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# An exploration of the quality of citizen participation: Consumer majority boards of community health centers in Iowa

Kristi Lohmeier Law  
*University of Iowa*

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**AN EXPLORATION OF THE QUALITY OF CITIZEN PARTICIPATION:  
CONSUMER MAJORITY BOARDS OF COMMUNITY HEALTH CENTERS IN  
IOWA**

by

Kristi Lohmeier Law

An Abstract

Of a thesis submitted in partial fulfillment of the requirements  
for the Doctor of Philosophy degree in  
Social Work  
in the Graduate College of The University of Iowa

May 2013

Thesis Supervisor: Associate Professor Jeanne A. Saunders

## ABSTRACT

Quality citizen participation in processes of policy development is crucial to a democracy interested in equity of voice for all its citizens. Citizens with less political power, however, are often absent from policy development for a variety of reasons, despite legislative and advocacy efforts for inclusion. In policy development processes, community representatives are a mechanism for traditionally marginalized or disadvantaged citizens to have a voice; yet the question remains how to effectively utilize that voice. This question stems from research demonstrating an increase in quantity citizen participation but not in quality citizen participation, which is more interested in the process of policy development as opposed to a final product. To understand quality citizen participation, a critical ethnography guided by a socio-ecological perspective allowing for the investigation of contextual as well as individual factors impacting policy development processes was conducted to assist in advancing knowledge about the best practices necessary to facilitate the quality of citizen participation in policy development. The policy development process explored in this qualitative study was the context provided by three CHCs in a Midwestern state. Information was gathered about these three CHC boards from multiple sources to best represent the context surrounding participation on the boards and that participation experience from the perspective of board members. The data analyzed included: descriptive statistics of seven counties which comprised the patient community of the three CHCs participating in the study, descriptive statistics of the patient communities of those three CHCs, interviews with national and state policy experts, the clinic directors and board chairs of the three CHCs and interviews with 16 board members of the three CHCs. Analysis of these data identified individual, relational, organizational, community and public policy level factors which impacted the participation of board members of three CHCs. For example, the education and background experiences of board members (individual) as well as relationships between board members and the management teams of the clinics

(relational) facilitated the quality of their participation on the boards. Contextual knowledge of economic, political, and cultural factors were discovered for each of the three clinics, and proved important to understanding the process of the quality of citizen participation of board members.

Social work educators and practitioners will benefit from the advancement of knowledge about what factors facilitate the quality of citizen participation in policy development processes. The results of this study suggest that practitioners interested in empowering consumers to have a role in the provision of services need to understand what facilitates the quality of citizen participation to ensure that consumers have a legitimate voice in policy development and implementation processes. The results of this study also inform our understanding of citizen participation in multiple policy development processes. For example, because legislators will benefit when barriers to the quality of citizen participation are identified, educators teaching social work students about macro practice will have concrete lessons from which to draw. In addition, practitioners who work with non-elected members of boards will benefit from barrier identification allowing them to assist in the empowerment of future board members engaged in policy development on a wide variety of boards. Finally, actual board members, especially those representing traditionally disadvantaged or marginalized communities, will benefit from knowledge gleaned from similar experiences, and educators teaching social work students about the benefits of advocacy and empowerment could assist to make their participation more effective.

Abstract Approved: \_\_\_\_\_

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Graduate College  
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CERTIFICATE OF APPROVAL

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PH.D. THESIS

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This is to certify that the Ph.D. thesis of

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This dissertation is dedicated to my family: The one I was born into, the one I married into, and the one I am creating with Chris. Your love and support have helped me accomplish this amazing feat and have no doubt made me the person I am today.  
Thank you.

Social advance depends as much upon the process through which it is secured  
as upon the result itself.

Jane Addams



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## **CHAPTER 1**

### **INTRODUCTION**

#### **Citizen Participation in Decision Making**

Citizens' equal participation in societal decision making is the fulcrum of a democracy. Equal participation by all citizens ideally requires policymakers to consider the needs, experiences, and opinions of these citizens when deciding how to prioritize resources. Access to citizen participation is crucial for the empowerment of disadvantaged and marginalized communities to have a legitimate voice in the crucial decisions policymakers wrestle with from Washington, D.C., to state capitals across the United States (Gutiérrez, 1990). The diversity of behaviors and activities on the continuum of participation spans from voting to legislative advocacy. Full citizen participation reflects the democratic value of all citizenry's representation in policy decisions (Verba, Schlozman, & Brady, 1995) and is a pathway to empowerment for consumers of services (Boehm & Staples, 2004); yet, recent trends suggest that disadvantaged and marginalized citizens are excluded (whether purposefully or inadvertently) from these vital policy-making processes (Lombe & Sherraden, 2008). Thus, understanding the policy process and the role of citizen participation in that process, especially for economically disadvantaged citizens who may have less access to the process, is of the utmost importance in achieving social justice.

More specifically, understanding the way access to policy development processes vary for economically disadvantaged citizens is particularly important considering that income inequality in the U.S. is at the highest levels in decades (Mishel, Bernstein, & Allegretto, 2007). Disparities in access, wealth (measured most frequently by assets), and income (measured most frequently by household dollars) decrease the "political interest, discussion of politics, and participation in elections among all but the most affluent" (Solt, 2008, p. 48). Social work scholars, educators, and macro practitioners need to

identify and critically evaluate the barriers to equal citizen participation by disadvantaged individuals to achieve equal access for all citizens.

### **Behavior and Activity Related to Citizen Participation**

Given the various existing definitions and conceptualizations of citizen participation, it is essential to clarify its use in this study. *Citizen participation* is defined as an activity or behavior in a decision-making process that is willingly engaged in by individuals and groups to impact challenging issues faced by disadvantaged communities (Gamble & Weil, 1995; Ohmer, 2007, 2010). Citizens can participate in policy development processes through a number of activities and behaviors, including attending a public meeting to express an opinion on a local, state, or federal problem (Cohen & Dawson, 1993; Wang, 2001; Weber, Loumakis, & Bergman, 2003); meeting with a state legislator to express support for or disagreement with a particular policy position (Cohen & Dawson, 1993); contributing to a political campaign through financial or voluntary means (Brady, Verba, & Scholzman, 1995); organizing through the structure of a neighborhood association to address problems in an unstable neighborhood (Alex-Assensoh, 1997; Brady et al., 1995; Casciano, 2007; Itzhaky & York, 2000; Perkins, Florin, Rich, Wandersman, & Chavis, 1990; Swaroop & Morenoff, 2006; Weber et al., 2003; Zimmerman & Rappaport, 1988); and casting a vote for a preferred candidate on election day (Alex-Assensoh, 1997; Casciano, 2007; Huckfeldt, 1983; Lelieveldt, 2004). Although the activities and behaviors that characterize citizen participation are a necessary measure in the literature, what is less clear is whether these activities and behaviors signal the legitimate voice of disadvantaged and marginalized communities in policy development processes.

One example of how the legitimate voice might be questioned is evident in voting behavior. Although electoral behavior (or voting) is a less involved dimension identified in a continuum of engagement as an activity of citizen participation in policy development due to the mediation of direct input of citizens to policy development by the

people whom citizens elect, an interesting trend was identified in the 2008 presidential election. More specifically, when Soss and Jacobs (2009) examined low-income individuals' participation in the 2008 presidential election, they discovered an imbalance of power and voice in this population. Despite an explicit focus of the 2008 Obama presidential campaign to mobilize marginalized and disadvantaged communities (Soss & Jacobs, 2009), 70% of the voters came from families earning \$50,000 or more (U.S. Census Bureau, 2010). That means the remaining 30% of voters who turned out for the 2008 election lived in households making \$50,000 or less; 13% lived in households making \$20,000 or less (U.S. Census Bureau, 2010). Therefore, measuring political power through the activity of voting suggests that less political power exists among people identified as economically disadvantaged. In addition, this statistic also points to the lack of voice in the policy process from those living in households making \$50,000 or less, which for a family of four is just above 200% of poverty. The day-to-day lives of these households are impacted by the policy process in which they have little to no voice.

### **Identifying the Problem: Citizen Participation, Policy**

#### **Development, and Political Power**

An opportunity for citizens to participate in policy development more directly than by voting in a democratic society exists in specific decision-making contexts in which citizens join with others in policy development processes. Policy development typically occurs in phases and includes problem identification, solution formulation, policy implementation, and policy evaluation. The first phase of this process is undoubtedly the most vital; a problem can be identified by an individual, a policymaker, a citizen's group, a community board, a city council, a state legislature, or a regional coalition. Problem identification is necessary if policy change is to occur, because this highlights problems whose solutions can be found in changes made to policy. Although there is room for input at multiple phases of policy development, traditionally problem identification sets the agenda from which other processes fall.

An examination of the variety of activities or behaviors related to policy development processes shows that levels of participation by marginalized and economically disadvantaged citizens in the U.S. have been low throughout the last 50 years (Verba et al., 1995). As the various activities and behaviors defining citizen participation demonstrate, many opportunities exist for citizens to participate equally. This suggests that quantity (of participants) is potentially present in that those with less power or disadvantaged or marginalized communities have a voice. However, what is less understood is how to maximize the quality of citizen participation, or legitimacy, in policy development among disadvantaged and/or excluded citizens. This definition of quality comes from Arnstein (1969) and her ladder of citizen participation, which suggests that for full citizen voice to be realized in policy development processes where those with varying levels of power are a part of the process, power has to shift from the status quo to those traditionally with less power. Arnstein (1969) based her ladder on the idea that there are variations of participation for disadvantaged and marginalized citizens (Rocha, 1997). The extension of quantity to quality is important to understand because of the role of this power shift in the empowerment of those in society seeking equality and social justice. This dissertation study addressed this gap by using a critical ethnography to gain a 360-degree view of quality of citizen participation from the perspective of citizens serving as community representatives in policy development.

Equal citizen participation in a democratic society ensures that all voices are heard in decisions impacting their lives. However, unequal distribution of political power in a society could result in the exclusion of citizens with less political power in policy development processes (Kaufman, 1969). For example, officials elected to the 113<sup>th</sup> U.S. Congress continue the legacy envisioned by the forefathers of this country that reinforced who had a credible voice in policy input and who did not. For those forefathers, only a certain type of citizen had a voice: someone who had money, was male, and was white. This profile of a “citizen” was the status quo for years, and although times have changed,

the overwhelming majority of current elected officials to Congressional office continue to fit this profile. Specifically, only 90 (16.8%) of the 535 seats in Congress are female and of those seats, 24 (27%) are women of color (Center for American Women and Politics, 2012).

These numbers indicate that despite years of hard fought battles for equal representation, the trends from the past definition of inequality remain. According to Homan (2011), representation is one component of political power or *force*. The representation in the U.S. Congress is an example of political power being held in the hands of a few, strengthening the notion that if electing representatives is one way citizens are able to contribute to policy development, the fact that these representatives are not minority status individuals (for example women or people of color) demonstrates that political power is unequal and those not enjoying the privileges of the status quo are not represented.

The problem of exclusion for disadvantaged communities in decision-making processes has roots in the unequal distribution of political power in U.S. society. Homan (2011) defined *political power* as a force “used to make or shape policies that have an impact on people” (p. 154). If political power does not increase despite efforts to bring more individuals into policy development, then the quality of citizen participation has not been achieved. Instead, an increase in quantity of citizen participation occurs through an increase in the activities and behaviors previously mentioned. In the policy decision-making process, if political power is held in the hands of a few who are responsible for identifying problems, which policy is then crafted to remedy, those without power are excluded. The status quo dictates the answer to the question of who has the power in the context of policy development. When it is held in the hands of a few, the status quo of concentrated power in the hands of a powerful minority is reinforced, which prevents other perspectives from joining the conversation.

Ideally, the purpose of participation by non-elected citizens in policy development activities and behaviors, such as voting, public meetings, and providing feedback on local issues to state legislators, is to afford opportunity for all citizens to have a voice in the policy development process. However, if voices are heard unequally or access to processes through which individuals can exert their voice (i.e., entrance into the above-mentioned phases of policy development) is limited for certain segments of society, then the main tenets of a democratic society are violated and the legitimacy is questioned when the marginalized and disadvantaged in society are denied democratic participation.

This study explored the quality of citizen participation of consumer representatives on a board charged with policy development for Federally Qualified Health Centers (FQHCs) or Community Health Centers (CHCs) in Iowa. Although the literature refers to these types of health centers in both ways, for the remainder of this document they will be referred to as Community Health Centers or CHCs. Given the potential for disadvantaged or marginalized citizens to lack political power or *force*, an absence of substantial voice in policy development processes, along with the evidence suggesting research has traditionally focused on increasing the quantity of citizen participation and not the quality of that participation, this study explored the quality of citizen participation from the perspective of CHC board members. A critical ethnographic methodology guided by Carspecken (1996) was employed to conduct a comprehensive exploration of CHC board members' experiences as participants in policy development processes to better understand the quality of citizen participation.

### **Historical View of Citizen Participation**

The lack of participation by one segment of society disadvantaged or marginalized in some way is not a new issue. In the 1950s and early 60s, there was a growing recognition of economic disparities between the haves and the have-nots in American society (Geiger, 2005). This recognition was coupled with a desire for civil rights and justice for all Americans, and woven in that desire was the need for

communities to be a part of the transformation taking place in society (Geiger, 2005). To address this problem, during the War on Poverty's Economic Opportunity Act of 1964, specific legislative edicts were included to address the lack of participation by low-income individuals in decision-making processes such as policy development.

A specific directive came with the concept *maximum feasible participation*, which was included in the Economic Opportunity Act and articulated an equitable distribution and voice at the decision-making table between program recipients and administrators, local decision-making leaders, and elected politicians (Reisch & Andrews, 2001). Social welfare programs, constructed as tools to combat poverty under the Economic Opportunity Act of 1964, were meant to address the injustice to which Civil Rights activists and leaders were drawing attention, one of which was exclusion in decision-making processes. The inclusion of maximum feasible participation in the legislation attempted to remedy situations of powerlessness in which individuals benefiting from social welfare programs and policies were voiceless in the governance and implementation of those programs and policies.

More specifically, this legislation required that a certain percentage of the marginalized or disadvantaged individuals served by social welfare organizations have a voice at the decision-making table. This requirement increased the quantity of participation by these groups but not necessarily the quality of these contributions. In other words, the groups had a seat at the table that reflected the quantity of their participation, but their political power in decision making, or the quality of that participation, remained questionable (Reisch & Andrews, 2001). This concept of requiring participation from low-income groups was applied in a number of different settings including Community Action Partnerships and Head Start programs. An additional program that benefited from the concept was Community Health Centers (D. Hawkins interview). This relationship will be further discussed in Chapter 2.

