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Amplifying Community Voice in Multi-Sector Health Collaboration: Case Study Exploring Meaningful Inclusion

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AMPLIFYING COMMUNITY VOICE IN MULTI-SECTOR HEALTH COLLABORATION: CASE STUDY EXPLORING MEANINGFUL INCLUSION

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ABSTRACT

AMPLIFYING COMMUNITY VOICE IN MULTI-SECTOR HEALTH COLLABORATION: CASE STUDY EXPLORING MEANINGFUL INCLUSION

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There has been recognition in a consistent and long-term way that the most complex health issues of our time cannot be solved by one sector alone. Actions of funders and new policy spanning the last two decades have successfully attracted a diversity of sectors into planning circles. Many multi-sector collaborations (MSCs) aiming to improve community health have the desire to include the voices of those with lived experience in collaborative efforts, but they are challenged by conditions that are inevitably disengaging because of continued power imbalances, excessive bureaucratic process, and lack of action for change. A collaboration operating in the Gorge region of Oregon offers insight on how to rise above these challenges to inclusively engage those with lived experience. The Gorge has earned national notoriety as a result of improved community health indicators and the structure for collaboration and engagement make it a positive outlier. This exploratory case study asked the central question of what shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement. Building off the assertion that improved community health outcomes in collaboratives require the inclusive engagement of participants who are most closely impacted by health issues, this study sought to precisely include the perceptions of these

individuals most closely impacted. Results were derived from 15 participant interviews, researcher observations of engagement, and a review of publicly available materials. A striking alignment was found between the perceptions of the three different study participant types participating in the Gorge MSC which confirmed the presence of three interrelated domains and ten themes. The study offers insight into (a) conditions that nurture a culture of collaboration and empowerment; (b) the role formal sector participants play in equitably sharing power; (c) how power viewed through an empowerment frame resonated most for those with lived experience; and (d) the ways collaborations can intentionally create meaningful inclusion through structure and informality. The study concludes with implications for future research and researcher reflections.

Keywords: Community health, popular education, voice of lived experience, empowerment, shared power, multi-sector collaboration, healthcare

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Chapter I: Introduction

Why do some collaboratives result in robust improvement plans and coordinated action while others languish? This question has long been a fascination for me. The community health improvement collaboratives I have participated in over the years share a distinct quality in that all have been intentionally multi-sector. Multi-sector collaboration (MSC) is both widely regarded as essential for addressing complex health issues and, simultaneously, is composed of a complex web of interactions inviting research. I define MSCs as collaborations in which multiple sectors are represented at the table working on a shared goal for community health.

There are team members from government, including from schools, public health, and law enforcement, and from the private sector, for example, for profit and non-profit organizations. In addition, team members come from the community itself; community activists, private citizens with a shared concern, and most importantly, other stakeholders who have intimate experience with the issues in focus.

On one hand, there has long been recognition that the most complex health issues of our time cannot be solved by one sector alone. However, what happens when all these diverse sectors are invited together to solve a problem or create a new future is something much less clear. I have found myself in diverse roles on these collaboratives: I have been a participant on long-standing committees. I have been asked to facilitate short-term community forums convened for a particular purpose. I have chaired a local health advisory board, and I have been a participant on a large multi-sector collaborative focused on child well-being.

The Impetus for My Research

Time is running out to figure things out slowly when it comes to improved community health. Collaborative conversations and trying to engage stakeholders in multi-sector formats are

slow processes, sometimes spanning several years. The pressing health issues of this time are getting worse, and the health gaps are increasingly widening. Each month that passes, the gap between current health and desired health widens and the goal grows further out of reach. Still, I show up and wonder if there is a better way to achieve breakthrough action. Is there a way to break out of the ways of meeting that are failing to create change and deliver new results? This sense of urgency is the motivation behind my research coupled with a deep sense of personal responsibility to make a difference in community health and use my talents for the greater good.

In my work as a healthcare leader with community responsibilities, I picked up the practice of capturing field notes whenever I found myself at MSC gatherings to satisfy this sense of urgency and growing dissatisfaction with collaboration processes. The interactions themselves were my focus, but something continued to capture my curiosity. The voices of those participating who had lived experience and were most impacted by the issues in focus were moving and provocative, but rarely did it seem to matter in the long run in terms of outcome.

I have had the opportunity to hear dozens of individuals share their first-person experience. The stories are often deeply vulnerable and cover a wide spectrum of experiences of loss, poverty, to addiction and more. When I hear them speak, I experience a flood of feelings through my body. I feel moved to action, but the rest of the meeting can go on and we sink deeper and deeper into process. It is almost like the moment for action has been lost. My whole nervous system wants to move towards that person and work for change, not slip back into flat, procedural conversation and get tangled in red tape and bureaucratic minutia by the end of the meeting.

These were individuals asked to share their stories and be full participants in the process. Other than some that were receiving small stipends to reimburse childcare or expenses, they

were not there in paid roles, nor were they representatives of private or public organizations. They are called many things; stakeholders, volunteers, neighborhood advocates, community members. Regardless of the name, those voices have become a recognized and expected seat at the collaborative table. Once at the table, however, what can we learn about the experiences of participants with lived experience in MSCs, and what impact does that have on improved community health impacts? And beyond that, under what conditions do participants feel that they are making the greatest contribution and what are the challenges experienced?

Multi-Sector Collaboration

Historically, the early popularization of multi-sector collaborations can be traced back to the 1980s–1990s when federal government reform increasingly put the onus of resolving difficult local problems into the hands of local government and community (Roussos & Fawcett, 2000). A study by Lasker (1997) titled Medicine & Public Health: The Power of Collaboration was an early example of research that called out the importance of working with non-traditional partners. Lasker wrote, "for collaborations to succeed, partners must perceive a compelling need to work with professionals or organizations in other sectors and be willing to do so" (p. 145).

Around 2015, the Robert Wood Johnson Foundation (2019) unveiled a comprehensive Action Framework in support of their campaign to build a Culture of Health. One of four areas listed for action was the call for "fostering cross-sector collaboration." The call to action included the declaration that "No single individual, organization, or sector can change the course of America's health" (RWJ, 2019, para. 1). This declaration combined with a multi-million-dollar commitment to fund research aimed at better understanding these four action areas is a great example of how foundations have shaped collaboratives by incentivizing work across sectors. Additionally, American Hospital Association and Healthy People 2030 have

issued their own version of the call for MSC to solve complex community health issues and promotion of well-being (American Hospital Association, 2019; U.S. Department of Health and Human Services, 2016).

The emergence of MSC in literature, often referred to as cross-sector collaboration or partnership, was closely tied to published reports funded or supported by various prominent health foundations. Foundations have both played a role in the call for MSC and in supporting measurement and reporting activities. The Robert Wood Johnson Foundation, the Ford Foundation, and the Kettering Foundation were three foundations named in numerous studies; they were also often named as special report funders.

Erickson et al. (2017) found that,

> A majority of responding partnerships (65%) formed after 2010. This is likely a sign of significant shifts occurring in the health and social sectors, including historic changes in healthcare access, delivery, and financing, along with an increased appreciation of the power of social, economic, environmental, and educational conditions. There have also been changes in funding opportunities that increasingly require multi-sector collaborations. Regardless of the specific causes, this trend is a reminder that many partnerships are likely in a relatively nascent stage of development. (p. 10)

The influence of foundations and national health policy naturally brought business frameworks and language to the forefront of collaborative processes. The dominant influence of the business sector permeated into collaborative formation, change methods, leadership and structure. Coincidentally, the rise of MSCs during the 2000s occurred during a time when many healthcare systems were consolidating, foundations were making bigger investments in health-related focus areas, the notion of social determinants of health became increasingly recognized

and federal policy called for greater collaboration. Professionals from the private and public sectors dominated the discourse and drove agendas. From what I can discern, this historical emergence was not the result of greater citizen or community engagement.

By comparison, community led and neighborhood organizing movements are most notably about the engagement of those who would benefit from community led change or who would suffer the greatest costs without change. Community-led organizing puts those with lived experience squarely at the center.

These historical influences are important to gaining an understanding of the underlying mindsets and values at work in MSCs. Who listens to whom? Who is seen as knowledgeable about how to design or redesign future changes? Even the language used in describing critical characteristics for MSC has business undertones. For example, it is not uncommon to hear words like strategy, shared vision, sustainable funding, and stakeholders used in discussion. Unlike the business undertones driving MSCs, Asset Based Community Development (ABCD), a framework for community led change, is grounded in quite different principles (Kretzmann & McKnight, 1993). ABCD principles place value on relationships, focus on lifting up the assets of the community, and emphasize recognizing local gifts and capacities (Kretzmann & McKnight, 1993). These differences form the environments in which changes are designed and acted upon.

Focus on Engagement

I believe focusing on engagement of those with lived experience is closely tied to collaborative results and real change in systems. My perspective on how change occurs in systems of health has been heavily influenced by the foundational work of community organizer and scholar John McKnight. In a study commissioned by the Kettering Foundation, McKnight (2013) offers a critical proposition that there are actually four sectors, not three, that come

together to form society. He grounds his assessment by sharing how historically non-profit organizations have been lumped into the civil sector along with associations. McKnight (2013) argues that this a great loss because of the unique contributions and distinctions that this additional sector contributes when not associated with institutions, namely the possibility that real reform and future health is predicated on the strength of a solid fourth sector he calls "associational life." It is this perspective combined with encounters in my professional and community life that make me a believer that we cannot make change without inclusion of the voices of those with lived experience.

There are a number of ways this additional sector is accounted for in historical works. Sometimes it has been referenced as the voluntary sector, but even that holds conflicting connotations depending on the country or region where the collaboration takes place. Building on the work of John McKnight, Wolff (2010) describes "two layers of helping systems, one that we easily recognize and one that we tend to overlook" (p. 12). Professionals, specialists, and service providers in many traditional settings are considered the experts. Problems arise when we don't consider the expertise of the second overlooked layer from within the community (Wolff, 2010). Confusion and blurring can often be traced back to the abundant use of the term community when referencing individuals who are included. Upon closer look, what is often missing is the voice of those participating in a truly voluntary way with lived experience of the issues. I argue that those working in organizations or institutions that serve those with experience is not the same as engaging those with living or living experience. One caveat could be interest groups or advocacy groups that are made up with individuals that have experience with the issue or problem the community is attempting to solve. Mattie and Cunningham (2003) describe the term community as "slippery," explaining,

> If it is used casually, therefore, the term can create the illusion that people in a particular location, neighbourhood, or ethnic group, are necessarily cooperative, caring, and inclusive. The reality may be very different, as power differentials in gender, race, and class relations may result in exclusion, and threaten the apparent cohesiveness of the group in question. (p. 475).

I have seen firsthand in my work as a healthcare leader how we can over or under design solutions or just plain miss the solution altogether when the voices of those with experience are not included. It is a real source of waste in health systems. One illustrative example was shared by Morrison (2016) who retold the story of a hospital trying to solve the issue of repeated preventable hospital stays by an individual experiencing diabetic emergencies. Thousands of dollars in provider time treating the emergencies were spent and hours wasted trying to solve the issue from the inside before a solution was found. The solution came when a doctor, driving an older model green truck, took to the community to visit the patient at their home, listened and discovered they had no refrigerator to store their insulin (Morrison, 2016). A far more inexpensive and simple solution to a troubling issue had been found and a refrigerator purchased, but it required listening to the voice of the patient.

Another example where community members closest to the issue seeking to be impacted sometimes contribute the most novel ideas came during a Children of the Setting Sun Productions (2019) presentation. High school graduation rates have an established linkage to long term health outcomes. Higher levels of education completion translate into employability and future wage-earning capacity (Hahn et al., 2015). The communities from which Children of the Setting Sun Productions (2019) shared examples have fewer youth of color that graduate, many of whom are indigenous Native American youth (Whatcom County Health Department,

2018). Lower graduation levels translate into poorer health outcomes on multiple indicators (Hahn et al., 2015). Healthcare professionals and other formal sector leaders working alone to try to impact this concerning indicator might imagine a variety of programs and interventions. But would those same professions ever suggest that access to orthodontics care could make a difference? This suggestion came from the mother and grandmother of children of the nearby tribal nation. When asked what would make the biggest difference in her community and improve health, she answered orthodontics care for children. She went on to explain that without orthodontics care, children are less likely to speak and participate in the classroom limiting their learning potential. It is unlikely that a room full of professed experts could come up with this need without the essential contribution of this elder who was currently living within the community. She had experienced marginalization and discrimination herself as well as limited access to health services. Neither of these examples originated from formal MSC processes, but they do show the significance of what can be missed when we do not ask.

Initial shifts toward more MSC community health work produced hopefulness as there was a spreading recognition of the need to move beyond silos. MSCs were setting up the conditions to discover the "*missing refrigerators*" in community. My experiences, though, have shown this hopefulness to be fleeting. I have been present at MSC meetings where the missing refrigerator has been called out. I have heard people with lived experience share the harrowing stories of trying to achieve health in the presence of things like: lack of available affordable housing, or lack of childcare slots in a community, or presence of food deserts where the only choices for miles are convenience stores, or worse (Zahner et al., 2014). Inside these stories are the cures to the big complex health issues of our time—diabetes, premature death, heart disease, addiction, and trauma.

Change can be a funny thing. Change can be the stimulus to draw people outside their comfort zones to join with others seeking solutions to complex problems. The anticipation of change can also be a trigger to retreat back to what is most comfortable. MSCs are an intriguing phenomenon for all the reasons previously mentioned that contributed to their rise in popularity. MSCs, by their very nature, are typically born out of organizations. A typical life course for an MSC might begin when individuals within an organization recognize that the problem has gotten too large to be effectively addressed by their sector alone. In the case of MSC formation, this recognition prompts an invitation to others to join in the work of the collaborative. The timing of inclusion and how that inclusion occurs can tell us much about how people with lived experience are engaged. Are they engaged early and seen as essential contributors to change? Are they engaged as an afterthought? Or are they engaged because there is a box that needs to be checked on a grant application for funds?

Overall, the research to date revealed a large number of qualitative studies focused on factors associated with the effective running or management of MSCs, but a gap in the research on how interactions contribute to a larger collaborative multi-sector process. Aside from identifying engagement as a critical factor in MSCs, there were few studies that examined the "how." Many studies stopped short of identifying how the interactions shape factors such as trust, engagement, and shared purpose or leadership.

Defining the Who in This Study

For the purpose of this study, I will refer to those at the center of my study as individuals, people or participants with lived or living experience. This distinction intends to capture a range of other descriptors, including those who:

- Bring the voice of experience with the community health issue at hand,

- Are impacted by the community health issues or future solutions in focus,
- Are participating voluntarily and not as agency or organizational employees. Note that this does not preclude the need for stipends and other supports that assist participation.

Those participating and contributing their lived or living experience have been described in a number of other empowering ways in the literature. Attygalle (2017) introduced the phrase context experts to describe this group of individuals who have unique attributes associated with their experience in contrast to those who are considered content experts. Another term comes from the tradition of rights-based approaches (RBA) which distinguishes rights-holders from duty-bearers (Gruskin et al., 2010). Some international groups have developed recommendations and frameworks to express how public health improvement efforts can be fully inclusive of rights-holders (Gruskin et al., 2010).

Purpose of Study

I propose that there is still much to be understood about how community health outcomes can be improved through the inclusive engagement of individuals with lived or living experiences in MSCs. The purpose of this study was to understand the conditions that maximize engagement of those participants in MSCs in which engagement is viewed as a critical factor needed to produce improved community health outcomes. This study explored the central question of what shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement. Additionally, I sought to explore:

- What are the larger contextual factors that influence engagement of those with lived experience in MSC efforts?

- What role do the perceptions of formal sector participants (e.g., from the public or private sector) play in efforts to include those with lived experience?
- How are the dynamics of power handled and managed in ways that facilitate positive, inclusive engagement of those with lived experience?
- How does structure (or formality) of the MSC make a difference in shaping engagement?
- What lessons can be derived from the meaningful ways that those with lived experience have been engaged in MSC work that has led to improved community health outcomes? What lessons can be derived from what has not worked?

Personal and Professional Positioning

I have always been a keen observer of human behavior. This came as a result of my academic study in organizational psychology and from my professional career as an organization development consultant and group facilitator. But there are more significant aspects of my past that have shaped the powerful observer I am today.

One particularly significant practice in my life has been Aikido, the Japanese martial art of reconciling difference through coming together. Aikido has been a big influence on my work with teams and how I participate in my relationships through the heightened body intelligence I have gained through this practice. What I have learned in this martial art transfers outside the dojo into everyday life; Aikido heightened my senses and grew my capacity to observe difference in community and how difference can be resolved through connection. In the dojo, I trained with many different partners and got to notice everything that was alive in my nervous system and how those sensations affected the outcome and quality of the connection with my partner. If I withheld or drew back, my partner had a myriad of possible ways they could

respond, none of which produced a quality outcome that was enjoyable. If I pushed on my partner, equally poor outcomes were felt through distance and pulling away. The Japanese word Aikido translates into “harmonizing-energy-way” and offers a third option, a way of being with my partner that is neither pushing nor pulling, and with a felt sense of oneness with each other, nature, the world, and the present moment. Sometimes referred to as being in a flow state, the quality of interaction is timeless, powerful, and freeing. The more years I trained, the more I got a feel for the powerful outcomes that can emerge from connection.

My early years of Aikido training were mostly focused on rewiring how I was conditioned to learn and learning a new, judgment free form of learning. I had to learn how to sense and feel, not through seeing but through exploration of tacit sensations. Simple things like noticing the sensations between where my feet touch the ground and the felt sensation of heaviness that comes from gravity pulling your weight to the center of the earth were new to me. I came to recognize the tacit sensations for things that before had been elusive. Our Aikido Sensei used to probe at length with questions about “what are you feeling?” The greater my awareness, the greater my ability to act in situations that had previously been confusing for me or had produced a fight-flight response.

In many ways, my experience working on MSCs is similar to those early years of Aikido training. The large portion of my day is spent in the professional sector surrounded by the familiar—people that I have worked with for years, somewhat predictable processes, delineated roles and responsibilities and hierarchal systems of work. Stepping into the arena of MSCs brings a flood of sensations to observe. It is not always clear what the rules or etiquette are for engagement, people speak different professional languages, and there is a lot of metaphorical bumping into one another and awkwardness.

My bias is that we have not prepared people well to step into the unfamiliar. We are largely conditioned to work and engage within the bounds of a silo, but the real complex health challenges today cannot be solved by a single silo. I do not believe that complexity in MSCs is something that can be managed or predicted, but I do believe that we can build collective practices that enhance our group sensing and acting together.

I hope my research contributes to the whole of the field of community health and MSCs, but I also have a particular affinity for healthcare leaders who come to the table representing one of the many critical sectors of community. My affinity comes from years spent in the field of leadership development both as facilitator and on the receiving end of ill-conceived training. I have seen the tendency to teach cookie cutter approaches, the tendency to pretend people work within predictable environments, and the allure of the latest recipe for healthcare leadership. It is important I mention this because my motivation lies in not repeating this past. I also see that healthcare leaders have much to contribute in terms of resources, skills, and care. To the degree that they can enter into these cross-sector teams and do good not harm will benefit society. Without a case for how engagement of those with lived experience contributes to enhanced community health, there is a real risk that healthcare leaders collaborating in community will perpetuate a past history of enacting improvements designed by professionals.

I am also biased that the power of connection has been underestimated and downplayed, especially its role in supporting powerful outcomes to emerge. My experience participating on community teams feels more individual than communal. When convened, I get a distinct sense that we are each there as individuals representing our particular sector, role or perspective. The

elusive oneness I have felt in other settings, remains just that, elusive. Trust, connection, present moment engagement are all qualities that are present when the sense of oneness shows up.

International Experience Brings Perspective

In 2018, I had the opportunity to visit Cuba to study their systems of health. This experience was pivotal in reifying my passion and interest in the complex dynamics when engaging the multiple sectors. Visiting Cuba was like a wake-up call shaking me out of my comfort zone. I saw people acting on behalf of community. In the face of real pressures and hard to fathom shortages in resources, they were taking action, they were impressively creative, they were focused and they were making improvements. The sense of community I felt in Cuba was like a big warm blanket. People were infinitely humble, loving with one another, supportive and not shy about making physical contact. I have no idea if that sense of community carried over into Cuban health meetings or board rooms, but I have to imagine that it makes a difference in the quality of outcomes.

This experience was a stark contrast to what I experienced when I returned home to the US and back to the community health planning tables that I was a participant in. Our intentions to come together had been noble and good. We came together genuinely wanting to make a difference in the health of our communities. With these great intentions, why did it feel like such a slog. More and more, I find myself at meetings that fail to yield new action, in conversations that feel like wading through a fog of veiled comments, and engaged in ways that feel more guarded than open. It has left me feeling less than hopeful about the future of our communities to take real action to improve the well-being and health of our neighbors and families.

Shared Recognition of Opportunity

I have queried colleagues to test if I am alone in my experiences and have found that others often share similar frustrations but are hesitant to name these frustrations in groups. One of my colleagues shared:

> We often pretend like we don't know what we need to focus on. Why don't we start from the premise of the obvious things, like 50% of kids live in poverty and we know the consequences of poverty? In order to impact those things, there are some obvious things we can start doing. Instead, we spend a lot of resources in the planning stages, figuring things out.

Another colleague shared how she too felt frustrated, specifically with how the group listens and who is listened to. She had concluded that the voices of those with academic and professional backgrounds hold more weight in the group than her voice as a parent who has lived a life of much less privilege.

Perspectives like these emerge from the interactions and relationships present in MSCs. Neither of these accounts nor my own experience would be descriptive of a thriving endeavor focused on health improvement for the whole and yet, that is exactly what it is intended to be. How many multi-sector groups experience the challenges we have faced and what are the conditions of engagement in which connection, co-creation, and action are present?

I have never met a leader or convener of a MSC that did not care tremendously about the effort and working to make a real difference, myself included when I found myself in the role. Unfortunately, good intent does not automatically translate into success, especially when faced with a great deal of complexity and long unresolved social health issues. I have often suspected

that the capabilities of leading change in this context extend far beyond models and the latest approaches in group engagement.

Preview of Upcoming Chapters

Chapter II includes a critical review of the relevant literature available in the study of multi-sector community health collaboration through the lens of inclusive, engagement of those with lived or living experience. I begin by sharing how historical influences have shaped the inclusion and engagement of those with lived experience, such as funder imperatives, regulation, and new policy in the field of community health improvement. I include a review of models and theories that have provided principles and guidance underlying engagement processes used today by community health practitioners and facilitators. I argue that these various models and theories have played an important role, but have been insufficient in understanding experience at the individual level. More is needed to hone in on how those with lived experience are included and engaged in community health improvement efforts led by MSCs. Special attention will be paid to the gaps in research on collaboratives.

Chapter III introduces the method of a qualitative, single case study design. Each of the analytical approaches selected are explained along with the rationale for selection. The timeline for conducting the study is proposed in this chapter as are ethical considerations and the processes used to protect participants. The community health collaboration underway in the Gorge region of Oregon is described as the feature case. The combination of documented successes, improvements in key community health indicators and the commitment to authentic community engagement makes this a unique case to study. I provide background context on how various collaborative features in the Gorge formed and describe the bounds of the study.

Chapter IV thoroughly presents how results were analyzed to produce a set of themes that answer the research question in focus. The resulting themes obtained in this study are presented along with evidence from qualitative interviews, researcher observations, review of publicly available materials.

Chapter V includes an interpretation of the results of the study. The main research question is discussed along with a discussion of the five supporting research questions. Each question is answered with respect to existing literature. Chapter V concludes with implications for practice, a review of study limitations and researcher reflections on learning.

Chapter II: Critical Review of Relevant Theory, Research, and Practice

A complex array of factors play a role in how collaborations for community health improvement include those with lived experience. For example, historical events shape the orientation of collaborations in relationship to community. Furthermore, important ramifications have come from medical and public health reform regulation and the increasing role foundations have fulfilled as funders of community change efforts to improve health. These trends have both enhanced the awareness of social determinants of health while also increasing the likelihood that formal entities (e.g., government agencies or private sector business) are the initiators or conveners of multi-sector collaborations for health (Wolff, 2010). When entities are in the driver's seat, there is a real risk that collaborative processes will fail to result in real change. In addition, power imbalances will persist, and the voice of those most affected by the problem in focus will be little more than consultative. Various authors have developed frameworks to assess where a given MSC falls along a continuum or model of participation (Lasker, 1997; Minkler & Wallerstein, 2012). These frameworks can help to identify how the collaborative is oriented. For instance, is it needs-based or strengths-based? Is it entity driven or grassroots driven?

MSC practitioners that are inspired to significantly align their engagement processes and methods to reach and include those with the most experience of the problem have turned to models, approaches, and theories for direction. Some of the practitioners and theorists have come from the larger field of community organizing (Kretzmann & McKnight, 1993). This literature review includes a tapestry of models and theories that span Community Coalition Action Theory, Community Based Participatory Research, Asset Based Community Development, and Collective Impact. All of these theories have driven engagement methods, but they have been insufficient in understanding experience at an individual level. The broad definition of

community in the literature and the ill-defined boundaries in the field of community organization have further made it challenging to hone in on specific studies with inclusive methods for engaging those with lived experience.

