Political environment
- Community assessment
- Leadership

Participants in both the core work group and stakeholder advisory group had longstanding histories with social change work, in both personal and professional capacities for many years. Their passion for this work was an important asset for the project.

Community specific knowledge was another type of expertise that heavily influenced the project. This expertise was drawn from both lay and professional experiences within the peer community. Community specific expertise included knowledge of recovery from a consumers' perspective, and professional knowledge of peer support services. This encompasses expertise that bridges experiential understanding as a peer and understanding of the mental health service sector. As one of the members in the stakeholder advisory group put it, this is the expertise relevant "in the real world." Within the peer community, sharing knowledge and expertise drawn from experience is common place and is a central form of support; this familiarity seemed to help the solicitation of expertise from peers to inform the project.

*Physical.* Finally, the importance of physical or tangible resource sharing was also evident. These concrete resources helped to begin to develop an infrastructure to support change. This category includes technological resources related to hardware, software, other tools for communication, and meeting space. Participants discussed tools related to publicity, visibility, media, and marketing as important aspects of this work. Finances or fiscal resources were also underscored, in many different capacities - the provision of incentives, intervention development (e.g. intervention materials, such as handouts), and fees that are required (e.g. attendance at conferences).

*Shared purpose: The transcendental system.* While it is unlikely that this system will be found in any biology text, it seems a most fitting (metaphorical) label for this elusive but poignant theme that emerged. While some spiritual groups might label this concept the "spirit," one's "essence," or the "divine spark"; regardless of the label, many traditions ascribe to something that is vital to our experience of being human, but beyond any directly observed experience. A sense of connection and drive that stirs our motivations and compels us forward, much like a sense of purpose can lead to action and motivation for change. This final mechanism was not identified as an a priori category, but emerged early in the analysis as a group of ideas that represent the shared motivation or sense of purpose that leads and sustains people in work related to

CBPR. Items related to this category were identified by participants as they discussed what led them to be engaged with the project and what motivates their involvement with the peer community. It is connected to their personal and/or professional values and interests, and is where they draw inspiration or energy. There were two central dimensions connected to this mechanism. The first was related to a sense of commitment to making a difference and a desire for change. The second dimension draws on the communal nature of this work and its ability to foster a sense of belonging and connection.

Desire for change. Some participants shared and reflected a strong desire to create change that motivated their action and their willingness to participate in the project. This desire for change was represented in variety of ways and held different significance across participants. Some participants expressed a strong desire to change the place that they live, expressing a strong dedication to improving their local environment, "this is my home." This hope for local change involved the specific focus of our project in addressing transportation needs, but it also extended more generically to improving organizations, service providers, and systems in any way they could; helping them to become more responsive to the needs of all residents and more focused on wellness and wellbeing. Being involved in change efforts was also seen as an important aspect of being a peer and part of the Recovery perspective. Various participants discussed the importance of empowering peers and supporting a path to greater independence and autonomy for peers. A basis for the peer community is the value that is placed on mutual support, and this was reflected in this project as well.

Peers involved as participants in this project felt strongly that if we could help peers with this issue, we would be making an important contribution. Finally, some participants also discussed a desire for change being at the core of who they are, like having the soul of a change maker. They identified a general sense of being frustrated with the status quo and the importance of making a "real change" for real people. They discussed the need to "create pressure" and to change the constraining and rigid systems that exist and continue to disenfranchise and deprive peers from autonomy and power over their own lives.

*Belonging, contributing, connection.* For many, participation was also based on the social aspects of this work. At times this was reflected in a sense of belonging and an outlet for contributing and the sharing of self with others. Our project was framed by some as an opportunity for peers to share in their (peer) community, learning more about what the community has to offer and how to shape it; furthering a sense of solidarity with the movement. Sharing the value of the peer community with outsiders (i.e. academia, service providers) was discussed as another important source of motivation for participation. Others described the value they found in being part of a shared environment that was fun, interesting, exciting; where they were learning new things and sharing what they knew with others. When asked about their initial willingness to participate and become involved, many people discussed the importance of social connections, having an existing relationship with the people involved and a desire to collaborate with them in the future, or finding the people involved to be likeable and interesting.

Just as the human body relies on a number of overlapping and interrelated systems to function, so too does CBPR. The study suggests that by developing an understanding of how the concepts of knowledge, task, power, resource, and purpose operate within a project, it can provide valuable insights into CBPR functioning. As indicated by the biological metaphor, these mechanisms do not act discretely, but instead inform each other in intricate and nuanced ways. For instance, the way in which knowledge sharing opportunities are structured or the division of task responsibilities may have very really implications for how power operates within a project. This case report and the data that informs it also emphasizes the need to understand context, in its many forms (e.g. organizational, socio-political, interpersonal, intrapersonal), as an important influential factor over these mechanisms. Awareness of these mechanisms can help CBPR researcher teams to better anticipate, navigate, and sustain their work together.

# **Chapter Five: Discussion**

# Study synopsis

This case study has examined a community based participatory health promotion project that has been conducted collaboratively between an academic researcher and members of the local peer mental health community. Through the exploration of the working process, including reviewing and analyzing meeting transcripts, interviews with participants, and other study documents, this research provides findings and insights into proposed mechanisms that may be helpful in guiding the planning and execution of other community based participatory research activities.