## **Difference Between Quantity and Quality of Citizen Participation**

### **Quantity of Citizen Participation**

The research on citizen participation, to be discussed in detail in Chapter 2, clearly shows an emphasis on quantity of participation and examines the influences of individual characteristics such as race/ethnic identity, gender, home ownership, and age as well as community characteristics such as neighborhood poverty level, neighborhood crime, and neighborhood appearance on the likelihood that individuals will participate in a number of activities or behaviors thought of as citizen participation. The dominant theme in this literature is a focus on individual and/or community-related characteristics affecting people's involvement in the policy-making processes to understand why some people do and do not participate. This theme focuses on the quantity of citizen participation because the literature quantifies the presence of participation through a set of activities or behaviors. Glaring omissions in this myopic focus on the individual or community are the potential structural or contextual factors which influence the process of quality citizen participation. These factors include the context of political power as well as the structure of the policy development processes and how that context impacts citizen participation. An understanding of political power within the policy development process helps to explain why those at the bottom of the power hierarchy in a society plagued with extreme inequality also have the meekest voice in policy development and change.

The varieties of ways citizens can participate in policy development have been described. One concrete example of citizens participating in these processes comes from representation on boards of community health clinics, specifically CHCs. An additional stimulus for the construction of these boards was that they were the offspring of ideas articulated in the Economic Opportunity Act of 1964, namely, the specific requirement that their board membership be composed of 51% representation from individuals



mirroring the demographic of the patients served by the clinic (National Association of Community Health Centers Manual, 2005). The current study will use the social context provided by the CHCs' community boards to explore this experience by the community board representatives to better understand quality citizen participation.

### **Quality of Citizen Participation**

Different from the quantity of participation, the quality of citizen participation refers to the way legitimate citizen involvement in policy development processes shifts political power (Arnstein, 1969). With the wave of interest in including consumers in the development and implementation of programs and policies meant to improve their lives were the challenges associated with including so many different voices in that process (Burke, 1968). Arnstein (1969) noted differences in citizens' participation: In some cases, structure existed for that participation but the quality of participation still did not exist; in other cases, elements of legitimate participation were present (i.e., consumers of services having the majority of seats on a governing board), but a legitimate power shift had not occurred. The investigation of increasing citizens' political power is crucial to power redistribution, and, until recently, research has focused on how individual and community characteristics influence an individual's citizen participation. Exploring the quality of citizen participation provides information as to how individuals can increase their political power and shift decision making to those who are underrepresented in policy development. This shift in power was what the concept of citizen participation originally meant to do (Arnstein, 1969, 1972).

Interestingly, despite the original inspiration behind the concept, the political power inherent in citizens' participation in policy development appears absent from contemporary research on participation. This absence could be a result of focusing on increasing the quantity of participation as mandated by maximum feasible participation language and not the quality. This insular approach to participation might be related to how political power influences the way citizens participate. Arnstein (1969) originally

introduced this idea in the 1960s to answer the call for evaluating citizen participation as understood within the Economic Opportunity Act of 1964, and, indeed, viewed the ladder of citizen participation as addressing an oversight of quality in participating processes. The motivation for Arnstein (1969) to examine the role of power in policy making was her belief that merely participating was not enough in the quest to shift power.

### **Arnstein's Ladder of Citizen Participation**

To illustrate this conceptualization of political power in the process of citizens' participation in policy development, Arnstein constructed the ladder of citizen participation (1969). This ladder describes an evolving process of citizen participation ranging from a low point of nonparticipation, moving up in participation to tokenism reflecting higher levels of engagement, and culminating in full citizen control at the top rung of the ladder. For a visual replication of the ladder of citizen participation, see Figure 1.1. In Figure 1.1, the three degrees of citizen participation on the far left include degrees of citizen power, degrees of tokenism, and nonparticipation. My interpretation on the right illustrates the increase in political power as the citizen moves up the ladder. This increase shifts power in decision making from a small minority to a large majority. This ladder is useful to understanding citizen participation, specifically the quality of citizen participation, because it highlights the importance of not only the outcome but also the process of participation along with the possibility that policy change can result as disadvantaged and/or marginalized citizens' voices increase.

Examining the quality of citizen participation through the lens of Arnstein's ladder requires consideration of multiple levels of influence on the quality of citizen participation, not only the characteristics that impact an individual's participation, and fits nicely with a critical ethnography and the socio-ecological model.

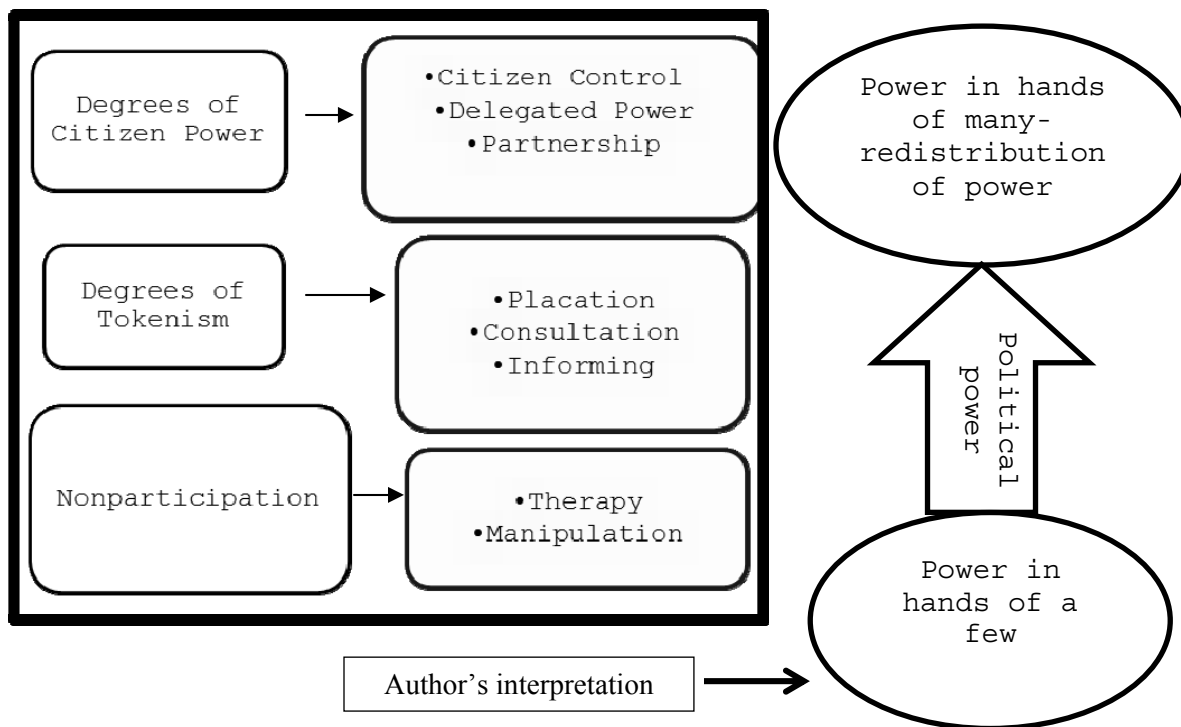


Figure 1.1 Arnstein's ladder of citizen participation and the author's interpretation related to political power

Source: Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association*, 35(4), 216-224.

### **Socio-Ecological Perspective Informs Quality of Citizen Participation**

The conceptual perspective this study utilizes to view the quality of citizen participation stems from a modified version of Bronfenbrenner's (1979) ecological perspective. Bronfenbrenner developed this conceptual framework from what he perceived developmental psychologists needed to understand about how children interacted with their environment and how those interactions influenced certain outcomes. Developed to describe further the exchanges between individuals and their environments, Stokols (1992) articulated how the socio-ecological perspective adapts the ecological perspective by emphasizing that the adaptation concentrates on "social,

institutional, and cultural contexts of people-environment relations” (p. 7), as opposed to interactions only among individuals, families, and groups.

A crucial contribution of the socio-ecological perspective is articulating a difference between individual and community levels of interaction on behavior while also considering the context surrounding that behavior. Context is essential given that it often shapes public policy development or, vice versa, public policy development may shape context (Milio, 1988). Figure 1.2 depicts the socio-ecological perspective based on the review of literature by McLeroy, Bibeau, Steckler, and Glanz (1988). In Figure 1.2, the original descriptions of each level by Bronfenbrenner (1979) are italicized and the new conceptualizations by McLeroy et al. (1988) are bolded. McLeroy et al. (1988) labeled each level differently to further demonstrate their influence within the broader political context that public policy provides.

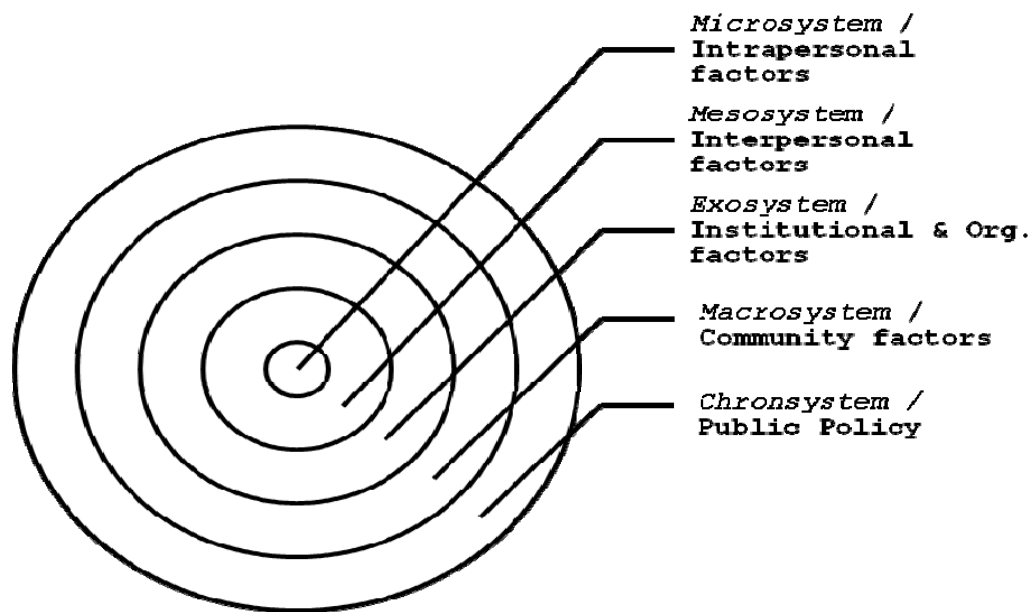


Figure 1.2 Bronfenbrenner’s *ecological perspective* and McLeroy et al.’s **socio-ecological perspective**

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Source: Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press; McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Behavior*, 15, 351-377.

Specifically, attention to context in the socio-ecological perspective provides an appropriate mechanism to identify how power imbalance in the policy-making process could restrict access to the quality citizen participation of marginalized or disadvantaged individuals. For instance, citizen participation within the context of policy development is of interest to quality in citizen participation. So it follows that understanding the role of power in decision-making processes highlights interactions suitable for investigation through the socio-ecological perspective.

The socio-ecological perspective enhances the importance of public policy's impact on relationships, environment, and individual characteristics present in an individual's social world. To this point, Lombe and Sherraden (2008) described five necessary facets and various units of analysis to understand how to include the excluded in policy development. Interestingly, these aspects and various units of analysis map on to the socio-ecological perspective and strengthen its utility in the present study. For example, at the individual level, the authors cited the utility of formal voting to measure the inclusion of disadvantaged citizens.

Strengthening its usefulness in understanding the quality of citizen participation, Lombe and Sherraden (2008) did not stop at voting as the only measurement to explore when seeking to increase participation by excluded citizens. Instead, they moved to the next level and suggested measuring experiences in policy development through the information exchanges between citizens. Continuing to the organizational and community level, they identified the involvement of citizens in community organizations and maintained that how those community-level groups contributed to policy development are important to measure when trying to understand exactly who was excluded from policy processes (Lombe & Sherraden, 2008). These examples demonstrate the perception that certain citizens are indeed excluded from policy development, and to include those citizens, a multidimensional exploration into the experience of participation

is necessary to identify exactly how the process of participation works and to craft successful interventions that improve the quality of citizen participation.

Citizen participation is a mechanism for underrepresented or excluded citizens to participate in policy-making processes. Unambiguously, policy development has complex layers of influence that include the products and the processes that construct, implement, and evaluate the policy products that are created. Stokols (1992) recognized the importance of this influence when he stated “efforts to promote human well-being must take into account the interdependencies that exist among immediate and more distant environments” (p. 8). In other words, simply identifying interactions among various levels of an individual’s life potentially overlooks the existence of these interdependencies.

The socio-ecological perspective informs this study in a crucial way. At the center of the perspective is the mutually influential role of both individual characteristics and the influences resulting from an individual’s relationships at the family, group, or community levels (Bronfenbrenner, 1979, 1994; McLeroy et al., 1988; Stokols, 1992). These multiple influences can affect the quality of citizen participation on boards because it harkens back to the concept’s original intent not only to include people’s voices at the decision-making table, but also to redistribute power and thereby increase the voice of the disadvantaged.

In the literature review, in Chapter 2, a modified version of the socio-ecological perspective is used to discuss and explore an individual’s context, which includes the multiple layers present in the socio-ecological perspective. This discussion provides a new lens through which to view the quality of citizen participation. Studying the quality of citizen participation through a critical ethnographic approach is appropriate because it allows one to investigate in depth the complexity of how context influences individuals while taking into account that the individuals might not be aware of those particular influences (Georgiou & Carspecken, 2002). As demonstrated by the example above,

understanding the complexities of citizen participation is assisted by a study attentive to the quality of participation of the policy-development process in which citizens are participating through an exploration that includes the context of that participation as well as the experience of participation from those doing the participating.

### **Importance of Understanding Quality of Citizen Participation**

The research question guiding this study examined the experiences of citizen representatives serving on boards to understand how that context facilitates the quality of citizen participation. An innovative contribution to the literature will be the emphasis on understanding the quality of citizen participation that extends the literature of the quantity of citizen participation. Despite the multiple theories and models that currently explain variation in levels of citizen participation and the interventions designed based on their results, the problem presented by a lack of quality citizen participation in which power and voice are not shifted to disadvantaged and marginalized citizens continues to exist disproportionately for those individuals (Boehm & Staples, 2004; Lombe & Sherraden, 2008; Verba et al, 1995). A gap exists in the literature accounting for contextual and structural impacts on citizen participation, which might play a role in political power redistribution and is located within the organizational, institutional, and community factors referenced in Figure 1.2 on the socio-ecological perspective. This gap suggests that an investigation guided by multiple levels of influence that are provided by the socio-ecological perspective paired with an exploration through the eyes of individuals currently involved in community health center boards will take the necessary steps towards filling that gap.