Literature Search Approach

My research process was extensive, supported with librarian guidance and evolved over nearly a year. This included an initial phase of research focused on MSC including the emergence of MSCs in community health, foundational models and historical influences shaping MSC, and an exploration of the works of repeat authors. My intermediate phase focused on engagement of participants in community health MSC, factors influencing engagement and gaps in the research. Finally, my focused phase narrowed my search to works examining how those with lived or living experience specifically have been engaged in community health improvement work involving multiple sectors. The focused phase also included a search of dissertations and theses published in the Proquest Dissertations and Theses Global database which located three dissertations that I reference in this review.

I utilized the Multi-Strategy search model as recommended by Dr. Steve Shaw. Starting with a Boolean subject search on the topic of multi-sector community health collaboration in PsycInfo, I was able to narrow down my findings to under 100 studies. I then worked backwards reading abstracts and mining reference lists of the various studies I found to be aligned with my topic of interest to find additional references. I took special note of authors who were mentioned multiple times and once I saw a substantial pattern, I searched for foundational works by those authors. I pulled full text articles and books based on my narrowed search of relevant abstracts and reference lists.

I used Microsoft OneNote to systematically organize my findings into a searchable catalog of references, notes, and connections between works. In addition to the traditional library and bibliographic subject searches, I also searched for other sources using Google Scholar, recommendations from mentors and resource lists found on various associations with ties to the field of MSC. I regularly came across practice-based guides, reports, and articles in my search process. I cross referenced these with scholarly works to assess for quality.

Initial searches in PsycINFO produced articles that tended to be more limited in scope and focused on collaboration among multidisciplinary teams in healthcare settings. Because my interest was squarely on inclusive engagement and how engagement of community voices was being studied in a multi-sector environment focused on community health related endeavors, I refined my searches to include "collaboration," "cross-sector," and "community health" as key search terms. I used the database thesaurus to find all associated terms for collaboration and community health, thereby, expanding the search. In my focused stage, I further refined the search to include terms associated with "empowerment' and "community health.". I reached a point in my nearly year long search that I found I was coming across the same references from much earlier attempts. This was an indicator that I had reached a level of thoroughness in my search that was satisfactory.

The review is organized into sections beginning with a primer on the historical influences in the field of health and social services that have had influence on the ways that community members have been engaged in health efforts for change. I include foundations because of the role they have played in funding efforts that include a call to action around engagement. I review the multiple models and theories with origins in community organizing before going on to

describe numerous studies that examine the dynamics of engagement in MSCs at both individual and group level of analysis. Finally, I conclude with implications for future research.

Historical Influences on Levels of Community Inclusion

Inclusion of people with lived experience in collaborative community work has a long and deep history influenced by significant time periods in the United States. Tax cuts to social and health programs during the recessions of the 1980s and early 1990s required communities to collaborate and close service gaps left by government cuts (Price, 2017; Roussos & Fawcett, 2000). The neighborhood organizing grassroots movement demonstrated local change could be powerfully led from the ground up (Campbell, & Jovchelovitch, 2000). Finally, historic periods of public health and medical care reform have called for greater involvement of community members (Patient Protection and Affordable Care Act, 2010; Public Health Accreditation Board, 2014). And the introduction of ethical principles into research led to new innovations in community engagement methodologies (Garcia, 2011; Minkler & Wallerstein, 2012). Since the early 2000s, the popularization in multi-sector collaborations for community health has provided more opportunities for academic observation about how inclusion and engagement of community members with lived experience has been cultivated. The next two sections describe how the entrance of regulation, in the form of medical and public health reform, and the rise in foundations as key funders, have both facilitated and inhibited processes that engage those with lived experience.

Regulation as a Driver of Engagement: Medical and Public Health Reform

The establishment of a public health accreditation process in 2007 and the Affordable Care Act (ACA) of 2010 are both examples of national policy driving the greater inclusion of individuals from community. The ACA wrote into law the requirement for nonprofit hospitals to

complete a community health needs assessment or risk losing their IRS tax exempt status (Patient Protection and Affordable Care Act, 2010). Every three years, hospitals find themselves in the position of engaging in the assessment and also developing and implementing health improvement strategies based on needs (Lightfoot et al., 2014; Prybil, 2017). The law also requires that hospitals gather input from key stakeholders in the broader local community. The law describes those considered as key stakeholders, but does not clearly call out those most affected by health issues with the exception of suggesting that those that represent those with lived experience be asked for input (Internal Revenue Service, 2019). With a similar emphasis on inclusion of diverse community sectors, the standards for accreditation by the Public Health Accreditation Board (PHAB) include an entire domain devoted to community engagement (Public Health Accreditation Board, 2014). Standards in the domain are based on the following explanation: "Members of the community possess unique perspectives on how issues are manifested in the community, what and how community assets can be mobilized, and what interventions will be effective" (Public Health Accreditation Board, 2014, p. 114).

Those living in the local community who have experience with the health issues that hospitals and public health aim to address should be considered important partners in identifying and defining public health issues, developing solutions or improvements, advocating for policy changes, communicating important information, and implementing public health initiatives (Public Health Accreditation Board, 2014). This important role of the local community is not called out in the regulation. For hospitals and public health departments, both the ACA and the PHAB require lengthy documentation and evidence that standard criteria, including who is engaged, are met. The regulations, however, do not specify the quality or inclusivity of that engagement. The requirements further leave open for interpretation of the question of who

counts as community or a key community stakeholder. For instance, is it sufficient to engage the general public or does special attention need to be paid to those who are most impacted by health issues in the community? These questions are left open for interpretation by those implementing the processes of engagement called for in medical and public health regulation. As Attygalle (2017) explains, "It's [engagement] mandated for positive reasons—the understanding that community input is essential when the end result will directly impact the community—but the execution is what can often be problematic" (p. 2).

One could argue that the ACA and PHAB necessitate processes that put non-profit hospitals and public health departments in the driver's seat, thus creating a power imbalance from the start. One could also question if private and public entities would seek out this type of community engagement and input without regulation that drives inclusion. Labonte (2012) warned, "As health practitioners attempt to organize people or to support community groups, they must be wary of "colonizing" these groups with institutional, often disease-based ways of defining health issues" (p. 107). Mathie and Cunningham (2003) also issue a similar warning and question overall effectiveness and outcomes when community collaboration efforts have been initiated as a result of regulatory drivers.

The recognition that PHAB standards were insufficient in guiding collaborative processes resulted in a 2018 report titled Advancing Health Equity in the Health Department's Public Health Practice (Human Impact Partners, 2018). Among the recommendations named to advance health equity, the report included specific direction for engagement including:

1. Establish a principle that "community engagement" is for the purpose of decreasing power imbalances and historical disenfranchisement among communities most impacted by health inequities.

2. Recognize that this is a bi-directional learning and capacity-building relationship, meaning that health departments have as much, or more, to learn from community groups.
3. Be explicit that health departments should engage community members to help build their power and create more sustainable change within government institutions, and encourage working with community organizers specifically as a strategy to accomplish this. (Human Impact Partners, 2018, p. 30)

These recommendations align with community engagement literature that stress the importance of addressing power imbalances. Even dating back 40 years prior to this report, community engagement, noted as participation, was called out as a key principle in a landmark 1978 global health policy commitment developed by the World Health Organization (WHO; Rifkin, 2009). Rifkin (2009) outlines a number of lessons learned in the years that followed since this commitment was made, including the guidance, "We should be looking at the views, experiences and perceptions of those involved in community health programmes and describe these findings without trying to fit them into our preconceived view of how the world should operate" (p. 35). This is further evidence of the need to ask, listen and include those who have been a part of community health improvement work and not assume how people will respond.

Foundations: Community Health Change Facilitators or Inhibitors

Health foundations have had an undisputed influence on stimulating the formation of collaboratives that include non-traditional partners coming together to work on community health improvement. In the role of funder, though, some dispute whether or not foundations facilitate or inhibit needed change in community. Erickson et al. (2017) observed that foundation funding criteria that required collaboratives to include diverse sectors was one of several changes

that led to a 2010–2017 rise in collaborative formation. For example, the Robert Wood Johnson Foundation (2019) called for "fostering cross-sector collaboration" as one of four areas needing attention in their Culture of Health Action Framework. This call came with the commitment of millions of dollars available for research that incentivized work across sectors. Ganz and Reyes (2019) describe a dilemma produced when working within this 21st century reality where funders have a great deal of power. Unfortunately, "Most organizing depends more on funders than on constituencies" (Ganz & Reyes, 2019, p. 8). This reality sets up a dilemma that is contradictory to how historical change movements have transpired throughout history (Ganz & Reyes, 2019). Price (2017) critically reminds us that foundations historically came into being as a way for the rich to avoid taxes and still feel good that they were doing charitable work. The downside was this resulted in a dramatic growth of non-profits, including foundations, that: "encourage social movements to model themselves after capitalist structures rather than to challenge them" (Price, 2017, p. 3). Price underscores the significant influence funders have on shaping and professionalizing the work of social change.

Foundational Models Encouraging Inclusion of Individuals with Lived Experience

The actions of funders combined with the entrance of new policy and regulation over the last two decades has created a paradoxical environment. The environment equally demands inclusion of the voice of those with lived experience in collaborative efforts while also setting up conditions that are inevitably disengaging because of continued power imbalances, excessive bureaucratic process, and lack of action for change. The next section looks back at some of the historical models and theories that have shaped engagement processes at the community level. I conclude with some of the challenges of putting these models and theories into practice.

Community Coalition Action Theory

Butterfoss (2007) defines coalitions at the heart of the Community Coalition Action Theory (CCAT) as involving a level of formality and shared purpose. “A community coalition is different from other types of community entities in that a structured arrangement for collaboration among organizations exists in which all members work together toward a common purpose” (Butterfoss, 2007, p. 71). In regards to engagement of coalition members, Butterfoss found higher engagement translated to greater participation but did not find evidence that tied engagement and satisfaction of members to the achievement of outcomes. CCAT is a comprehensive theory with 23 propositions that address the context of the community in which the coalition exists, how the coalition functions, needed structure and membership, and the stages of development the coalition moves through (Butterfoss, 2007). The 23 propositions have their roots in the philosophy of community development, which puts forward, “that people deserve a voice in designing changes that affect or take place in their communities, that communities have the capacity to address their own problems, and that resident involvement and ownership in community change leads to greater sustainability” (Butterfoss & Kegler, 2012, p. 314). Butterfoss and Kegler (2012) describe empowerment and belonging as critical aspects of engagement and stress the importance of recruitment of diverse perspectives during the coalition’s formative stage.

Community-based Participatory Research

Community-based participatory research (CBPR) is recognized as an approach for building community capacity and engagement while being sensitive to values of inclusion, respect and preventing additional harm to communities that have experienced marginalization (Garcia, 2011; Minkler & Wallerstein, 2012). CBPR is defined by its truly collaborative nature,

focused on trust-building, shared decision making and working in direct partnership with communities in focus to ensure the efficacy of interventions being designed (Christopher et al., 2008; Collins, 2018). “CBPR as an orientation to research bridges the traditional academic-community divide by engaging those most affected by an issue as part of the solution” (Garcia, 2011, p. 17). One example of CBPR at work in a community was featured in a study that showed how trust was built in an American Indian Nation with researchers from a university setting (Christopher et al., 2008). The researchers practicing CBPR saw new levels of engagement and involvement in health efforts on the part of the community as a result of the trust building practices employed by the CBPR approach (Christopher et al., 2008). Trust is a significant characteristic of effective partnership. The history of injustice and harm inflicted on many marginalized US communities requires trust building paired with engagement, like those in the CBPR approach, if we expect to see lasting community health improvements.

Another example of the CBPR approach occurred in Pennsylvania where four hospitals came together to conduct a regional health assessment with extensive community engagement (Lightfoot et al, 2014). Conveners showed respect for the local culture, addressed issues that would hamper participation, attended to the need to compensate community member time investment, and kept the community engaged throughout the process (Lightfoot et al, 2014). Both these examples demonstrated a change in how the community viewed conveners and opened the door for effective collaboration on matters of health improvement. Ultimately, the ability to nurture and sustain trust is a distinguishing challenge faced in community engagement (Laverack & Mohammadi, 2011). Collins et al. (2018) shared a case study on the use of CBPR in a Seattle housing community where residents actively participated in the research process. Residents experienced homelessness, behavioral health and substance use challenges and even

after the Housing First intervention was implemented, residents continued to express needs that had not been sufficiently met. The case study found that respect shown to residents for their expertise and knowledge was highly valued but residents required more. Acting on what was of value to residents, establishing boundaries and roles, and supporting research activities through formal supports like stipends for resident time and ongoing times to meet all helped to sustain engagement (Collins et al., 2018). In another case study by Davis et al. (2014), CBPR principles were used to engage rural multi-sector community health improvement collaboratives in Oregon. The intervention was designed to integrate research into the practices of the collaboratives through the use of training and identification of pilot research studies (Davis et al., 2014). Davis et al. concluded, "Involving community members as partners in research is critical to generating relevant evidence, developing tailored interventions, and improving health outcomes—particularly in underserved communities" (p. 305).

Asset Based Community Development

John McKnight's community building work highlights how substantially different mindsets underlay the way processes of engagement transpire. McKnight (1995) wrote, "The raw material of community is capacity. The raw material of medicine is deficiency" (p. 77). In this comparison, McKnight describes these different mindsets in fundamental opposition. McKnight (1995) argues "Each creates a map of community that guides community residents, local groups, major institutions, and governments toward competing visions of healthful communities" (p. 77).

Asset Based Community Development (ABCD) is a methodology born out of John McKnight and John Kretzmann's combined experiences in community building. The methodology contains principles that emerge from an asset informed view of the world that sees solutions for greater health and thriving as existing within the community (Kretzmann &

McKnight, 1993). Kretzmann and McKnight (1993) describe the typical or traditional approach to building up communities as being a "needs-based" or deficient informed way of positioning community and individuals as in need. The ABCD methodology presents an alternative way of engaging with individuals in community with lived experience, not as beneficiaries or needy, but as the ones who hold the solutions and ideas that will build a healthier community. Pan et al. (2005) describe how the ABCD framework contributes to social capital development which has been shown to be a key condition of community health. "Social capital is characterized by participation in networks, reciprocity (with which members can expect to give and receive), mutual trust, shared recognition of social norms of behavior, shared ownership of common resources, and collective efficacy" (Pan et al., 2005, p. 1185). A framework like ABCD has the capability of enhancing health overall in a community in addition to being an effective framework for inclusive engagement of those in community with lived experience. Even though inclusion is the heart of ABCD, Mathie and Cunningham (2003) posit that ABCD may not go far enough in addressing how to support participation and engagement of individuals when they have experienced great historical oppression and unequal power dynamics. Mathie and Cunningham (2005) suggest a key asset-based differentiator comes in the form of, "Uncovering the strengths that exist in the shadow of the obviously powerful within the community, and bring them into view" (p. 184). Care and attention must be given to ensuring that power dynamics at the local level are considered when applying asset-based processes, like those found in ABCD (Mathie & Cunningham, 2005).

Collective Impact Sweeps the Scene

On the needs-driven end of the spectrum far from the asset-based roots of ABCD, the Collective Impact (CI) model first appeared in a 2011 article in the Stanford Social Innovation

Review. CI is included in this review not as a foundational model, but rather to illustrate the strong influence the business sector can have on collaborative engagement methods. CI also widely cemented the notion that complex community health and social health challenges of our time require the coming together of multiple sectors joined by a shared vision. Kania and Kramer (2011) described several case examples out of which the definition of CI was formed. "Collective impact initiatives involve a centralized infrastructure, a dedicated staff, and a structured process that leads to a common agenda, shared measurement, continuous communication, and mutually reinforcing activities among all participants" (Kania & Kramer, 2011, p. 38).

A critical review of the CI model included significant concerns that the top-down CI model had been quickly popularized by funders and government despite major pitfalls including weak evaluation and lack of experience (Wolff et al., 2016). Before encountering the critical reviews of CI, I had been similarly wooed by CI's notoriety. I had the opportunity to observe a coalition in action that was using the CI framework and was impressed by the shared vision, overall level of participant engagement and well-organized action plans. I recognize that my observations came from a dominant business professional lens thus clouding my ability to see other perspectives on engagement. Wolff et al. (2016) criticized, "Community coalitions that are funded and encouraged by foundations and government to use a top-down approach that likely will maintain the status quo and do little to alleviate the problems they were designed and funded to address" (p. 47). A further criticism of CI is the missing focus on the voice of those that have been historically invisible in community health change efforts. Christens and Inzeo (2015) wrote, "One of the most pronounced differences between collective impact initiatives and community organizing initiatives concerns the engagement of residents who are not involved in the effort as

professionals, decision-makers, or elected officials" (p. 428). Christens and Inzeo encourage a focus on three related areas: "(1) deep resident engagement; (2) analysis of power; and (3) capacity to address conflict. Clarifying these distinctions can lead to more effective efforts to achieve changes in local communities" (p. 428).

Wolff et al. (2016) developed six principles for building collaborative spaces that specifically address the gaps CI misses when engaging community.

1. Explicitly address issues of social and economic injustice and structural racism.

2. Employ a community development approach in which residents have equal power in determining the coalition's or collaborative's agenda and resource allocation.

3. Employ community organizing as an intentional strategy and as part of the process. Work to build resident leadership and power.

4. Focus on policy, systems, and structural change.

5. Build on the extensive community-engaged scholarship and research over the last four decades that show what works, that acknowledge the complexities, and that evaluate appropriately.

6. Construct core functions for the collaborative based on equity and justice that provide basic facilitating structures and build member ownership and leadership. (p. 51)

The critiques of CI shared by Wolff et al. (2016) and Christens and Inzeo (2015) have encouraged other researchers to look deeper into the sharing of power in CI. In a study examining four cross-sector CI initiatives working to address homelessness, Walker (2020) explored how participants viewed and experienced power in the initiatives. Walker recommends specific actions for engaging with power in CI initiatives of a similar context and proposes expanding on the CI Model to include power as an integral element woven throughout. Walker

(2020) suggests future studies should work to include more representative consumer voices to validate these specific CI practitioner actions for engaging with power:

> Partners can commit to making understanding power dynamics central in their work, to looking at the systems that construct the problems they are solving, to elevating folks outside of traditional power structures into decision-making roles, and to curb or limit the power of partners with financial resources and positional authority. (p. 166)

Grassroots or Top Down: Where We Begin Matters

These models and theories described previously present an array of orientations to engagement. "Once community collaboratives have formed using a top-down approach, converting them to models that involve community residents as equal partners—whereby they have real influence over the agenda, activities, and resource allocation—is very unlikely" (Wolff et al., 2016, p. 45).

While these models, approaches, and drivers offer a good start, they have been insufficient in guiding processes for engaging individuals with lived experience. This insufficiency relates back to the root level upon which these models and approaches have been built upon. Models and approaches that come from a deficit or needs based frame are likely to continue to inspire processes that are disengaging at best and, at worst, marginalize. The context in which each model was formed also contributes to the insufficiency. CCAT is a theory centrally focused on attracting organizational entities to unite around a shared focus for the long term (Butterfoss, 2007). CBPR has introduced essential practices for enhanced equity and inclusion of those that have been historically marginalized in community making it a much-needed research methodology, but still insufficient in addressing the questions of inclusive engagement of those with lived experience. The ABCD framework’s primary concern with driving development from

the “inside out” contains important lessons for engagement but is limited because studies have been focused at the community level (Kretzmann & McKnight, 1993). Finally, the recent dominant influence of Collective Impact on the processes of community health MSC formation and development has put increasing focus on the organizational level and much less on individual level engagement.

These models, approaches and theories create a rich history that has informed current practice and inclusion of those with lived experience in MSCs, but there remains an opportunity for further analysis at the individual level. Bowen et al. (2010) conducted a literature review of how community engagement has been studied across various disciplines and they emphasized the importance of understanding first how community has been defined in the literature. Of the more than 200 sources reviewed, roughly half came from strategy publications and of those sources, only 18% defined community at the individual level (Bowen et al., 2010). Sources examining how community members are engaged are often lumped in with studies focused on engagement of individuals with lived experience. In this next section, I will share examples of articles and studies that have examined the dynamics of engagement at both the individual and group level of analysis.

Contributors to Meaningful Engagement

The search for literature focused on engagement often turned up studies where the research question focused on collaboration. When collaboration is the focus, the attention is placed on the inter-relationships between individuals or the end result of collaboration and less attention is paid to how individuals experience meaningful inclusion. An example of this comes from Mattessich and Rausch (2013) who focused on what types of action can be taken to foster greater collaboration. In this mixed methods research study and report for the Robert Wood

Johnson Foundation, Mattessich and Rausch provided evidence that skilled leadership was among one of the critical success factors needed to support collaboration when diverse sectors come together. Funding and trusting relationships were also cited in the top three factors by survey respondents (Mattessich & Rausch, 2013).

In a study of 12 successful public-private health collaborations, researchers identified that successful partnerships are ones in which the "partners demonstrate a culture of collaboration with other parties, understand the challenges in forming and operating partnerships, and enjoy mutual respect and trust" (Prybil et al., 2014, p. 47). Trust was a central characteristic that was supported by a demonstrated history of working together in a collaborative manner. Peterson et al. (2006) included trust as one of six factors named to be important in building community engagement in coalition efforts.

In a critical review of 34 research studies, Roussos and Fawcett (2000) identified four factors that they qualified as might having an impact on collaborative effectiveness. All four could also be viewed through the lens of engagement. Roussos and Fawcett described social capital (trust plus connections) as one of those four factors shaping collaboration results; suggesting that social capital can both be the outcome of collaboration and a critical input.

Mizrahi and Rosenthal's (2001) research of social change coalitions in the northeastern US touched on the dynamic interplay between trust, respect and power. "As a coalition amasses power, it becomes a place where organizations want to be—which in turn, contributes to its power base and its legitimacy" (Mizrahi & Rosenthal, 2001, p. 71). Coalition leaders participating in the focus groups described scenarios in which there was limited trust between groups in the community, but they came together despite that because they had respect and trust for the work of the coalition (Mizrahi & Rosenthal, 2001). Power and legitimacy are two

elements to explore further to better understand the role these factors have in bringing individuals to the table to participate and creating a sense of inclusion.

Lasker (1997) described how, “Tensions can develop when partners have different ‘languages’ and values as well as different resources and skills. In these situations, the viability of the collaboration depends on its capacity to foster tolerance, respect, and trust” (p. 148). Here again Lasker has identified one of the viability hurdles that others have also found, but not how collaborations foster those key attributes of tolerance, respect, and trust.

Frerichs et al. (2017) found a significant difference in the importance that community members placed on “communication, credibility and methodology to anticipate and resolve problems” (p. 187) as a dimension that was important to both developing and sustaining trust. The context for this study was partnerships that included an academic partner, members of the community sector, and healthcare providers (Frerichs et al., 2017). Unfortunately, the methods described were not detailed enough to determine if the community members that participated were individuals with lived experience with the issues in focus or more generally members of a geographic area. The authors selection of a concept mapping mixed method methodology was appealing in the way it highlighted how diverse groupings of individuals perceived the importance of various dimensions (Frerichs et al., 2017). This study also went deeper into the nuances of trust and vulnerability explaining that “trust is perceived differently among the involved parties due to imbalanced levels of vulnerability” (Frerichs et al., 2017, p. 183). This is certainly an area and methodology worthy of further consideration.

While not specifically focused on engagement within the coalition itself, Nageswaran et al. (2013) used social networking analysis to measure how various factors contributed to collaboration overall and the likelihood that agencies would collaborate to serve children with

special healthcare needs. Nageswaran et al. found that organizations who were actively participating in a local coalition were 1.5 times more likely to collaborate compared with those that were not. This finding caught my attention because of the larger potential implications that a coalition can have within a community to spawn engagement and greater coordination between health service providers.

One promising study by Berardo et al. (2014) focused on "micro-level" engagement in MSC and conflict. Using previous existing meeting minutes coded for analysis and exploratory interviews, Berardo et al. found that engagement in the collaborative increases when less dominant or less powerful voices are contributing to the discussion, this includes non-profits and especially members of tribes. While the authors acknowledged the limitations of the study and methods, they also described the innovative way they went about studying interactions asserting this may be one of the few studies of this kind. Berardo et al. suggested future implications for research and advised, "Such efforts should be geared towards developing more versatile coding schemes to clearly identify neutral engagement from clearly cooperative behavior" (p. 714).

The qualitative comparative case study conducted by McFall et al. (2005) touched on some of the limitations of using a case study approach when there is a need for broader applications for practice. While there were only three featured cases in the study, the researchers did highlight some of the tensions inherent in creating a sense of engagement and commitment in collaboratives. McFall et al. suggested, "Scaling back the demands of participation thus likely reduced participants' commitment and, through lower engagement, reduced community ownership of the coalition process" (p. 324). The study included interviews of 42 individuals across the three sites spanning nine different sectors. Community participation is frequently cited

throughout the study, but unfortunately, there is no evidence that those with lived experience were included.