Extant literature on CBPR has begun to examine a variety of aspects of implementation, including: forming and developing research partnerships (Arroyo-Johnson et al., 2015; Peters et al., 2013), monitoring progress (Bazos et al., 2013), adapting interventions for community context (Loi et al., 2017; Cabassa & Baumann, 2013); however, there remains a great deal of variation in how research is conducted in this tradition. Variation in community based participatory work is perhaps unsurprising and even encouraged (reflecting the great diversity within communities); however, developing a more cogent and cohesive understanding of the central mechanisms that drive this work can help to both refine and critique the craft of CBPR, improving our

rigor and accountability as CBPR researchers. The findings provided here are certainly not a definitive statement on what is essential for the conduct of CBPR, however, it is offered as a reflexive tool to help examine the inner workings of the CBPR process. Table 5 situates a summary of existing CBPR implementation literature alongside what was proposed and discovered in the course of this study.

Representation of the peer community in this CBPR project also draws attention to the opportunity and the potential for academic researchers to partner with the recovery or peer community in mental health. While much of the existing community based participatory research focuses on communities defined either by geography or ethnicity, communities of shared experience, such as the peer community, are also important groups to consider. Some meaningful insights on the role of peers in the CBPR process were drawn from this project and will also be explored, particularly as valuable allies in fighting health disparities and promoting greater health equity for people who experience persistent mental health problems.

In the remainder of this chapter, relevant findings related to CBPR implementation, partnering with peers for (CBPR) health promotion, and the importance of addressing health disparities for people who experience persistent mental health problems will be shared. Implications for CBPR will also be discussed, along with implications that this work may hold for social work research, education, and practice. Finally, strengths and limitations of the study will also be examined to help provide a direction for future research.

# Table 5

An Emerging Understanding of CPBR Implementation

What we have already been learning about CBPR (existing literature)	What was proposed in this study to extend our current understanding	What was learned in this study regarding CBPR implementation
<ul> <li>Models for CBPR Implementation <ul> <li>Methods of implementation</li> <li>Tools or strategies</li> <li>Components of CBPR</li> <li>project</li> </ul> </li> <li>Principles that Guide CBPR <ul> <li>Operationalizing principles for design &amp; evaluation</li> <li>Adapting principles for specific populations</li> </ul> </li> <li>Partnerships in CBPR <ul> <li>Building &amp; sustaining partnerships (including readiness assessment &amp; preparation activities)</li> <li>Equity in partnerships</li> <li>Levels, forms, and perspectives on participation</li> <li>Unique requirements based on population</li> </ul> </li> </ul>	To better understand the practice or implementation of CBPR, this study examined a CBPR project to analyze the processes that guided this work. Four a priori mechanisms were proposed, derived from the extensive CBPR practice experience shared by Wallerstein & Duran (2003). They are as follows: 1. Knowledge Sharing 2. Power Sharing 3. Resource Sharing 4. Shared Action for Change	In the case of this project, based on the perspectives of participants involved and across a variety of data sources, evidence was found to support the functioning of a number of interrelated and overlapping processes (closely related to those a priori propositions that had been proposed at the onset). The metaphor of biological systems of the human body was identified to represent the integral and interdependent mechanisms that were exposed. This study offers a preliminary understanding of these mechanisms, grounded in the context of this CBPR project.

What we have already been	What was proposed in this	What was learned in this study regarding CBPR
learning about CBPR (existing	study to extend our current	implementation
literature)	understanding	
<ul> <li>Key Issues Related to CBPR <ul> <li>The role of knowledge (and knowledge translation)</li> <li>Distribution of resources</li> <li>Ethics in the practice of CBPR</li> <li>Power dynamics &amp; the role of researcher reflexivity</li> <li>The influence of context</li> <li>Opportunities, challenges, proposed solutions</li> </ul> </li> <li>Training for CBPR <ul> <li>Curriculum</li> <li>Competencies</li> </ul> </li> </ul>	It is hoped that understanding these mechanisms or processes might aid in integrating the various aspects reflected in the existing literature on CBPR implementation (summarized to the left) and provide a reference for CBPR researchers in planning for and conducting their work.	<ul> <li>Knowledge Sharing: Nervous System <ul> <li>Multi-directional</li> <li>Multi-dimensional</li> </ul> </li> <li>Power Sharing: Muscular System <ul> <li>Understanding agency as it relates to activity in CBPR</li> <li>Awareness of status(es) and the messages that they send</li> </ul> </li> <li>Resource Sharing: Circulatory System <ul> <li>The invaluable of the intangible – people and time as precious resources</li> <li>The importance of stewardship in effective use of limited resources</li> </ul> </li> <li>Task Sharing: Skeletal System <ul> <li>Planning for structure, while anticipating flexibility</li> <li>Thoughtful attention to creating and sustaining a productive milieu</li> </ul> </li> <li>Shared Purpose: Transcendental System <ul> <li>The power of similitude – like minds in the same room</li> <li>Transparency allows us to see commonality</li> </ul> </li> </ul>

## Findings

**Findings relevant to CBPR implementation.** As indicated above, these findings are not intended to be prescriptive, but rather are offered as a reflexive tool for CBPR researchers based on the findings of this case study and the experiences of the participants involved. The a priori proposed mechanisms, derived from the work of Wallerstein and Duran (2003), were a helpful tool in conducting this analysis. They were used as a frame to initially organize the data and then, iteratively and reciprocally, the data helped to redefine and refine the understanding of these mechanisms. The original four mechanisms (knowledge sharing, power sharing, resource sharing, and shared action for change) are briefly discussed here, in their newly re-conceptualized forms, along with the emergent mechanism, shared purpose. Considerations for CBPR researchers attached to these mechanisms are also examined.