### **Purpose and Research Question**

The purpose of this critical ethnography study was to explore the social setting and context surrounding CHC board members in policy development to understand better how that context facilitates the quality of citizen participation for those members. For this

investigation, the experiences of board members of CHCs were explored through researcher observations, a review of relevant documents, and semi-structured interviews. Access to individuals participating on CHC boards was facilitated by the Public Policy Center (PPC) at The University of Iowa. At the time of this study, the PPC was investigating the impact of the Affordable Care Act of 2010 on the health care safety net in Iowa.

The research question guided this study *How do community health center boards facilitate the quality of citizen participation in policy development?*. Semi-structured interview questions explored the experiences of participation on the community health center boards with board members as they made policy development decisions for the community health center. An adaptation of a socio-ecological perspective described in the next section guided the development of the questions in the interviews, and Carspecken's (1996) critical ethnography guided the overall data collection and analysis.

### **Contribution to Social Work Education, Community, and Policy Practice**

For social work education, providing a better understanding of how political power influences the quality of citizen participation processes in a variety of settings assists in the instruction of these abstract concepts to future social workers. To teach these lessons at the social work community practice level, which includes individuals gaining a better sense of control over the course of their lives by fully engaging in society through citizen participation and social work practitioners facilitating that engagement, it is vital to understand individuals' experiences in many circumstances so that appropriate interventions to empower individuals to increase their engagement can be identified. In addition, a part of this empowerment is a recognition of how political power and social inequality factor into the policy development process (Gutierrez, 1990), upon which the context of this research sheds light given the environment in which CHCs were developed and continue to operate today. Social work educators must help their students



to connect the field of citizen participation with the reality of political power to better understand how the quality of citizen participation contributes to the knowledge necessary to design better interventions in the future.

The findings from this study have policy implications regarding how an increase in citizen participation can strengthen the end product of policy. Specifically, sweeping social reform like that present in the Affordable Care Act of 2010 (ACA) or “health care reform” or “Obama care” is made stronger and more sustainable when everyday Americans impacted by the policy reform understand and are engaged in the reform, not only in its implementation, but also in other phases of policy development such as creation, evaluation, and restructuring (Crawshaw, 1994; Hoffman, 2003). Given that the next phase of the ACA will be implementation and evaluation at the local, state, and federal levels, decision makers would benefit from a better understanding of the quality of citizen participation from the angle of those currently doing the participating in order to make that participation as effective and meaningful as possible. Understanding quality citizen participation is in line with principles important to social work: When the quality of citizen participation is not fully understood, a significant social justice issue is presented.

To answer the research question, *how do community health center boards facilitate the quality of citizen participation in policy development*, five objectives guided the data collection and analysis for this study:

1. To explore the context that surrounds the social site, community health center boards in Iowa.
2. To describe the social site of community health center boards in Iowa using three of the 14 boards.
3. To map the complex relationship between the community health center boards and their members, leaders, and communities.

4. To explore the experience of participation on the community health center boards by board members, both consumer and nonconsumer members alike.
5. To identify the factors that impact the quality of that participation from the multiple perspectives and voices present in the study.

### **Organizational Statement**

This investigation includes five additional chapters. In Chapter 2, the history of participation is revisited with a narrowing focus on citizen participation and concludes with an articulated contrast between quantity and quality citizen participation guided by the socio-ecological perspective. This review will include relevant literature, identification of gaps in the literature, and how the current study fills those gaps by deeply examining the quality of citizen participation from the perspective and experiences of consumer members on CHC boards in Iowa. In Chapter 3, the study methods are discussed. This discussion includes the proposed methods used, the gaining of entry into the research setting, the steps of each phase of data collection, and the focus during analysis based on the data collected. In Chapter 4, the information gathered for the primary record (Carspecken, 1996) of the three clinics that agreed to participate in the study and their relevance to understanding the overall study results will be presented and discussed. In Chapter 5, the influences based on the socio-ecological perspective identified by study participants are discussed along with the major themes that emerged from the overall study. Chapter 6 concludes the investigation with a discussion of the results and conclusions based on the conducted research, implications for social work education and policy and community practice, and future direction for the study of the quality of citizen participation.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter will describe the evolution of citizen participation as a concept. The description of this history demonstrates how the concept evolved and how that evolution has continued to impact the way the concept is measured. A discussion of the various complexities surrounding citizen participation will provide an ample background for the present state of the literature and describe how the current study is a logical step in the continued progression to understand the quality of citizen participation.

Additionally, a thorough description and analysis of the modified socio-ecological perspective and its application to the current study will be discussed. Specifically, each level of the perspective describes levels of analysis measuring various influences of individuals' context that are necessary to understand the quality of citizen participation. These levels are crucial to understand because they provide an in-depth inquiry into how multiple influences contribute to understanding the quality of citizen participation. Additionally, they are the foundation for the interview questions utilized in the exploration of CHC board members' experiences in policy development processes.

Next, the research methods used to understand citizen participation from multiple perspectives are reviewed. Strengths and weaknesses of these methods and how they informed the methodological choices for this study are discussed. The chapter concludes with a critique of the current research addressing the assumption that equity in citizen participation is a commonly held belief in U.S. society (Verba, 2003)—a critique that is beneficial to constructing a comprehensive exploration of the quality of citizen participation.

#### **Evolution of Citizen Participation in U.S. Society**

The term “citizen participation” is historically associated with the War on Poverty because of the context provided by the 1950s and 1960s, the Civil Rights Movement, and an increased interest in community engagement with social problems. However, the roots

of the concept extend long before this time to as early as the colonial settlements (Roberts, 2004). Early settlers modeled their version of citizen participation on the Magna Carta and required due process and self-regulated churches. The townspeople's engagement in town meetings masked equal participation, however, because this engagement was limited to the elite: white, free, adult, male property owners (Keyssar, 2000). The expansion of citizen participation beyond this elite group began during the 19<sup>th</sup>-century presidency of Andrew Jackson. Throughout the 1820s and 1830s, the quantity of citizen participation was more important than the quality of that participation, specifically speaking to the lack of attention to the diversity of voices participating. This trend from the early to mid-19<sup>th</sup> century continued into the 20<sup>th</sup> century where participation was extended to include citizen involvement on city and localized planning committees, as well as participation motivated by environmental issues. In these contexts of participation, increased citizen engagement was imperative, but the quality of that participation and the legitimacy of their voices were ignored.

### **Legislated Participation as a Solution to Social Policy Exclusion**

#### **Voting Rights**

An interesting element of the citizen participation history in U.S. social policy decision making is the identified solution that in order to address the problem of exclusion, participation must be legislated. In fact, this solution was also used to remedy the exclusion of certain citizens from U.S. political life in the 19<sup>th</sup> and 20<sup>th</sup> centuries as well with the passage of the 15<sup>th</sup> and 19<sup>th</sup> amendments to the Constitution in 1870 and 1920, respectively. These amendments guaranteed that citizens' voting rights cannot be denied based on "race, color, or previous condition of servitude" (U.S. Const. amend. XV) nor on "sex" (U.S. Const. amend. XIX) and were the result of many years of battle to secure those rights. Despite these legislative actions to improve voting for disadvantaged and marginalized citizens, their turnout remains low compared to majority

groups (Freeman, 2004), and despite the evidence that the quantity of their participation in voting has increased over time, the quality of previously disenfranchised citizen's representation by elected officials and community engagement remains in question. Indeed, a fascinating question surfaces as a result of this history: What impact does legislating participation have on the quality of citizen participation?

### **Housing Act of 1949**

Citizens' direct involvement in a variety of civic and social activities permeated legislation in the 1940s and culminated with the Housing Act of 1949, which "on paper" was the first piece of legislation to require participation of everyday citizens in government-related activities (Roberts, 2004). The original intent of the Housing Act of 1949 was to provide entrepreneurs the opportunity "to direct the path of development" (Poindexter, 2000, p. 662) in order to clear out urban slums and prevent residents of the area or local legislators charged with making decisions about the area from contributing to how that decision happened. The result was a program of urban removal, as opposed to urban renewal where residents had absolutely no say in what occurred in their neighborhoods and were displaced with no input at all. A disproportionate number of the displaced also happened to be from marginalized and disadvantaged communities (e.g. low-income and minority families; Massey & Denton, 1993). The legislation required participation as a contingency of federal funds, called it "part of the workable program for community improvement" (Hallman, 1972, p. 421), and implemented advisory committees composed of local leaders without the participation of actual residents of the neighborhoods set for demolition.

### **Urban Renewal Act of 1954**

The history of the Housing Act of 1949 demonstrates the influence of those in power on the decision making that impacts disadvantaged individuals, despite legislative mechanisms to improve the voice and access of the powerless. This theme is extended in later public policy through the passage of the Urban Renewal Act of 1954, which

continued a commitment to “on paper” inclusion. The reality was exclusion despite the experiences of the Housing Act of 1949 in which invitations were extended to citizens such as local leaders and business owners to serve on advisory boards (Roberts, 2004) instead of invitations to everyday citizens. Participation by residents in these processes called into question *who* was participating, given that those called to the table were not residents of the afflicted areas but were local leaders and representatives possibly out of touch with the reality of the neighborhoods involved (Roberts, 2004). The desire for genuine resident participation was apparently not to gain input, but rather to improve resident acceptance of their neighborhood’s fate in terms of the changes it would undergo during the urban renewal/removal/redevelopment decision-making process.

The goal of the Urban Renewal Act of 1954 was “legitimacy and a change in citizen attitude” (Burke, 1983, p. 107) and signaled a fundamental distinction of participation’s purpose at this time. Resident buy-in was the purpose in the midst of changing urban city centers. Prior to this, equal participation was absent. Consequently, any increase in citizen involvement was seen as an improvement. Public policy provided the foundation to increase residents’ voices previously represented by community leaders. It is important to understand this foundation as the political, social, and economic turmoil of the 1960s laid the groundwork for expansion by the number, legitimacy, and diversity of voices heard.

### **Economic Opportunity Act of 1964**

One place the political, social, and economic turmoil collided in social policy was during the “War on Poverty” and passage of the Economic Opportunity Act of 1964. Among other programs, this act created semiautonomous Community Action Programs (CAPs) across communities in the U.S., which served as a significant catalyst for increased citizen participation (Reisch & Andrews, 2001). The CAPs’ goal was to center power with residents in low-income neighborhoods and consumers of the services provided in those neighborhoods through the programs developed as part of the

Economic Opportunity Act. This goal was accomplished through resident engagement in local political activities and an increase in their political power. Guided by a different purpose than urban renewal, engaging participants in local politics provided those most impacted by policy decisions with a voice in decision making and resource distribution (Burke, 1983). Although the focus of the War on Poverty programs was to create opportunities for disadvantaged and marginalized communities (Reisch & Andrew, 2001), CAPs addressed these concerns by directly involving those most impacted by the programs in the implementation of the programs.

### **Community Health Centers**

Community Health Centers began as a demonstration project, but health care was not originally part of the mandate addressed by the Equal Opportunity Act of 1965 (Sardell, 1988) and the Act is, or can be, renewed each year. In fact, it was not until the programs of the Office of Economic Opportunity (OEO) associated with the Equal Opportunity Act were up and running did the problem of inadequate access to health care by the majority of consumers of the programs become an issue policymakers felt needed to be addressed (Sardell, 1988). The CHCs created to specifically address the unique health needs of citizens in disadvantaged and marginalized communities across the country were initially a pilot project with two pilot site states, Mississippi and Massachusetts (Lefkowitz, 2007). As a direct result of the historical context provided by the turmoil of the 1950s and 60s, CHCs were created with an explicit focus on community involvement, governance, and active engagement that previously did not exist on a national scale for health care (Geiger, 2002). This idea hinged on a premise adopted from maximum feasible participation that those who experienced inequities of health care service provision were the best voices to identify the issues faced by the community. Because of this premise, those voices should therefore have an active role at the decision-making table regarding the implementation, delivery, and evaluation of those services.

Specifically, the CHC movement can be traced to three key historical events: community health care in South Africa, the Civil Rights movement, and the realization that there existed “another” American (that is, the distinction between those who do not live in poverty and those who do; Geiger, 2005). John Cassel worked for a time as clinical director of the Pholela Health Center, the pioneering South African program where the first community-oriented primary care concept (COPC) was implemented, a model that integrated public health with social justice to provide access to primary health care services in impoverished and disadvantaged communities (Geiger, 2002). Combining the Civil Rights movement characterized by social unrest and a demand for social change with the recognition that those who live in poverty lived a different life than others in America provided fertile ground for reformers to incorporate the model from South Africa’s COPCs into primary health care centers in the U.S. (Lefkowitz, 2007). From these events the CHC founders drew, among other ideas, on the principle of community involvement and engagement, a principle that many believe has been vital to the CHCs’ stability and survival (Lefkowitz, 2007; Sardell, 1988).

As mentioned in Chapter 1, the literature on CHCs discusses them in some cases interchangeably with Federally Qualified Health Centers (FQHCs) and Neighborhood Health Centers. Today, CHCs are one entity along with Migrant Health Centers and Public Housing Health Centers who are designed as Federally Quality Health Centers (FQHCs) to increase and improve access to care for communities who experience barriers to receiving quality health care services. According to a United States Health Center Fact Sheet distributed by the National Association of Community Health Centers (NACHC, 2011), these FQHCs have the following characteristics: 1) located in areas of high need (defined by high poverty, high infant mortality rates, and low physician to patient ratios); open to all; 2) have tailored services based on the needs of the community being served; 3) provide comprehensive primary health care, along with other health care services which help eliminate access to primary health care (such as transportation to



appointments and case management); and 4) are cost effective. Also according to the United States Health Center Fact Sheet (NACHC, 2011): The total number of FQHCs around the country is 1,128, and these FQHCs served over 20 million patients in 2011 where 22% of those patients were low income and uninsured, 13% of those patients were Medicaid beneficiaries and 18% were at or below 100% of the FPL.

### **Historical View of Quality Citizen Participation**

Citizen participation moved from a focus on ordinary residents providing input on urban renewal decisions in the 1950s to residents assisting in the creation and implementation of policies governing poverty programs in the 1960s. The concept of the quality of citizen participation came into focus with the realization that the process was just as valuable as the outcome; it was no longer good enough to have just anyone at the table. Those at the table had to have a legitimate voice in the process. Before this realization, the outcome of residents at the same table was enough to claim full integration of their voices. This new conceptualization of citizen participation was evident in a key term from the CAPs legislation, “maximum feasible participation.” This concept referred to the goal of War on Poverty programs to involve the desired targets or beneficiaries of the programs in their administration and implementation.