Zakocs and Guckenburg (2007) conducted a case study of 13 sites receiving funding for substance use prevention to ascertain the relationship between key factors and coalition performance. They found coalitions outperformed lower performing coalitions when the coalition leader stayed in place for longer periods of time and was rated as effective in their work. They also did not find a relationship between successful collaborative efforts and presence of a diverse, multi-racial or multi-ethnic group (Zakocs & Guckenburg, 2007). Instead, they found that sites performed better when there was a diverse representation of local organizations and public sector representatives (Zakocs & Guckenburg, 2007). This finding supports the case for inclusion of diverse perspectives and voices, but focuses rather exclusively on formal sectors.

A case study featuring four New Hampshire health collaboratives focused on how the collaborative as a whole perceived "meaningful community voice" (Shinn, 2012). "A collective expression of individual voices about community needs and concerns" was the common answer provided when asked to explain meaningful community voice (Shinn, 2012, p. 39). While there were limitations due to small sample size and administration of the focus groups, the findings were consistent with other studies that mentioned key challenges and facilitators of engagement of those with lived experience (Shinn, 2012). The likelihood that a collaborative would include and engage those directly impacted by local health issues decreased the more traditional the collaborative was in structure. Conversely, collaboratives founded on principles more aligned with grassroots organizing were likely to "be more aggressive in employing strategies to elicit and incorporate direct community voice" (Shinn, 2012, p. 58). Without these strategies to reduce

barriers to participation (such as stipends or onsite child supervision), it is hard to predict how much more included and engaged individuals would feel.

A multi-case study of three historically marginalized California communities by Garcia (2011) found that the CBPR framework itself contributes to engagement of individuals with lived experience. Garcia examined how women and youth participating in CBPR efforts were able to influence policy changes that had positive health impacts at the local level. In one of the sites, Garcia found that the women, "[as a result of their participation] have a belief in who they are, their contributions and the ability to institute change in community that had endured decades of environmental injustice" (p. 35–36).

Homer (2019) produced a practitioner guide with the help of an advisory group made up of representatives from across Canada who are involved in multi-sector poverty reduction collaboration. While the context was not specifically focused on community health collaboratives, the ten practical suggestions for how to engage those with lived experience in this practitioner guide mirror findings from other studies that highlight what makes for meaningful engagement. The 10 suggestions touched on values that repeat in the engagement literature: inclusion, power sharing, building of mutual respect, trust, and addressing barriers that would inhibit participation (Homer, 2019). One suggestion focused on the importance of creating both safety and diverse venues for discussion:

> Instead of a group calling in people with lived/living experience on demand to advise on internal operations, … consider resourcing autonomous and self-determining spaces for people with lived/living experience. These safer spaces allow the voices of lived/living experience to be heard. They empower people with lived/living experience to reflect on

> and discuss issues privately before bringing consensus proposals back to the larger group. (Homer, 2019, p. 13)

Another example featured in the guide described how social media was used to create a private chat space where those with lived experience could share and discuss safely before bringing issues forward to the multi-sector collaborative (Homer, 2019). These non-traditional ways of engaging are designed to foster inclusion.

The importance of trusting relationships and mutual respect were the most commonly cited contributors to both group and individual engagement (Homer, 2019; Lasker, 1997; Mattessich & Rausch, 2013; Mizrahi & Rosenthal, 2001; Prybil et al., 2014;). Skilled, committed leadership was also named as a contributor (Mattessich & Rausch, 2013; Zakos & Gukenburg, 2007). A number of studies touched on the challenges inherent in trying to facilitate inclusive, engaging collaboratives for community health (McFall et al., 2005; Shinn, 2012). While there was some commonality in the contributors of engagement that were named, there was also diversity in how these contributors were experienced depending on individual stakeholder groups queried (Frerichs et al., 2017). Across the studies reviewed that highlighted the benefits of multi-sector involvement of diverse stakeholders, it was difficult to tease out of the methods section how individuals with lived experience had been included in the collaborative, much less the study itself. Shinn (2012) did find that more traditional collaborative structures correlated with less likelihood of authentic engagement of those with lived experience. Comparatively, non-traditional ways of engaging were found to produce greater trust and were helpful in breaking down barriers that inhibit participation (Homer, 2019).

Situating Engagement of Those with Lived Experience Inside a Larger Phenomenon

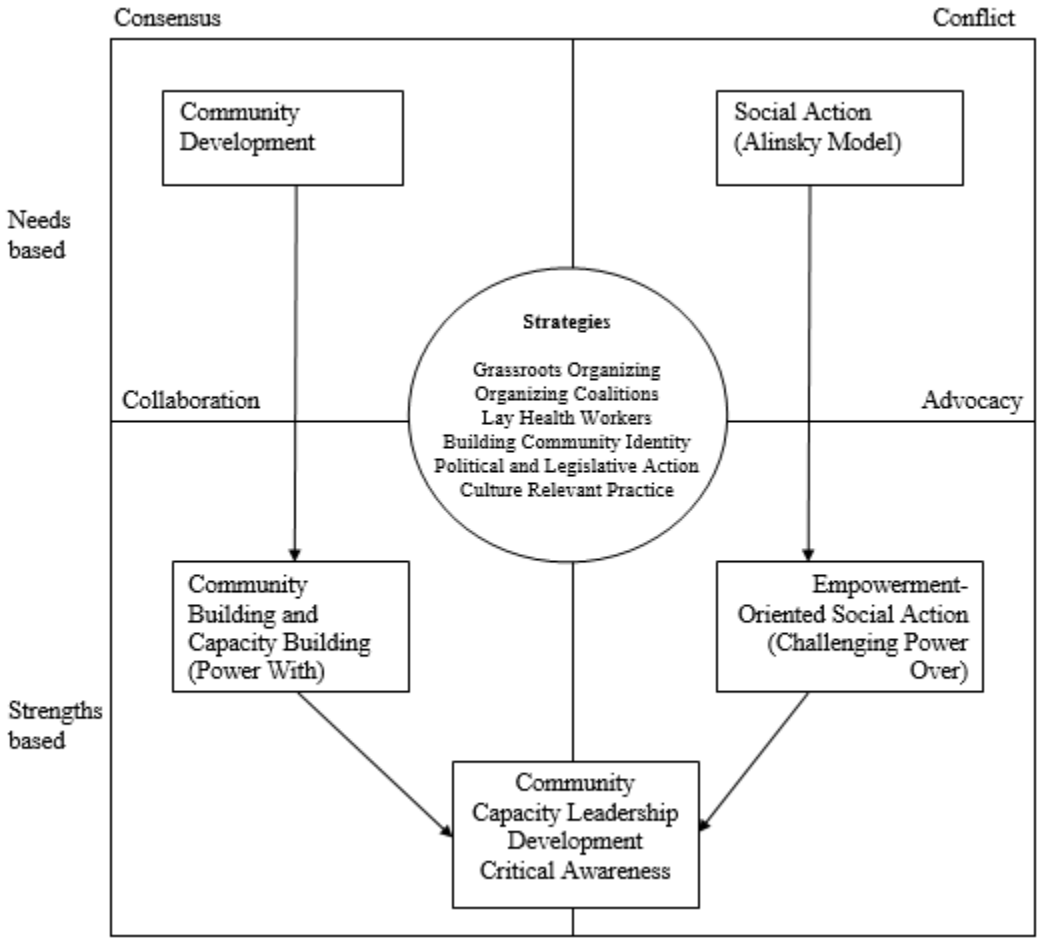
The abundance of engagement literature and research that touches on principles and practices of community organizing requires further explanation in this review. Community organizing as defined by Minkler and Wallerstein (2012) is "the process by which community groups are helped to identify common problems or targets, mobilize resources, and develop and implement strategies to reach their collective goals" (p. 37). A limitation in the research is the loose definition of community coupled with overuse of the term. Community is often used so broadly in the multi-sector literature that inclusion could be falsely assumed. Community engagement and participation also commonly appear in the literature associated with community organizing making it difficult to discern whether or not those with lived experience have been included (Butterfoss, 2006). Minkler and Wallerstein formulated a useful typology to capture the spectrum of community organizing models; the various methods are displayed in relationship to continuums that include needs based to strength based, consensus to conflict and collaboration to advocacy (see Figure 2.1). The typology highlights the absence of a single organizing approach to community building and shows how various strategies originated from classic works.

For the purposes of this study, I view community organizing as the larger phenomenon within which engagement of those with lived experience in community health change occurs through diverse strategies that are grounded in various theories and traditions. Understanding where a multi-sector collaborative for community health falls on any given continuum in the typology is a useful starting point for unpacking the organizing intentions. My experience with collaboratives has mostly been in the consensus, needs-based quadrant and minorly, in the consensus, strength-based quadrant. In the chapter that follows on methodology, I will describe

how cases will be identified and contextually described in relation to where they land on the typology.

Figure 2.1

Community Organizing and Community Building Typology



Note. Community Organizing and Community Building Typology from Morgan, M. A. & Lifshay, J. (2012). A ladder of community participation in public health. In M. Minkler (Ed.). *Community organizing and community building for health and welfare* (3rd ed., pp. 95–109). Rutgers University Press. https://doi.org/10.1080/10705422.2013.812438 Reprinted with permission.

Popular Education and Empowerment

Popular education overlaps a good portion of the right-side quadrants of Figure 2.1 having characteristics of Social Action and Empowerment-Oriented Social Action from the typology. The basic tenets of popular education are introduced in this section as a precursor for deeper discussion that will follow in Chapters IV and V. The emergence of the popular education movement in the United States can be traced back to Myles Horton's work at the Highlander school in the mountains of Tennessee where students of civil rights and labor organizing came together to learn, but it was also an international movement synonymous with Paulo Freire in Latin America (Freire, 2000; Wiggins, 2011). It should be noted that while Horton and Saul Alinsky agreed on a good many things about social organizing, Horton believed that education produces organizers and organizing and Alinsky believed in the power of organizing as a form of educating (Horton & Freire, 1990). Wiggins (2011) explains popular education to be: "a philosophy and methodology that aims to construct a just society by creating settings in which people who have historically lacked power can discover and expand their knowledge and use it to eliminate societal inequities" (p. 358). Social justice-oriented values and highly inclusive non-traditional teaching methods that integrate the arts and drama are characteristic of a popular education intervention (Wiggins et al., 2014). In 1981, Myles Horton famously spoke on camera with Bill Moyers about what makes popular education radical in comparison to other interventions:

> Official education is all about preparing people to fit into the systems and support the system and turn them into nuts and bolts to keep the system together. Highlander says, no, you can't use people that way. People are creative. You have to allow them to do a lot of things that don't fit any systems… There are a lot of dynamics and power in that that

> scares people…People have all this power that is suppressed. We have loyalty to people, not to institutions. (Smith, 1981)

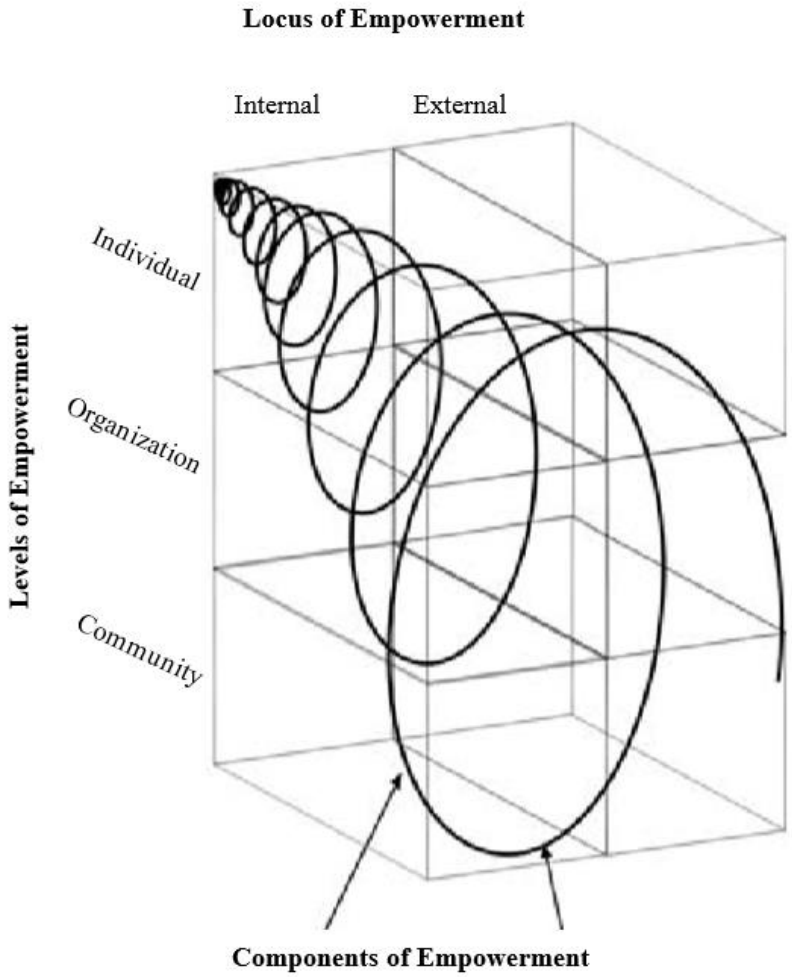
Horton's explanation demonstrates how power and wrestling with power imbalances is central to the conversations in the larger territory of community organizing. As such, Minkler and Wallerstein (2012) name empowerment as a necessity, inherent to the process of community organizing. Labonte (2012) explained, "The essence of community development (community organizing) is the transformation of these power relations such that there is more equity within and between institutions and groups" (p. 108). Fawcett et al. (1995) offer a broad definition of community empowerment as "the process of gaining influence over conditions that matter to people who share neighborhoods, workplaces, experiences, or concerns" (p. 679). Community empowerment focuses on capacity building and development, but must also include clear processes and means by which real change can be enacted alongside greater influence (Minkler, 2012).

The multi-dimensional nature of empowerment transpires at different levels and across different dimensions and is captured in the "Dimensions of Empowerment" figure by Wiggins (2011) shown in Figure 2.2. Wiggins (2010) stated: "Empowerment is generally acknowledged to have at least three levels: individual, organizational, and community" (p. 73). Additionally, another dimension of empowerment, identified as the "locus of empowerment" can be thought of as either the internal or external embodiment of empowerment happening at multiple levels (Wiggins, 2011). Finally, it is Wiggins' (2011) third dimension of empowerment that is so intriguing; the spiral shape illustrates the movement and growth inherent in empowerment theory as various dimensions and levels come into connection with one another and produce generative outcomes. MSCs for community health improvement are an ideal setting for studying the

dynamism of empowerment because of the different sectors involved, the gradients of power, and the complexities of change at the individual, organizational and community-wide levels.

Figure 2.2

Dimensions of Empowerment



Note. Dimensions of empowerment. From Wiggins, N. (2011). Popular education for health promotion and community empowerment: A review of literature. *Health Promotion International, 27(3),* 356–371. https://doi.org/10.1093/heapro/dar046 Reprinted with permission.

Himmelman (2001) goes deeper to discuss how empowerment can show up in the formation stages of coalitions and become rooted before other stakeholders are invited to participate and contribute. Coalitions engaged in what Himmelman terms collaborative empowerment build in mechanisms whereby external agencies are beholden to the practices established by grassroots community participants and not the other way around. This assertion is supported by a tool Wolff (2010) developed to assist coalitions in reflecting on the level of empowerment achieved in key processes of the coalition. The Coalition Empowerment Self-Assessment includes a series of descriptions of how empowerment would be expressed within the coalition along with open-ended reflective questions (Wolff, 2010). In the next section, I expound on additional tools aimed at measuring engagement. These tools may not directly tell us how individuals with lived experience would rate the presence of inclusive, engagement, but they do frame conditions that nurture engagement.

Measures of Engagement: Participation and Effective Collaboration

Numerous methods and scales exist to measure participation and effectiveness in collaborations that include both diverse sectors and individuals with lived experience contributing on behalf of the community. An early example is the Ladder of Citizen Partnership that was first published more than 50 years ago at a time when there was little discourse about the great range of ways community members were included in social change (Arnstein, 1969). Arnstein (1969) introduced strongly descriptive labels, such as “manipulation, placation and citizen control” (p. 217) to describe more precisely the level of participation that was taking place in a time when transparency about true intentions had been lacking. Arstein’s ladder has persisted and been adapted over the years, including the public health adaption by Morgan and Lifshay (2012) that features just seven instead of eight rungs and couples participatory

descriptions of each rung alongside examples of how the level of participation might be expressed in structural form. Both the original ladder and adaptations provide a way for efforts to assess how those with direct experience and knowledge of the issues in community being included (Wolff, 2010).

Partnership synergy was a measure featured in a mixed method study of 63 partnerships by Weiss et al. (2002), which found that leadership effectiveness and the efficient operation of partnerships were the two factors that most closely related to partnership synergy. Weiss et al. exploring the relationship between collaborative synergy and how the partnerships functioned did not find a strong relationship between community factors (e.g., trust and relationships) and the synergy of the partnership. Weiss et al. alluded to being surprised by this finding and said, "One possible explanation for these findings is that measuring partner involvement and conduciveness of the community to the work of the partnership as challenges was not an optimal measurement approach" (p. 694–695). While inconclusive, the authors did suggest that more study is warranted especially because of the growing acknowledgement that multi-sector partnerships are needed to solve complicated community health concerns and yet, many face collaboration challenges. The methods did not indicate how people in the partnerships were participating from a lived experience perspective, only that it was not uncommon for partnerships surveyed to be inclusive of those community members as participants.

Literature Summary

The predominance of theoretical works but relative lack of empirical studies examining the effectiveness of inclusive engagement of those with lived experience presents an opportunity for further research. The dominant lens of the empirical studies included in this review came from the position of the researcher. Researchers were by in large focused on process elements

and effectiveness of the collaboration on the whole. What was missing were studies focused on the experience of those with lived experience from their unique stakeholder perspective with an appreciation for the surrounding context. Rifkin (2009) writes about the dynamics that are missed when cause and effect research methods are applied to the study of this phenomenon. These factors include leadership, compassion, bonding relationships and building of partnerships. All these factors are difficult to quantify and are heavily influenced by community history, culture and social development (Rifkin, 2009).

This review confirmed that there are complex factors influencing engagement beginning foundationally with intent upon which the collaborative is formed. More can be learned about inclusion of those with lived experience, especially in the context of MSCs that have been convened by formal entities as opposed to driven by the community. Future studies will need to take this into consideration while also appreciating how larger contextual factors have shaped inclusive engagement in the MSC.

This review shows that the landscape is laden with calls for engagement of community members most closely impacted by health issues. Guidelines for engagement are also offered, but there is a shortage of real examples where these engagement guidelines and principles are thriving in practice. To get at the gap in research studies, future studies will need to discern the presence of intentional engagement of those with lived experience as distinct from general community engagement. This is supported by the finding that sources examining how community members generally are engaged are often lumped in with studies focused on engagement of individuals with lived experience. Focusing on community members broadly is a blunt approach, while careful discernment to ensure the individuals with actual lived or living experience are included is the precision needed for future studies.

Given the frequency with which trust and mutual respect were named in previous studies, more inquiry is needed to understand how those with lived experience working on MSCs perceive the role these elements play in engagement. Similarly, care and attention must be given to examining how power dynamics at the local level are attended to when applying asset-based processes (Mathie & Cunningham, 2005). It will be necessary to assess how power dynamics and power imbalances play out within MSCs and are managed effectively by the collaborative. There is a need to go deeper to see if community members with lived experience have real power and influence over aspects of the MSC that translate into major changes and impact.

Chapter III: Methodology

Chapter III introduces the study design and outlines how the proposed exploratory case study can answer the central question of what shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement. The timeline for conducting the study is described in this chapter as are limitations, ethical considerations and the processes used to protect participants. Readers will also be introduced to the feature case, a community health collaboration underway in the Gorge region of Oregon. Background context about the collaborative is shared as evidence of the match between case selected and research questions.

Introduction to Methodological Fit

A key test of quality research begins with evaluating how well does the method selected match the research question. My research inquiry requires a method that supports going deep into the case in focus to understand both how those with lived experience were inclusively engaged in the group process as well as how the surrounding context shaped engagement. For this reason, a case study methodology was selected. The case study methodology is a good match for research studies that seek to explore how or why questions where the context is as important as the phenomenon and a deep analysis will be conducted (Yin, 2014). The ability to go deep into analysis of the case itself as well as the surrounding context are important attributes of a case study researcher. Stake (2008) emphasized fascination with the case itself as the defining and special quality of case study research as a methodology. Yin (1999) also wrote, "The all-encompassing feature of a case study is its intense focus on a single phenomenon within its real-life context" (p. 1211).

In addition to Robert Yin and Robert Stake, Sharan Merriam is another methodologist most commonly recognized in the literature for shaping the rigorous application of case study methodology in practice (Yazan, 2015). Yazan (2015) wrote:

> Yin, Merriam and Stake have their own epistemic commitments which impact their perspectives on case study methodology and the principles and the steps they recommend the emerging researchers to adhere to while exploiting case study method in their research endeavor. (p. 137)

A theme across differing methodologist orientations is a respect in case study research that there are multiple variables interacting within various contexts that cannot be controlled, unlike a traditional experiment design (Baxter & Jack, 2008; Verschuren, 2003; Yin, 1999; Yin, 2014). Baxter and Jack (2008) explain the case study approach is grounded in a constructivist philosophy wherein, "constructivists claim that truth is relative and that it is dependent on one's perspective" (p. 545). This philosophy places emphasis on the multiple ways that people make meaning of the world. The complex nature of exploring engagement within the context of multi-sector collaboration (MSC) lends itself to a methodology like case study research. The qualitative, exploratory techniques support the study and analysis of varied contexts (social, political, cultural, etc.) that encompass the case in focus. This also aligns with my position as a researcher and the research skills I possess. Yin (2014) outlined three types of case study purposes, including exploratory, descriptive and explanatory. Case study, as a research method, includes both qualitative and quantitative methods of data collection and analysis (Yin, 2014). This study will be exploratory because it entails exploration of what happened among the participants to create inclusive engagement.

A key finding from the literature review was the paradox that has been created by the actions of funders combined with the entrance of new policy and regulation over the last two decades. This paradox is a source of challenge within MSCs in which influences from outside the community call for the inclusion of the voice of those with lived experience in collaborative efforts while also setting up conditions that are inevitably disengaging because of continued power imbalances, excessive bureaucratic process, and lack of action for change (Ganz & Reyes, 2019; Price, 2017). A real contribution to the field can be made by featuring a case that exists within this larger environmental context but has risen above the challenges and inclusively engaged those with lived experience. The purpose of this study explores the phenomenon of inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement.

Design of Study

Selecting the case and defining the bounds has been described by Yin (1999) as the most challenging aspect of case study research. “One of the common pitfalls associated with case study is that there is a tendency for researchers to attempt to answer a question that is too broad or a topic that has too many objectives for one study” (Baxter & Jack, 2008, p. 547). Boundaries are just as they sound; boundaries define the limits of what is within the design of the study and what is outside (Baxter & Jack, 2008). With this challenge forefront, I outline in the following section the selection of the Healthy Gorge Initiative (HGI) as the case selected, how I have scoped the boundaries, and I provide evidence as to why the case study methodology is a good fit.

Case Selection

The HGI was selected as the feature case in this study because of the notoriety the initiative has earned in the national community health improvement landscape. The Healthy Gorge Initiative was recognized by the Robert Wood Johnson Foundation in 2016 as a Culture of Health prize winning community. An important feature of this case is the existence of two interrelated councils. The first council is the Community Advisory Council (CAC) made up of community members with lived experiences of health and the issues the Healthy Gorge Initiative seeks to improve. The other is the Columbia Gorge Health Council (CGHC) which includes representatives from various sectors working and intersecting in the field of healthcare along with community members noted as consumers on the list of membership (Columbia Gorge Health Council, 2019). From what I have observed after analysis of materials available online, both the CAC and the CGHC are multi-sector collaborations (MSCs). Council members come from all different sectors and represent companies (private for-profit and non-profit), government agencies (public), and those with lived experience but not specifically associated with an agency or entity. The CAC meets monthly and draws roughly 40 or more participants to each meeting. There is a core group of individuals that are designated as voting members within the CAC, but many additional individuals attend consistently and participate in the meetings.

The Columbia Gorge region is in the northern part of Oregon roughly an hour drive east of Portland bordering the Columbia River that marks the Washington Oregon state border. Hood River, Oregon is the major town in the area and home to the HGI. The HGI has been spawning collaborative meetings for a number of years. This relatively well-established multi-year history was an important consideration when selecting HGI as the case. This history means councils

have had time to develop a track record of advising on community change initiatives as well as see the results of that advice.

Formation of the CAC was in part a result of a requirement for community engagement called for by the state of Oregon's Coordinated Care Organization (CCO) structure which mandates that the CCO form and engage with an advisory council made up of participants who have lived experience (Community Advisory Council, 2019; Dillon et al., 2019). Part of the unique context is the investment in community engagement that has been driven by the state level. Hodin and Tallant (2020) noted:

> Oregon has made substantial investments in this type of engagement. About a decade ago, the state embarked on an ambitious transformation initiative that established CCOs, local networks of health care providers that receive a global budget to serve Oregon Health Plan (OHP)/Medicaid enrollees. (p. 3)

The CAC advises inside the larger HGI, which is defined as, "a loose collaboration of community-based organizations (CBOs), healthcare providers, government agencies, public health, the region's CCO, early childhood, and K-12 education as well as state and regional funders" (Healthy Gorge Initiative, 2019, para. 6). The HGI has an impressive string of successes. In addition to being named a RWJF Culture of Health prize winning community, HGI has received over $11 million in grants since its 2013 formation (Lindberg, 2020a). HGI serves the Hood River County zip code and in 2020, Columbia County was ranked 3rd overall for health outcomes among 35 counties in the state of Oregon (Robert Wood Johnson Foundation County Health Rankings, 2020). In his role as a Collective Impact Health Specialist for the HGI, Lindberg (2019) writes that this significant number of awarded grants and successes, "reflect efforts to build trust, strengthen relationships, accept a common understanding of the

community's needs and, amplify the voices of those community members who traditionally have been kept out of the conversation" (para. 7). The combination of documented successes, improvements in key community health indicators and the commitment to community engagement makes this a unique case to study.