*Knowledge sharing.* CBPR has served many capacities related to knowledge, including knowledge creating (Hayashi et al., 2012), reclamation or rediscovery of knowledge (Etowa, Matthews, Vukic, & Jesty, 2011), and the identification of gaps or the absence of knowledge (Riffin et al., 2016). Additionally, existing research focuses on the potential that CBPR holds for knowledge translation, or the "dynamic and iterative process that includes the synthesis, dissemination, exchange, and application of knowledge" (Alley, Jackson, & Shakya, 2015, p. 426). Advocates for CBPR emphasize a central advantage as it's potential to incorporate and value various sources of information (e.g. academic researchers, community members, allies, and practitioners).

Most evident in the findings of this study, and perhaps a helpful contribution to the existing literature, is the drawing of attention to the directionality of knowledge sharing. As we consider other more traditional forms of research, knowledge tends to flow more unidirectionally, data gathered from population (e.g. community) to academia, analyzed and disseminated within the confines of academia. However, the work involved in this project suggested that knowledge flowed in many directions, from community to project, from academia to project, from project back out to academia and community, and finally, knowledge also internally circulated within our group. This multi-directional knowledge served many purposes within our project (e.g. recruitment, communication, interpretation, dissemination) and was present in many ways (e.g. presentations, dialogue, data). By anticipating multi-dimensional knowledge sharing in CBPR, researchers may be better able to plan for and support opportunities for knowledge sharing to take place.

As noted above, knowledge sharing within this study was a reciprocal process, with flow between the CBPR project, the community, and academia. Furthermore, this knowledge sharing that took place helped to make information, multidimensional. It transformed 'static' data or ideas by giving them affective significance, historical context, theoretical understanding, and alternate interpretation.

*Power sharing.* Power, privilege and positionality carry particular significance for the practice of CBPR (Curry-Stevens, 2012; Muhammad et al., 2015). Analyzing power dynamics within the context of CBPR is often framed as a key component of rigorous CBPR work (Darroh & Giles, 2014; Freundenberg & Tsui, 2014). This is

especially important since this work often involves vulnerable or disenfranchised populations, and without conscientious attention to power on their part, academic researchers can become "toxic partners" and complicit in the inadvertent use of research as yet another tool of domination (Curry-Stevens, 2012; Janes, 2016).

Power proved to be an elusive target to track in this project; however clues to where power exists, how it is exercised, and the potential for shifting power through the use of CBPR, were evident. Prominent among findings related to power was a developing understanding of the role that status and agency played within this project and its complexity. Status extended to many levels, including personal, organizational, and status via affiliation with a movement or cause. The use of status was vital for forging relationships, gaining entrée, and accessing opportunities. Understanding these many levels of status and their influence may aid other CBRP partnerships as they form collaborative networks and consider important associations and affiliations for their work. For this project, the emphasis that was placed on the project being associated with local peer organizations, and more specifically having Cora (the co-facilitator) involved in the work, was unmistakable. As a representative of State Organization, and highly recognized across all participants, she brought a strong sense or familiarity to the project that this writer strongly suspects aided in rapport building in forming groups. Investing the time, energy, and resources to find out who the "Cora" for any particular CBPR project is seems like a wise commitment towards the success of that project.

The concept of agency was also associated with how power operated within this project. Interview discussions provided valuable insights into perceptions surrounding

the sense of agency that participants felt in connection to this project, and clues to this information were also present when reviewing meeting transcript information (e.g. who introduced topics, how were decisions negotiated, who participated in discussions). Evidence of agency in this project was reflected in a number of ways:

- Participants acknowledging the freedom to share ideas and feeling comfortable doing so.
- The ability of group members to constructively disagree and continue to problem-solve.
- Comments by participants feeling like their input was valued.
- Soliciting ideas, balanced discussion engaging all participants (in our small group), and democratic decision making, like the project's focus on transportation.

• Collaboratively negotiating the time, place, and frequency of project meetings. However, through the use of reflexive journaling and peer debriefing, this writer's role in crafting agendas, summarizing meetings minutes, and providing updates and outreach communications reflected the strong influence of power exerted by this academic researcher.

While identifying and reviewing evidence of power expression and influence in CBPR projects may be challenging, it is important for conducting research in ways that honor the influence, commitment, and wisdom of community members. That is not to say that each participant needs to be fully engaged in all aspects of every CBPR project, indeed, many researchers acknowledge a continuum of participation related to CBPR

work (Jacobs, 2010; Nation et al., 2011). However, acknowledging level(s) of involvement at the outset of the project, monitoring it during project activity, and renegotiating when necessary has the potential to enhance transparency during the research process and foster a sense of respect amongst research partners.