### **Maximum Feasible Participation (MFP)**

During the 1960s and 1970s, the concept of citizen participation was linked to the idea of maximum feasible participation (MFP). Cited in point (3) of the Economic Opportunity Act of 1964, [Title II, Part A, Section 202(a)], the term was used to describe how a program is defined in the legislative term “community action program.” Relevant sections for the current study included parts 1, 2, and 4 of the legislation. More specifically, part (1) of Section 202(a) described *who* and *where* the resources were mobilized and utilized; part (2) described *what* the assistance was designed to affect, which was to abolish poverty through developed opportunity from educational benefits, social networking, or improvement of living conditions; part (4) defined *who* was to

administer the program (Boone, 1972). As with any piece of legislation or policy, to extract the policy from its context is not only dangerous but provides little direction for implementation and evaluation.

Within this legislation's context, MFP was associated with parts 1, 2, and 4 (Boone, 1972). The concept's ambiguity is evident when the actual legislation is broken down. The rationale of MFP in the legislation was to address the malaise at the time of advocates, community organizers, and others who witnessed the exclusion of urban city center residents in the decisions being made about their neighborhoods (Garrity, 1969; Hallman, 1972; Poindexter, 2000; Rubin, 1969; Strange, 1972). Maximum feasible participation should have provided clear direction and commitment to the idea that those with less power deserved to be involved in decision-making processes that impacted their lives. The reality of the term's meaning and the way that meaning could improve the lives of the marginalized and disadvantaged was much less clear.

### **Complexities Surrounding Maximum Feasible**

#### **Participation (MFP)**

Consensus did not exist around many elements of the concept of MFP, which demonstrated the complexities surrounding it. In fact, Rubin (1969) noted that, for the social policy reformers of the 1960s and 1970s, the lack of consensus about the concept's origins made it abstract at best and dangerous at the least. Two complexities emerge with MFP and its role within citizen participation. These complexities help to understand the controversy of the quality of citizen participation given the history of the term and the reaction to its implementation in policy decision making. The first complexity involved whom the concept targeted and the second addressed whether an increased quantity of participation improved the quality of that participation. These key questions highlighted the difference between, on one hand, placing individuals at the decision-making table to increase the quantity of citizen participation and, on the other hand, acknowledging the importance of the quality of the citizens' participation.

First, Hardina (2003) expanded on *who* participated by describing the term's original intent to act to resolve poverty. Increased participation of economically disadvantaged citizens during the 1960s and 1970s through the CAP agency structure was the goal; therefore, economically disadvantaged citizens were the original target. Elaborating on the original target of the legislation, Hardina found that individuals increased their participation in some service organizations through their placement on boards of directors. Hardina described this complex picture of participation as one strived for by some organizations and not by others, suggesting that the legislation and subsequent actions were intended to increase the presence of disadvantaged individuals in decision-making processes because they were absent previously.

The second MFP complexity was that despite the goal of quantity of citizen participation to boost contributions of those marginalized from decision-making processes, results that measured the effectiveness of that increase in participation on boards revealed that the quality of their participation was questioned. The origin of this question came from the fact that although citizens were at the table, they were not included in the process, and therefore their participation was seen more as "on paper" as opposed to their having a contributing role. Moynihan (1969) addressed the original systemic target of the clause MFP related to the political process in the South. This connection was the reason the concept revolved around activities and services provided by the CAPs embedded within the Economic Opportunity Act of 1965. Participation in the decision-making processes of those activities and services was not explicitly articulated in the implementation of the legislation and, according to Moynihan (1969), was in fact, "utterly ignored" in political discussions and practice in the 1960s. Strange (1972) attributed the decision-making participation aspect of implementing MFP to the underdeveloped, underspecified, and underfunded mandate, which thereby created more problems than solutions. Austin (1972) supported these fears in an investigation of

participation in the post MFP era and found the power and voice questionable for those residents supposedly targeted by the alleged mandate.

### **Problems With Maximizing Citizen Participation:**

#### **View From Multiple Angles**

The original concept of citizen participation focused on increasing the power of the have-nots in society and was linked to the quality of citizen participation. Because of the pushback, however, the concept as well as the quality of participation faded to the background in the literature in favor of increasing the quantity of citizen participation. Therefore, an important piece of the original concept of participation was the desire to involve the have-nots of society, namely those disadvantaged or marginalized by their specific position in society at the time. The problems associated with the legislation's inclusion of the concept of MFP to address the lack of voice in policy processes occurred because of a lack of political power by disadvantaged citizens and, as such, can be viewed at multiple levels that span decades of research on the topic. These multiple levels are located at the individual, neighborhood, community, and public policy levels and are described in the next section.

At the individual level, people view the system as a failure if it does not measure up to their own perceptions of MFP. Given that the meaning of the system was not clear because of the ambiguity previously noted (Arnstein, 1972; Boone, 1972; Brieland, 1971; Burke, 1968; Hardina, 2003), the situation was doomed to failure. At the neighborhood level, the way residents impacted the advising and policy-making decisions of HUD agencies seemed vague. This ambiguity led residents to believe it was more about tokenism or appeasement than power shifting (Arnstein, 1972). At the community level, mayors of Chicago, Boston, and New York City expressed frustration in what they felt was not only an unfunded mandate, but also one that created multiple problems that challenged the status quo of decision making and in essence turned it upside down (Burke, 1968). Additionally, observers of the process advocating on the side of the

residents of the process agreed with the fears of the mayors and felt that the community organizers dedicating time to engage residents in citizen participation activities, such as membership on advisory boards, would not have enough power to make changes (Hallman, 1972). Finally, the public policy level revealed, despite the postulation by some that more voices at the table in policy making and implementation would make the finished product better, that MFP was not a value held by all who crafted the legislation or all who were charged with living in its aftermath (Day, 1997; Lombe & Sherraden, 2008; MacNair, 1981; Moynihan, 1969; Roberts, 2004).

Several critics challenged the legitimacy of legislating participation in contexts where power was unequal. Arnstein (1969) critiqued the implementation's reality into public policy and believed citizen participation was a responsibility of the governed, an important aspect of living in a democracy and a value enthusiastically supported by practically all citizens in a society. Arnstein demonstrated this paradigm shift related to participation and power when she noted that who participated and why they participated caused the vehement support of such participation to diminish and pointed to the need of legislating MFP to challenge this exclusionary mentality. When the principle of MFP was carried out by "the have-nots" (Reisch & Andrews, 2001) in society, resistance to it increased.

Another person interested in broad societal change, social policy reform, and the power of people's voices was Saul Alinsky. Alinsky believed that in order for progressive social change to occur, those in power needed to feel uncomfortable (Alinsky, 1971). He believed that power redistribution was the only path towards empowerment of those most impacted by social policy reform. He questioned how a legislated requirement like MFP might result in the tokenization of citizens' voices in policy-making decisions (Alinsky, 1971).

Accordingly, the original connection between the ambiguity and subsequent problems of the concept of MFP created as a legislated tool to increase citizen

participation was a major catalyst for a framework to understand this process, which was through Arnstein's (1969) ladder of citizen participation. According to Arnstein's ladder of participation, both power redistribution and legitimate voice are seen as necessary components of the quality of citizen participation and clarify the potential reasons for the gap in the literature. This ladder, replicated in Figure 2.1, identified increasing steps or levels of participation that began at nonparticipation or participation with goals of manipulation or therapeutic aims. The second tiers of participation were degrees of tokenism, and more specifically the expectation that participants acted as consultants or informants in decision-making processes. At the top tier of participation were degrees of citizen power, where participants acted in partnership with decision makers and ultimately gained complete citizen control. Participants at this top tier were expected to experience a shift in power from the hands of a few to the hands of the majority, or the people, to increase their political power and strengthen the resolve that their voices would not be silenced. This defined the quality of citizen participation.

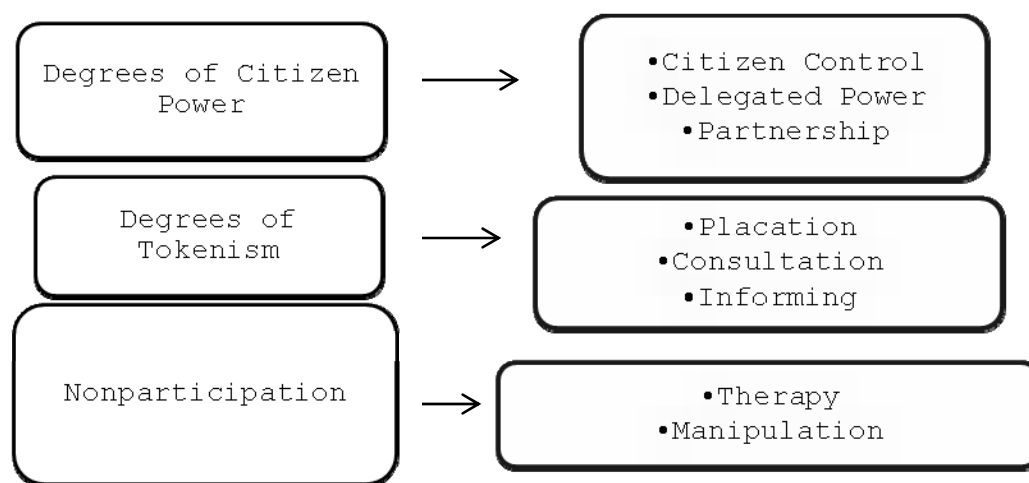


Figure 2.1 Arnstein's ladder of citizen participation

Source: Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association*, 35(4), 216-224.

The ladder of citizen participation (Arnstein, 1969) acted as a “typology provocatively describing the amount of citizen power present at each level of participation in three federal social programs: Urban renewal, anti-poverty, and Model Cities” (p. 216). This ladder provided entrance into the dynamics of power and quality to understand the role of power, isolation, and exclusion in participation processes so citizens could participate in their democracy through policy development processes.

### **Responses to Maximizing Citizen Participation: Fade**

#### **From Quality to Quantity**

Scholars developed an interesting response to the complexities of the quality of citizen participation by low-income citizens in the 1960s and 1970s. Cloward and Piven (1966) described the *Cloward and Piven Strategy* as a strategy that hoped to inspire an economic justice revolution. The conviction that this type of revolution was necessary stemmed from their belief that the welfare state was further disadvantaging low-income people, and was motivated by the potential power found in the numbers if low-income individuals were to demand the benefits for which they were eligible through the social welfare system. Piven and Cloward (1977) noted that many civil rights activists shifted their energies at this time towards economic justice issues and capitalized on the momentum built from the Civil Rights movement in the 1960s. Within this strategy existed a call to arms for activists and those interested in economic justice issues to get involved and “join in a massive drive to mobilize the unaided poor to disrupt the relief system all the more by demanding relief” (Piven & Cloward, 1977, p. 276).

Unfortunately, the plea was short lived.

Instead, the result was a swelling of the welfare rolls and a backlash against what public policy talk dubbed the *undeserving poor*. Silverman, Taylor, and Crawford (2008) noted the contemporary influence of Arnstein’s ladder of citizen participation as impacting the behavior of professionals to increase the participation of citizens, but not necessarily through the mandate of citizen participation. A continued commitment to a

required directive of citizen participation, however, could have provided the disenfranchised a legitimate voice in conversations about their lives.

### **Measuring Citizen Participation in Terms of Quantity and Quality**

Consequently, understanding how to measure participation and what is being measured is central to understanding the concept's implementation and effectiveness. This point is strongly made given the documented ambiguity in the legislation discussing citizen participation along with the above described implementation problems. Strange (1972) extended these concerns around the concept's measurement, and noted the controversy over what *feasible* meant, ways the statute could be met, and how the definition of the scope and the role of participants would be filled. Rosener (1978) demanded an acknowledgement of how the term's complexity, both in definition and measurement, was linked to the ambiguity around its evaluation. Despite these concerns, the articulation of the quality of citizen participation all but vanished from the literature and presumably has been viewed as unnecessary in contemporary discussions given the demonstrated increase in the quantity of citizen participation when more voices participate.

When reviewing definitions used to investigate citizen participation, Cornwall (2008) described the concept as "infinitely malleable" (p. 269), signaling the importance for fully comprehending its complexities for the purposes of research, policy, and practice. Common themes of participation's contemporary elements to those most impacted by disadvantaged situations include the need for inclusivity (Lombe & Sherraden, 2008; Morrissey, 2000), the benefits of participation in decision making (Hardina, 2003; Itzhaky & York, 2000; Morrissey, 2000; Wang, 2001; Weber et al., 2003), and participation to solve local problems (Bolland & McCallum, 2002; Itzhaky & York, 2000; Marschall, 2004; Ohmer, 2007, 2010; Wang, 2001). Exploring these themes in the current study through the context provided by community health centers in Iowa



uncovered how these contemporary themes are applied in a context formed by the ideas of empowerment and inclusion.

Quantitative analysis found in census, administrative, or survey data drives citizen participation's measurement in order to recognize what impacts its variation. Morrissey (2000) offered a potential explanation for the amount of quantitative analysis, citing that the focus of citizen participation literature is a means to an end instead of an appreciation for "participation for its contributions to democratic processes" (p. 63). This process contribution would emphasize the developmental benefit to citizens who participate and the benefit to policy development because of that participation. This contribution to the process emphasizes the benefits of improving the quality of citizen participation and not just the quantity, though quantity is an important first step to understanding quality.

Moreover, an interest in a final product such as the activities and behaviors that contribute to the quantification of citizen participation, as opposed to the quality focus of process, was further expressed by Checkoway and Zimmerman (1992), Jennings (2001), and Wang (2001). These researchers involved chief administrators and leaders in neighborhood organizations as the primary respondents. The involvement of leaders reinforces citizen participation's measurement and definition, which seeks to descriptively quantify activities and behaviors, instead of to explore the experiences of those traditionally powerless and hence with the most to gain from having a legitimate voice in participation. The latter exploration examines the process by which that participation occurs as opposed to the outcome of participation. Indeed, absent from the literature is what understanding the experience of those doing the participating would provide if given the opportunity to discuss their experiences comprehensively as board members on a board in policy development processes.

In this study, the quality of citizen participation is defined as a process in which power is redistributed to citizens through voice and power shifting, and that redistributive process results in those with less power having a legitimate voice in decision-making

processes having a direct impact on the lives of the citizens participating (Arnstein, 1969). To understand, for example, how citizens participating in policy development processes are able to legitimately influence that process, it is important to explore the experience of citizens participating in situations where they are intentionally representing the voice of those with less power. The multiple relationships and interactions impacting an individual's life, environment, and context are vital to explore in order to understand the quality of citizen participation. For Arnstein (1969), achieving a legitimate voice in decision making comes not only from understanding whether those with less power are present in the process, but also from the legitimacy of their voice in the processes of which they are a part.