Dillon et al. (2019) wrote about the structural ways that the CGHC and CAC have addressed power dynamics directly to facilitate and raise up the voices of people with lived and living experience:

> Strategies used with the group include grouping vote tallies by consumer members, other voting members, and other participants separately; supporting involvement of consumer members in all facets of the meetings from strategic planning and agenda setting to facilitating meetings; and prioritizing consumer voices before other participants. (p. 371)

CAC members benefit from training and development opportunities as well as direct involvement in processes whether that be creation of agendas, planning efforts, exercises in priority setting, and participation in research (Dillon et al., 2019). These structural ways that power is addressed along with the membership make-up of the CGHC and CAC drove the decision on case study selection. The CGHC and CAC membership aligns with that of a MSC, This HGI MSC provides rich context that can help to answer the study's research questions regarding: (a) how are the dynamics of power handled and managed, (b) how does structure of the MSC make a difference in shaping engagement, and (c) what lessons can be derived from the meaningful ways that those with lived experience have been engaged in MSC work.

Data Collection Procedures

A multi-faceted data collection strategy that explores the various contributors to inclusive, engagement of those with lived experience aligns with the recommendations by Yin

(2014) and Stake (2008). Four types of data were collected in this study including: qualitative interviews, document review, observation, and digital material review. The different types of data collected was an important way I strengthened the case evidence overall and supported triangulation (Yazan, 2015; Yin, 1999). The procedures used for collecting each type of data are described in the section that follows.

I adhered to a process of purposeful selection in the identification of participants to be interviewed in this study which meant selecting individuals to interview based on the anticipated contributions they could make toward a better understanding of the research questions in focus (Creswell & Creswell, 2018). The names of all members of the CAC and CGHC are publicly available online. Meeting minutes also showed member participation over the last several years of meetings. I developed a proposed list of participants by cross-referencing meeting minute attendance to identify potential participants. A key criterion for inclusion was active participation in the CAC. I defined active participation as participation in at least four CAC meetings between 2018-2020. I reviewed the proposed participant list with an on-site case sponsor to identify members to send the recruitment letter. That same on-site case sponsor emailed the initial letter of introduction to the case study to various members of both the CAC and the CGHC. As a first priority, I sought to interview members who were designated as consumer members of the CAC. In order to explore the question of, what role do the perceptions of formal sector participants play in efforts to include those with lived experience, I also recruited participants to interview that represented other sectors to explore how these participants (e.g., from the public or private sector) perceive the value of inclusion of those with lived experience. These participants were labeled as agency partners. Staff were the final category of participants interviewed.

The timeline for recruitment took longer than initially estimated. This was in part because of the disorienting nature of the COVID-19 pandemic and because the on-site case sponsor wanted to be sure that participants had the autonomy to self-select as participants voluntarily. The on-site sponsor introduced the study during a voting member only CAC meeting and then, followed-up with the recruitment email. The recruitment email produced nearly immediate responses from participants volunteering to be a part of the study. Most replied directly within 1–3 days of receiving the email and scheduled their interview. I noted this response as indicative of the engagement of members within the CAC and their commitment to continuous learning.

Participants

A total of 15 participants voluntarily agreed to participate in an interview. I started with consumers first ensuring that what consumers identified as most meaningful to inclusion would be forefront as I interviewed the next group, agency partner participants. I waited to interview staff participants last so that I could explore questions that came up during interviews with consumer and agency partners. Participant demographics including age, gender, education and race are not included in Table 3.1 to ensure identity of participants are safeguarded.

Table 3.1

Study Participants

Participant ID	Participant Type
1C	Consumer
2C	Consumer
3C	Consumer
4C	Consumer
5C	Consumer
6C	Consumer
7C	Consumer
8A	Agency partner
9A	Agency partner

Participant ID	Participant Type
10A	Agency partner
11A	Agency partner
12A	Agency partner
13S	Staff
14S	Staff
15S	Staff

Interviewing

Interviews were semi-structured and encompassed open-ended questions exploring how participants with lived or living experience have been inclusively engaged in multi-sector collaborations (see appendix A for interview protocol). Qualitative interviews had to be conducted virtually via Zoom because of the risk of meeting in-person during the COVID-19 pandemic. All interviews were recorded with permission of participants and transcribed using the Zoom record on iCloud transcription feature. Each downloaded transcript was reviewed closely line by line while I replayed the interview recording and made corrections to ensure accuracy. This proved to be a useful part of the analysis as I came to know the transcripts extremely well.

The iterative nature of this exploratory care study required decision points along the way to determine additional questions that would be asked during interviews with participants later in the data collection period. Interviewing agency partners and staff of the CAC in the final stages allowed for a deeper exploration into various themes that emerged with consumer participants. Upon further review of the data, the first consumer participant was asked for a second follow-up interview and they agreed resulting in a more in-depth interview. A number of participants interviewed also suggested additional people to interview and various documents that would be helpful for review.

Additional Review

A detailed review of documents was an important aspect of data collection. I reviewed the last two years of meeting minutes for the CAC and CGHC. This document review supported the research process and filled in important contextual information needed to understand the context in which the phenomenon occurs. Besides meeting minutes, I also reviewed materials such as council charters, role descriptions for members participating, applications, and reports produced by the councils. Finally, several published studies and reports about projects in the region were reviewed. These studies and reports offered insight into surrounding context.

An additional form of qualitative data collection was collected through observation of meetings. I dialed into virtual CAC and CGHC scheduled meetings that occurred between March 2020 and November 2020. I used a practice of taking field notes during community meetings that involved following a loosely structured process organized around questions I wanted to understand better for this study. I referenced Emerson et al. (2011) book which features one chapter devoted to coding field notes with guidance on how to process observational data with integrity. The observational protocol I used for the field notes consisted of two columns, on the left were my direct observations (things I heard said or saw) and on the right, my perceptions or assessments about what I observed (Creswell & Creswell, 2018). Observations were typed concurrently and then, reviewed for analysis.

One final form of data was collected from the various digital materials available featuring the HGI. Videos, webpages, social media and a blog were among the materials accessible online for review. Some of these digital materials include commentary and stories from participants who have been a part of the initiatives and describe their experience making them particularly meaningful forms of data.

The sheer volume of additional data collected required organized methods of storage and naming for quick retrieval. I developed a file naming convention and followed it methodically. The web-based application Dedoose Version 8.3.35 (2020) to document all the data collected as a supportive analysis tool. Yin (2014) recommends developing a database as a primary means of organizing the data gathered and to provide transparency for readers who may desire to review the data archive. Features in the Dedoose application supported organization of the data.

Data Analysis

Creswell and Creswell (2018) describe a generative process for case study data analysis that allows for the concurrent review of data in conjunction with collection processes. Analysis in this way begins before data collection is complete. Analysis is also emergent as the case is explored and findings emerge that may require additional data collection in the form of follow-up inquiry. Stake (2008) wrote, “It [case study] gains credibility by thoroughly triangulating the descriptions and interpretations, not just in a single step, but continuously throughout the period of the study” (p. 120). Yin (2014) goes on to suggest approaching the analysis phase with a playful orientation, “searching for patterns, insights or concepts that seem promising” (p. 135). This allowed for an analysis strategy to unfold. Of the four strategies described by Yin (2014), the inductive strategy was the best match for this exploratory study. The inductive strategy is in keeping with the theme of digging into the data collected and seeing what emerges. This strategy was enhanced by my use of Dedoose to catalog information into the online application, making for an easier starting point when I was sorting and scanning through all the various information.

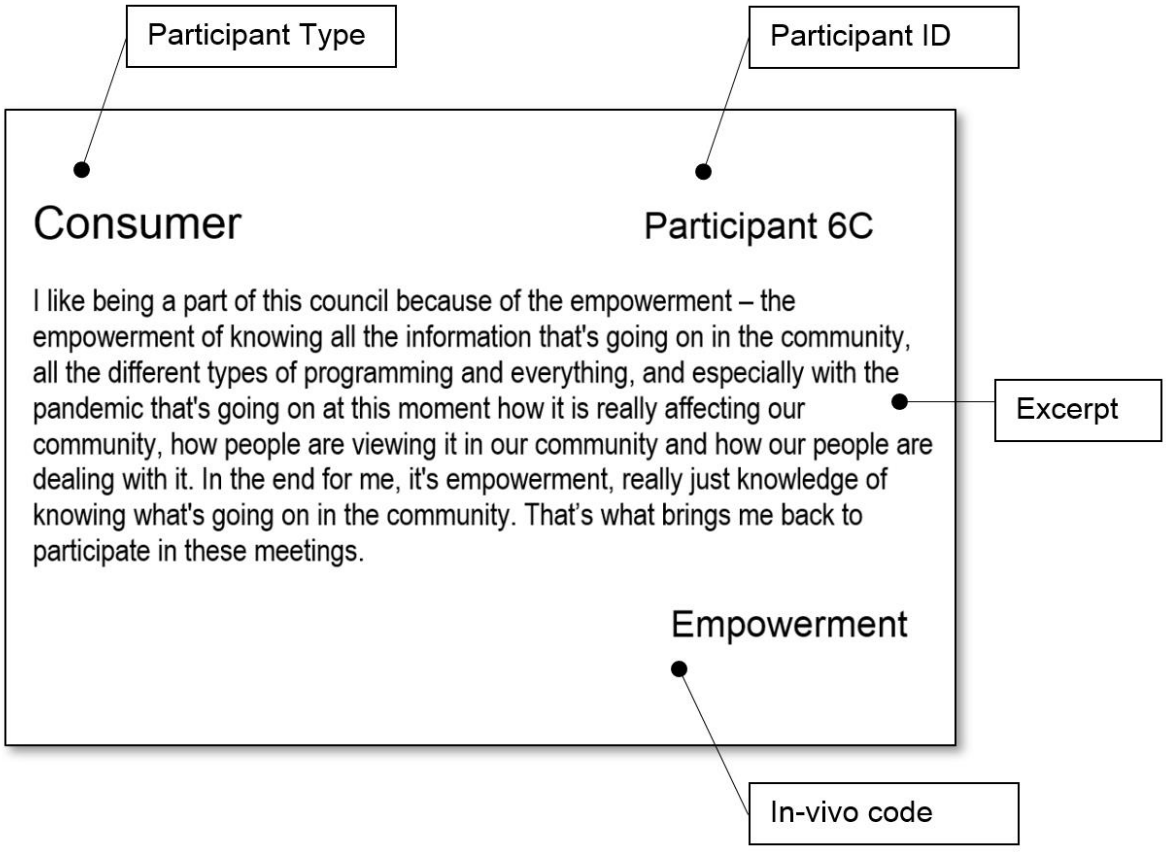
As a further step, both Yin (2014) and Creswell and Creswell (2018) described coding as a useful analysis method. Coding involved breaking the data down into smaller fragments and

then assigning a single word or several words to the excerpt. The unit of coding is referred to by Boyatzis (1998) as, “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (p. 63). Each of the 15 transcripts were uploaded to Dedoose after review for accuracy. I concurrently coded the transcripts even while additional interviews were being conducted. Initial coding of the 15 qualitative interviews resulted in 493 individual excerpts. Excerpts were coded using the in-vivo coding method of using participants’ own words to describe the essence of the participant excerpt. Codes were then grouped conceptually in Dedoose into a hierarchy of topical areas.

The next step of analysis was to cluster the excerpts thematically while noticing what emerged. To accomplish this, I opted to export and print all of the individual excerpts onto 3x5 inch cards (see Figure 3.1). Each card included the excerpt and for reference, the Participant ID, the Participant type, and any pre-labeled in-vivo codes from the exercise in Dedoose were also printed on the cards. Exporting the individual excerpts was an important step because it allowed me to interact with the data with a fresh perspective, freeing me from any preconceived groupings I had initially captured in Dedoose. Like type individual excerpts were first roughly sorted into small piles. As the piles grew, I would label the piles with a word to describe the theme that was emerging. Subsequent cleaning and sorting of themes led to the refinement of 10 themes with a cluster of related codes. Nine of the 10 themes contained five or more in-vivo codes and only two of the themes contained fewer.

Figure 3.1

Sample Card Showing Contents Printed



Themes that emerged from the qualitative interview data were cross walked with my observational field notes to identify overlapping themes. This process of triangulating several sources of data is one strategy for establishing study validity (Creswell & Creswell, 2018). To strengthen validity, I discussed the themes I was detecting with several colleagues who engaged with me by asking questions and testing my assessments; this additional validity strategy is recommended by Creswell and Creswell (2018). Qualitative reliability was achieved through the careful and detailed documentation of procedures and periodic checks for accuracy to prevent errors (e.g., accuracy of transcriptions and consistency of coding; Creswell & Creswell, 2018).

The additional sources of data collected were used to assist in answering the study question that asks what are the larger contextual factors that influence engagement of those with lived experience in MSC efforts. These additional data sources were also useful in achieving completeness by demonstrating a thorough review of all available contextual data sources were reviewed (Yin, 2014).

While organizing the 3x5 cards into themes, a dynamic interrelatedness emerged between themes. Upon describing this interrelatedness, E. Holloway (personal communication, October 9, 2020) suggested that domain analysis might be a useful analysis tool for meaning making. Leech and Onwuegbuzie (2007) explain, "Domain analysis should be used when researchers are interested in understanding relationships among concepts" (p. 571). Once the thematic groupings were identified, I labeled them as related domains noting the relationships within and between the domains using descriptive language consistent with participant language.

Limitations

McFall et al. (2005) touched on some of the limitations of using a case study approach when there is a need for broader applications for practice. Generalizability in case study research is addressed by Yin (2014), who notes this is a common concern. Yin (2014) describes a key distinction that "case studies, like experiments, are generalizable to theoretical propositions and not to populations or universes" (p. 21). This limitation of single case study design is an important concern to keep forefront during analysis and final composition.

Ethical Protections

Utmost care and sensitivity were taken to ensure the confidentiality and protection of human subjects who elected to participate voluntarily in the study. All participants were introduced to the study through a recruitment email letter with opportunity to ask questions and

provide informed consent. I did not anticipate potential risks of harm to the participants in this study. There was a chance that participants might have felt their time was wasted in the interview or kept them from other work, but I anticipated no greater risk than what they might have experienced on a typical day. Many participants ultimately reported that they experienced small or moderate benefit from reflecting on what contributes to inclusive, engagement of those with lived experience. For society-at-large, there is much to be learned about how MSCs inclusively engage those who have the most experience with the issues needing enhancement. This case has the potential to serve as a beacon for other communities seeking to lead this work in an inclusive and engaging way.

I received Institutional Review Board (IRB) approval for this study through Antioch University's IRB. This also required proof of certification in the Collaboration Institutional Training Initiative (CITI) program. I followed the protocol I outlined in my IRB application to safeguard confidentiality and dimmish the potential for negative outcomes. To safeguard confidentiality, I used study codes to code the interviews. I have maintained a study code document in a locked location separate from the interview that matches the participant to their interview transcription. First and last name, professional job title, date interviewed, and other identifiers are included on the study code document. The study code keeps the identity of participants confidential. I also made every effort possible to write up my research in such a way that responses cannot be connected to participant identity. The informed consent form clearly explained that any participant who chose not to participate would not suffer any consequences. When I reviewed the informed consent at the start of interviews, I reinforced that they could choose to discontinue at any time.

The rural Gorge region is fortunate to have support from the Community Health Advocacy and Research Alliance (CHARA). Founded in 2013, CHARA was formed because of community members wanted to be engaged in research and wanted to see how health was improved as a result of initiatives (Dillon et al., 2019). CHARA helped fill a need during a time when requests to study the community were increasing. Dillon et al. (2019) wrote, "It became apparent that there was a need for alignment across these research efforts, and local leaders agreed to explore establishing a centralized hub to manage requests from researchers interested in working in the region and to secure support for program evaluation and research to address local needs" (p. 375). A representative of CHARA requested that I present back findings following the completion of this study.

Role of Researcher

The macro context in which this case exists is of special interest to me and a context that I have some familiarity with as a healthcare leader working in the Pacific Northwest. I have worked with hospitals on community health improvement collaboratives in both Washington and Oregon. Both states have created structures to engage Medicaid beneficiaries as well as health and social service agencies (private and public) in the work of transforming how health services are delivered to produce improved population health outcomes. In Washington state, this structure is called Accountable Communities of Health (ACH) and in Oregon, the structure is the Coordinated Care Organization (CCO).

The hospitals that I work for receive incentive payments to engage in the work of the ACH and CCOs within their geographic areas of service. I have been especially impressed with the efforts to engage those with direct lived experience in the community health improvement work. Some ACHs and CCOs have formed advisory councils or committees made up of these

members and others have established governing board seats to be specifically filled by a proportion of those with lived experience. While I have familiarity with the case selected through a colleague who worked there years ago, I personally do not have any connections or contact with individuals in the community and the hospital system I work for does not operate services in that geographic area.

My past experiences serving on MSCs has certainly shaped the way I make meaning and form interpretations. This is especially true of the negative MSC experiences I have had and what I have heard from participants with lived experience who have felt tokenized by the process. These stories have left a lasting impression and made me prone to looking for the underrepresented or minority experiences.

Summary

The case study methodology supports a deep exploration into a case example known for lifting up the voices of those with lived experience in the work of community health improvement. The feature case from the Gorge contains a number of elements that align with the research questions at the center of this study. Most notably, the HGI has received national recognition for its methods of engagement, has improved community health indicators, and has been awarded millions in grant funding (Lindberg, 2019; Robert Wood Johnson Foundation County Health Rankings, 2020). Additionally, the structure of community health collaboration in the HGI occurs through a MSC structure. This enabled exploration of the research question—what shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement. Contained in this question, the reference to what shapes inclusive engagement was intended to get at the aspects of inclusive engagement

that may not be easily visible and require dialogue and probing of participant experience to get at the various influences, conditions, and interactions that are perceived as meaningful.

The case study design included multiple tools for data collection, with semi-structured interviews serving as the primary data collection tool supported by other data sources needed for triangulation. Data analysis consisted of a generative process that allowed for findings to emerge as the case was explored. Both observational notes and transcribed notes were coded for themes. Confidentiality and protection of human subjects was safeguarded through careful documentation, clear communication, and informed consent. In combination with intentional case selection, the methods supported exploration of the conditions that maximize engagement of those participants in MSCs in which engagement is viewed as a critical factor needed to produce improved community health outcomes.

Chapter IV: Results

The purpose of Chapter IV is to report the results of the Healthy Gorge case study. Chapter III included an initial introduction to the Healthy Gorge Initiative (HGI) and explained why the HGI was selected as the feature case in this study. Before advancing to the presentation of results, additional context will be provided. This will be followed by an explanation of how the results are organized and a review of the analysis tools utilized in this study. The featured results answer the research question—what shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement.

Context

The added contextual details were mostly derived from participant interviews and publicly available materials which frame the case from the perspective of those actively involved. Community health improvement activities are the central work of the HGI and the vehicle that makes this possible is the two-council governing structure. All participating study participants were active members of the Community Advisory Council (CAC) at the time this study was published. Additionally, four of the 15 study participants also served on the Columbia Gorge Health Council (CGHC). The majority of CAC voting members are first and foremost community members who have living or lived experience with the health issues and social determinants that the HGI seeks to improve. Other members represent various sectors of health and social services and are herein referred to as CAC agency partner members.

The results that follow place the perspectives of consumer participants and how they experience inclusive engagement in the CAC in the foreground. In the background are the important structures that facilitate and raise the voices of members with lived and living experience. Agency Partner 9A noted that the CAC evolved in fertile conditions with the help of

supportive structures, explaining: “This region has a history of incredible collaborative efforts together. It's like planting a seed in a rich soil. I think we had rich soil at the beginning. And the idea was able to take off.” Speaking to the significance of having the right structure supporting the work, Agency Participant 9A added:

> I’ve been a part of collaborative and coordination entities for a very long time. Probably for a significant portion of my career and there's something that is right about the way that this is structured that other coordination entities haven’t necessarily gotten right. And I think that it has to do with the authority that is given to the CAC and that our Health Council supports in decision making. It’s connected to the CCO, connected to the insurer, connected to metrics, and connected to incentives, so that there really is a very empowered connected opportunity.

While the formation of the CAC was indeed a state level requirement mandated by Oregon’s CCO structure, participants were quick to share that the methods and ways of working are unique to the CAC in each region. Overseeing the Community Health Assessment (CHA) and the Community Health Improvement Plan (CHIP) are the two principal community health activities being driven out of the CAC. These activities hold regional influence and significance and are documented in the CAC Charter. The Columbia Gorge Health Council (2020) has posted the CAC Charter online as follows:

> **Community Advisory Council (CAC) Mission**: We identify needs, barriers, and opportunities in the Columbia Gorge. At the same time, we advocate for solutions that support health and well-being in the region.
>
> **CAC Vision:** We envision a region of communities where all people enjoy improved health through equitable access to and engagement with coordinated resources.

CAC Values:

- Engage
- Collaborate
- Be transparent
- Be inclusive
- Ensure equity
- Ensure diversity
- Empower

Additionally, the authority to make funding decisions is a key way that the CAC has been structurally empowered in the region. Staff described that a key turning point occurred in 2016 when the CGHC designated over a $1 million to the CAC thereby granting them the authority to decide where those funds would be invested in the community. Agency Partner 11A acknowledged how uncomfortable this was at first for agency participants who have now come to appreciate the significance of not only having funds to distribute, but also the power to set the CHIP priorities.

Staff Participant 14S talked in detail about the important role the CAC plays in setting the common agenda for the community within the context of the Collective Impact framework:

> The CAC becomes an anchor for relationships because the CAC and the CHIP that it produces is our common agenda that everyone agrees are our top needs. The sheer fact that we have the CAC venue and the common agenda and the regular meetings allows anyone to hold that up and say, this is what our real goal is (e.g., reduce food insecurity). It's not to make sure that your organization stays alive or you get this one particular grant. It's a goal to ensure that we do the best job collectively to meet that real goal.

The context added by study participants shows the trajectory of a community collaboration that has developed trust and influence over time, bolstered by structure and delegated authority. Table 4.1 lays out the timeline of key events occurring in the HGI.

Table 4.1

Timeline of Key Events

Date	Event
2012	Oregon legislature passes bill that requires CCOs to establish a CAC (Hodin & Tallant, 2020)
	Formation of the CAC
2013	Community Health Advocacy and Research Alliance (CHARA) founded
2014	Annual statewide CAC conferences initiated to share learning
	Collective Impact Health Specialist hired to pursue grants
2016	HGI awarded Robert Wood Johnson Culture of Health prize
	CGHC allocates over $1 million to CAC to allocate to health initiatives
2018	Transition in CAC coordinator and chair role
2019	CAC members grieve sudden death of consumer member and her dog
	Stipend raised to $50 per meeting
	Columbia Gorge publishes 3rd regional Community Health Assessment
	In-meeting translation from English to Spanish begins
2020	Oregon CCO 2.0 released
	Hired new Executive Director Columbia Gorge Health Council (CGHC)
	COVID-19 pandemic shifts all in-person meetings to virtual

The events included in Table 4.1 reflect key occurrences that study participants discussed in their interviews. Role transitions, funding inputs, external recognition, release of new or updated

regulations, and changes to CAC meeting processes were discussed as having a memorable influence on engagement.

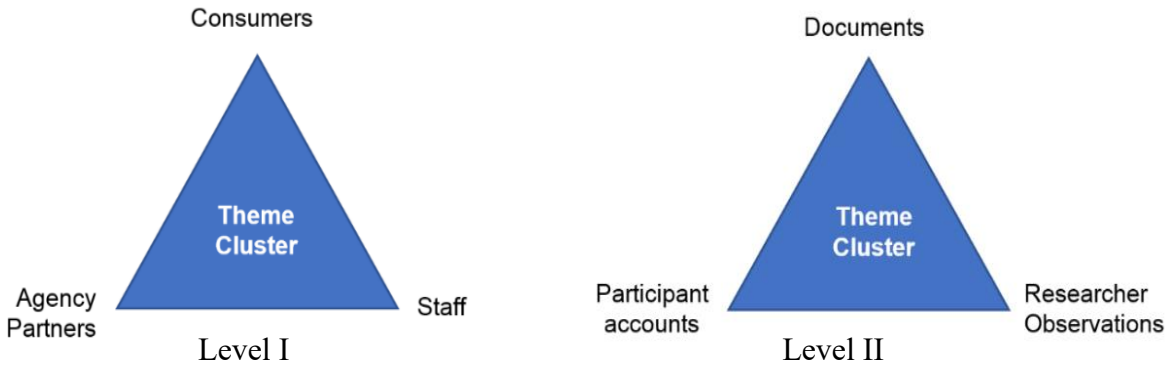
Results

Results are organized around the central question of this study—what shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement. The key contributors shaping inclusive engagement were explored from three perspectives. Consumer members provided direct responses to questions about what attracted them to participate in the CAC, what has been the most meaningful aspects of participation and how they have felt included. CAC agency partner members were asked to reflect on what happens in meetings that helps members feel included and the outcomes of inclusion of members with lived experience. The third perspective came from staff participants who illuminated important context for the case and shared their insights and learning based on years of facilitative practice inside the CAC. All study participants were asked to describe how power shows up in the CAC, the changes they've seen in the community as a result of the CAC, and how they have seen authentic engagement and collaboration practiced.