Finally, and consistent with the literature (e.g. Wallerstein, 2002), participants in this study emphasized the potential for empowerment inherent in this project. Participants felt that this was an important opportunity for them (and potentially other peers) to develop skills that would further support their ongoing development, learning, and a sense of recovery in their life. However, as a cautionary note, it is equally important to consider how easily power may be usurped, constrained, or manipulated in CBPR research. Some authors argue that claims of the potential for empowerment are overstated, or at the very least, under scrutinized (Janes, 2016; Paradiso de Sayu & Chanmugam, 2016).

**Resource sharing.** Resources, particularly in non-profit world, can often be scarce, coveted, and contested. Resource competition and periods of economic instability can have pronounced effects on CBPR relationships (Weiss et al., 2012). However, resource sharing is essential for CBPR. Resources may take many forms, depending on project, scope, and aim. In addition, community resource needs may be focus of CBPR intervention (Thomas, Donovan, & Sigo, 2010).

First, participants repeatedly identified the very important role of intangible resources. Prominent among these were time and "people." Time was discussed as a scarce and valuable resource, underscored by competing demands and priorities.

Understanding and appreciating how time is valued by participants and how this affects the quality of commitment they are able to make was an important lesson for this researcher. Similarly, fully appreciating the diverse areas of expertise that participants possess and the range of expertise that a project may require was also identified as an important intangible resource for CBPR researchers to anticipate.

"People" were also recognized by participants as an integral resource to the success of this project, perhaps unsurprising for a <u>social</u> change project. People resources were discussed in connection to objectives that needed to be accomplished by the project. Based on these project needs that were identified and the perceived importance of collaborating with people to fulfill these needs, a number of roles are outlined here. These roles represent the various ways that individuals (and groups) acted as a resource for the work that was being accomplished.

- Power holders: These are individuals who hold social capital. These may be people who have connections to other resources or network connections. They are recognized as holding status within the community and they may also be associated as people who can 'make things happen'.
- Knowledge holders: These are people who are in-the-know. They possess current knowledge of events, issues, services, organizations and other resources that exist in the community that may be helpful to the project. This may also include academic knowledge and skills that can help the group function. This may take the form of historical and localized

knowledge that helps the group to account for the context of where the work is taking place.

- Navigators: These were described or exemplified by people who possessed the skills, information, and status to act as navigators or guides within the community. This could mean arranging or facilitating meetings with boards or other groups, or helping to gain admittance at a local conference to gather community assessment information.
- Organizers: Organizers provided oversight, direction, gathered details, and disseminated communications.
- Ambassadors: Like navigators, these individuals help the project to interface with the community; however, the work of ambassadors is largely focused on spreading our message or "getting the word out there." They help connect with potentially interested audiences though their drive and enthusiasm. As one work group member shared in discussions about survey data gathering..., "you got get out there and sell it!"
- Communicators: Communicators are people who have a working ability to describe the project in a language that will be understood by intended audience(s). These include skills in translating (information going out) and interpreting (information coming in).
- Visionaries: Participants also identified that we needed people involved who were resourceful, creative, and possessed ingenuity. They could envision possibilities and pathways for how to get there.

That is not to say there was one person that filled each of these roles, but more so that these various knowledge/skill sets were reflected in the work and functioning of the project by the people involved. Many of these roles are closely linked with other mechanisms (e.g. power holders to power sharing; knowledge holders to knowledge sharing; organizers, communicators, navigator, ambassadors to task sharing), however, they are specifically discussed here as the embodiment of these mechanisms in the people doing this work. Based upon our learning during the project, it seems important for CBRP researchers forming relationships to consider the roles that will be required for the work that is to be accomplished and the people that may be well-suited for these roles.

Finally, while CBPR research is gaining greater prominence in (relatively) resource rich institutional networks and is beginning to acquire increased attention and support from funding bodies like NIH and other foundations (Braun et al., 2012; Cain, Theurer, & Sehgal, 2014; Tendulkar et al, 2011), this study represents CBPR research conducted in more of a grass-roots tradition, not attached to any specified or dedicated funding stream, supported through the dedication and commitment from within the community. As such, the work for this project relied on physical resource provision (e.g. meeting space, production of project materials, access to technology) from a combination of existing personal and organizational resources. Because there was a limited resource pool to draw from, implicit in the data was a need to harness energy, enthusiasm, and existing momentum within the community to maximize efficiency. Furthermore, this was also likely implicit in interview responses that emphasized the

role and importance of intangible resources for project success. While engaging funding and institutional supports for CBPR projects that will enrich communities, a desirable goal under many circumstances, this project represents a model of accomplishing the work of CBPR with limited (tangible) resource commitments. It is an approach to this work that may be advantageous for small groups seeking to remain nimble and unencumbered by funding stipulations as they pursue change efforts.

**Task sharing.** There is likely a great amount of variation in tasks across CBPR projects, reflecting a diversity of project aims and community needs. However, perhaps more universally applicable, is a framework for considering task sharing within the CBPR process that was evidenced in our data. This entails considering both "the what" that needs to be accomplished and "the how" this can be supported within CBPR teams.

"The what" of our tasks was guided by the conceptual model that framed our work (Bracht, Kingsbury, & Rissel, 1999), the structure provided by co-facilitators, and needs identified by our group. Identifying tasks required attention to both conceptual (e.g. how are we defining community?) and practical (e.g. who is able to administer surveys?) issues. While the nature of community engaged work demands flexibility and adaptability, anticipating tasks can help us to make the best use of participants' valuable time.