Therefore, a multi-dimensional view was necessary to study this complex influence because of the many factors to be understood. The socio-ecological perspective (McLeroy et al., 1988; Stokols, 1992), adapted from Bronfenbrenner's (1979) ecological perspective, provided this lens and therefore was an essential perspective guiding this study. The perspective was important because it facilitated an exploration of multiple levels and how those levels interact. The following section presents an in-depth examination into the socio-ecological perspective and its application to this study.

### **Socio-Ecological Perspective: Examining Influences on Citizen Participation**

The socio-ecological perspective is modified from Bronfenbrenner's (1979) ecological perspective (see Figure 2.2). The slightly transformed version of Bronfenbrenner's perspective enables the study of public policy, political power, and its impact on an individual's life within the context of CHC boards. Health promotion and public health literature has used the socio-ecological perspective to better understand social problems that are influenced by a complex web of factors on multiple levels in an effort to craft appropriate interventions to address these problems. For example, Robinson (2008) utilized a socio-ecological perspective to study the eating habits of low-

income African Americans in order to improve the dietary patterns of this community. The connections between the elements of the socio-ecological perspective provide a suitable prism to investigate the ways these multiple levels of an individual's life might impact the extent to which his or her experience in citizen participation is one of quality or one of merely having a seat at the table without a legitimate voice.

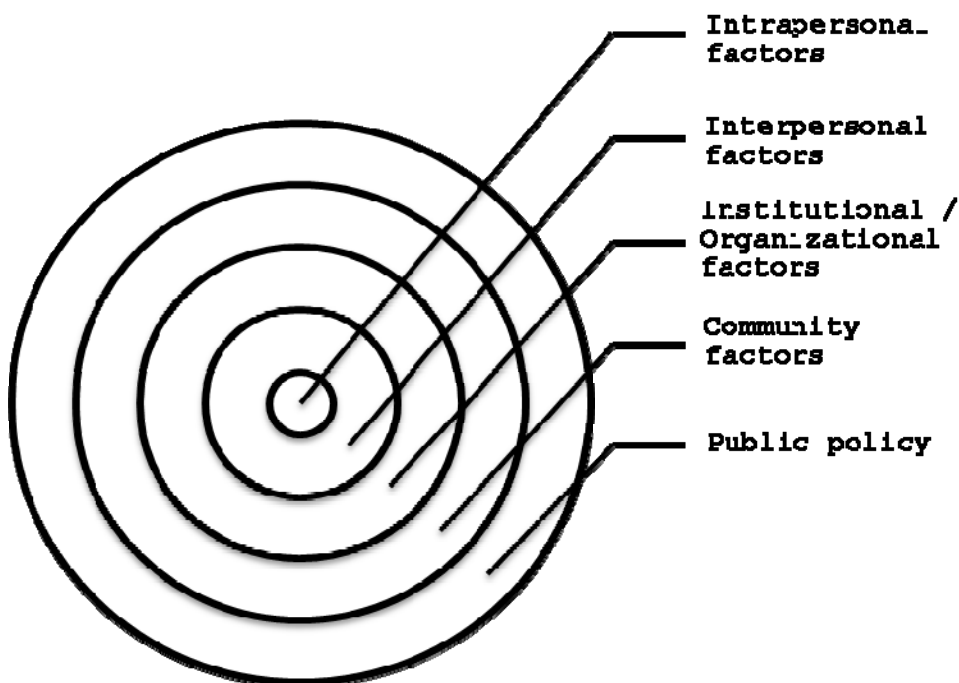


Figure 2.2 McLeroy et al.'s socio-ecological perspective

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Source: McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Behavior*, 15, 351-377.

The discussion below provides a description of each level of the socio-ecological perspective, presents literature relevant to understanding citizen participation at each level, and discusses how the levels in the socio-ecological framework relate to Arnstein's (1969) ladder because of the role of the ladder in understanding the quality of citizen participation. The socio-ecological perspective is composed of the following five levels:

intrapersonal level, interpersonal level, organizational/institutional level, community level, and public policy level (McLeroy et al., 1988).

### **Intrapersonal Level**

According to McLeroy et al. (1988), the intrapersonal level of the socio-ecological perspective encompasses features of an individual that influence various behaviors and include interventions at the individual level of behavior. More specifically, these include “characteristics of the individual, such as knowledge, attitudes, skills, or intentions to comply with behavioral norms” (McLeroy et al., 1988, p. 356). An example of the difference between interventions at the intrapersonal level and those at other levels are found in teenage smoking cessation. To convince a teenager not to smoke from this level of the perspective, intervention strategies at the intrapersonal level would convince that teen to ignore the peer pressure to smoke (alter individual behavior) as opposed to addressing the norms that permit smoking to occur despite its health consequences (McLeroy et al., 1988).

To apply this level to the literature on citizen participation, two key elements that align with the features mentioned above include the resources (knowledge and skills) an individual possesses and the characteristics of an individual’s identity (race, gender, age, socioeconomic status) that influence the quality of his or her citizen participation. For application to this study to understand the quality of citizen participation, it is necessary to reframe these elements to understand how they might contribute to a shift in political power, thereby providing a better conceptualization of quality citizen participation.

**Knowledge and skills.** A central element in this level is a resource model of participation called the civic voluntarism model (Brady et al., 1995). The civic voluntarism model is used to explain why some people become involved in political processes and activities and some abstain, and is a model that integrates theories based on both individual and group influences on a person’s interest in political activity (Ritter, 2008). Brady et al. (1995) identified three areas important to explaining the variety within

levels of participation: access to resources (including time, money and civic skills), ability to engage (involving activity in politics or other civic participation), and whether an individual is recruited (relating to the request by others for an individual to participate). Specifically, what makes the civic voluntarism model different from previous models seeking to explain participation, such as those rooted in political science or economics, is how access to resources impacts a person's participation.

The main idea in Brady et al.'s (1995) civic voluntarism model is the interplay between resources, engagement, and recruitment to explain who participates in various activities providing input to policy decision makers. Huckfeldt (1979) considered socioeconomic status (SES) as a main place where understanding societal stratification assists in documenting the variability in degrees of participation. In a test of the civic voluntarism model on licensed social workers' levels of political participation, Ritter (2008) tested the model's significance and found it to be significant in predicting levels of political activity among social workers. Evidence exists, therefore, not only in the accuracy of elements within the model to better understand participation, but also in the accuracy of the model as a conceptual perspective to investigate the quantity of citizen participation. This focus on quantity with the civic voluntarism model sheds light on what might bring citizens to the table of policy development decision making, but does not further the knowledge on how one might facilitate a citizen's legitimate voice in that process.

**Intentions to comply with behavioral norms.** The next element incorporated in the intrapersonal level signals an individual's intentions to comply with behavioral norms. Research suggests that certain types of behavior demonstrate the building of trust. Trust and trustworthiness are aspects of social capital between individuals (Coleman, 1988) and describe how the closure of social networks contributes to the quality of citizen participation. Trust is a necessity for the formation of social networks, and if those networks form, individuals are prompted to act both individually and collectively.

Behavioral norms form within social networks, thus creating a cycle of social network formation, trust, and individual and collective activism establishing the behavioral norms of the network. Additionally, social networks might connect individuals to one another, but if the relationship is devoid of a point of closure ensuring that all in the network benefit from the existing interrelatedness (Granovetter, 1973), the social capital the relationship is able to produce is altered.

Given the focus on relationships in the production of social capital, it follows that strong relationships produce positive outcomes. Foster-Fishman, Cantillon, Pierce, and Van Egeren (2007) expressed this point in their finding that the presence of social ties (relationships not individual characteristics) are ample predictors of individual activism and collection action in low-income neighborhoods. However, one must consider the individuals within these relationships, the relationships themselves, and access to other elements potentially affecting the relationships. Specifically, Wilson (1987), who investigated the impact of isolation on African Americans in Chicago's poor communities, and Putnam (1993), who was interested in explaining economic development differences in Italian communities, are two examples of how varying access to social capital in different social structures influenced outcomes (i.e., in neighborhoods in Chicago and villages in Italy). Pyles and Cross (2008) discovered social capital measured by trust in a predominantly African American neighborhood destroyed by Hurricane Katrina to be low while levels of both political and civic participation were high. These findings demonstrate the importance of the context with an understanding of the relationships to which citizens have access and those that they in turn find valuable through what the relationships are able to produce.

Another variation on how certain types of behavior might increase or jeopardize trust and trustworthiness between individuals is found in other characteristics such as the race/ethnic identity of the individuals. For example, Lee, Campbell, and Miller (1991) discovered that neighboring behavior, which plays a role in building trust, differed for

white and black respondents. More specifically, black respondents demonstrated neighboring behaviors by interacting with their neighbors more frequently than did white respondents in the study. Bolland and McCallum (2002) discovered that the presence of neighboring behavior was significant in predicting various activities and levels of participation. Verba, Schlozman, Nie, and Brady (1993) discovered that civic activity differed by demographic characteristics and refuted the idea that engaged citizens equally represent all in society. Foster-Fishman, Pierce, and Van Egeren (2009) uncovered individual characteristics, such as the ability to organize, to be important predictors of the extent to which residents engaged in citizen participation. Lelieveldt (2004) found neighborliness and sense of duty to positively correlate with two forms of participation (informal governance and conversion of problems with action) but not voting, and articulated the importance of activity type when expressing how neighboring behavior influences levels of participation. This finding suggests that individual qualities might determine who is wanted or volunteers for citizen participation activity.

**How identity influences attitudes toward participation.** A final element of the intrapersonal level that is useful in understanding the quality of citizen participation is the influence of identity on an individual's attitudes towards participation. Identity is conceptualized at two distinct levels of influence: the self-identity factors such as race/ethnic identity, gender identity, and socio-economic status, and the collective identity features such as characteristics of a neighborhood (i.e., the poverty rate of a neighborhood). Some aspects of self-identity were discussed above and collective identity is discussed below.

Swaroop and Morenoff (2006) linked the impact of concentrated disadvantage with trust in their discovery that such disadvantage was associated with increased participation in neighboring activities. Additionally, neighborly interactions and participation in community organizations was related not only to characteristics of the immediate neighborhood surrounding the individual, but also to the larger context

expanding beyond the boundaries of the neighborhood (Swaroop & Morenoff, 2006). This focus on multiple levels of an individual's identity that might make them more or less likely to participate assists with understanding what about an individual and his or her background might bring that person to the table. However, it does not help to explain the quality of that experience when the individual becomes part of the policy process through citizen participation. Hence, the role of relationships in the presence of citizens' legitimate voice in policy development processes is discussed below.

### **Interpersonal Level**

Within the second level of the socio-ecological perspective, McLeroy et al. (1988) described the influence of relationships on participation. These relationships can occur with a number of individuals essential to a person's life, and can include relationships with family members, friends, neighbors, work colleagues, and other acquaintances. These particular relationships are significant influences on an individual because of their indispensable role in providing resources, support, information, and social contacts, which assist individuals to appreciate the obligations and responsibilities intrinsic to living a meaningful life. Key elements extracted from research to demonstrate the relevance of this construct to citizen participation include the composition of relationships and how behaviors, norms, and expectations foster or neglect those relationships. Each will be discussed in turn.

**Relationships shaping individuals' behavior.** One element of the role of relationships in citizen participation is how self-efficacy relates to varying degrees of expectations for various activities. McLeroy et al. (1988) reported that the relationships of interest to the socio-ecological perspective include those between individuals and the people not only in their family, but also in the community and neighborhood, at their workplace, and in their circle of acquaintances. Indeed, relationships are an important part of understanding the legitimate influence of those with less power when they participate in policy development processes and whether that influence makes a



difference. Inherent in the discussion of how relationship strength and composition vary by the individual is how expectations for those relationships impact individual behavior.

*The role of self-efficacy.* Bandura (1977) demonstrated the influence of an action's knowledge and outcome on individual behavior by separating out expectations. Bandura (1977) distinguished between "efficacy expectations and outcome expectations" (p. 193) when he described the psychological processes involved in self-efficacy. Bandura (1977) suggested that the psychological execution of individual decision making is the difference between expectations: Outcome expectations describe what an individual knows has to be done in order to produce a specific outcome whereas efficacy expectations describe an individual's belief that he or she can start the initial process to produce the desired outcome. More specifically, individuals could have knowledge of what actions they should take in order to get the desired result, but if they do not feel they can accomplish those actions or if the actions are outside of the individuals' skills, then the knowledge they have of what they should do is irrelevant.

Swidler's (1986) toolkit concept described the skills individuals possess and how varying degrees of access to what they know result from the different implicit knowledge based on personal "symbols, stories, rituals, and world-views, which people may use in varying configurations to solve different kinds of problems" (p. 273), otherwise known collectively as an individual's "cultural toolkits" (Swidler, 1986). The importance of toolkits in individuals' understanding of their world and their perception of control over that world are key features for self-efficacy, have an impact on how individuals construct knowledge, and are useful in articulating how difference exists between individuals' level of quality participating in the same policy development process such as that of community board members of CHCs. Efficacy is a key feature of the quality of citizen participation because quality is impacted by both the presence of board members at the table and a recognition that the board members play a role in the process.

Research points to a variety of instances where individuals' perceived ability, either individually or collectively, might impact the quality of their citizen participation. Wandersman and Giamartino (1980) found that individuals' perception of their ability to change the neighborhood block (i.e., efficacy) was influential to their participation in change activities. Zimmerman and Rappaport (1988) agreed that the ability to take action contributed to the psychological benefit from doing so. Checkoway and Zimmerman (1992) established personal perceptions to be key predictors of participation. Foster-Fishman et al. (2007) discovered that residents were more likely to engage in neighborhood activities in low-income neighborhoods to address problems if the residents believed their environment ready and able to support not only the activity, but also the change accompanying successful activity implementation.

***The role of collective efficacy.*** In research on why neighborhoods vary, two ideas borrowed from social capital helped build the foundation of collective efficacy (Sampson, Raudenbush, & Earls, 1997); relationships are a resource different from physical and human capital and trust is important to the processes of cohesion (Coleman, 1988). The ability for collective efficacy to convert relationships between individuals into courses of action to improve the neighborhood as a whole distinguishes it from self-efficacy. Revisiting the concept's relevance to the present study, relationships are seen as crucial to the development of trust between individuals. The trust is a product not only of what exists between neighbors, but also the existing trust in a reciprocal exchange of support, which occurs when individuals respond to neighborhood issues.

Sampson et al. (1997) posited that collective efficacy articulated how social relations within a neighborhood impacted the individuals to act against disrupting behavior or actions. This concept considered the level of cohesion between individuals when untangling what drives individuals' capability or lack thereof, thereby acting to stop the occurrence of disorder in the neighborhood. In this instance, cohesion acknowledges that how individuals feel towards their neighborhood context influences

whether or not they would act, for example, to stop a car window being broken on their street. Sampson and Raudenbush (1999) further developed the concept of collective efficacy by adding how contextual factors existing at the community level influence individual-level processes.