The presentation of results is arranged to show two different types of triangulation as illustrated in Figure 4.1. The first level describes each theme using sample excerpts from each of the three perspectives (consumer, agency partner, and staff). Additionally, for each domain, a feature example in practice is described to illustrate a second level of triangulation resulting from a comparison of researcher observation, participant account and documented evidence in publicly available materials collected. As described previously in Chapter III, the domains serve to label and categorize the dynamic interrelatedness that emerged between themes in this study.

Figure 4.1

Depicting Results Triangulation at Two Levels



I outline results beginning with a description of the domain followed by the themes contained within each domain. A summary of the overall results is shown in Table 4.2. In addition to the themes, I have included the in-vivo codes that clustered into each theme. The in-vivo codes feature the participants' own language. Results are presented within the context of the domain in which they are categorized. The three domains: (1) Heart, (2) Interaction, and (3) Outcomes build on one another, each adding insight into the research question—what shapes inclusive engagement of participants with lived or living experience. I found that a single domain without the others was insufficient in answering the research question. It is the relationships between the domains and mutuality that best captures the way that participants described inclusive engagement. Wherever possible, I have used plain language to describe the results. This is out of respect for the value that participants placed on making communications accessible and easy to comprehend.

Table 4.2

Results Organized by Domains, Themes, and In-Vivo Codes

Domain	Themes	Themes continued…
Heart	**Care**	**Elevated Consumer Voice**
	Difference in life of person	Bring my voice
	Do best by their community	Consumer voice has more weight
	Impacted by	Elevate consumer voice
	Ingrained in us	Make sure you get heard
	Losing members	More about consumers
	Really care	Preserve voice
	Serve	Space for sharing
	True friends	Value people
		Respect
	Authentic	Very real grounding
	Actually present	
	We go more authentically	
	Let guard down	
	Realness	
	See one another as human	
	Sincerity	
	True authentic engagement	
	Voicing realness	
Interaction	**Deliberately Informal**	**Continuous Improvement**
	Feel familiar	Continuous improvement
	Good vibe	Integrating feedback
	Humanizing	Meeting evaluation
	Let guard down	Tracking progress
	Lowers barriers	Voting member only meetings
	Open and honest	
	Plain language	**Inclusive Facilitation Shared**
	Welcoming	Applying popular education
		Attentive
	Democratic Process	Challenged us to be better
	Addressing participation barriers	CHW mentors
	Democratic	Co-creating agendas
	Like the United Nations	Encouragement
	Part of process	Everyone has chance to speak
	Practicing equity	Hold space
	Sharing power	Self-aware
	Voting process	Supportive listening
		Use variety of techniques
Outcomes	**Empowerment**	**Collective Power & Resilience**
	Collaboration	Attracts high participation
	Consumers have power	Navigating tension
	Empowering	Nimble
	Learning is empowering	Powerful together
	Really be heard	United
	Unstoppable force	
	Community Change	
	Better design	
	Community partner change	
	Creates ripples	
	Made a difference	

Domain of Heart

The domain of heart describes the core anchoring values and intention beating at the center of the CAC and rippling out to the other domains. Heart conjures up the active not static way that all members of the CAC are shaping an atmosphere of care, authenticity, and elevated consumer voice. Table 4.2 includes the various in-vivo codes clustered within these three themes. Consumer participants described these attributes as both part of the draw to the CAC as well as serving as an anchoring point from which they and others engaged. Hence, the label of heart for this domain was given. Similar to the anatomy of a human heart which pumps oxygen-rich blood throughout the body, the domain of heart provides a visual inspiration for the phenomenon at work in the CAC.

Theme: Care. Participants described care in terms of both an intention of caring and an expression of caring for one another and the larger community. Consumers and agency partners even used the word love on occasion to describe other CAC members that they had come to know. Others, like Participant 4C, described becoming "true friends" with another member as their relationship grew over time through mutual respect. Seeing others as "really caring" was a frequently described by participants. Consumer Participant 1C said:

> There's a little bit of a kind of a camaraderie, or a shared support system there. Because like I said, most of the people have a social service background of some kind or deal with the public... It seems they really care about this. Like I said, it's not just a job that they go to, it's something they really want to participate in and when you have people around like that, it just makes you feel at ease.

Consumer participants noticed care being expressed in the CAC and placed value on the expression of caring. Consumer participants also experienced caring as a form of respect and

value for their contributions. Consumer Participant 1C added: “We respect one another and value each other for what we can bring. It’s kind of ingrained in us; that’s just the way people are.” The presence of genuine caring contributed to the atmosphere of the CAC, which, in turn, contributed to the sense of inclusion experienced by consumer participants.

Conveying urgency of community needs was another way that CAC members demonstrated the theme of care. Staff Participant 13S recalled a time when a consumer passionately spoke about the needs for housing, saying:

> One lady was advocating and she was almost like screaming like we need to pay attention to housing. Housing is one of the needs that is needed here in our communities. It’s costly. There’s not enough low-income housing here. We need help here and we need help as quick as possible. …These people really, they’re not only here to take a seat in the community on the board. They're here to make a difference. They’re here because they are passionate about making a difference for their community and they know the needs and they live here and they love this community.

I found it notable that passion in this example was interpreted by the staff person as love and care for community. Even though the staff person described that the lady was almost screaming in the meeting about the needs present in the community, there was no mention by the staff person that this was conflictual. Vocalizing care had become commonplace and normative in the group. This is further evidence of how care is one of the defining anchoring values of the CAC.

Care was expressed in caring about one another and caring about the larger community. Participants were able to describe their own motivation of caring and wanting to make a difference. They also described feeling a sense of unity that this motivation was shared by other CAC members. Agency Partner 11A shared perspective on how funding decisions were acts of

care: “Like maybe if we fund this program, it’ll make a difference in the life of this person we’ve actually come to be in relationship with, even if it’s not a super deep relationship but it’s a regular dialogue.” Another agency partner talked about being deeply impacted and caring about one consumer member in particular who despite working at a professional job still struggles to have their basic needs met. Similar to the perspectives of consumer participants who experienced care as a form of respect, agency partners also shared examples of respect manifesting from a foundation of care. Agency Partner 8A responded to what has been most meaningful about participating on the CAC and said:

> I think it’s been the opportunity for me to sit at the table with people that have the lived experience, I almost don’t like to call them consumers, but people with that important lived experiences that we can learn from and then, some of the people that are in leadership positions, there is that opportunity to be elbow to elbow and to learn and find out how can we really integrate the way we want to help care for people.

Agency Partner 8A’s concern about the label of consumer not fully respecting the value and important contributions of those with lived experience is indicative of underlying care. In the domain of heart themes that follow, I demonstrate how the CAC’s foundation of “care” unites with other core anchoring values—authentic and elevated consumer voice—to facilitate inclusive interactions and powerful outcomes.

Theme: Authentic. Authentic engagement is described on the Healthy Gorge website as one of two ingredients in the secret sauce that makes the Healthy Gorge regional work so successful. Participants described authenticity as an unguarded realness characterized by being truly present with one another and receiving the same sincerity in return. Agency Participant 10A said: “The collaboration seems very, very real and very deep and multifaceted.”

In addition, several participants described the authentic atmosphere as a shared understanding. Consumer Participant 5C said, “It’s like a place where everybody has kind of an understanding that you can let your guard down. Even if you’re on the business side, you can let your guard down and be like, this is the reality.” Consumer Participant 2C said something very similar, saying: “Overall, I see that that's actually just an unsaid understanding that they all listen to what everybody has to say with the same sincerity and interest as every other person.” These descriptions are reflective of an authentic atmosphere within the CAC where participants experience self and others presenting authentically as unguarded, sincere, and caring. Comments also reflected an openness and receptivity among CAC members to hear the hard truths about how health systems and services might be failing their consumers.

Staff participant 14S demonstrates how the value of authenticity shows up as a key driver influencing engagement practices from the beginning of setting any agenda:

> True authentic community engagement is “let’s talk about what the needs are, let’s talk about what the menu items are, and then, let’s talk about you all choosing which you think is most important and/or what could be most effective.” So, it’s including that voice of individuals in those conversations from the very, very beginning. It’s not just having a meeting where we present a bunch of information and ask them to choose from options that they had not input into or frankly even what the questions were.

The themes of authentic and care were closely intertwined in the ways that participants described the heart or core of the CAC. Authentic and care were used in both active tense and as adjectives by participants, but their presence and importance were undeniable in the shaping of the CAC atmosphere. This was similarly true for the next theme which is also situated in the domain of heart.

Theme: Elevated Consumer Voice. Across all interviews, elevating the voice of the consumer was held up as a core anchoring value of the CAC. When consumer participants were asked about how their lived experience was respected and what they found most meaningful, they commented on the experience of having their voice elevated. Consumer Participant 4C framed it this way:

> I think everything that we say as a representing consumer member is given a little more weight. And I don't mean that in a negative way. I mean, not that everybody else who works for agencies aren't important. But you're especially listened to if you're a consumer member because you're speaking for the consumers not for an agency. So, I think that's very empowering.

Consumer Participant 4C explained further that this elevation of consumer voice was rooted in a value and a respect for experience. Other consumers identified with the role of speaking up as if it were a job. Consumer Participant 7C said: "Being part of this CAC is also unique because in a way we get to do or speak for those that are not able to be there or make the meeting. So, I really feel special." Elevating consumer voice was a value shared by those bringing the consumer voice forward and equally important, a value for those making space for consumer voice.

Staff of the CAC play a key role in holding up this value and holding open the space, but as will be presented in the next section, staff do not solely facilitate the expression of this value for elevating the consumer voice. Staff Participant 15S explained,

> [We] try very hard to create an environment, recognizing that there is a space held out for the consumer voice but all voices are welcome. And it's a balance, right, because I think that community partners are used to these large meetings and they're used to sharing their

> voice and they are there in their role as a community partner so they feel responsible for talking to everybody about what their role is. But if we do that, then we drown out our consumer voice, which is really the reason why we're there.

Agency partner comments mirrored this understanding that consumer voice is the central reason the CAC exists. “I think there's an overall feeling of people trying to be, ‘*it doesn't matter who you are*.’ The consumer voice is a priority,” commented Agency Partner 8A. Agency Partner 10A added, “In the CAC there’s an intention to remove some of the barriers around power dynamics and elevate the voices of people with lived experience and who are the consumer members.”

Domain of Heart Observed. I experienced this domain illustrated firsthand when I heard and saw the memory of a past consumer member honored. Karen was a long-standing consumer member of the CAC who attended with her service dog Steve. Both Karen and Steve were beloved. Tragically, Steve was hit by a car in February 2019 and Karen died from grief having laid down beside him, at the young age of 55. Karen and Steve’s passing were noted in CAC meeting minutes a month later when the group met on March 18, 2019. The meeting minutes noted the group were led through a remembrance for Karen that culminated in stories shared about how both Karen and Steve brought joy to the lives of many.

When I started observing meetings a year later in March 2020, the loss of Karen and Steve was still present in the hearts of those I met and talked with. When asked about what has been particularly meaningful about participating on the CAC, Consumer Participant 3C spoke about experiencing loss together, supporting one another, and healing as a group. Karen’s memory came up again on a call with Agency Partner 11A when asked about the most meaningful aspects of participating. There was a long pause as the participant stepped away from

the computer screen only to return moments later having retrieved Karen's memorial service booklet. Holding the booklet, they described to me the loss felt when Karen passed away. Then, they went on to describe the loss of another consumer member as well as his son who died of diabetes. Agency Partner 11A said:

> We watch people up close, really, really struggle with their health and then they couldn't get the care that they needed. The system just didn't work for them. So those were powerful experiences I think for all of us. And one of the things I noticed was that it was pretty unusual to have like the Oregon Health Authority liaison and the members of the CAC coming to funerals and singing and crying and missing people.

I was so struck by that interview. More than a year later, Karen was loved and her memory had a place displayed on the shelf of an agency partner. This whole tragic storyline illustrated so well what Consumer Participant 5C shared about how the CAC was a "a place where everybody can let your guard down" and see the reality. Agency partners and consumers alike were describing what comes from the intersection of caring authentically about people and being in a space where the consumer voice really is honored and lifted up above all other experiences.

Reading far back in the meeting minutes to the times when Karen was actively participating on the CAC, her voice and experience left a lasting legacy. Agency Partner 8A said, "I think she was such a great advocate for that and she studied, she studied all the time … So, she was an outstanding consumer member that we had and really challenged us to look much deeper." Agency Partner 9A echoed those statements, saying, "Karen was a special person and brought her bravery and her honesty about her experience." All in all, five study participants, including two consumer members and three agency partners, brought up the memory of Karen,

often emotionally recounting the impact her life experience, her leadership as a consumer member, and her passing had on their life and the way they engage in the CAC.

Domain of Interaction

The domain of heart is at the core of the CAC radiating outward shaping the domain of interaction. It is in this domain where action can be observed. These actions I observed and heard participants describe do not exist outside the context of the anchoring values of the heart domain. Those values are expressed through interaction between participants acting from a base of shared values. Four themes make up the domain of interaction; they are: deliberately informal, democratic, inclusive facilitation shared, and continuous improvement. Refer to Table 4.2 for a listing of the in-vivo codes clustered with each of these four themes. Each theme is distinct and interdependently related to the other themes within the domain of interaction. This produces the unique set of interactions that make the CAC an exemplar case for inclusion of those with lived experience in community health collaboration.

Theme: Deliberately Informal. Comfortable, at ease, at home, and welcoming are among the ways that participants described the experience of participating in CAC meetings. "It's a good vibe and it's not like a usual meeting to go to," said Consumer Participant 7C. "This group makes you feel more comfortable, they feel familiar," added Consumer Participant 3C. Feeling at ease and comfortable was noted by consumer members as part of what made them feel included in CAC meetings. Consumer Participant 1C recalled feeling unsure about attending the first meeting and not knowing what to expect:

> When I came in the door, I saw all these people are dressed up, and I was like oh my goodness… You know, I don't have dressy clothes or anything and then, everyone started talking. It just made me feel more at ease.

The comment, “then, everyone started talking,” was a sentiment that other consumer members shared. So, while first impressions might have been a little intimidating, such as professionals coming straight from the office dressed in formal clothes, the environment inside the meeting and the interactions put people at ease allowing them to let down their guard.

The staff participants also commented on the vibe and how it compares to other meetings. Staff Participant 15S discussed serving on a number of different boards and how different they can be:

> I'm on three other boards as a board member and I see the difference between the various ones. I know which ones that I feel like I really contribute to and which ones are having meaningful conversations and meaningful relationships and which ones are feeling stuffy, stifled and limited. I think when they're stuffy and stifled, then you don't hear from the different voices, because people aren't willing to be wrong or they're afraid to be wrong. And so that is very intentional and our hope is that all of our board meetings can be more like.

Agency partners also see the value in the deliberately informal tone of the meetings. “The best thing that can happen is that we don’t wear name tags in this meeting and we just really get in there and look at the issues,” commented Agency Partner 8A. The shedding of formality in meetings enhances the sense of inclusion that all are welcome and welcomed to come as they are. Use of humor was another way that participants cultivated informality. Agency Participant 10A said, “Consumer members sometimes bring an element of humor to our group that those who are in a more professional role—that's not how they would naturally engage … I think that humanizes our relationships in a different way.”

This willingness to be silly with one another and shed formal personas was on display at the virtual August 2020 CAC meeting. As members were waiting for everyone to join the

meeting, one member broke out briefly in song, “I don’t want a pickle, I just wanna ride my motorcycle.” Others joined in spontaneously reciting together the first couple lines of Arlo Guthrie’s Motorcycle Song, “I don’t wanna die, I just want to ride my motorcycle.” Others laughed and smiled and in that short moment, a message was conveyed that the space was welcoming and safe. It was safe enough to break out in spontaneous song.

The commitment to simplify language used in meetings and materials and ensure accessibility for all is another way that the theme of deliberately informal presented in CAC interactions. Language used inside community collaboration work can be a source discontent. When people in professional roles use industry terms or unfamiliar nomenclature, disconnects can emerge between the professionals and those outside the profession. The CAC has deliberately worked to prevent this disconnect by committing to both use plain language in meetings and make sure that outreach materials are written in plain language (e.g., surveys, plans, etc.). These are additional ways that members take action together to establish a deliberately informal tone inside and outside the CAC. Numerous consumers spoke about the use of plain language as an accomplishment and important outcome of the CAC.

I observed that typical meeting processes were followed in both CAC and CGHC meetings, such as Robert’s Rules of Order, agendas, assigned roles, and focused presentations. However, the way this was carried out in the CAC meetings differed substantially in tone and feel compared to the CGHC. Others also spoke to how this informal tone has not quite seeped over from the CAC to the CGHC. Agency Participant 11A spoke about the use of popular education Dinámicas (dramas) and an attempt they made to try to bring those to the CGHC, explaining:

> Some of the very same exercises we've done in the CAC and the feeling of the CGHC board is like, '*no way we can't do that'* —this sort of professionalism wouldn't allow for it. But in fact, I think what we found at the CAC is a case study for these groups that consider themselves more serious and important. If they would let their hair down and goof around a little bit, together they'd probably get a lot more done.

I sensed a lightness in the CAC almost instantly when I attended meetings. The tone conveyed a sense that all are welcome, there is no wrong question, and come as you are. This came across in the way people greeted each other informally like friends, the way meetings seamlessly transitioned from easy conversation into the topics of the day, and the way people were included throughout. CAC members have been able to establish a deliberately informal tone that pervades the CAC. This is important because consumer members indicated that feeling at home in the meetings, the use of plain language, and lack of formality really matter to how they feel included and at ease in the meetings. A little bit of goofing around and showing humanness matters.

Staff Participant 15S shares that this is deliberate,

> [We] are really good at being humble and really open with our mistakes and our errors and our flubs. And just being like, "Oh, we totally screwed up or we don't know what we're doing right now" to show that we're not more important or we don't have the answers. We're learning alongside everybody.

I regularly observed the staff demonstrating this humility. On more than one occasion, I captured observations of how the staff seemed quick to say things like, "We don't know what we're doing" or "we're not sure how this will work, but let's try."

Theme: Democratic Process. Consumer Participant 3C was the first interviewee to describe the interactional processes within the CAC as very democratic. While other consumer participants did not use the word democratic specifically, it became the best fit to describe a number of processes including the voting process, how equity was practiced within the CAC, and how the CAC addressed participation barriers. Agency Partner 9A provided a simple explanation of the CAC in action when she explained, "You're not making decisions about people out there, you're in a co-operative space, where the people are actually a part of the process."

Ensuring this democratic reality that "people are actually a part of the process" rests importantly on identifying and addressing barriers to participation. Consumer participants discussed how various supports such as transportation vouchers, childcare, stipends, and translated materials made the difference in their ability to participate. Speaking to the lengths that staff go to ensuring participation, Consumer Participant 1C said, "They'll do everything they can in their power … to make sure that anything that would stop a consumer from attending, they would take care of." Consumer participant 6C also shared with great emphasis,

> I feel privilege being part of this, of being included. They are doing as much as they can to have me come and participate. They are providing me all these tools so that I can be there, otherwise I wouldn't be part of it. I really feel included. I really do and it's shown in what they are doing for me.

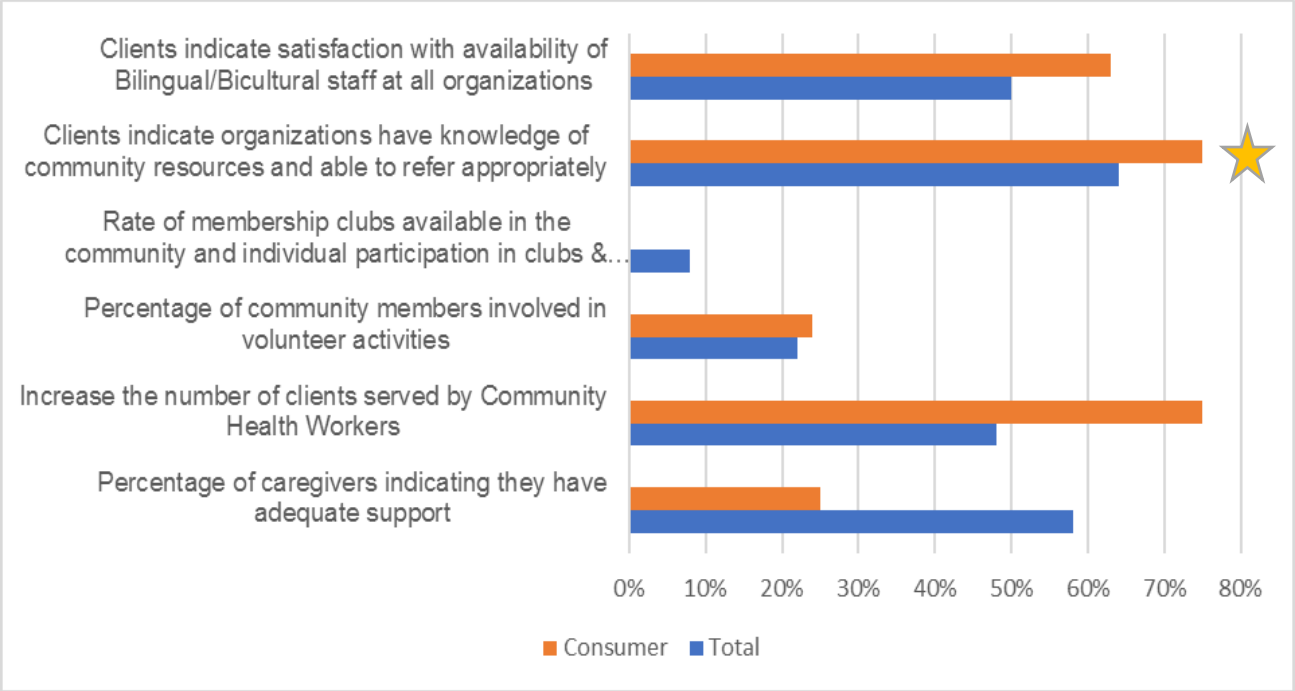
CAC consumer members who participate in meetings and have a voting role are eligible for a $50 per meeting stipend. This democratizes the participation since most agency partners and staff participating are attending during work hours and the same is not true for consumers. The Stipend Agreement form indicates "*the stipend is intended to cover incidental personal expenses a consumer incurs through attendance at a committee meeting*." The use of stipends to

compensate the value for consumer time is consistent with findings from Collins et al. (2018) that found respect shown to residents for their expertise and knowledge was highly valued but residents required more. Interesting, only one consumer participant interviewed spoke to the value of stipends as a factor in their engagement. Comparatively, nearly every consumer participant interviewed discussed feeling supported by the ways that barriers to their participation were actively identified and removed.

The CAC has a uniquely structured democratic voting process that they have refined over the years. The voting process applies to how community health improvement priorities are agreed upon and used in the decisions about where to allocate funds distributed by the CAC. Agency Partner 11A reported, “Early on, we agreed as a group that the consumer members would have the most weight in their votes and they were the ones who decided on the allocation of millions of dollars really.” Figure 4.2 illustrates how results from voting exercises are displayed for all.

Figure 4.2

Result of a CAC Vote to Determine Measure for Driver 1.2 Sense of Community



Note: Star indicates the final measure selected which received the greatest percentage of consumer votes and secondarily a high share of total votes. This transparency reinforces for consumers the weight of their vote.

Transparent voting processes and addressing participation barriers were meaningful to those participating with lived experience. Equally meaningful is how the CAC practices equity and attends to equity throughout its meeting processes. Consumer Participant 3C said, “Justice is when you practice equity. Equity has different aspects. Equity is when you invite the community to be a part of the meetings. Equity is when you provide language, when you ask everyone how they are feeling.” Consumer Participant 7C described the processes involved in working on the Community Health Improvement Plan (CHIP) as both inclusive and equitable:

> We were very involved; we had some stickies and we had to stand up and actually write down our own thoughts. I felt like we were very inclusive and we were ensuring equity. It empowers you to be able to more than just look over a statement and have your opinion taken to actually, you know, edit, change, add, delete. I think their vision of having a community where all people enjoy and improve health through equitable access to engagement is very key in the CAC … I feel there's an opportunity for everyone.

Language translation during meetings and translation of materials from English to Spanish was recognized collectively as a key step the CAC has taken to practice equity. While members agreed there was still room for improvement, overall, most participants expressed pride and gratitude to CAC staff for working diligently to make materials and meetings accessible to Spanish speaking members. Agency Partner 9A recounted a meeting where the language spoken was shifted to Spanish and translated to English describing it as "such an important experience to have because you can't help it, but experience empathy for what it's like for people who sit in English language meetings all the time and our expectation is that they should just come along." Staff Participant 13S said, "Many organizations really don't take that initial step of trying to accommodate someone." Overwhelmingly, there were a chorus of participant voices praising the democratic ways that the CAC practices equity, addresses participation barriers, and has processes like voting.