"The how" of task sharing reflects an understanding of and attention to the working environment that is created in CBPR projects. Qualities that seemed to be encouraged (or encouraging) in our teams included flexibility, adaptability, receptivity, curiosity, creativity, dedication, nurturing or supportiveness, ingenuity and respect.

Humor and enjoyment were also evident in our work. Finding ways to encourage and develop these qualities may aid in fostering a collaborative task-sharing milieu in CBPR projects. Anticipating challenges, such as shifting community participants' mistrust of research (James, West, & Madrid, 2013) or accommodating for community specific needs (e.g. developmental needs when working with youth and adolescents) (Merves et al., 2015), may also be important for creating and sustaining a productive milieu.

**Shared purpose.** Finally, the emergent mechanism derived from these data that focuses on the development of a shared purpose may aid researchers in tapping into the affective dimensions of the CBPR process. Andrews et al. (2012) and Mohammed et al. (2012) underscore the importance of negotiating shared interests when entering into CBPR partnerships. Understanding the common threads of motivation and drive that fueled participants' willingness to engage in this work and commitment to this project certainly aided myself as a researcher and facilitator in supporting the functioning of our group; but it also seemed to be an important aspect for all participants, helping us to relate to each other. Miller and Vaughn (2015) specifically outlined an overarching goal for their CBPR project of "developing a shared vision" (p.98). Team members in this project commented that the act of being in the same room with people that they could learn from, people that shared their values, and people that desired change for peers was a rewarding aspect of this work, instrumental in their involvement. As community engaged researchers, developing a transparency of purpose (for ourselves and our co-researcher team members) in the early phases of

project formation may help us in engendering group cohesion and furthering the collective motivation for change within the group.

Taken collectively, these mechanisms are closely interrelated and highly nuanced. This made them challenging to differentiate and define. The subjectivity that was involved in categorizing and discussing these mechanisms is acknowledged, but seems inherent and perhaps unavoidable in beginning to understand these mechanisms from a place of involved engagement in this work. This study is intended to provide a platform for dialogue about what forces drive this work and how they shape the practice of CBPR. It is highly likely that these labels will change and evolve, at least that is the hope of this writer. Future research in the area of CBPR implementation needs to continue to examine these mechanisms, across a variety of CBPR settings and arrangements. In addition, tools need to be developed and tested that will assist CBPR teams in cultivating these mechanisms, especially tools that are meaningful and accessible for academic researcher and community researcher, alike.

**Findings relevant to partnering with peers for health promotion.** This study also reveals a number of relevant findings related to peers actively engaging in the work of health promotion. First, the peer community may be especially well suited for the work of health promotion because of their existing commitment and familiarity with the values and language of wellness for its members. Additionally, the mental health peer community (at least the community engaged in this project) had a well-developed infrastructure for communication and information sharing amongst members. Finally, health promotion, particularly non-individualistic environmentally focused health

promotion, is an opportunity for researchers to support the Recovery movement and challenge the residual effects of the historic mistreatment of people who experience persistent mental health problems through the collaborative creation of environments that support health and wellness.

The peer community is well-versed in the concept of wellness (Sterling et al., 2010; Swarbick et al., 2011). For instance, Wellness Recovery Action Planning (WRAP) has been steadily gaining prominence in the peer community as a tool (and evidence based practice) for peers to use for reflecting on, articulating, and advocating for their personal health and wellness needs (Cook et al., 2012; Copeland, 2002). Health promotion advocates, researchers, and practitioners may well benefit in learning from peers about the significance and practice of individualized wellness planning, as this community's experience in this domain is rich. For example, recognizing that health promotion and wellness comes in many forms, programing at Regional Organization includes groups devoted to recovery through music and art, meditation, social support, herbal healing, and walking. Furthermore, through the efforts of our team's collaboration and the insight of the peers involved, we are focusing on transportation as our dedicated topic; conceptualizing adequate, accessible, and acceptable transportation as a vital link to health and wellness. Peers and the recovery movement can provide valuable contributions in shifting the discussion of health promotion and wellness beyond a reductionist focus on healthy lifestyles, to more fully realizing the benefits of health-promoting environment.

Another lesson from this project, that is likely not surprising to anyone who has involvement with the recovery community, but is nonetheless essential for peers being involved in the work of community engaged health promotion, is that peers know how to organize. The peer community is a community that is grounded in the ideal of shared support, and as such, the groups that the researcher worked with had extensive social networks, good local communication infrastructure (e.g. newsletters, conferences, listservs, contacts in their phones), and were fundamentally interested in sharing information that would support each other's wellbeing. In this researcher's estimation, this infrastructure and motivation seem like important assets to recognize in how well positioned peers are to engage in the work of health promotion, especially health promotion that involves community change.