The role of relationships is a key piece in understanding how neighborhoods vary and therefore how contextual influence varies as well. Viewing the strength, quality, and frequency of cohesion between neighborhoods makes clearer the elements of a neighborhood that contribute to or prevent cohesion from occurring. Therefore, to foster participation, social relationships must be established between neighbors. These social relationships create the trust and cohesion necessary for collective action described by collective efficacy (Sampson et al., 1997). Additionally, neighbors must feel like the neighborhood as a whole can absorb the desired change efforts brought on by the activity in order to fully engage in the activity, which supports the notion that residents must believe there will be an impact and others will stand with them in order to increase the likelihood they will participate.

Relationships are a key component to understanding the quality of the participation of those with less power in policy decision-making processes because, according to Arnstein (1969), legitimacy of voice is only accomplished when power is redistributed. As the literature above demonstrates, collective action requires relationships, trust, and self and collective efficacy in order to facilitate the quality of a citizen participation experience. The reason these are necessary to facilitate citizens with less power having a legitimate voice is because power redistribution does not befall an individual, but a collective. Therefore incorporating the role of relationships in citizen participation is crucial to achieving the quality of that experience.

### **Organizational or Institutional Level**

The third level of the socio-ecological perspective related to citizen participation is the influence of organizations and institutions. More specifically, organizations or

institutions support or constrain behavioral change for individuals, making this level an important target of intervention for social change (McLeroy et al., 1988). The context in which organizations and institutions exist is a critical conduit for behavior change (McLeroy et al., 1988) and suggests that knowledge of context is crucial in order to influence the quality of citizen participation. Two different mechanisms stand out at the organizational or institutional level to provide citizens the opportunity to participate in policy development processes: neighborhood associations (or neighborhood councils) and CHC boards (the focus of this study). Below, the conceptual relevance of these two mechanisms to the study will be discussed in greater detail.

Neighborhood associations, also known as neighborhood councils, are seen as a structure for citizens in a neighborhood to have an impact on decisions made on behalf of that neighborhood. However, other factors that impact the work of these associations point to the importance of understanding the contextual influence on the citizen participation of these organizations. Altschuler, Somkim, and Adler (2004) discovered that, for neighborhoods composed of upper income residents, the focus of their work tended to be on beautification projects (e.g., clearing out debris from a creek); whereas for neighborhoods composed of lower income residents, the focus of their work was on issues of safety. Houston and Ong (2011) explored voter turnout rates in newly formed neighborhood councils in Los Angeles, found that voter turnout overall was lower (1%) than turnout in other general elections (4%), and speculated the cause was the neighborhood councils' advisory role to actual policy decision making at the local and city levels. In both instances, an organizational structure existed at the neighborhood level to facilitate residents' citizen participation; however, contextual factors such as the socioeconomic status of residents in the neighborhood and the lack of legitimate voice of the neighborhood councils created variation in the effectiveness or impact those organizations were able to make.

A second mechanism for citizens to engage in policy development processes at an organizational level is provided by CHC boards. In addition to the ability of this structure to encourage involvement of consumers of CHCs, these boards also require a patient majority to compose their membership. Indeed, Hunt (2005), when exploring how CHCs in Massachusetts have fared since the birth of the CHC movement in the 1960s, discovered that these early health centers impacted not only the patients who walked in the door, but also the communities of the health centers (through economic development and job creation) and as such, the broader local economy and the political environment of which they were a part. This multi-tiered impact had much to do with the fact that the boards of these organizations were patient majority (Geiger, 2005; Hawkins, 2010; Lefkowitz, 2007) and was therefore intertwined within the community on multiple levels. The structure provided by the CHC board organization, therefore, has an influence on the contextual factors surrounding the health centers.

The organizational/institutional level of the socio-ecological framework provides insight into the quality of citizen participation because it explores a structural mechanism for those with less power to have a legitimate voice in policy development processes. When the tradition has been for these disadvantaged and marginalized communities to be excluded, whether intentionally or unintentionally, the research above demonstrates the importance of understanding the context that surrounds not only the experience of the participation but also the contextual background of those with less power. This complex understanding contributes to an overall comprehension of a quality citizen participation experience and therefore demonstrates the utility of this level to the current study.

### **Community Level**

While McLeroy et al. (1988) described the community level to exist from three different connotations, the one most important to the study of quality citizen participation is described in “geographical and political terms, such that a community refers to a population which is coterminous with a political entity, and is characterized by one or

more power structures” (p. 363). Power structures at this level of influence include the role of formal community institutions, such as city councils, county boards of supervisors, and state legislatures, in policy development (McLeroy et al., 1988). These structures are a key component to the context’s function in developing policy agendas, and the elements that influence these structures include the neighborhoods and communities covering the areas that the specific power structures represent.

The factors that influence the rules and regulations within a community and the informal relationships between neighbors in a community potentially constrain or promote preferred behavior (Austin, 1972; Chavis & Wandersman, 1990; Checkoway & Zimmerman, 1992; Hardina, 2006; Kasarda & Janowitz, 1974; Ohmer, 2007, 2010; Swaroop & Morenoff, 2006). Social networks are viewed as having both informal and formal structural power, which makes the quantification of these networks important to how they might impede or encourage community attachment. For Kasarda and Janowitz (1974), networks in a community signaled community attachment. Although described as being either informal (i.e., friendship linkages) or formal (i.e., community institutions); both were viewed as influencing individuals’ attachment to their surroundings (Kasarda & Janowitz, 1974). Kasarda and Janowitz (1974) based this view on a systemic model of community interrelatedness, suggesting “the local community is viewed as a complex system of friendship and kinship networks and formal and informal associational ties rooted in family life and ongoing socialization processes” (p. 777). The complexity identified by Kasarda and Janowitz (1974) further investigates the role of disorder in a community as a contextual factor and the extent to which that disorder affected a citizen’s ability or perceived necessity to act in order to change it.

Empirical evidence examining the role of physical and social disorder in various outcomes for individuals demonstrates that it is not only individual characteristics that impact individual’s outcomes, but also characteristics within an individual’s surrounding community or context. For example, Perkins et al. (1990) found that the crime level

related to the physical and social environment typical of urban neighborhoods assisted in forming block associations. Cohen and Dawson (1993) discovered a threshold effect on the impact of neighborhood poverty on political participation and believed the effect to occur when greater than 20% of the neighborhood lived in poverty. Both of these findings suggest that physical and social disorder might ignite participation in community organizations or institutions in certain contexts.

Conversely, other scholars have arrived at varying conclusions. Bolland and McCallum (2002), for example, found that perceived social disorder did not have an impact on participation. Swaroop and Morenoff (2006) discovered concentrated disadvantage to be associated only with increased participation in neighboring activities and interactions, whereas participation in community organizations was related to the surrounding context. Casciano (2007) found that neighborhood conditions are important predictors of not only if, but to what extent, an individual engages in individual and collective action. These research findings demonstrate a conversation between the two perspectives and suggest that the effects of contextual factors on the quality of citizen participation require further investigation.

**Perceived disorder and its effect on citizen participation.** Useful in examining the impact of community level on the quality of citizen participation is an understanding not only of what disorders are occurring in communities or neighborhoods, but also the implications of those specific disorders (Wilson & Kelling, 1982). An example of this type of community level and its relation to participation is what the image of street gangs gathered on a corner represents to residents of the neighborhood. This perception changes the focus from the presence of disorder to how the inference of disorder impacts behavior and, more specifically, how that implication of disorder might encourage or discourage a shift in power differentials. A broken bottle on the sidewalk signals something to individuals living on that street and suggests negligence (Wilson & Kelling, 1982); this fosters an environment ripe for crime. The specific signal from the broken bottle is that

no one is keeping watch on the street; no one is discouraging that type of behavior. Therefore, no one is there to exert social control to prevent it from happening again.

The pathways of these processes and the perceived disorder, however, are less clear. Sampson and Raudenbush (2004), interested not only in how observed disorder impacts perceived disorder but also in how community characteristics of a neighborhood might shape those perceptions, found “the social structure [of the neighborhood] proved a more powerful predictor of perceived disorder than did carefully observed disorder” (p. 336). Gau and Pratt (2010) agreed and found that with an increase in cognizance of disorder in a neighborhood came an increase in the ability to distinguish between disorder and crime. In other words, perceptions of those living with the concept’s reality impacted how those particular individuals viewed their surroundings.

Sampson, Morenoff, and Gannon-Rowley (2002), in a review of neighborhood effects on a variety of outcomes, concluded that the perception of disorder does influence some processes of residents within certain neighborhoods, such as efficacy and perceived powerlessness as well as mistrust in situations where constant exposure to disorder occurs. Sampson and Raudenbush (2004) described the pivotal assumption that “perceived disorder is thought to reflect external problems that influence local residents’ mental and physical health” (p. 320). These findings strengthen the relevance of perceived social disorder to citizen participation given the role context plays in better understanding an individual’s having a quality citizen participation experience. Specifically, citizens were more likely to become involved when the issues or problems in their direct context were a motivation to that involvement.

Additionally, empirical evidence demonstrates a connection between how citizens’ perception impacts whether those citizens believe participation to be useful or worthwhile. Wandersman and Giamartino (1980) reported that the perception of neighborhood problems and neighboring behavior impacted residents’ participation levels. Marschall (2004) found that contextual influences on citizen participation



indirectly shaped the nature of neighborhood problems and residents' perceptions of those problems. Given the need to understand community-level factors, including informal and formal social networks and norms, the focus on the environment of a community and its social disorder alongside its formal physical disorder is an appropriate fit to conceptualize quality citizen participation.

Intriguing aspects of these conclusions challenge the idea that there is merely one component to the intricacy surrounding the quality of citizen participation. For example, Marschall (2004) found that context influenced citizen participation indirectly through the nature and perception by residents of problems in the neighborhood but did not specify what organizational or institutional entities were present (or should be present) in order to facilitate an increase in political power for residents in the neighborhood. When coupled with other elements of the socio-ecological perspective, the many complexities and angles present in what influences the quality of participation to shift political power help provide clarity to what exactly facilitates a quality participation experience for those with less power in processes where they are engaged with those who have power.

### **Public Policy Level**

Due to the socio-ecological perspective's attention to the variety of ways environmental factors can impact behavior and how to use that variety to construct environmentally motivated interventions, the final level within the perspective brings attention to public policy at the local, state, and federal levels of decision making. Specifically, the attention of how public policy impacts the quality of citizen participation is found at the public policy level. McLeroy et al. (1988) described this level as the regulations and laws that are put in place to act as interventions to public health problems. To apply this level to the quality of citizen participation, one would look at legislated interventions designed to impact the quality of citizen participation. This view provides a point of entry for Arnstein's (1969) ladder of citizen participation and her critique on such legislated remedies as MFP. This critique would be joined by voices who

questioned the ability of this legislation to make much of an impact when there were other influencing factors that were not on board with the idea that those with less power should have an equal voice in policy development processes (Freeman, 2004; Keyssar, 2000; McDonough, 2010; Roberts, 2004). This study fills a gap by contributing to the conversation on whether context impacts the quality of citizen participation, and if it does, in what ways, through an exploration of the experience of participating on a board designed to give legitimate voice to disadvantaged and marginalized communities in primary health care service provision through the CHC model.

### **The Relationship of Socio-Ecological Perspective, Context, and Quality of Citizen Participation**

A gap in the literature on citizen participation is a lack of research to understand the influence of political power and context in quality citizen participation. This gap has been perpetuated by previous research that quantified citizens' participation activities and behaviors, while not understanding the influence of quality citizen participation in policy development. Hardina (2008) acknowledged that this shift to examining the quality of participation is important in the research given that the process of providing input is rarely studied. Cornwall (2008) stated "being involved in a process is not equivalent to having a voice" (p. 278). The concept of the quality of citizen participation and its investigation centers on process, and when combined with a variety of activities and behaviors, creates a mechanism for filling the knowledge gap in this area. Adding to what is known about what activities and behaviors count as citizen participation is the knowledge of how multiple levels of influence, found through the prism of the socio-ecological framework, facilitate the quality of citizen participation for those in policy development processes with less power. The literature has investigated participation from a variety of angles and the surrounding contexts that Arnstein began investigating in the 1960s through the lens of the ladder of citizen participation (Arnstein, 1969). Her focus

on political power is an essential one to explore given the identified gap. This focus also encourages inclusion of these elements in further study of quality citizen participation.

### **Summary**

Broadly speaking, the participation literature reviewed above describes an evolution. The evolution of participating in policy processes began with involving those previously excluded to participate at the decision-making table and to include them in the product of the status quo opinions that established who counted and who did not. Citizens were asked to participate at the decision-making table to obtain their buy in for the relocation that took place in urban city centers. This participation was not necessarily to elicit the full involvement of those with less political power in decision-making processes with a direct impact on the citizen's lives. Instead, those who were thought to know the desire of the citizens spoke for them instead of with them.

With the War on Poverty came a second wave of change regarding participation, and specifically addressed *who* was participating and *why*. This movement sparked the inclusion of the concept "maximum feasible participation" and signaled the desire for as much participation by as many people as possible (Moynihan, 1969). The articulated concept shifted power to places those expected to make room at the decision-making table were uncomfortable with (Arnstein, 1969, 1972), while theorists and activists interested in this type of participation rallied in its favor in order to ride the wave. The scale of the status quo was not in favor of this wave, and the focus of participation drifted back to increasing voice but not necessarily political power. This increase, though not altogether negative, did not have the desired effect of power shifting as leaders of the 1960s and 1970s social justice movements had hoped (Cloward & Piven, 1966; Piven & Cloward, 1977, 2000), and the citizen participation became stuck in the cycle of counting activities and behaviors necessary to identifying instances of quantity citizen participation at the disregard of the quality of that participation.

## **Critique of Methods Used to Investigate Citizen Participation**

Given the previously stated complexity in defining citizen participation in the literature, a key strength of the overall literature is its consistency of term definition. Generalizing findings is an important part of building knowledge, and one easy way to ensure the absence of generalizability is to vary a definition. Equally, an essential first step to create the possibility of generalizability is to define an outcome with a certain degree of consistency.