Theme: Inclusive Facilitation Shared. The sharing of facilitation within the broader CAC membership was a surprising and important finding that was both observed and described by participants. While the CAC is staffed by a coordinator and chair role who both have responsibilities to provide a base support of facilitation, it is clear that agency partners and consumer members perceive a shared sense of responsibility for inclusive facilitation. Consumer

members shared accounts of how members beyond just the staff helped to facilitate their experience of inclusion. Similarly, agency partners demonstrated self-awareness of how their presence and interactions shaped inclusion. Here are some ways consumer members described how inclusive facilitation is shared:

- Attentiveness
- Opportunity to co-create agendas
- Supportive listening
- Mentoring provided by community health workers
- Encouraging remarks and communication
- Application of popular education

When asked about, “how they knew their voice was heard and respected,” consumer participants were quick to share examples. Consumer Participant 6C said, “I know right away that people are paying attention, especially when I give my opinion or my point of view. There's a lot of feedback coming back to me and someone will start agreeing with what I'm saying.” This level of attentiveness, supportive listening and mirroring back of comments was shared by others. Consumer Participant 1C added that they could tell people were attentive because they could see it in their body language and they would often hear affirmative comments linking their own name to something they had said in a meeting. Half joking, Consumer Participant 2C said one of the staff “is like an auctioneer; reading your body language before you even know you want to speak.” For consumers, these interactions showed a real attentiveness and respect, especially when other members mentioned them by name.

> The respect and the encouragement to really speak up is really nurtured in our meetings.
>
> And we're also encouraged to talk about things that have happened to people that we

> know and to advocate for that to change. [Another member] would take me aside and say you have such good questions you need to ask more. But I didn't want people to get mad at me. They said, "No, you're asking the questions we all want to ask, but we can't."

Other consumers talked about the encouragement they received from others and the difference it made for them. Agency partners also expressed an awareness that things they said or the times that they simply held back and did not speak were meaningful to consumer participants. Agency Partner 11A recalled calling a consumer after a meeting and sharing with her that she had really done a good job in the meeting and "she told me later that really mattered to her to get encouragement like that." This encouragement was bi-directional in the CAC. Agency Partner 8A described how they often felt encouraged by a particular consumer sharing, "[his approach] always makes us want to be open to become more responsive because it's the right thing and we want to serve him and he's such a great representative because he's so appreciative."

The ability to be self-reflective and aware in meetings was described by multiple agency partners and staff members. Some spoke about how difficult it has been for them to learn how to shut up or talk less in meetings and others discussed becoming more aware of the power they have. Agency Partner 9A said,

> I really am grateful for the chance to sit with my own discomfort around that and to rethink the way that I am in meetings that allows for more consumer voice and to really incorporate that. That has been a transformation for me personally and professionally.

Staff Participant 14S added, "I recognize how I respond to anyone is reflective of how anyone in the room will feel about speaking up."

After hearing a number of participants talk about this inclusive CAC meeting culture, I started to ask the question about what important influences, people or events have shaped inclusion in the CAC. In response, many participants described how popular education principles were one of the influences that cultivated this style of interaction in the CAC. Staff Participant 15S said, “What popular education does is recognize that everyone in the room has lived experiences and is a teacher and the learner both. And also, that you learn with your whole body and not just from a typical presentation style.” Consumer Participant 3C added that popular education instills a recognition and respect for different experiences that culminates in learning, saying, “Then, people start to share with each other, [and] we can reach a learning from each other—a wisdom.” These collective examples show that inclusive facilitation in the CAC does not fall to a specific role, but rather is held by as a shared responsibility of membership in the CAC.

Theme: Continuous Improvement. The final theme in the domain of interaction is continuous improvement. Consumer, agency and staff participants consistently mentioned how the process for evaluating meetings, integrating feedback, follow through and tracking progress were meaningful and instrumental to inclusion. Consumer Participant 6C said: “I feel and see when a suggestion or specific lesson is being discussed that it is continuously focused on. It doesn’t just start there and die there, never discussed again, no it continues on down the road.” Six of the seven consumer participants interviewed were all complimentary of how CAC processes supported continuous revisiting of items and closing the loop. Consumer 7C appreciated how they can always count on hearing back about issues they have raised and the corresponding resolution or outcome. Ultimately, this has built a trustworthiness and integrity within the culture of the CAC that is meaningful to consumer participants.

Meeting evaluation at the end of all meetings is a continuous improvement process practiced in the CAC that helps to ensure that trustworthiness is sustained. Participants noted that their practice of meeting evaluation stemmed from their adoption of popular education principles. Staff Participant 15S elaborated:

> The evaluation is a way of sharing power. It gives people an opportunity to say I did like this or I didn't like this. I think it's really, really important to make sure … that you're listening to their opinion, whether you did a good job or bad and then trying to do things differently afterwards. It also hopefully helps the people who are serving them serve them better.

Agency Partner 9A also described meeting evaluation as "really important," adding that it contributes to creating a "safe space." Multiple participants commented that feedback was welcomed in the CAC and there was evidence that changes resulted from this feedback. An example of this was shared by a consumer participant who detailed making a suggestion to the staff that maybe they should try swapping the dominant language spoken to Spanish and provide the English speaker participants with headsets to experience what it feels like to "be in the shoes of the other person." This suggestion was carried out at the next meeting, producing a new perspective within a majority of the group. Other consumer participants gave examples of changes that occurred over a longer trajectory of time, such as how the CAC tracked larger community health improvements that were progressing year over year and kept tracking mechanisms visible for all to see.

Overall, the agency participants interviewed had a lot to share about opportunities for continuous improvement. The tone in which they shared these opportunities was in large part positive, but also persistent in tone. Few agency participants expressed contentment that enough

was being done to engage consumer participants and nearly all talked about being focused on continually finding ways to improve. Agency Partner 11A said:

> I think the further we go into it, the more we can realize how much more we could be doing in this direction. How much more consumer members could be empowered with real decisions. How much more they could be equipped with information, how much more their perspectives could be drawn out carefully, their stories.

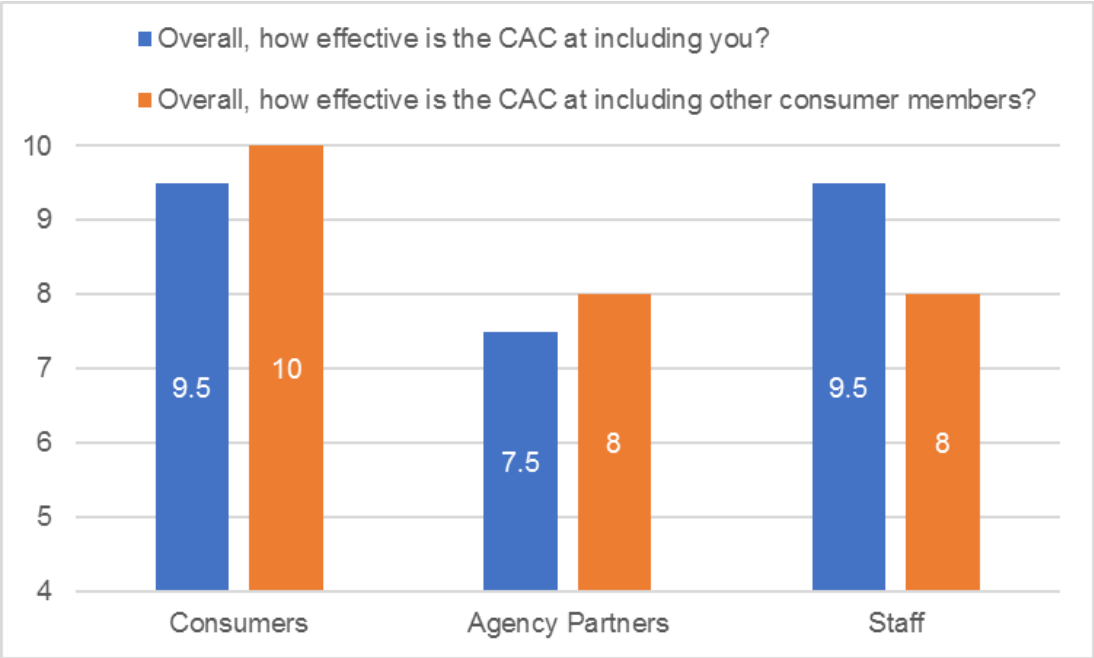
The more critical evaluation by agency participants of opportunities for improvement also presented when they were asked to rate their response to the following two questions on a scale of 1-10 to

- Overall, how effective is the CAC at including you?
- Overall, how effective is the CAC at including other consumer members?

All participants in the study were asked these two questions. The median perception results are presented in Figure 4.3. Agency participants gave the CAC a median rating of 8 for effective inclusion of consumer participants. Comparatively, consumer participants gave the CAC a 9.5 median rating of effectiveness. While not a huge numerical difference, agency participant interview responses were consistent with this slightly more critical view.

Figure 4.3

Median Perception of Inclusion Effectiveness



Note: Participants were asked to rank two questions on a scale of 1 to 10 with 10 being extremely effective and 1 indicating not effective. One staff participant and one agency participant did not rank the question on how effective the CAC was at including them.

Agency participants that had critiques could also identify how far things had come in the CAC and the positive response to critique. Agency Participant 9A summed it up with the following:

> Anytime you try an effort like this to truly restructure power to the place where it needs to be, it takes time. It's not going to be overnight so as many places as I could be critical, I would also acknowledge that they've responded to the criticisms positively and then made an effort to adjust.

Continuous improvement is both occurring at the interactional level within CAC processes and it shows up in the core purpose of the CAC – to continuously improve the health system. Consumer Participant 3C routinely touched on continuous improvement making the linkage back to the CAC purpose, remarking: “the final goal is continuous improvement of health access and quality of health.” In this way, the theme of continuous improvement is pervasive throughout the CAC.

Domain of Interaction Observed. The previous section demonstrated how the four themes comprising the domain of interaction, deliberately informal, democratic, inclusive facilitation shared, and continuous improvement, are distinct and interrelated. Each of the four themes reveal the unique interactions occurring in the CAC that were perceived as most meaningful by consumer members. Staff and agency responses confirmed the presence of these themes and made it clear that it is not by accident that interactions are deliberately informal, democratic, inclusive and continuously being improved upon. All spoke to how these collective interactions are modeled, encouraged, and reinforced in practice.

One example stands out from my research that highlights these interrelated themes. During a 2020 meeting, CAC members took turns sharing the Community Health Improvement Plan (CHIP) priorities, reading them aloud on the virtual call. The staff reminded members that the CHIP priority areas had been thoroughly vetted and one consumer member commented on the impressive process and how pleased she was that everyone had spoken up. A conversation ensued about the ways in which the CAC practices equity and ensures openness to hear all voices. Moments later, an agency partner and CAC voting member shared:

> I applaud all the areas and I have experienced the exact opposite of that with this community when I presented [recently]. I didn’t feel open arms. I’m not trying to stir up a

> hornet's nest or derail the meeting. When we have these great hopes and dreams, how do we hold ourselves accountable to work towards these goals? How do we ensure it's not just words? I love what's written and wholeheartedly support and want to really walk it.

Staff immediately jumped in, thanked the agency partner for sharing, and acknowledged they hoped that would not happen again adding "You bringing this up is exactly what we need to do. It's good and relatively easy to write down these values, it's more challenging to practice and raise our hand when it doesn't feel well." This near instant acknowledgement and praise of critical feedback was accompanied by an offer staff made to follow-up with the participant after the meeting. Everyone observed the short interaction and skillful inclusive facilitation. Equally important was the modeling of unguarded realness by the participant who demonstrated by speaking up that it was a safe environment to offer suggestions for continuous improvement. When the meeting minutes were published, the feedback was also captured in writing. The minutes read:

> [Participant] raised concerns about the CAC living up to the values we stated in the CHIP document – specifically, inclusion, equity, and practicing trauma informed practices. Several participants responded in agreement and [staff] committed to being open to feedback of this nature and encouraged others to call it out when they see it at the CAC.

The whole interaction was a memorable moment that stood out to me as an observer. I noted that the tone of the conversation was such that even the person raising the concern remained open and all those that responded matched the level of openness. All in all, it was a short interaction that probably lasted fewer than five minutes. This brevity aligned with what I noticed over many months attending CAC meetings; rarely did topics drag out and rarely did participants pile on with additional illustrative examples. Consistent with the CAC being an

environment of high trust, so too would I expect to observe this level of open and inclusive interaction.

Months after observing this interaction, it was also recounted during an interview with Agency Partner 9A who remembered quite clearly what had been shared and the significance. Agency Partner 9A said:

> For her to be brave and to speak up in meetings about what's really important or to say in a meeting, "*You know guys. I brought you something that was really important to me a few months ago and you didn't treat me very kindly and I felt bad about it. And so, I'm really reluctant to come back and tell you something new*." For her to say that—that's authentic engagement.

Here the experience of participants connects full circle back to the anchoring value of authentic in the domain of heart. Participants make the important connection between the underlying values of the CAC and how they translate into interactions that are memorable and meaningful.

Domain of Outcomes

The domains of heart and interaction combine to generate the domain of outcomes. All three domains are necessary to produce the experience of meaningful inclusion for consumer participants. Participants described multi-level outcomes that were manifesting at the individual level, at the group level within the CAC, and in the community. Each level translated into a theme in the domain of outcomes. At the individual outcome level, the theme of empowerment presented. The theme of collective power and resilience presented at the group level. And the theme of community change emerged from participant descriptions of community level outcomes. The in-vivo codes clustered with each of these three themes are shown in Table 4.2. Most of the responses clustered into the larger domain of outcomes originated from participant

responses to the interview question that asked, “How does power show up in the CAC?” This association of power and outcomes is a finding that will be further discussed in Chapter V. The resulting themes from the domain of outcomes are presented in the section that follows along with examples of each.

Theme: Empowerment. Consumers identified the learning, insights and information they obtain in the CAC as empowering. Empowerment presented at the individual level and as will be shown later, it also presented in other ways. Consumer Participant 6C emphasized that knowing about community resources and services and how the community is coping was essential, adding: “In the end for me, it's empowerment, really just knowledge of knowing what’s going on in the community. That’s what brings me back to participate in these meetings.” Another talked about gaining greater insight into the experience of those providing health services, the various complexities, and ultimately, feeling greater empathy as a result. Staff Participant 15S reflected on how members might be feeling, saying: “I think it’s empowering for people to recognize that they have a voice and can make a difference; their voice and their experience can make a difference in how things are done and someone's listening.” Several consumer participants described empowerment in terms of how effective collaboration fostered a greater capacity to solve real problems in the community. Feeling empowered to be of help to those who are facing challenges was a key attractor for individuals to the CAC. Consumer Participant 4C added: “We’re a group that really does come to the aid of somebody that needs it.”

Agency partners shared examples of consumer members becoming stronger and stronger advocates and voices for change. Over the years, consumer members were often invited to

participate in annual learning conferences and present alongside CAC staff. Access to ongoing learning and consumers feeling empowered to share their voice strengthened the CAC overall. Agency Partner 11A said:

> When you have a person who's able to use their voice—who has become comfortable in a group and can integrate both their lived experience recognizing the value of it and what they've come to understand about how the systems work. It's like an unstoppable force. It's really, really powerful.

Additional agency participants also touched on the effective ways that consumers had learned to use their voice for strong, empowered advocacy. It was clear in the staff interviews that there was an intentional striving for greater and greater consumer empowerment. Staff were adamant about centering power with those who have lived experience in the issues facing community. This adamancy was reflected in the comments by Staff Participant 14S who said:

> We are continually and constantly trying to change the power dynamic not only in the room, but ultimately in the entire community. Because back to the idea of keeping needs front and center and lived experience of who we are trying to help. That's where the true power is. Because they are the ones who basically say if we succeed or fail.

The conviction of staff and agency partners to elevate the voices of consumer members combined with the consumer perceptions that they really do feel empowered provide evidence that individual empowerment is being cultivated in the CAC. Also important is the confirmation that empowerment was identified by consumer members as a valued and meaningful outcome of inclusion.

Theme: Collective Power and Resilience. At the group level, the outcome of collective power and resilience was identified as a theme in this case study. I clustered into a single theme

because both collective power and resilience formed sort of a protective webbing that strengthened and sustained the CAC through some difficult times and transitions. In this way, the strength of the group is an enduring quality recognized as an outcome of effective functioning.

A small but important difference presented in the way that consumer members spoke about power compared to agency participants and the majority of staff participants. Consumer participants were more likely to describe power as a collective power expressed as being powerful together. This was especially emphasized by participants who identified their race as Latino or Hispanic. All five of the 15 total participants (33%) who identified as Latino or Hispanic made reference to this collective power in their interviews. Consumer Participant 6C shared with great emphasis: “In the CAC, I see power – the power of the community coming together for one specific reason, the health of everyone who lives in our area that's been covered by the CAC.” Achieving this level of togetherness was important to participants and explained as one of the outcomes the CAC had achieved in the community. Consumer Participant 7C said:

> I think the power in the CAC is about more of a like an organization connection. The power that is being represented there as a community is more of being together, empowering each other, including everyone, ensuring diversity, and ensuring equity.

Participants talked about the strength of being united in working on a shared goal and how meaningful that was for them. Consumer Participant 4C added that the strength lies in the collaboration; describing it as the type of collaboration where everyone jumps in to say: “Okay, let’s solve that problem, and everybody weighs in on it. You’re not working alone; you’re not an agency of one standing alone. You’re an agency of 30 different agencies to help solve the problem.”

Other agency participants and staff also talked about collective power, but in a slightly different way. Many touched on how the CAC is the place to be in the community and the one meeting no one wants to miss. Agency Partner 11A talks about how the CAC, "is one of the most significant tables to be at in the Gorge in terms of the breadth of who all is there…it's kind of the meeting where all the other meetings come together." This type of collective power is more descriptive of gathering power to influence. Consumer participants were also aware of the notoriety the CAC had achieved in the community. They noticed that meetings had become so popular that they often ran out of seating when meetings were hosted in-person. While some found large attendance to be a bit intimidating, they also saw this as a positive outcome.

Theme: Community Change. The Healthy Gorge has earned national recognition for some of its community collaboration, including the notable 2016 designation as a Robert Wood Johnson Culture of Health prize winning community and recipient of grant awards exceeding 12 million dollars. The CAC can take a substantial amount of credit for those outcomes at the community level. Having known about these published accolades, I was eager to hear how CAC members perceived changes in the community resulting from the work of the CAC. I was especially interested in the responses from consumer members with lived experience. Participants shared the typical or classical examples of change stemming from the CAC legacy, including the long-revered veggie prescription program and growth of the Bridges to Health Community Health Worker program (Bridges). They also touched on community level outcomes that may be more difficult to subjectively measure or claim, but were important to participants. Those outcomes were the incremental shifts detected in the community that overtime is amounting to major shifts in orientation of health programs and services to focus on those they exist to serve.

Consumer Participant 6C spoke about first hand experiences with these shifts in the community, sharing:

> I have seen differences and changes in our community ranging from helping people with transportation. I have seen more people are accessing transit and it's more economically priced. And even for me, dealing with the hardship of paying rent; I have seen the help from the housing organizations and organizations around that have helped me with paying my rent (some or all of it).

In this sense, the CAC is facilitating downstream change in community and in organizations that agency partners represent. Consumer Participant 3C indicated the opportunity before the CAC is to continue its work in building community wide awareness of services coupled with ongoing advocacy so that better systems can be designed. Agency participants concurred that their experience in the CAC has translated into seeing new and different opportunities to engage with clients in their own organizations. Agency Partner 10A said: "I would say that seeing some of those supports for the consumer members in the CAC has helped me think about ways that we can support people with lived experience to provide input and engage in our organization."

Besides engaging clients in a more inclusive way, participants also reflected on examples of shifts they've seen community organizations making towards greater language accessibility. One participant talked about how surprised he was that his mother received a follow-up call from the local medical clinic after a recent appointment. He described how this showed the organization was "taking notice" and was "astonished" by how accessible the communication was for his mother who spoke only Spanish. In his view, this reflected positive forward progress. Staff Participant 14S summarized the community shift that has been occurring:

> If you ask a non-profit, how do you make your decisions? Sometimes they say they ask their clients, but really, they ask their program coordinators. They don't really ask their clients. In the Gorge, they really do ask now and it's been a change… That's a fundamental change that the CAC can have on the community—changing how individual organizations see the community and interact with their own clients.

Domain of Outcomes Observed. The onset of the 2020 COVID-19 Pandemic occurred just months before the data collection phase of this study began. As the regularly scheduled March 2020 CAC meeting approached it was becoming clearer by the day that an in-person meeting would not be possible. Schools districts were closing, COVID cases were spiking across the globe, and uncertainty was extremely high. The CAC staff had a decision to make and little time to make it. The March 16, 2020 CAC meeting proceeded as planned with one significant change – the group would meet virtually. The minutes showed the meeting started promptly just two minutes after the hour. The minutes also noted that staff welcomed all, normalizing that virtual meetings can sometimes be challenging, but that the focus would still be on making certain that all voices are heard. Comparatively, in the community where I reside, meetings were being canceled left and right, all community health initiatives were in effect paused, and few teams were transitioning easily to a virtual format. From what I have heard from colleagues across the nation, challenges like these were the norm. All the more evidence of exemplar performance by the CAC. In the months that followed, the council continued to meet virtually as scheduled month after month. Even the staff expressed surprise on how well things progressed. Staff Participant 15S said:

> Surprisingly, I'm almost feeling like, especially our consumer members are a little more vocal than they were in person. Is it because they don't recognize that there's 45 other

people in the room because they are on the phone? And we've gotten good great participation, which is surprising and awesome.

The nimbleness and resilience of the CAC during this extraordinary difficult time for communities demonstrated the pinnacle of multi-level outcomes achieved by the CAC. Individuals were participating, engaged and feeling empowered and at the group level, processes continued at the same levels of effectiveness. The community also showed tremendous adaptation and response to the pandemic.

Beyond the bounds of the CAC, there was additional evidence that the larger community and agencies linked to the CAC also showed resilience and adaptation. Early in the onset of the pandemic, an essential worker communications campaign launched embracing the migrant farm working community. This provided positive community messaging uplifting the work of essential workers and equipping them with important safety information about masking. CAC agency partners also talked about how non-profit partners like the United Way adapted their processes quickly to award and distribute COVID relief dollars on a near weekly basis. The Columbia Gorge Health Council (CGHC) also responded nimbly. At the April 2020 CGHC meeting, a funding proposal was presented to fund local public health efforts to address the pandemic. One of the board members presenting said that the proposal had been shopped around the community prior to bringing it to the CGHC and community feedback had been unanimously trusting that public health could be trusted to responsibly use the funds where they were needed most. Other members added that public health could be counted on because they had a track record of working with trusted community health workers to do the contract tracing. The board voted quickly to approve the funds for allocation. This decision was notable because of the high level of trust displayed. At this point in the pandemic, other US communities were still just

coming to grips with what needed to happen to prevent community spread. These collective community examples show the positive ripples of change radiating out from the CAC including: trustworthiness, responsive to needs of consumers, and uplifting.