Closely tied to power sharing and the potential for empowerment recognized by participants in this project, CBPR may be an important tool for supporting the recovery movement in helping peers to address oppression inherent in the historic treatment of people with serious mental illness. By providing skills and opportunities for people who experience mental illness to transform their environment and use their voice, "even if it is small one" (a quote from core work group participant), it may be a valuable and transformative experience. One of our participants in the stakeholder advisory group, who has worked in an inpatient psychiatric facility for many years, shared her concern about the tremendous loss of autonomy for patients in these systems, "...hospital structure is more like a dictatorship (than a democracy)." But she also shared that projects like this and other opportunities, such as having peer facilitated groups on the

inpatient units and more active peer representation and involvement in hospital governance, may begin to provide a sorely needed consumer perspective in shifting some of the power dynamics prevalent in these systems of care. Examples of peerinvolved CBPR projects influencing service design and delivery do exist (several previously described) and have potential for shaping the service delivery landscape and the broader environment (Cabassa et al., 2013; Davidson et al., 2010).

Findings relevant to health disparities for people who have experienced **persistent mental health problems.** As an indirect or implicit finding, this study also supports the problematizing of the social determinants of health as a contributing factor to health disparities for people who experience persistent mental health problems. Our project team's choice to frame transportation as a very real and tangible threat to health, based on their own experiences, as well as the assessed needs and experiences of other members of the community, sends a poignant message regarding the necessity of considering how inequities in life circumstances of peers can contribute to health disparities. Particularly surrounding times of acute (mental health) crisis in their lives, participants described how disorienting, frightening, and unfamiliar their surroundings became. These periods often led to life altering circumstances that included numerous adjustments, sacrifices, and a demand for new knowledge, skills, and resources. Prominent among these adjustments were issues related to transportation and having to navigate new transportation systems or structures. This could interfere with their ability to coordinate with their (medical) care team, their procurement of medications, their access to their support network, and their ability to

access other resources like food. Thinking about issues like transportation (or stable house, employment, education, social isolation), and how people who experience persistent mental health problems may disproportionately be affected by environmental conditions, begins to build a strong case for addressing these structural contributions to poor health outcomes for this population.

#### Implications

**Implications for CBPR social work research.** This study has highlighted a number of considerations for social work researchers, especially those invested in CBPR. In this project, reflexivity helped to bring a sense of mindfulness to this writer's role as a co-facilitator. Being heavily involved in many of the administrative tasks for this project, it would be easy to inadvertently usurp power as a researcher and dominate the research process; however, reflexivity helped to provide a counterbalance to this. By reflecting on his role (through the tools discussed), this researcher attempted to craft agendas, seek input from his co-facilitator, and bring a meta-awareness to his meeting facilitation style as a means of encouraging participation and sharing power and influence with others. Reflexivity requires the social work researcher to bring dynamic awareness and an adaptability to change in response to this awareness, to all phases of the research process. Offered here are some points of reflexivity that guided the reflections of this writer in his reflexive journaling, combined with insights that he gained in the data analysis process, which he will carry into his CBPR work in the future (through reflexive journal, project planning, and evaluation and assessment of CBPR work).

- What role have I played in shaping the research question?
- What is my investment in the outcomes? What do I stand to gain or lose?
   What do others stand to gain or lose by their involvement?
- What is the commitment that I am asking of other participants (individuals and organizations)? What is the significance of this in the context of their lives?
- What is my status (statuses) coming into this process and how may they influence the group dynamics within the project?
- What are my biases coming into this project (e.g. preferences, expectations, priorities) and how could they shape our direction?
- What areas of expertise do I possess that may benefit the project? How may this expertise constrain or limit us?
- How aware am I of the expertise of other participants involved in the project?
- What (task-oriented) roles am I taking on within the project? How am I creating opportunities for task sharing?
- What commitment of resources am I making to this project and what resources do I expect others to commit?
- What do I (as a social work researcher) represent to my community partners, and what might that mean for our work together?

Some of these are self-reflective, while other might be informed by input from others. These questions may lead to action or change, but they also may solely be a tool for increasing the conscious awareness that the researcher brings to the research process. Social work researchers should hear familiar echoes of 'use of self' in this language. In practice, the work of CBPR comes in all shapes and sizes, and consequently the extent and form of community involvement is anything but uniform. However, as a community based participatory researcher, it does seem incumbent upon us to consider what we bring to the research process, how we shape the research discourse, and how we are shaped by this participation.

Social work researchers are also well positioned to aid the development of tools to transform this conscious awareness into action. For example, we have well established clinical tools, like the ecomap, that could be easily adapted for the purposes of knowledge and resource mapping, or more formalized asset mapping (Lightfoot, McCleary, & Lum, 2014), helping CBPR teams to more explicitly and concretely consider these areas in relation to their project. Furthermore, we can develop exercises to intentionally and collaboratively facilitate power sharing and examine mutual appreciation of purpose. Finally, throughout participation in this project, this researcher increasingly became aware of the role that nurturing plays in this type of research. This was evident through our use of humor, through asking questions about one another's needs being met (through the project), or just generally inquiring about the wellbeing of our team members; we were supporting the development and growth of each other. As social workers, we can bring our skills in rapport building to the forming, nurturing, and sustaining of these collaborative research relationships.