Given the complexity of citizen participation, a second strength in methods is the use of multiple levels of inquiry. This technique involves using data about a person as well as aspects of his or her environment and provides information not only about the person's individual characteristics but also the characteristics of that person's environment. For example, Perkins et al. (1990) used surveys, observer assessments, and police reports to understand how the built environment, social climate, and transient physical environment were significant and independently related to the participation of respondents in block associations. Alex-Assensoh (1997) applied a similar methodological structure and used telephone surveys in four Columbus, Ohio, neighborhoods. By supplementing this information with census data, Alex-Assensoh found that when increases in income and education occurred, political participation increased. Marschall (2004) used the Detroit Area Study to link individual characteristics of respondents to questions related to citizen participation, and matched tract-level census data for community characteristics to conclude a positive correlation between neighborliness and duty with informal governance and conversion of problems into action but not with voting in municipal elections. The identification of these two strengths is useful for the present research because it provides the background knowledge to extend the concept of quality citizen participation.

Key among the weaknesses of measuring citizen participation is that the majority of what is known about citizen participation, with a few exceptions (McBride, Sherraden, & Pritzker, 2006; Pearlmutter, 2002; Quoss, Cooney, & Longhurst, 2000; Ravensbergen & VanderPlaat, 2009), comes from survey, census, or administrative data. While data from these sources are a necessity to build evidence of an issue or problem, a weakness arises from it as well. Typically a necessity given the time and costs required of large scale studies, these data sources remain an existing weakness because what is known about citizen participation is centered in one research paradigm. This weakness potentially could further suppress the voices of the marginalized and disadvantaged individuals and communities that comprise the voices the studies are attempting to include.

Moreover, census or administrative data is less than ideal because it analyzes individuals in the aggregate, making it more difficult to identify unique patterns and experiences specific to individual circumstances and contexts. Given the sources of data for most of what is known about citizen participation, a future direction is to incorporate qualitative methodologies to increase knowledge of quality citizen participation. The strategy has proven useful in other areas of inquiry. For example, when Newman and Massengill (2006) reviewed qualitative research on hardship, they concluded that the research paradigm of qualitative research enhanced what was already known and provided direction for further quantitative analysis.

Within the last 40 years, measurement of citizen participation has revolved around counting the activities and behaviors listed in the area described above. Reviews of the literature (Marschall, 2004; Roberts, 2004) have included calls for exploration of citizen participation processes, which signal a return to quality citizen participation, given how far the literature has progressed in demonstrating the prevalence of citizen participation and the contextual role of large cities such as Chicago and New York in understanding citizen participation. The socio-ecological perspective described by McLeroy et al.

(1988) provides an appropriate backdrop to inform one element of the current study: that of semi-structured interviews with community board members serving on the boards of CHCs in Iowa. This perspective explores the interactions of an individual's life to understand that individual's experience of participating on community boards and how that board might facilitate quality citizen participation in policy development processes. A less specific aspect of the literature on quality citizen participation through the lens of the socio-ecological perspective, and indeed, the gap the current study will fill, is articulating Arnstein's ladder (1969) to contemporarily understand quality citizen participation. Next, a critique of the literature including the strengths and weaknesses of how we know what we know about citizen participation will be presented.

From the perspective of scholars interested in citizen participation, equal participation's desired effect continues to this day. Hallman (1972) introduced an issue related to the onset of citizen participation when he questioned whether the government should be federally financing participation at all. Roberts (2004) questioned, in a review of past experiments of direct citizen participation, if we knew what success or failure looked like through results of outcomes or process evaluations. In other words, do we blindly assume there to be benefits of increasing citizen participation without critically evaluating the measures we would use and whom we would deem as beneficiaries to that participation? Indeed, criticisms exist around what is the stated goal of equal direct citizen participation.

An important distinction between quality and quantity citizen participation is whether a difference in motivation to participate might affect participation levels. For example, low-income individuals might be motivated to participate if the effect of the decisions made in a policy process in which they participated has a direct beneficial impact on their lives. Cornwall (2008) described a situation of those economically disadvantaged individuals participating "as a means to gain access to benefits or to improve their own access to services" (p. 275). In other words, these individuals

potentially are only able to improve their lives through participation, as opposed to families in higher income brackets who might have the resources to make other choices. The distinction evident in Cornwall's example reveals differences in motivation for individuals from different socioeconomic groups and provides further evidence of reasons for the variability of the expectations and motivations of participation.

A demonstration of the anticipated future direction of the quality citizen participation literature comes from more recent reviews of that literature. Levi and Stoker (2000) reviewed political trust and trustworthiness, and recommended the use of experimental methods or analysis of panel data as components of future directions for research on participation. Roberts (2004) suggested two pathways for the future of citizen participation research: First, evaluate citizen participation activities for effectiveness, and second, continue to build theory around the motivation of citizen participation. Cornwall (2008) added to these suggestions by encouraging the pursuit of "clarity through specificity" (p. 281) and signaled the aspiration for clearer definitions of both citizen participation and the object of study when investigating the concept.

A clear direction of future research is based on understanding the roots of conceptualizations of terms as well as how those roots were established. The weaknesses identified above do just that for the current study in one crucial way. Knowing that literature is based predominantly on census, survey, and administrative data provides a good foundation upon which to build a qualitatively motivated inquiry. Typically in knowledge development, prevalence is a necessary first step, which is what administrative and census data provide. To best understand these processes, a study exploring that experience with those on smaller scales in smaller areas of the country is useful.

To that end, the purpose of this critical ethnographic dissertation was to explore and better understand the social setting and context surrounding quality citizen participation in policy development. The following research question guided the study:

*How do community health center boards facilitate quality citizen participation in policy development?* To answer this question, I observed two board meetings of three CHCs in Iowa, reviewed board meeting documents such as board meeting minutes and patient characteristics of those served by the three CHCs in the study, and interviewed national and state policy experts, clinic directors, board chairs, and consumer and non-consumer members of three CHCs to explore their experience participating on these boards. The next chapter will detail the methods used for data collection.



## **CHAPTER 3**

### **METHODS**

This chapter will detail the methods used to address the main research question of how CHC boards facilitate the quality of citizen participation in policy development. The review of methods used will include an application of Carspecken's (1996) methodology for a critical ethnography to the subject of the research, how the samples used were chosen, how data were collected and the instruments used in that collection process, how data were recorded and stored, human subject protections, data analysis methods, and adherence to Creswell's (2007) criteria of good qualitative research.

#### **Design**

According to the epistemology that guided this qualitative research study, the best way to achieve familiarity with human beings, their actions, and their orientations is through face-to-face interactions (Lofland, Snow, Anderson, & Lofland, 2006). Given this epistemology, direct observations, reviews of relevant documents from CHC boards in Iowa, and semi-structured interviews were the main pieces of data collected and analyzed. A critical qualitative methodology, *critical ethnography*, was used to carry out this research study. This methodological approach is used "...to understand the relationship of culture to social structures" (Hardcastle, Usher, & Holmes, 2006, p. 152). The approach not only reconstructs reality but also articulates the reality's influence on social structures and the actors within those structures (Georgiou & Carspecken, 2002). Understanding the quality of citizen participation in policy-making processes with participants at the decision-making table requires an analytical strategy that privileges the experience of multiple realities. Given the study's emphasis, this specific approach was a necessary next step to understanding the quality of the citizen participation process.

Researchers in multiple disciplines have utilized Carspecken's methodology to explore a host of social injustices in disadvantaged and marginalized communities (Baumbusch, 2010; Bransford, 2006; O'Mahony, Donnelly, Este, & Bouchal, 2012;

Vandenberg & Hall, 2011). Bransford (2006) utilized a critical ethnographic framework to scrutinize power and authority exhibited by social workers in a health maintenance organization and “identified and critically examined the historical and cultural precedents, contexts and conditions that facilitated or inhibited their exercise of authority” (p. 184). Baumbusch (2010) applied a critical ethnographic framework to explore the sociopolitical contextual influences in long-term residential care facilities in British Columbia. O’Mahony et al. (2012) explored the contextual factors that impacted the behavior of immigrant and refugee women in Calgary experiencing postpartum depression and searching for help in order to improve services for this population. A critical ethnographic perspective not only seeks to understand and interpret a culture but also seeks to contribute to social change by identifying social injustice and working through inquiry to spur social change (Baumbusch, 2011). CHC boards, the focus of this study, are interested in facilitating a legitimate voice for those served by the clinics that previously did not have that voice in the decision-making process and still do not have that voice in multiple contexts of their lives. The CHC boards in Iowa, therefore, are an intriguing one in which to explore the experience of participation in the board member’s own voices from a critical perspective.

### **Carspecken’s Critical Ethnographic Method**

The research design for the current study was guided by the critical ethnography methodology of Carspecken (1996). The critical element of the study is captured by Carspecken and Apple (1992) when they describe critical researchers as being “politically minded people who wish, through their research, to aid struggles against inequality and domination” (p. 512). More specifically, viewing the quality of citizen participation from the perspective of CHC board members engaged in a process in which political power could be unevenly distributed across the board members were an opportunity to understand how a structure like a CHC board is able to facilitate policy development.

The ethnographic element of this study can be conceptualized through two factors: one, how the data are viewed and two, the role of the researcher. The data used for analysis in this study included observations, interviews with policy experts and CHC board members, and board structure and governance documents (e.g., meeting minutes and governance and committee structure documents). The context of this study was CHC boards in Iowa, and the researcher, a doctoral student in social work not affiliated with the CHC structure was viewed as an outside participant observer (Lofland et al., 2006).

An important part of the methodology used in this study was the process for data collection. An explanation of the five phases used in this process comes from Carspecken and Apple (1992). These phases are phase 1 - *monological data collection*, phase 2 - *preliminary reconstructive analysis*, phase 3 - *dialogical data generation*, phase 4 - *describing system relationships*, and phase 5 - *explaining system relationships* (Carspecken & Apple, 1992, p. 514). The first phase, monological data collection, entailed collecting primary data in an objective way. Specifically, the data collected in this phase were used to describe “what is and what takes place” in a contextual setting (Carspecken & Apple, 1992, p. 517). The second phase, preliminary reconstructive analysis took the data collected during the primary record in phase one and analyzed it to infer meaning. The third phase, dialogical data generation took information from the first two phases and used it to inform the interviews with participants in the study’s social site context to gain more clarity on the reconstructions occurring in phase 2 (Carspecken & Apple, 1992, p. 530). In phase four, describing system relationships, the critical research examined the relationships between social sites and social groups (p. 535). In phase five, explaining system relationships, the charge for the critical researcher was to connect the findings from phases 1 – 4 with broad views of society. As Carspecken (1996) suggested, in some cases for dissertation research, phases 4 and 5 are outside the specific scope or timeline but can be undertaken later in a researcher’s career (this suggestion was

followed). In Table 3.1, the five phases are outlined, and activities for the current study that correspond to each phase are described.

Table 3.1 *Five Phases of Carspecken: Purpose and Associated Activities*

Phase	Purpose	Activities
1 - Monological data collection – constructing the primary record	Collected data through observation of social site.	Tour of health clinic; attending community board meetings; reviewing minutes of board meetings; reviewing descriptive statistics for county and clinic patient community demographics.
2 - Preliminary reconstructive analysis	Reconstructed the social site through observations where the focus is on interaction patterns and roles of those being observed and their power dynamics.	Search for content themes, commonalities, and discrepancies possibly among the variety of board member roles?
3 - Dialogical data generation	Used the information from phases 1 and 2 to substantiate observations made.	Semi-structured interviews and follow up conversations with executive directors and policy experts.
4 - <i>Describing system relationships</i> <b>Future research</b>	Investigate connections between social site reconstructions and other sites which influence it.	Search for themes in other sites and make comparisons to reconstruction found in social site of interest.
5 - <i>Explaining system relationships</i> <b>Future research</b>	Explain stages one through four findings by reference to the broadest system and specifically seeks reasons for what was found in the reconstruction influenced by the social stratification in society.	Using critical theoretical positions to explain influences, relationships, and re-constructing discoveries found in stages one through four.

Source: Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. New York, NY: Routledge (pp. 41-43).

### Setting

Given the multiple systems of influence on a particular social site (an influence illustrated by the socio-ecological perspective in Figure 1.2 and Figure 2.2), interview analysis was not sufficient to investigate the contextual impact of the social site in this study (Carspecken, 1996). This fact justified a critical ethnographic investigation into the

experiences of the quality of citizen participation by board members of CHCs in Iowa. To that end, to answer the research question, *How do community health center boards facilitate the quality of citizen participation in policy development*, a critical ethnography was used that included participant observation of CHC board members, review of various CHC and board documents, and semi-structured interviews with citizens participating on CHC boards to understand the quality of their participation.

### **Social Site**

The social site for this study was CHC boards in Iowa where three of the fourteen in the state were approached for participation. For Carspecken (1996), the *social site* is situated within a locale, which is also influenced by economic, political, and cultural structures. Carspecken's (1996) definitions provided specificity to understand the setting of a critical ethnographic investigation: the *social site* is the primary object of interest.

### **Locale**

Carspecken (1996) identified a *locale* as anything that "influences the social site" (p. 35). In addition, Carspecken added that *locale* is the wider area surrounding the social site and articulates the existing regionalization between multiple social sites due to a shared geographic area. For the current study, the *locale* of interest was the CHC served by the board and included patient characteristics of the three CHCs chosen for the study and additional information of the three CHCs chosen for the study.

### **Structural Influences**

Carspecken (1996) suggested that economic, political, and cultural structures also influence the locale and by definition influence the social site. More specifically, Carspecken viewed wider systems of influence to include political and economic structures impacting numerous regions and multiple social sites. This type of influence was present in the case of CHCs because the health centers, originating in the spirit of War on Poverty programs were located in communities that experienced limited access to services. Care was administered by teams designed to address medical issues with a

philosophy of prevention that included the provision of care in the social and environmental purviews of individuals' lives (Dievier & Giovannini, 1998). Figure 3.1 illustrates the social site, locale, and structural influences as they apply to this study.

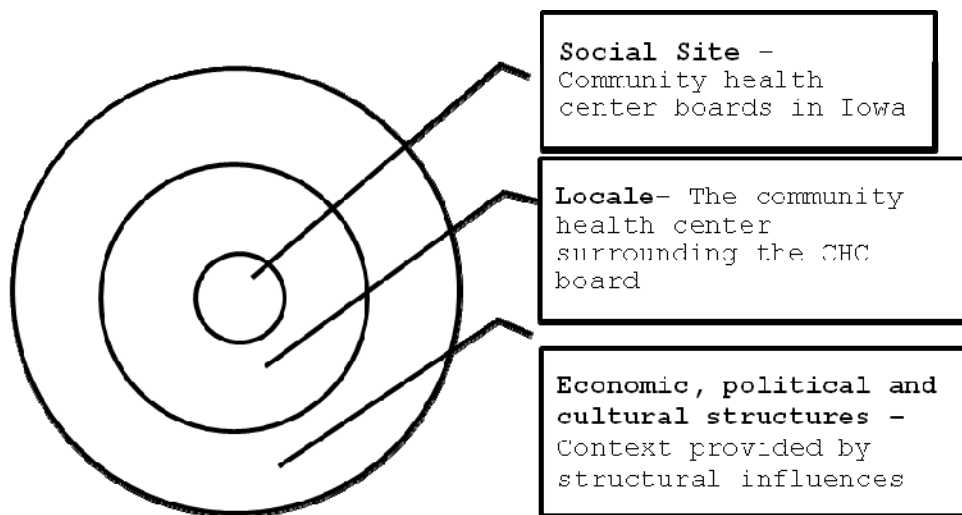


Figure 3.1 Carspecken's description of levels with application to present study

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Source: Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. New York, NY: Routledge.