Summary

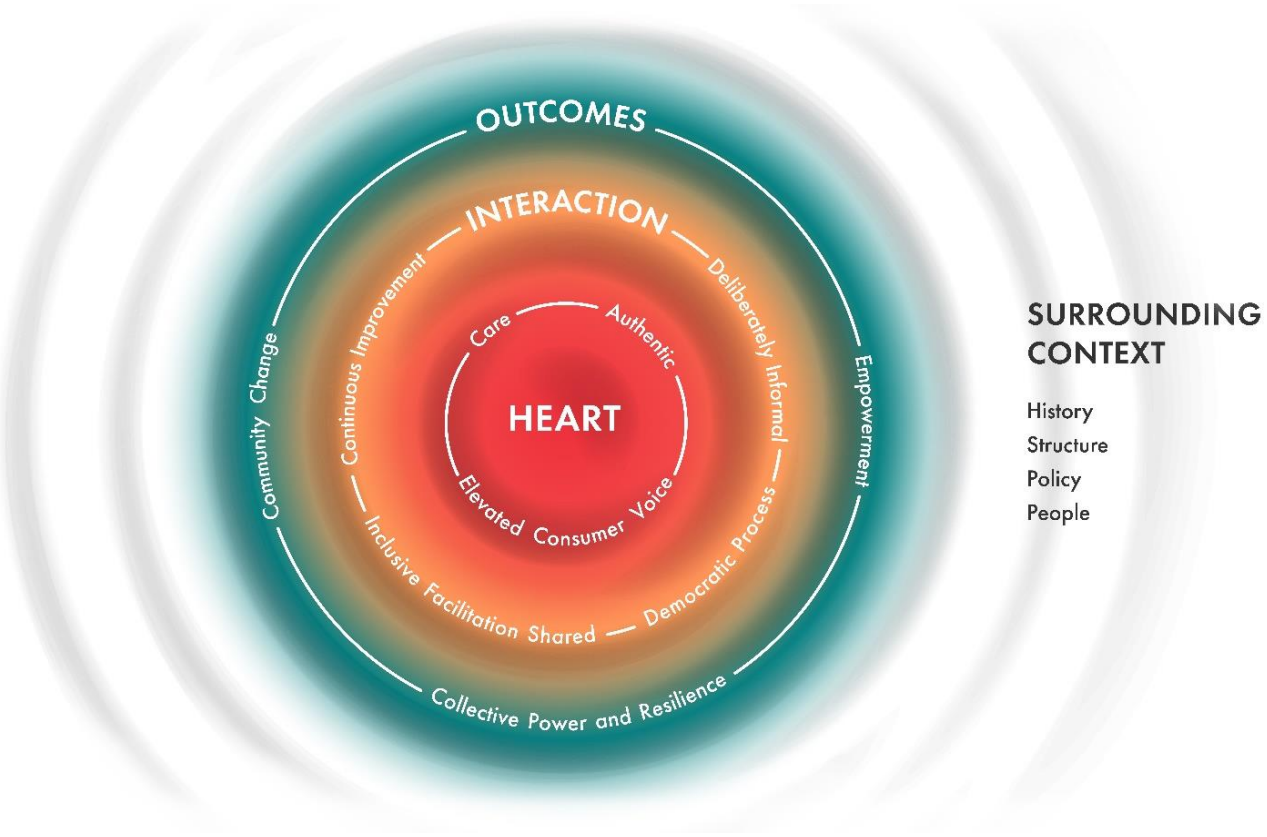
This study found striking alignment between the perceptions of the three different study participant types—consumers, agency partners, and staff—participating in the CAC. By definition, the CAC is a multi-sector collaboration (MSC) working towards a shared vision for community health improvement in the Gorge region of Oregon. Consumer participants offered detailed and descriptive accounts of what contributed to them feeling inclusively engaged in the CAC. Further, the results collected from agency partners and staff participant interviews added supporting evidence of aligned perspectives. The ten themes relating to inclusive engagement in this case study were organized into the three interrelated domains of Heart, Interaction, and Outcomes. The ten themes that emerged presented in:

- Domain of Heart: (1) Care, (2) Authentic, (3) Elevated Consumer Voice;
- Domain of Interaction: (4) Deliberately Informal, (5) Democratic Process, (6) Inclusive Facilitation Shared, (7) Continuous Improvement; and
- Domain Outcomes: (8) Empowerment, (9) Collective Power and Resilience, and (10) Community Change.

The diagram presented in Figure 4.4 shows how the domains interrelate and ripple outward.

Figure 4.4

Domains of Inclusive Engagement Presenting in the Healthy Gorge Case Study



These results were also observed in a review of publicly available materials associated with the Healthy Gorge collaboration and findings were strengthened by researcher observations of CAC and CGHC meetings. The collective presence of the ten themes combined with the emergence of three domains provide a complete answer to the research question of how consumer participants experience inclusive engagement in this setting. Beginning at the center of Figure 4.4, the domain of heart describes how core anchoring values of care, authenticity and elevated consumer voice ripple outward creating a CAC atmosphere that is welcoming, inclusive

and affirming of the contributions of lived experience. The domain of heart anchors how CAC members relate with one another in the domain of interaction. It is in the domain of interaction, where the work of the CAC comes to life in action. Participants described acting from a base of shared values. The four themes making up the domain of interaction produce a unique set of interrelated actions. Deliberately informal interactions, democratic process, shared responsibility for inclusive facilitation, and continuous improvement were the dominant themes that produce a unique set of interactions in the CAC. The three domains are depicted within the larger surrounding context. History of the region, the influence of various structures and policies, and the people involved were all aspects of the surrounding context that had an influence on engagement.

Finally, without recognized outcomes, the CAC and Gorge Region would not have the notoriety it has earned as an exemplar. The domains of heart and interaction build on one another to produce the domain of outcomes. The results of this study show that outcomes are necessary for consumer participants to identify with experiencing inclusive engagement. Community change was among the most obvious of outcomes identified by participants. There were additional multi-level outcomes, though, that participants valued as outcomes of meaningful inclusion that manifested at the individual level (empowerment) and the group level within the CAC (collective power and resilience). In Chapter V, I provide an interpretation of the results and discuss the implications for practice in the field of community health improvement involving MSC.

Chapter V: Discussion

This Healthy Gorge case study contributes to the field by closing an existing gap in empirical studies examining the effectiveness of inclusive engagement of those with lived experience. This study brings to the forefront the factors that participants with lived or living experience place as most meaningful in creating a rewarding, inclusive, and outcomes focused collaborative. The results obtained answer this question, but maybe more importantly, provide an exemplar for how one community has become a rare caring and authentic multi-sector collaboration generating value for those involved.

In Chapter IV, I reported the results of the Healthy Gorge case study highlighting ten resulting themes organized into three domains. The ten themes provide an answer to the central research question: What shapes inclusive engagement of participants with lived or living experience in MSCs working towards community health improvement. Additionally, the case study investigated five supporting lines of inquiry:

1. What are the larger contextual factors that influence engagement of those with lived experience in MSC efforts?
2. What role do the perceptions of formal sector participants (e.g., from the public or private sector) play in efforts to include those with lived experience?
3. How are the dynamics of power handled and managed in ways that facilitate positive, inclusive engagement of those with lived experience?
4. How does structure (or formality) of the MSC make a difference in shaping engagement?

5. What lessons can be derived from the meaningful ways that those with lived experience have been engaged in MSC work that has led to improved community health outcomes? What lessons can be derived from what has not worked?

The purpose of this chapter is to interpret the study results and explore the insights gained. Each of the supporting research questions are discussed and linkages are made to existing literature. This chapter concludes with implications for practice, a review of study limitations and researcher reflections on learning.

Context Shapes Engagement

My first inkling that I was about to encounter something very special in the Gorge region came during my February 2020 visit. The drive leaving the city of Portland, Oregon to Hood River is a short 50-minute highway trip stretching along the southern shoreline of the majestic Columbia River. It is one of the most picturesque drives I've ever made. Opposite the river shoreline are massive forested peaks bordering both sides of the river peppered with waterfalls and snowcapped Mt. Rainer dominating the northeastern landscape. It is breathtaking.

I felt instantly at home in the rural community of Hood River as it reminded me of the community where I grew up. My first stop was a small café connected to a food cooperative where I grabbed lunch. Left behind on the table was a local publication featuring all the area non-profits filled with pages and pages of stories of how organizations were serving the community. From there, I drove further through town past acres of cherry tree orchards just starting to develop their springtime buds. My destination was the food bank where the CAC meeting was being hosted that afternoon. I arrived early, but the room was already bustling with people and the staff were opening closets to retrieve more chairs so that everyone would have a

seat. Despite clearly being a newcomer to the meeting, I received no awkward glances. People were welcoming and laid back. It felt like a gathering of friends and community.

Little did I know at the time what a gem of a community I had stumbled upon. The fertile soil in this region that one agency partner noted was nourished by a history of collaboration is part of the rich context surrounding this case study in engagement. The history of the area, the community geography, and the local and state politics are some of the larger contextual factors influencing the ways that individuals with lived experience engage in the community. Having lived in a rural community for my whole life, I have experienced some of the defining assets of a rural area—cultivated community self-reliance, supportive networks, and a familial culture. These assets are consistent with what I saw in the Gorge region.

The Gorge region, situated in the Pacific Northwest, is known for possessing predominantly democratic values and has been at the leading edge of healthcare reform efforts. Even before the Oregon Health Authority was awarded Medicaid Transformation dollars, community health innovations were already afoot. The Gorge region was early to embrace the role of community health workers (CHWs) and has a history of community organizing efforts. These community values fertilized a rich soil for planting the seeds of engagement that have long sustained the CAC.

Participants confirmed that the passing of the ACA in 2010, the corresponding introduction of the CCO structure in Oregon, and ongoing public health influences played a role in the formation of the CAC. Consistent though with the literature, the results of this study confirmed literature findings that regulations often don't specify quality of inclusivity expected. So, while CCO standards may have created the impetus for a CAC, the directives for engagement of consumers lacked guidance and the CAC evolved without a lot of specific

direction until the 2.0 standards were released many years later in 2020. Literature included warnings about warding off the ills that can come from regulatory driven collaboratives (Labonte, 2012; Mathie & Cunningham, 2003). Perhaps then, what makes the CAC collaboration so unique is that it evolved from a history deeper than the entrance of the CCO, a history grounded in community organizing for health improvement. The CAC is an example of a formally chartered public sector collaborative imbued with the heart and activism of a community organizing effort. This meddling of supportive structures, in the form of governance, authority, and funding, matched with principles of community organizing where consumer voice is elevated and people are activated to create more just systems is an effective marriage.

Participants, especially consumer participants, were most likely to discuss the influential role popular education has had on creating meaningful engagement in the CAC. Staff also cited influences of Collective Impact. The influence of popular education on health improvement initiatives in the Gorge region dates back to the 1990s and possibly, even earlier. Popular education was the methodology used for years to train community health workers (CHWs) in the region. Study participants reported a high degree of trust in the effectiveness of CHW programs and their ability to improve health outcomes. In some cases, CAC consumer members were recruited to the council by their CHW and it was noted that some CHWs provided mentorship to consumer members new to the council, such as accompanying them to meetings. This level of CHW interaction in the CAC reinforced and encouraged the sustainment of popular education principles practiced inside the CAC. The clear integration of popular education in the CAC aligns with Shinn's (2012) finding that collaboratives most likely to insist on including and elevating the voice of those with lived experience were also most likely to be aligned with grassroots organizing interventions. Furthermore, the history of the region shows the decades

long influence of popular education has infiltrated CAC values, interactions, and outcomes. Popular education principles have also influenced the behavior of formal sector participants, whose role in engagement is discussed in the next section.

Formal Sector Participants: Servantly Engaged

I defined the formal sector participants in this study as those coming from either private or public sector professional roles. Unlike consumer participants in the CAC, agency partners represent the formal or business sector of the collaborative and participate as a function of their paid organizational roles. Entering this study, I was curious, "What role do the perceptions of formal sector participants play in efforts to include those with lived experience?" My previous less than ideal experiences with MSC efforts had biased me and I had anticipated that I would hear more challenges stemming from the participation of formal sector participants. That was not the case.

Formal sector participants featured in the literature were often central. Disproportionately, studies of MSC focused on engagement from the perspective of the formal sector. The unique contribution of this study is that it provides insight into how formal sector participants contribute to meaningful inclusion and engagement of those with lived experience from both the perspective of consumer participants and agency partners. Formal sector participants in this exemplar were described by consumer participants as supportive, encouraging, and caring. Agency partners talked about their participation in terms of behaviors that I would connect with a role of coach, facilitator, or change leader. Agency partners especially identified with having a caring orientation that consumer participants valued.

Literature emphasized trusting relationships and mutual respect as most commonly cited contributors of group and individual engagement. Butterfoss and Kegler (2012) describe

empowerment and belonging as critical aspects of engagement. This study demonstrated that all roles, including formal sector participants, play an active role in facilitating that sense of belonging and empowerment. Agency partners displayed facilitative behaviors like encouraging others, offering support, expressing self-awareness, and continuous focus on improvement; all of which cultivated an environment in the CAC that was trusting, respectful and authentic.

In the heading for this section, I intentionally described formal sector participants as servantly engaged. I borrow the adjective servantly from the literature on servant leadership first conceived of by Robert Greenleaf in the 1970's (Eva et al., 2019). The spirit of servant leadership as defined by Eva et al. (2019) is apparent in the facilitative behaviors of agency partners who possess an authentic, caring approach, the expression of empathy and self-awareness, and a commitment to put the community and others first. Eva et al. describes:

> Servant leadership is an (1) other-oriented approach to leadership (2) manifested through one-on-one prioritizing of follower individual needs and interests, (3) and outward reorienting of their concern for self towards concern for others within the organization and the larger community. (p. 114)

The presence of servant qualities of leadership in the CAC should not come as a surprise given the social service, religious and non-profit backgrounds of agency partners. In a study testing how servant leadership was perceived in different cultural contexts, Tirmizi and Tirmizi (2020) found: "U.S. respondents show the strongest relevance of servant leadership for nonprofit, religious, and community sectors (over 80% in all three cases)" (p. 50).

The agency participants I interviewed showed that they had an impressive understanding of how systems and structures sustain inequities in community. They also spoke passionately about working for change. They tempered their passion, though, with a patient respect for the

community process and the commitment to elevate the voice of consumers above their own. Agency Partner 11A reflected on how this isn't always easy: "I think a lot of us in the room who are in leadership roles in our organizations struggle with—how do we step back so that others can step forward?" Agency Partner 9A added: "I think learning how to shut up is big. And I say that with all compassion and respect to myself and fellow leaders, but I really do think that it took us a little bit of space to learn how to invite space." The awareness of the need to step back and even shut up at times corresponds with a study by Berardo et al. (2014) that found engagement in the collaborative increases when less dominant or less powerful voices are active in the discussions.

Another agency partner talked at length about the importance of constantly challenging CAC members to speak up, to raise difficult issues and see that it's safe to participate openly. Agency Partner 8A echoed the sentiment I heard from other agency partners that there was still much work to do. This critical evaluation originated from a strong motivation to continuously work together toward better and better outcomes. Never did I hear an agency partner direct their criticisms toward an individual in the CAC; all critiques were presented as opportunities for the collective "we" to work toward together. The resounding "we" spirit was captured in this comment from Agency Partner 8A:

> But again, we've got to leave our name tag at the door and it's like, here's the outcomes we want to achieve, what are we willing to put in? And what are we willing to give up, so we get that outcome? And I think we're making really great strides. But we're not there yet. It'll take years. It's just too complex, but I think because of the collaboration and the authenticity, we will get there faster.

All of these accounts show the benefits of a very engaged formal sector participating in the MSC. While formal sector participant voices must intentionally take a back seat to the experiences of participants with lived experience; that doesn't mean formal sector participants can be passive. Quite the opposite, the Gorge study showed formal sector participants to be very engaged in supportive actions. These supportive actions ranged from encouraging others to raising challenging topics. The collaborative environment also benefited from formal sector participants who were committed to continuous learning and had the ability to be self-reflective. Formal sector participants had to be especially aware of how their own power and privilege could negatively influence collaboration and drown out the voices of those with lived experience. The collective group awareness of power will be further explored in the next section.

Dynamic Interpretations of Power as a Facilitator of Engagement

In Chapter IV, I introduced the different ways that CAC participants perceived power in the collaborative. I also shared how themes clustered in the domain of outcomes were derived from participant responses to the interview question that asked, "How does power show up in the CAC?" There was a clear connection between how power is perceived and the effectiveness of the collaborative in producing multi-level outcomes. More explanation, though, is needed to explain how dynamics of power are handled and managed in ways that facilitate positive, inclusive engagement of those with lived experience?

The results of this study showed that the vantage point for examining power inside the collaborative matters. Formal sector participants tended to speak in terms of managing or mitigating power dynamics. In contrast, consumer participants spoke about being drawn to being a part of something larger that had the power and influence to affect community level change.

Consumer participants talked about power used for the right reasons and the expressed feelings of individual empowerment and confidence to bring about meaningful change. The CAC's multi-levels outcomes are consistent with the literature on empowerment. Empowerment literature frames power as relational and interactional, implying the multi-dimensional nature of power shared (Wiggins, 2010). By adopting popular education principles in practice, the CAC nearly guaranteed that power dynamics would evolve and grow to be viewed from through an empowerment frame. The results demonstrate that this is true in large part for consumer participants and a growing edge for formal sector participants including staff and agency partners.

The CAC staff showed a great deal of awareness about the need to interact with power differently depending on the frame of reference. For instance, staff engaged in gate-keeping practices to prevent didactic presentations from making their way into the council meetings. These insights are supported by a study examining engagement inside three CACs in Oregon. Holdin and Tallant (2020) named several best practices for engagement and highlighted:

> The single most effective way to engage Medicaid beneficiaries in health system transformation efforts is to provide them with meaningful and important work. Advisors can readily tell if they are just "window dressing" or a means to satisfy externally imposed requirements for consumer engagement. (p. 12)

Whenever possible, the CAC staff work to persevere the democratic processes and non-traditional ways of engaging consistent with a popular education approach.

Staff facilitating the council must be both attune to how empowerment is manifesting over time and alert to outside influences which may view power from a win-lose frame. Illustrating this balancing act and practice of attention, Staff Participant 14S shared:

> It's a goal to ensure that we do the best job collectively to meet that real goal. So, the CHIP and the CAC provide that arm's length ability to say "let's make sure we keep the focus on the needs and try to stay away from these relationship issues. Let's just stay focused on what's important. My mission isn't any more important than yours and not any less important." Let's worry about how we best address these needs.

This example shows how staff navigate potential conflictual mine fields that could be time consuming and perceived as a distraction for those showing up to contribute meaningfully.

A Winning Combination: Structure and Informality

In Chapter IV, I shared the results theme titled deliberately informal and here I expound on how structure (or formality) of the MSC makes a difference in shaping engagement. The observation I made that interactions were deliberately informal, however, did not imply the CAC was without structure. Actually, quite the opposite was true. I observed a good deal of structure and formality at work. This has been perhaps one of the more difficult of the case study results for me to convey. While CAC meetings are comfortable and have a conversational tone that invites participation and puts people at ease, there is still a level of structure and formality that undergirds the design. The CHA and CHIP processes, especially, are laden with structure. Plus, the CCO governance structure demands a high degree of structure. There is an application process to participate, documentation to complete, formal note taking procedures, Robert's Rules of Order, and even an organizational chart showing how the CAC connects with other councils and the CGHC overall. Somehow, though, staff and CAC members have effectively fostered and sustained informal interactions within the council. This is somewhat at odds with the finding by Shinn (2012) that more traditionally structured collaboratives were less likely to include and authentically engage those with lived experience. In this case, the structure of the CAC could be

interpreted as traditional, but the interactional component of how it operates is far less traditional and more consistent with grassroots, community driven style of collaboration. Literature supports that non-traditional ways of engaging produce greater trust and were helpful in breaking down barriers that inhibit participation (Homer, 2019).

Chapter II included a review of some of the historical models and theories that have shaped engagement processes at the community level. Literature review findings also summarized a number of challenges resulting from public policy and private funder demands. These demands can unintentionally set up conditions in MSCs that are susceptible to becoming disengaging for those with direct lived experience. Despite receiving millions in grant awards and being a central partner in the CCO structure, the Gorge region has been able to defy these challenges or at a minimum, work effectively through these challenges. The unique combination of the CAC's formal structures at work in the background and forward facing deliberately informal interactions have produced a winning combination where engagement is flourishing. Beyond the influence of popular education which I have emphasized has been significant in shaping CAC interactions, there are two additional models at work in the background that have reinforced inclusive engagement. Community-based participatory research (CBPR) and Collective Impact (CI) have each played a role in how collaboration and engagement has developed over time in the region.

The CAC core anchoring values and interactional processes mirror the collaborative nature of CBPR which is focused on building trust and direct partnerships with communities to ensure those most impacted by an issue are involved in the research design (Christopher et al., 2008; Collins, 2018; Garcia, 2011). While CBPR is not specifically mentioned as a key underpinning approach of the CAC, CBPR has an important influence on partner collaboratives

linked to the CAC. The Community Health Advocacy and Research Alliance (CHARA) is one such partnership based on CBPR principles with an active presence in the region; several CAC members also sit on the Advisory Board for CHARA (Davis et al., 2018). The crossover in memberships allows ideas and approaches to community engagement in research to flow between the CAC and CHARA. The membership overlaps and the CAC-CBPR values alignment creates a positive feedback loop that reinforces practices that elevate the voice of lived experience in community partnerships. The motivation to form CHARA was fueled by community members wanting to be a part of research and curious about how health was improved as a result of initiatives (Dillon et al., 2019). I experienced this interest firsthand. Even though the methodology for this study was not CBPR, participants communicated a desire to hear back and expressed an expectation for follow-up engagement. It is complementary regional partnerships, like CHARA, that create a highly formal structure in the background reinforcing the values of community engagement.

Finally, I propose that the CAC has been diligent in attending to structure and process in such a way as to close the inherent gaps in the CI framework. In reviewing Wolff et al. (2016), I found evidence for how the HGI and the CAC have clearly addressed at least four of the six principles for building collaborative spaces that address the CI gaps. I was also able to find weaker evidence of the remaining two principles in practice. Table 5.1 lists each of the principles from the work of Wolff et al. (2016) and a corresponding example from this case study.

Table 5.1

Principles for Closing Gaps in CI Framework as Addressed by the HGI and CAC

Principles (Wolff et al., 2016, p. 51)	*HGI or CAC Example in Practice*
1. Explicitly address issues of social and economic injustice and structural racism.	*Published statement declaring the centrality of equity in the design of the HGI and pledging to "do everything in our power to dismantle systemic racism" (Lindberg, 2020b). CCO 2.0 standards mandate health equity impact assessment.*
2. Employ a community development approach in which residents have equal power in determining the coalition's or collaborative's agenda and resource allocation.	*Community benefit and social determinant funding decision-making delegated to CAC voting members. CAC also holds authority to set priorities for the CHA and CHIP.*
3. Employ community organizing as an intentional strategy and as part of the process. Work to build resident leadership and power.	*The central role of popular education methods in all facets of the CAC formation and evolution is indisputable evidence of this principle at work as is the promotion and engagement of CHWs in the region.*
4. Focus on policy, systems, and structural change.	*In 2019, 17 partner organizations signed onto a memorandum of understanding affirming the role of the CAC as a decision-making body for CHA and CHIP and committing to principles for collaboration.*
5. Build on the extensive community-engaged scholarship and research over the last four decades that show what works, that acknowledge the complexities, and that evaluate appropriately.	*The commitment to learn from available research is reflected in the sheer diversity of approaches and models visible in the work of the CAC and HGI (e.g. CBPR, popular education, community health improvement frameworks, and evidence-based programs).*
6. Construct core functions for the collaborative based on equity and justice that provide basic facilitating structures and build member ownership and leadership	*CAC democratic processes like voting, consumers involved in agenda setting and disciplined meeting evaluation have cemented the core functions into practice. Consumer members also co-present and co-represent the council in other forums.*

Note. Left hand column principles from, Wolff et al. (2016). Collaborating for equity and justice: Moving beyond collective impact. *Nonprofit Quarterly*, 9, 42–53. Reprinted with permission.

Table 5.1 demonstrates alignment between consumer identified meaningful structural and interactional elements and the principles identified by scholars calling for more just and equitable collaboratives. An understated yet prominent example of the attention to structure was the 2019 Gorge memorandum of understanding (MOU). The MOU was signed into policy by 17 organizational partners in the region. Agency Partner 11A described the importance of this agreement adding: “It speaks to the authority of the CAC and the commitment to listen to voices that are closest to the experience we want to be responsive to.” The effort required to gain this commitment from so many different organizations is symbolic of the attention paid to formalizing structures that share power.

In summary, the dual presence of both formal structure in the background and a deliberately informal interactional tone has been difficult to describe, but it has important implications. It is the dual presence of these attributes that contributes to meaningful engagement for those with lived experience. Both are necessary. Additionally, these formal structures in the background also nurture the conditions that are so critical for greater justice and equity.

Lessons on Meaningful Engagement

The previous section threads together insights validated by those with lived experience about what is most meaningful when different sectors come together seeking to make a difference. This case study illustrated that:

1. Surrounding context nurtured a culture of collaboration and empowerment;
2. Servantly engaged formal sector participants were needed to shift power in community collaboration;
3. Power viewed through an empowerment frame resonated most for those with lived experience and building collective power was viewed as an asset; and

4. Formal structure helped cement needed change, but it was the invisibility of that formality in practice that contributed to a sense of inclusion and comfort.

Still questions remain about what else explains the engagement transpiring in this case. What makes it so unique. This brings me to the culminating questions framing this research study: "What lessons can be derived from the meaningful ways that those with lived experience have been engaged in MSC work that has led to improved community health outcomes? And what lessons can be derived from what has not worked?"

Mandating Inclusive Engagement of Those with Lived Experience is Insufficient

Consistent with findings from the literature review, mandates, regulations and outside influences may dictate the formation of a MSC, but they are insufficient in specifying the quality or inclusivity of the engagement of those with lived experience in the effort. The HGI history and evolution of the CAC demonstrate that state and regional regulations and standards associated with the CCO structure certainly contributed to the structure of the CAC. However, these contributions were minor when compared to other influences fostering meaningful inclusion. Yet, there still remains a proliferation of examples of private and public entities who are investing time and resources into the development of standards and policy in the hopes of mitigating the problematic nature of regulatory driven collaboratives. An example of this was the publication of the CCO 2.0 standards that happened during the course of this study. The publication of such standards undervalues the dynamic collaboration needed in a community to truly realize inclusive engagement of those with lived experience and the underlying supportive conditions that are present. Standards also undervalue the direct contributions and leadership of community members. More is needed to elevate these voices and their contribution to community health collaborative outcomes.