**Implications for social work education.** By providing an exemplar of social work partnering with and learning from the recovery community, this research holds implications for social work education, as well. First, there is an opportunity for more consistent exposure to the Recovery Paradigm and the peer perspective in social work curriculum. It is an opportunity to represent diverse perspectives, especially as a counterpoint to psychopathology and the influence of the medical model. My cofacilitator in this project is both a peer and a social worker, and is strongly committed to exposing developing health practitioners (particularly social workers) to the principles of recovery. I support her in this, particularly in light of the invaluable education that I have received in working with my co-research partners in this project. Peers in this project openly discussed the important role that providers (such as social workers) play in their lives and in their pursuit of recovery. For social workers to embrace this role, we need to find opportunities to enhance our own recovery education. As Slade and colleagues (2014) identify, the recovery paradigm holds much promise, but also potential for misuse, and needs to be thoughtfully integrated into our mental health service system. Peers have much to teach social workers about validation, acceptance, and the maintenance of hope. To guide this education, Lakeman (2010) suggests a number of recovery competencies for mental health workers to consider, developed through the input of "experts by experience" in recovery. If, as indicated by participants in this study, this research approach (CBPR) offers a path to empowerment for vulnerable groups, it is worth our effort and investment as social work educators to integrate skills related to CBPR into our curriculum, with implications for research and

practice behaviors. Resource sharing, power sharing, task sharing, knowledge sharing, and developing a shared purpose may provide an organizational framework for social work skill development in work with oppressed groups.

There remains work to be done in social work education related to realizing a more holistic conceptualization of health and wellness. While our commitment to biopsychosocial spiritual assessment training is certainly an expansion on a biofunctional focus, we still need better tools for assessing the impact of the environment on the individual. By expanding our assessment outward to encompass the social determinants of health, and helping social work students to actively connect circumstance to symptom, we are more concretely committing to an ecologically informed understanding of health.

**Implications for social work practice.** The process of conducting this study holds some potentially valuable implications for social work practitioners, as well. Among these are opportunities to strengthen our commitment to intervening for wellness, seeking out and creating opportunities to partner with peers, and even some parallel lessons shared between research and practice regarding the nurturing of relationships.

Social work practice has the capacity to make a stronger commitment to wellness and health promotion for our clients. The focus of the project in this study, and indeed, much CBPR work, is to create change in environment. This means a conscientious shift in our interventions from person-<u>in</u>-environment to person-<u>and</u>-environment. As social work practitioners, we need to work with our clients to identify and modify those

environmental factors that threaten their health and wellness, and to strengthen those influences that promote it.

The foundation for the work of this project is an ongoing partnership with peers and peer provider organizations. In a general sense, peers are invested in their own wellbeing and supporting other peers as they seek recovery. Social work practitioners are potential allies in this journey. The peers involved in this project were eager to network in mutually beneficial and respectful ways, especially as opportunities to expand awareness of peer experiences, educate on the value of peer support, and encourage the development of resources to empower the peer community. Peers may be a powerful ally in our work as we seek hope, support, and healing for our clients, as they are dedicated to this work themselves.

Finally, the mechanisms outlined in this study are focused on understanding the workings of a social process. While the ultimate aim of the social process may differ between CBPR and the practice relationship, the relational foundation of the two are the same; social relationships are the vehicle through which the work is to be accomplished. Branom (2012) explicitly discusses how CBPR's emphasis on empowerment, community participation and potential for transformation for social justice make it particularly relevant for social workers. As such, practitioners may consider how these mechanisms are evident in practice. What forms of knowledge or expertise are being represented in the helping relationship? How are we valuing the time and commitment of our clients? How well have we arrived at a shared purpose in our work together? How is power conveyed within the context of our relationship?

What kind of milieu has been created within our rapport and how is this conducive to the work (tasks) at hand? These questions can be considered at micro, mezzo, or macro levels of intervention and again, used as reflexive tools for bringing conscious awareness to the practitioner and the practice relationship.

### Study strengths, limitations & future directions

As a case study examining a singular case, there are some inherent opportunities and limitations. Case study design allows the researcher to gain deeper and more nuanced understanding of real-word context in which the inquiry is taking place (Yin, 2014). Through focused inquiry, case studies allow researchers to ideally provide a rich description with the data, a detailed story of one rather than a generalized description of many. CBPR is rapidly expanding approach to scientific inquiry, representing many design configurations, with variation across areas such as academic researcher role(s) and discipline, level of community involvement, definition of community and community member, resource support, and project aims. This project represents one example of that vast diversity. By studying the process for this project, it is hoped that other CBPR researchers will be able to draw parallels to their own process; even though the details may be starkly different. However, it would be naïve to think that some of these project-specific details might not influence process, as well. For example, this study was largely grassroots driven, with no grant funding, had small work teams, and explicitly involved agencies that are well acquainted with community advocacy work and value community-member empowerment. The process might look considerably different if the project had a context where organizational involvement was more hierarchal, there

was a large stakeholder team with disparate interests, and there was grant funding that dictated a number of deliverable outcomes. Consideration of the bearing that context has on these proposed CBPR mechanisms is important. Future research exploring the application of these mechanisms (and potentially others) to a range of CBPR projects will be important for furthering our understanding of these mechanisms and their applicability across projects, communities, and disciplines.