Embrace Power from Mindset of a Consumer

MSC participants can benefit from embracing the perspective of consumer participants who emphasize the empowering qualities of shared power. Benefits are far reaching when power is shared and facilitated through a sincerely caring, authentic, and relational orientation as has been illustrated in the CAC. The first step in realizing these benefits is the awareness that power can be an asset and not just a liability to be managed. Consumer excerpts highlighted this important lesson; overwhelmingly consumers perceived power as an asset that when amassed collectively could be used to transform systems and make meaningful difference in community. Results support Walker's (2020) findings that suggest the CI model should be expanded to include power as an integral element informing interactions. Walker (2020) found mostly negative impacts when examining perspectives of power dynamics but cautioned future studies should focus on including more consumer perspective. The results of this study validate the real difference in how people from diverse sectors approach power dynamics.

Continuous Improvement Supports Longevity in Outcomes

The CAC is an example of a long-standing MSC that has evolved and continuously improved as a council, growing more inclusive over time. Longevity of the CAC is strengthened by its continued ability to attract high participation and the inclusive processes that keep people returning. The Healthy Gorge CAC provides a living case exemplar for Butterfoss and Kegler's (2012) assertion that greater community involvement will produce longer lasting outcomes. I would anticipate that as more time passes, the region will experience more pronounced evidence of improved health outcomes and transformed systems of health designed by the very beneficiaries of those systems. Change of this magnitude takes time which is why sustaining longevity through continuous improvement is such an important lesson. Consumer, agency, and

staff participants were unanimous in praising continuous improvement processes, such as evaluating meetings, integrating feedback, follow through and tracking progress, as meaningful and instrumental to inclusion. In review of all the themes in the domain of interaction, the theme of continuous improvement provides the clearest vehicle for sustaining longevity of the MSC long enough to produce lasting outcomes.

Implications for Practice

I encourage readers to consider the implications for practice offered here as an invitation to be curious about the dynamic interplay of values, interactions, and outcomes present in MSCs. I hope these implications prompt greater dialogue among MSC practitioners about what is actually meaningful to those with lived experience in community health improvement collaboratives. There are lessons from this exemplar case for others who are operating in a similar context.

One implication that stands out is the balance and the skillful attention to multiple elements of importance that members of the CAC were able to hold in dynamic tension. Attending to 10 interrelated themes across the three domains of heart, interaction and outcomes could easily be experienced as overwhelming for an individual and it certainly would be—for an individual. The balanced attention to these interrelated domains requires community to approach the facilitation together. Similarly, the three interrelated domains only become visible in a context where power is actually shared and community is meaningfully included. I am in awe of how what could be so problematic when approached in a siloed manner, is so easily reconciled when approached by a caring community. A commitment to shared values, a common vision, learning together, sharing facilitation and feeling co-responsible for outcomes define this caring

community approach. These nurtured group practices have developed into a collective ability to engage with dualism.

The context surrounding this case and the inner workings of the CAC are fraught with potential tensions that could be experienced as conflict. Instead, I observed the CAC embracing:

- Principles of community organizing AND formal top down organizational approaches;
- Unique perspectives shared by voices of those with lived experience AND holding belief that all people bring experience;
- Formality AND informality;
- The need to challenge systems to change AND seek stability;
- Being outcomes focused AND experience focused.

A prime example of this is the tension present in who participates in the CAC. On the one hand, community-based partner agencies must be engaged because without their participation the changes in the systems won't occur. On the flip side, the CAC exists to elevate the voices of consumers with lived experience. There is a real community mastery in creating a venue that agency partners do not want to miss that it is not about them. Reflecting this duality, Staff Participant 14S shared: "Part of the tension, and I always use tension, because it's not conflict, it's differing opinions … is who is the real audience of the CAC?" Another staff participant also described their work in terms of finding this balance. I found it enlightening that staff and other participants were so matter of fact in their descriptions of working through various tensions. Hargrave and Van de Ven (2009) suggest: "The advantage of the both/and approach is that it provides a source of creativity. The framing of contradictory ideas as interdependent elements of a unity rather than as opposed provides a source of creative tension" (p. 128). Hargrave and Van

de Ven lean on the teachings of Saul Alinsky to make their point that creativity and innovation emerge from the masterful application of a both/and approach. The results of this study contribute to this body of thinking while also adding that this both/and skill can become characteristic of the culture for the collective as a whole. This case illustrated that inclusive facilitation practices don't just fall to those in designated coordinator or facilitation roles. The collaborative is perceived as meaningful by those with lived experience when both those in agency partner roles and consumers members themselves take up the work of facilitating inclusion.

The implication and challenge for other communities that are navigating a tension filled landscape is to see the possibilities that can be generated from adopting a both/add orientation. This sounds so simple in theory, but the relative rarity of community collaborations demonstrating this collective ability indicates that it is much harder to put into practice.

Areas for Future Research

The changes that community-based partner organizations described as a result of participating in the CAC were intriguing. Most agency partners participating in this study were able to describe examples of how consumer voices had led to changes in their organization. This may be an opportunity for further study especially if there were a way to measure the level of change influence consumer members can have on formal sector participants and their respective organizations. One of my favorite illustrations of this influence was a comment from Agency Partner 11A, who said this about how their organization had changed as a result of listening to consumers:

> Over the years, we've come to kind of bet on the community more and more. So, we've funded a ton of facilitation and project management to help launch coalitions with no

> guarantee that the coalition is going to accomplish anything. But now, we prefer to fund that stuff, as a matter of course, because we trust that people are going to show up. They're going to be engaged. They're going to work together and they're going to achieve something bigger in the collective than they could alone, and our investment is going to really be leveraged.

More evidence of the ways in which agency partners from the formal or professional sector have been influenced by those with lived experience could shed important light on the systems change potential of MSC.

I see another area for potential research examining the responsiveness of government or public sector led community health improvement efforts to structures like the CAC. The CAC is an excellent example of a MSC that has grown into a powerful organizing entity capable of decision-making and building public engagement in initiatives with staying power. This translates directly into improved community health outcomes that can be measured. Future research could explore how and when this growth in capability and capacity becomes recognized and rewarded at the same levels of existing traditional structures, such as medical clinic or hospital-based services. One possible source of data for this research could come from reviewing the funding of community led efforts powered by the voices of those with lived experience in the context of Washington Accountable Communities of Health (ACHs) and Oregon's Coordinated Care Organizations (CCOs). As described in Chapter III, both Washington and Oregon have these structures in place to engage Medicaid beneficiaries as well as health and social service agencies in the work of transforming how health services are delivered to produce improved outcomes. The CAC was even mandated in part as a requirement for community engagement called for by the Oregon CCO structure (Community Advisory Council, 2019; Dillon et al.,

2019). This is an area ripe for critical review. This study demonstrated that in fact the CCO was empowering the CAC with some critical funding authority and decision making to the tune of several million dollars depending on the year. What was not included in this study was a review of the funds allocated for programming and efforts within the scope of CAC funding authority and how that compared to the vast funds committed to traditional health service delivery modalities. I conjecture that future research will find there remains significant opportunity for government led community health improvement efforts to invest in MSCs like the CAC. This is an important area for future research study because even exemplar MSCs are questioned on their effectiveness to produce measurable community level change. This questioning often occurs without respect for how minuscule funding for these efforts are in comparison to investments in traditional health care service delivery.

Study Limitations

The single case study methodology landed on for this study has some inherent limitations related to generalizability; and inferences should not be made beyond the case study (McFall et al., 2005; Yin, 2014). I took care to present results with respect for this design limitation and to outline additional limitations in the section that follows. These additional limitations were extracted during the course of data collection and analysis.

Variation in Depth of Interview Responses

All interviews in this case study were conducted virtually which may have been one of the factors that contributed to a variation in the depth of interview responses. Only two of seven consumers were able to join their study interview by video compared to 100% of agency partner participants and two of the three staff participants interviewed by video. Audio only interview calls tended to be shorter than the video interviews suggesting that qualitative responses might

have been limited by the connection modality. Some participants provided very descriptive and detailed responses to interview prompts while others answered more succinctly. Transcript length showed the lengthier responses came from the community-based agency partner participants and staff in the study. I observed that it was easier for me to stay present and ask questions that went deeper with agency partners because I related with the frame they were speaking from. I also interviewed consumer participants first, prior to other participants, when my interview skills were more novice and my understanding of the case study context was still developing. Naturally, the more people I interviewed, the more I learned, and the more comfortable I became in drawing out detailed responses.

Sample Size and Diversity

Relatively speaking, the purposeful sample size was small; 15 study participants were interviewed and of those, only seven participants identified as consumer participants. The available pool of possible participants was limited by the requirement that participants were active in the CAC as defined as participating in at least four CAC meetings between 2018–2020. This requirement shrank the number of people eligible to sign up. Further limiting was the recruitment process that I adhered to by working with the on-site case sponsor. It is possible that having a sole source of introduction to the study may have disproportionately attracted those with a positive view of the collaboration to sign up. In regards to diversity, 66% of participants identified as female and the rest as male. Despite 33% of participants identifying as Latinx, no other people of color participated in the study.

Time Period for Study

The shift from in-person to all virtual meetings as a result of the COVID pandemic limited my observations to the virtual setting. I had to rely significantly on the experiences of participants to describe the interactional nuances that I might have observed if we had been in-person. Participation in CAC virtual meetings remained high throughout the period of time that I attended as a researcher. Meetings regularly surpassed 40 people in attendance. Unfortunately, most participants joined meetings with audio only, so I was not able to observe body language. This was also noted as having potentially impacted the depth of consumer interview responses.

As would be expected with a long running MSC such as the CAC, the longer the observational period, the more opportunity there is to observe the group working through different types of collaborative action. Observations of the CAC and related CGHC meetings were limited to a little less than a year period between February 2020 and November 2020. During that time, I observed the CAC engaged in community need based discussions, priority setting work relative to the CHIP, and had only limited observation of decision-making or voting processes. I would propose that observations conducted over a longer time span combined with the opportunity to observe in-person meetings would yield stronger case evidence overall and support results triangulation.

Researcher Reflections

The process of engaging in this research study has been deeply meaningful and reflective. The study has led me to seriously consider how I contribute to community collaboration endeavors in the future. During the year and a half that I was steeped in proposing, researching and finally, writing up the results of this study, I was also simultaneously working on community

health collaborations with community partners. A constant source of internal dissonance has been my failure to manifest some of the insights gained from this study. Most challenging has been watching the local collaboratives I am a part of struggle to meaningfully engage those with lived or living experience with the issues we're trying to improve locally. The Healthy Gorge Initiative has helped me appreciate the rich context surrounding community collaboration, the conditions that support engagement, and the collective will it takes to pull together and stay together over time. The findings also reinforced something that I know to be true about my own motivations to engage. I care deeply about people and places. I don't just care; I fall in love and in friendship. Finding care at the heart of this study fortifies my belief that all action, especially collective action, begins with care. Similar to what I saw motivating participants in the Gorge, when I am engaged in a collaborative and those with lived experience are present, I am drawn to connect and motivated to make a difference in their life because I have come to care about them and the community. There is a real power and longevity in efforts of the heart; care is central.

This study has provided an opportunity for me to observe community trust from multiple different vantage points during a very unique time. Unique may actually understate the experience I had conducting this research while also working in healthcare in the midst of a global pandemic that coincided with a period of significant national racial tensions and calls for justice surrounding the 2020 US presidential election. The experience was disorienting at every turn and required personal resolve to stay with the research questions at hand. Trust was low in nearly every setting I interacted with, but the case study in focus gave me hope. When cultivated over time, community collaboration and high trust can support resilience and collective action even in the face of great adversity.

I can see now looking back that I entered this research biased that those living with the experience of struggle and oppression were the only experiences that counted. As a result, I often diminished my own life experiences. Coming to appreciate the value of everyone's lived experience has been an important personal shift. This is a core tenant of popular education practiced in the Gorge. I often recall what Staff Participant 15S said: "We try very hard to create an environment, recognizing that there is a space held out for the consumer voice, but all voices are welcome. And it's a balance." It sounds so simple, but it is in this balance where respect and trust are cultivated. While I may continue to favor those facing struggle embracing their wisdom and solutions for change, I've also become more open to making space for all experiences.

I am grateful to the consumer participants in this study for helping me to see an expanded view of power in community collaboration. They spoke the language of empowerment and got me to see that power can attract people to come together in meaningful ways and stay together when intentionally shared.

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Appendix

Appendix A: **Semi Structured Interview Guides**

Consumer Member Participant Interview Guide

Theme	**Question prompt or probe**
Introduction	Thank you for agreeing to this interview. As I mentioned when I reached out to you, I'm currently a graduate student of Antioch University focused on better understanding what shapes inclusive engagement of participants on the community advisory council.
Inquiry in what's meaningful	To begin, can you tell me about how you first heard of the community advisory council (CAC) and why you decided to join? If you were trying to recruit a fellow community member to join, how would you describe the CAC? What would you tell them about your role? What have been the most meaningful aspects of participating in this group? Have you or do you participate on other types of councils or committees? What is different about the CAC?
Illuminating details	Tell me about a time when you felt most included in the work of the council? Be as descriptive and detailed as you can. Probing q's 'what were you thinking?' 'what were you feeling?' How do you get feedback that your voice and experience matter? What difference does it make when you are able to share your life experience with the others? How do you know what you share is respected and valued by others? Can you think of a time from a past meeting when you shared something and saw that it made a real difference or resulted in change? What ways does power show up in your meetings? What kinds of power do you have and use? What other kinds of power do you notice? Who has power in the CAC? How have you seen change occur in the community as a result of the CAC? I understand that this Spring, the CAC decided it would be good to have some voting member only meetings. Can you tell me more about how that came up and what you thought about it? The Healthy Gorge website describes the secret sauce includes two ingredients – collaboration and authentic engagement. Can you share more about how you see one or both of those things being practiced inside the work?

Theme	Question prompt or probe
Lessons	What happens in the meetings that helps you feel included and keeps you returning for future meetings? Have there ever been times when you did not feel adequately included? If you were to make a change in how members are included, what would it be?
Wrap up questions	Is there anything I didn't ask you that you wish I had asked that you'd like to share related to your experience as a CAC member? Is there anything else you want to add?

Non-Consumer Member Participant Interview Guide

Theme	Question prompt or probe
Introduction	Thank you for agreeing to this interview. As I mentioned when I reached out to you, I'm currently a graduate student of Antioch University focused on better understanding what shapes inclusive engagement of participants on the community advisory council.
Inquiry in what's meaningful	To begin, can you tell me about how you first heard of the community advisory council (CAC) and why you decided start attending meetings? If you were trying to recruit a fellow colleague to join, how would you describe the CAC? What have been the most meaningful aspects of participating in this group? Have you or do you participate on other types of councils or committees? What is different about the CAC?
Illuminating details	Tell me more about the consumer role on the council and what you perceive the consumer role contributes? What difference does it make when consumer members share their life experience? [If they answer that the experience shared makes a difference, ask] 'How do you or others from agencies show respect or convey appreciation? Can you think of a time from a past meeting when a consumer member shared a perspective, story or idea that resulted in change?

Theme	Question prompt or probe
	I understand that this Spring, the CAC decided it would be good to have some voting member only meetings. Can you tell me more about how that came up and what you thought about it? The Healthy Gorge website describes the secret sauce includes two ingredients – collaboration and authentic engagement. Can you share more about how you see one or both of those things being practiced inside the work? Are there particular events, organizations or individuals that have had an influence in shaping engagement and outcomes of the council?
Power	Tell me about how you perceive power in the council. What ways does power show up in your meetings? What kinds of power do you have and use? What other kinds of power do you notice? Who has power in the CAC?
Change	Can you describe any changes in your own organization that have resulted from your participation at the CAC? How have you seen change occur in the community as a result of the CAC?
Lessons	What happens in the meetings that helps members feel included? Why do you keep returning for future meetings? If you were to make a change in how members are included, what would it be?
Wrap up questions	Is there anything I didn't ask you that you wish I had asked that you'd like to share related to your experience as a CAC member? Is there anything else you want to add?

Scale item

On a scale of 1-10 with 1 = Note Effective and 10 = Extremely Effective,

- Overall, how effective is the CAC at including you?
- Overall, how effective is the CAC at including other consumer members?

Demographic Questions Asked at End of Each Interview

How many years or months have you been a part of the CAC?

Which age group describes you?

- o 18 to 29
- o 30 to 39
- o 40 to 49
- o 50 to 59
- o 60 to 69
- o 70 to 79
- o 80 or over

How do you currently describe your gender identity?

What categories best describe you?

- o American Indian or Alaska Native—For example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community
- o Asian—For example, Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese
- o Black or African American—For example, Jamaican, Haitian, Nigerian, Ethiopian, Somalian
- o Hispanic, Latino or Spanish Origin—For example, Mexican or Mexican American, Puerto Rican, Cuban, Salvadoran, Dominican, Columbian
- o Middle Eastern or North African—For example, Lebanese, Iranian, Egyptian, Syrian, Moroccan, Algerian
- o Native Hawaiian or Other Pacific Islander—For example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshallese
- o White—For example, German, Irish, English, Italian, Polish, French
- o Some other race, ethnicity, or origin, please specify: _____
- o I prefer not to answer.

What is your employment status?

- o Employed
- o Employed part time
- o Self-employed
- o Unemployed
- o Under employed (wage is below industry standard)
- o Retired
- o Student
- o Other

What is your highest level of education?

- o Less than high school
- o High school certificate
- o Higher diploma
- o Bachelors
- o Masters
- o Doctorate
- o Other

Appendix B: Informed Consent Form

This informed consent form is for Columbia Gorge Community Advisory Council (CAC) and/or the Columbia Gorge Health Council (CGHC) members who are invited to participate in a research study.

Name of Principle Investigator: Rachel Lucy Cecka
Name of Organization: Antioch University, PhD in Leadership and Change Program
Name of Study: Engagement in Multi-Sector Collaborations for Health

You will be given a copy of the full Informed Consent Form

Introduction

I am Rachel Lucy Cecka, a PhD candidate for Leadership and Change at Antioch University. As part of this degree, I am completing a research study. The study explores engagement of community members in collaborations for health improvement in the Columbia Gorge region.

I am going to give you information about the study and invite you to be part of this research. You may talk to anyone you feel comfortable talking with about the research, and take time to reflect on whether you want to participate or not. You may ask questions at any time.

Purpose of the research

The purpose of this study is to learn about how people with lived experience are engaged and included in health improvement collaborations. This information may help us to better understand what contributes to inclusive engagement of community members in this context.

Type of Research Intervention

This research will involve your participation in an approximately 45 to 60-minute interview. Interviews will be audio recorded for analysis later, but all of your contributions will be de-identified prior to sharing of the research results. These recordings, and any other information that may connect you to the study, will be kept in a locked, secure location.

Participant Selection

You are being invited to take part in this research because of your experience on the Community Advisory Council (CAC) as a consumer member and/or the Columbia Gorge Health Council (CGHC).

Voluntary Participation

Your participation in this study is completely voluntary. You may choose not to participate. You will not be penalized for your decision not to participate or for anything of your contributions during the study. You may withdraw from this study at any time. If an interview has already taken place, the information you provided will not be used in the research study.

Risks

No study is completely risk free. However, I do not anticipate that you will be harmed or distressed during this study. You may stop being in the study at any time if you become uncomfortable.

Benefits

There will be no direct benefit to you, but your participation may help others in the future.

Reimbursements

You will receive a $40 gift card for your participation in this study at the time of interview. If you withdraw from the interview before it is completed, you will still receive the gift card. The researcher may reach out following the first interview to ask some follow-up questions. You will not be provided any monetary incentive for the follow-up contact. This follow-up is completely voluntary.

Confidentiality

All information will be de-identified, so that it cannot be connected back to you. Your real name will be replaced with a false name in the write-up of this study, and only the researcher will have access to the list connecting your name to the false name. This list, along with recordings of the interviews, will be kept in a secure, locked location.

Limits of Privacy Confidentiality

Generally speaking, I can assure you that I will keep everything you tell me or do for the study confidential and comments will not be identified with you. Yet there are times where I cannot keep things private (confidential). I cannot keep things private (confidential) if I find out that

- a child or vulnerable adult has been abused
- a person plans to hurt him or herself, such as commit suicide,
- a person plans to hurt someone else,

There are laws that require many professionals to take action if they think a person is at risk for self-harm or are self-harming, harming another or if a child or adult is being abused. In addition, there are guidelines that researchers must follow to make sure all people are treated with respect and kept safe. In most states, there is a government agency that must be told if someone is being abused or plans to self-harm or harm another person. Please ask any questions you may have about this issue before agreeing to be in the study. It is important that you do not feel betrayed if it turns out that the researcher cannot keep some things private.

Future Publication

This research will be shared in a dissertation published online via several open access dissertation databases. Additionally, the plan is to seek publication in a journal and possibly, present the study at a conference.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and you may withdraw from the study at any time without any consequences.

Who to Contact

If you have any questions, you may ask them now or later. If you have questions later, you may contact Rachel Lucy Cecka.

If you have any ethical concerns about this study, contact Lisa Kreeger, PhD, Chair, Institutional Review Board, Antioch University Ph.D. in Leadership and Change, Email.

DO YOU WISH TO BE IN THIS STUDY?

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant_____

Signature of Participant _____ Date _____
Day/month/year

DO YOU WISH TO BE AUDIOTAPED IN THIS STUDY?

I voluntarily agree to let the researcher audiotape me for this study. I agree to allow the use of my recordings as described in this form.

Print Name of Participant_____

Signature of Participant _____ Date _____
Day/month/year

To be filled out by the researcher or the person taking consent:

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____
Day/month/year

Appendix C: Rutgers University Press Reprint Permission Request Form

Please complete the form below to the best of your ability and return it to:

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Title of RU Press book: Community Organizing and Community Building for Health and Welfare (3rd Edition)
Copyright year: 2012
Page number(s): Page 43, Figure 3.1
Brief description of requested material: Figure 3.1 Community Organizing and Community Building Typology

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I am currently a PhD candidate at Antioch University. I'm requesting permission to reuse figure 3.1 in my dissertation. My dissertation will appear in:

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See attached copy of figure 3.1 as it would appear in my dissertation.

Contact Information:
Name: Rachel Lucy Cecka
Affiliation: Antioch University

Elisabeth Maselli Jan 16, 2020, 8:29 AM (2 days ago)

to me

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Appendix E: Nonprofit Quarterly Reprint Permission

Request for permission to reprint the 6 principles that appear in Wolff et al (2016) in Nonprofit Quarterly

10:34 AM (4 minutes ago)

To whom it may concern at the Nonprofit Quarterly. I am currently a PhD candidate at Antioch University. I'm requesting permission to reprint the six "Collaborating for Equity and Justice Principles" in my dissertation. These principles appear on page 51 of the reference:

Wolff, T., Minkler, M., Wolfe, S. M., Berkowitz, B., Bowen, L., Butterfoss, F. D., & Lee, K. S. (2016). Collaborating for equity and justice: Moving beyond collective impact. *Nonprofit Quarterly*, 9, 42-53.

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Attached is a copy of the page proposed that would appear in my dissertation side by side with the original content.

Thank you in advance for your consideration.

Rachel Lucy MA

NPQ Info
to me

Feb 11, 2021, 1:14 PM (18 hours ago)

Yes, you can proceed, it has become automatic to send the citation guidelines when permission is granted.

As long as it properly cited, we grant permission.

Thank you, and also Tom Wolff has contacted us approving the permission request. So you are all set.

Please let us know if you need further assistance or have any of questions.

Thank you, stay safe.

Kind Regards,

The *NPQ* Team

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Appendix F: Recruitment Letter

Initial Contact Email Letter

Dear _____ ,

I'm writing to see if you would be willing to participate in one-hour interview with me. I am a PhD candidate studying in the Healthcare Leadership and Change program at Antioch University. As part of this degree, I am completing a research study focused on the experiences of people who have been members of Columbia Gorge Community Advisory Council (CAC) and/or the Columbia Gorge Health Council (CGHC).

This study explores engagement of community members in collaborations for health improvement in the Columbia Gorge region.

If you would be willing, I will send you more information along with a consent form for participation and we can set up a time for the interview. A $40 gift card is offered for participation in this study at the time of interview. If you'd like to discuss further, please reply to this email or call me on my phone.

Thank you so much for considering participation.

Rachel Lucy Cecka, MA
PhD candidate Healthcare Leadership and Change program
Antioch University

Second Contact Email Letter

Dear _____ ,

Thank you for replying and for your willingness to participate. I would like to set up a one-hour interview with you at a time that is convenient for you. At that time, I will review the research consent form with you and you will have the opportunity to ask me any questions you may have. You can decline or opt out at any point. If after reviewing the consent you are still willing to participate, then, you'll sign the form and we will commence with the interview.

These are time frames that I would be available. Please let me know if any of these times would work for you or if you need me to send more options.

- [available times would go here]
- [available times would go here]

As I shared in prior communications, I am a PhD candidate studying in the Healthcare Leadership and Change program at Antioch University. As part of this degree, I am completing a research study focused on the experiences of people who have been members of Columbia Gorge Community Advisory Council (CAC) and/or the Columbia Gorge Health Council (CGHC). This study explores engagement of community members in collaborations for health improvement in the Columbia Gorge region.

I will be asking you questions during our interview about your experience serving as a member of the CAC and/or the CGHC. I will be interested in hearing your thoughts about what engages members with lived experience in health improvement collaboratives.

Thank you so much for considering participation.

Rachel Lucy Cecka, MA
PhD candidate Healthcare Leadership and Change program
Antioch University