This study also represents an intersection of research methods, in that it is using one research approach (qualitative inquiry) to examine the implementation of another research approach (CBPR). While the two are certainly appropriate to use concurrently in a research project, the use of one to examine the other presents some points to consider. Perhaps primary among these is that while CBPR ideally advances an active role in community member participation throughout the research process, this qualitative case study relied on this writer, in the capacity of qualitative observer and inquirer, to make sense of a shared process. On the one hand, this allows the researcher the opportunity to more objectively consider the process that is taking place and account for his role in the process (e.g. reflexive journaling, peer debriefing, member checking, positioning statement), while being intimately involved in the process as a first-hand observer. However, by virtue of this first-hand experience, he provides a decidedly situated and potentially biased interpretation. Far from a detached onlooker, his influence is undeniably part of these data and their interpretation. For instance, the identification of the "what" and "how" of task sharing categories, while evident in the data, was also likely reflective of his own clinical training and practice

experience, attending to the "what" and "how" within the clinical relationship. Furthermore, the identification of the emergent mechanism of shared purpose is also similar to concepts identified in previous research conducted by this writer surrounding the meaning of wellness for mental health peers, where the construct of wellness was tied to an ability to experience connection and purpose in one's life (Cummings & Bentley, 2017). As an alternative approach in the future that may strengthen or challenge the durability of these findings, a CBPR team could collaboratively arrive at their own findings of what mechanisms drove their process – a collective self-study, perhaps in the form of a collaborative autoethnography (Chang, Ngunjiri, & Hernandez, 2013). This would present its own unique set of challenges, such as demanding additional work for CBPR participants who may not directly benefit from or value such activities.

The use of a priori propositional codes were both valuable and potentially constraining to this study. Ultimately the decision in favor of their use was made to assist with the management of data, which can be expansive, disparate, and diffuse in case study research; additionally, these propositions were anchored in CBPR practice research experience (Wallerstein & Duran, 2003). They provided an initial categorizing mechanism in the early coding process, helping to sort data units and make sense of emerging themes under these broad categories (i.e. mechanisms). It is encouraging that a new mechanism emerged (developing a shared purpose), and the other mechanisms developed greater detail and definition, including a new incarnation of shared action for change as task sharing, providing some evidence that these a priori

propositions were treated in a dynamic way, allowing for meaning to be driven by the data. Additionally, these a priori propositions provided excellent coverage within the data, meaning very little information went un-coded with these propositions as the initial coding framework. That being said, had a completely emergent approach been taken in this analysis, it may have led to different labels or categorizations.

Time constraints did not allow an examination of the full duration of the project (inception through dissemination and reassessment), there well may be additional information regarding the mechanisms that drive this process in later phases of work. In the future, work tracking changing perceptions of progress, exploring the developmental life cycle of CBPR projects may be a considerable contribution to this literature, particularly following participants (individuals, groups, organizations) postproject to examine the factors related to sustainability of change. The interviews in this study were reflective of various participant perspectives and attempted to capture a variety of experiences connected to the project, however other methods may also be helpful in gathering detail and nuance. For example, journal clubs for collaborative writing and reflection (Vadaparampil et al., 2014) or Photovoice® for the depiction of participant experience, may be particularly useful options giving participants potentially greater autonomy in how their experience is captured and shared (Castleden & Garvin, 2008). Finally, the use of the peer debriefer offered this researcher a valuable tool during the data analysis process. It may have benefited this study to have the peer debriefer working throughout the study process, potentially increasing reflexivity at earlier stages of this work.

It is hoped that this case study has provided information that is helpful, provoking, and encouraging for other CBPR researchers, social work practitioners, and members of the mental health community. CBPR can be a useful and meaningful tool, but at its best, it requires conscious awareness and reflexive attention throughout its implementation. Just like our own bodies, it runs best when all of its systems are attended to and functioning well.

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## **Appendix A. Interview Guide**

**Document: Interview guide** 

**Participant Group: Core Work Group Members** 

Date:

**Pseudonym:** 

## **Introduction and Explanation**

Hello and thank you for agreeing to participate in this interview, taking the time to talk with me regarding your experience as a participant in our project. The responses from this interview will be used as part of a study that is examining the collaborative process of community members and academic researchers coming together to support health promotion efforts for the local mental health consumer community.

There are no right or wrong answers to these questions. Please feel free to share your experiences openly.

I do have digital recording device and will be recording this interview because I want to make sure to capture all of your comments accurately and it is hard for me to both listen attentively to your comments in the moment and take notes. The digital recording will be transcribed and the recording itself will then be destroyed. All names and identifying information will be removed from the transcribed copy of the notes from this interview to help protect confidentiality. Additionally, while it is not anticipated, if any of the information or questions are upsetting or cause distress or discomfort, you may choose not to answer a question and you may stop the interview at any time.

If any of the questions require additional explanation or follow up, please make sure to ask me to clarify.

Are there any questions before we begin?

## **Interview Questions**

- 1) How would you describe our project?
- 2) What has your experience been like so far?
- 3) What kinds of information or knowledge are important for our group during the course of our work?
- 4) Where does the information come from?/ How is it best obtained?
- 5) How do/should we use this information?
- 6) What types of influence did you have on this process?
- 7) How do you see this reflected? What does this influence look like?
- 8) What promoted our encouraged you to participate?
- 9) What stifles or discourages your influence or participation?
- 10) What resources do we need for this project?
- 11) How have/should we identify these resources?
- 12) What sorts of change do you hope to see from this project?

Sample Probes: What will help to produce this change? What is needed for

change to happen? What do we need to be successful?

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Sample Probe: What could interfere or get in the way of us producing change or being successful? If no, what impeded change, what got in the way?