### **Social Site and Locale Description**

**Demographics of CHCs in Iowa.** The 14 FQHCs in Iowa at the time of this study included 13 Community Health Centers and one Migrant Health Center. The majority of revenue for CHCs in Iowa, in 2009, came from Medicaid dollars totaling over \$33 million (Uniform Data System Report, Bureau of Primary Health Care – Health Resources and Services Administration, 2010). A summary of additional key characteristics of the 13 CHCs in Iowa is found in Table 3.2. These characteristics provide a potential profile of who might be represented from the patient perspective on CHC boards in Iowa and therefore be part of this study.

Table 3.2 *Summary of Patient Characteristics of CHCs in Iowa*

Characteristic	% of patients
Insurance status <sup>a</sup>	
Medicare/Medicaid	39.6
Uninsured	38.9
Private/Commercial insurance	21
Other public insurance	.4
Geographic location <sup>a</sup>	
Rural	52
Race <sup>b</sup>	
White/Caucasian	69
Race unknown	16
Black/African American	12
Asian Pacific Islander	2
Ethnicity <sup>b</sup>	
Not Hispanic/Latino	66
Hispanic/Latino	18
Ethnicity unknown	16
Age <sup>b</sup>	
0-17	34
18-34	25
35-54	26
55 and older	14

<sup>a</sup> <http://www.nachc.org/client/documents/IA10.pdf>;  
[http://www.nachc.org/client/state\\_X\\_key\\_facts\\_2009.pdf](http://www.nachc.org/client/state_X_key_facts_2009.pdf)

<sup>b</sup> Iowa Collaborative Safety Net Provider Network CY 2010 Data Report, p. 32.

An additional distinction of CHCs is that the centers not only provide services to disadvantaged and marginalized communities but also include their patients in the governing structure of the clinics through representation on their boards (Dievier & Giovannini, 1998). More specifically, the National Association of Community Health Centers (NACHC), a governing body of CHC boards, distributed a manual in 2005 entitled, *So, you want to start a health center? A practical guide for starting a federally qualified health center*. The manual described that the board composition “must be representative of the community being served and at least 51% of board members must be regular consumers of the health center” (NACHC Manual, 2011, p. 17). In addition to

the 51% consumer board members, no more than half (50%) of the remaining positions on the board may be citizens who derive more than 10% of their annual income from the health care sector (NACHC Manual, 2011). The total number of board members required, according to the NACHC (2011), is between nine and 25 members. At the time of this study, the majority of CHC boards in Iowa consisted of 12 to 15 members. For example, if a board had 13 members, the typical board composition was as follows: at least seven of those members had to be consumers of care from that specific center, and of the remaining six, no more than three were health care earners (NACHC Manual, 2011).

### **Gaining Entry to Site**

To gain entry to a site in a qualitative study, Guba and Lincoln (2005) discussed the need for trust and rapport between the researcher and the study participants. To that end, the role of the researcher in the study must be articulated as one that builds rapport between researcher and participants. An important step in the process of gaining entry in qualitative research is to acknowledge the role of the researcher. Identifying the role of the researcher within the context of the research study and the context to be investigated is vital to building rapport and establishing trust.

Lofland et al. (2006) defined the researcher's multiple roles and articulated the elements necessary for building trust and rapport in a research study with the term *outsider participant researcher*. According to Lofland et al. (2006), this is a researcher who is "seeking admission to a setting for the purpose of observing it or securing access to individuals for the purpose of interviewing them" (p. 41). For this study, both were accomplished. To understand the context in which CHC board members functioned, I observed two board meetings at each of the three clinics in the project and toured each clinic. I also reviewed relevant documents for each of the three boards in the study which included board meeting minutes and demographic information on the patient communities of each clinic. Semi-structured interviews were conducted with national and



state CHC policy experts, the CHC clinic directors, and the chair of the CHC boards to provide context for how CHC boards facilitate quality citizen participation in this setting.

### **Sampling and Selection Criteria**

Of the 13 CHCs in Iowa, three were chosen for participation. This research study stemmed from an existing collaboration between the Commonwealth Fund in New York and the Public Policy Center (PPC) at the University of Iowa, which worked through a coalition of health care safety net providers in Iowa to understand the impact of the Affordable Care Act of 2010 (ACA) on the care provided in the health care safety net. Community Health Centers is an important part of that safety net. The PPC was partnered with a coalition in this collaboration that was convened by the Iowa Primary Care Association (IAPCA).

The IAPCA was an important community partner in this study because they assisted in identifying the three clinics to recruit for participation. Interviews were conducted with two key staff members of the IAPCA to assist in identifying the clinics to approach for participation (see Appendix B for interview guide). During the interviews, the IAPCA staff were asked (a) which CHC boards in Iowa were the most actively engaged with the legislative advocacy work of the IAPCA and local policy development; (b) whether the IAPCA staff had discussed the collaborative project mentioned above with any of the clinic directors and, if so, what was their level of enthusiasm for the project; and (c) to the IAPCA staff's knowledge, what was the role of the community health center boards in policy development. Based on the answers to these questions, the researcher, in consultation with two dissertation committee members, identified the three clinics that provided the best fit with the study's interest in understanding the quality of participation in CHC boards.

The purpose of the initial meetings with the CHC clinic directors prior to approaching the CHC board presidents and board members was twofold: to create transparency and to establish rapport. As the only employee of the CHC board, the CHC

clinic director makes all management decisions regarding the day-to-day operations of the clinic. To create a research collaborative in which participants and others contacted through the course of the research study felt they understood the study's intentions, it was essential to begin with the leader of the CHC's day-to-day functioning. Participation of the CHC was cleared with the clinic director as a key first step to full transparency of the researcher's intentions. The clinic director of each health clinic was on the frontline in each clinic and was able to provide information important to the study, which required a trusting relationship with the clinic director from the beginning.

After I interviewed IAPCA staff and decided which boards to target for participation, the IAPCA notified the three clinic directors about the study and encouraged their participation (see Appendix C for correspondence email language). The IAPCA informed the directors that the study was part of the larger PPC project with which they were familiar to increase the likelihood of the clinic director's participation and subsequently of the board's participation. The clinic director indicated his or her willingness to participate, and an interview was conducted. After the interview, the clinic director provided me with contact information for the board chair. Next, the three clinic directors sent an initial email/letter to the three board chairs (see Appendix E for email correspondence with the board chairs), and a follow-up letter with a phone call was used to set up a time to meet with the board chair to conduct an interview (see Appendix F for interview guide). In the interview, I requested permission to view board meeting minutes, observe two board meetings, and begin to solicit participation of board members in the study.

This critical ethnography drew participants from a sample of CHC board members of CHCs in Iowa. Selection criteria were supplemented by information obtained during initial conversations with staff at the IAPCA, as previously mentioned. To that end, the initial sampling and selection conversation was a result of information IAPCA staff provided and was the next step in participant recruitment.

## **Sample Size**

For a goal of theoretical saturation, 20 to 30 interviews lasting from 60 to 90 minutes are sufficient (Creswell, 2007). Carspecken (1996) discussed that observation saturation occurs from 20 observations of a social site to provide ample information in the primary record forming the first phase of a critical ethnography. The three clinics included in the project were named Clinic A, Clinic B, and Clinic C to protect the confidentiality of the information shared by the clinic directors, their board chairs, and their board members. In total, one interview was conducted with a national policy expert at the NACHC, two interviews were conducted with policy experts at the IPACA, three interviews were conducted with clinic directors, three interviews were conducted with board chairs, 16 interviews were conducted with board members, and two board meeting observations were conducted at each of the three CHCs participating in the study. Carspecken (1996) suggested a total of 20 data collection points to reach theoretical saturation. Table 3.3 identifies the 76 total data points collected for the analysis and discussion of results (Chapters 4 and 5).

## **Data Collection**

A variety of data was collected to answer the research question that guided this study. As previously noted, the clinic directors and board chairs of the three clinics each provided documents that were reviewed. These included one calendar year of the board meeting minutes, documents that governed the board and their activities, and a report filed with the Health and Resource Services Administration (HRSA) that included demographic characteristics of patients who received services from the clinics. In addition to reviewing these documents, I observed two board meetings for each of the three clinics, recorded the observations in a field journal, and conducted interviews with members of each of the three boards. More details about the information collected, and how it was used are provided in the following sections.

Table 3.3 *Data Collection Points*

Data source	Total data # collected	Data analyzed
National policy expert interview	1 expert total	Semi-structured interview transcribed to identify themes
State policy expert interviews	2 experts total	Semi-structured interview transcribed to identify themes
County characteristics	2 + 2 + 3 = 7 counties total	Age Race/ethnicity Income distribution Veterans
Clinic patient characteristics	1 + 1 + 1 = 3 clinics total	Age Race/ethnicity Income levels of patients Insurance status of patients
Clinic characteristics	1 + 1 + 1 = 3 clinics total	History of expansion Services offered Clinic building description Map of each floor of clinic Special populations of clinic
Clinic director interviews	1 + 1 + 1 = 3 interviews total	Semi-structured interview transcribed and entered to identify themes
Board chair interviews	1 + 1 + 1 = 3 interviews total	Semi-structured interview transcribed and entered to identify themes
Board meeting observations	2 meetings x 3 clinic boards = 6 board meetings total	Field journal used to record observations of board member interactions, entered to identify themes, differences and similarities
Board meeting minutes - Calendar year 2010-2011	10 + 12 + 10 = 32 meeting minutes total	Entered minutes to identify themes, differences and similarities
Board member interviews	Clinic A (5) + Clinic B (7) + Clinic C (4) = 16 total	Semi-structured interview transcribed and entered to identify themes
<b>Total data points</b>	<b>76</b>	

## **Instruments**

**Review of documents.** The board chairs of the three clinics granted me permission to read and analyze board meeting minutes and any documentation pertaining to board structure and governance. These documents were used as triangulation tools for conversations with the CHC clinic directors and the CHC board members during the semi-structured interviews. Specific attention was paid to examples of ways the board facilitated the quality of citizen participation in the policy development processes for which the CHCs were responsible.

**Observations.** Permission was granted by the board chairs of each of the three clinics to attend and observe two board meetings for each of the CHC boards. The observation guide can be found in Appendix G. Observational data was used to understand the context in which the CHC board members operated. I observed interactions among board members and between board members and others such as the leadership team of the clinic, clinic director, and chair of the board. In the interest of legitimizing the study with the board presidents and board members, each clinic director provided a tour of the specific CHC. The tours were important given the researcher's interest in understanding the full CHC context that board members inhabited and were used as background to understand the social context in which the CHCs operated.

**Semi-structured interview guide.** Spradley (1979), Lofland et al. (2006), and Marshall and Rossman (2011) provided guidance regarding how to construct an interview guide, how to ask main questions, and how to utilize prompts to encourage board members to talk about their experiences in a way they might not have considered previously. The interview questions addressed each of the levels in the socio-ecological perspective identified and discussed in Chapter 2, which are the intrapersonal, interpersonal, institutional/organization, community, and public policy levels. Table 3.4 provides examples of questions and probes for each conceptual level. Each of the

interview questions and probes was chosen to shed light on the main research question. The interview guide used for board member interviews is in Appendix H.

Table 3.4 *Sub-Questions and Probes Utilized in Semi-Structured Interviews*

Conceptual level	Sub-question	Probes
<b>Intrapersonal characteristics</b>	<b>Please tell me about yourself.</b>	<b>Root of involvement in board Other activities in community</b>
Interpersonal characteristics	Please tell me about your experience on this community health center board.	Prior knowledge or relationships before involvement on board Length of time on board Definition of community Definition of community representative
<b>Organizational / Institutional characteristics</b>	<b>Please tell me how you view your role on the board</b>	<b>Board's purpose as an organization Activities of board relating to everyday activities of clinic</b>
Community characteristics	Please describe the obligation or expectation you feel as a community member	Report back to community you represent
<b>Public policy characteristics</b>	<b>Please describe the influence of the CHC board on policy development</b>	<b>Decision making within the board Translation of the influence on policy</b>

### **Data Recording Plan**

In accordance with suggestions for qualitative researchers entering the field to observe a social phenomenon, I kept and recorded in a journal every day (Lofland et al., 2006). Information from background interviews with policy experts and executive directors of health clinics and from semi-structured interviews were digitally recorded. Interviews then were transcribed as they occurred, which allowed for the recursive process of the data collected to inform future interviews and theoretical and conceptual saturation processes. Interviews were transcribed by me and two outside companies. As information was collected and transcriptions received, various elements were coded

according to Carspecken's (1996) method. To ensure that elements of the interview were accurately captured, the themes were checked with a dissertation committee member most familiar with qualitative research and with another committee member most familiar with the sample of interest

### **Data Storage Plan**

Information was stored on a network at The University of Iowa and on a personal flash drive (for backup) that was kept in a secure location in the main office of the School of Social Work.

### **Protection of Human Subjects**

According to Creswell (2007), nine specific elements (see Table 3.5) must be included to consent participants to a research study. All participants were assured these elements in the consent process, which was approved by The University of Iowa Institutional Review Board (IRB) on April 12, 2012 (see copy of approval in Appendix I). Consent documents approved by the IRB are located in Appendix J, K, and L. In accordance with IRB requirements, all potential informants and participants were given the option to participate and if they agreed, consent was obtained. However, formal consent was not needed for the state and national policy experts who provided background information for the study because they were not providing opinionated information about the CHC boards, merely background policy and procedural clarification on the role of the boards in policy development. The approval procedures with board members began when permission was granted by the board chair to attend the first board meeting. At the first board meeting, I introduced myself and discussed the project with board members. At the end of the presentation, two handouts were distributed to board members: the first was a description of the study and the second was a consent form that informed members what they were agreeing to if they agreed to participate and provided a space for them to fill out their contact information (see a copy of the consent information form in Appendix M which was distributed to all potential

participants). It was indicated to the board members that if they were interested in participating, they could mail the contact information form back to the researcher, and I would contact them in the next few weeks to set up an interview. At this time, board members had the opportunity to direct questions about the project to the researcher.

Board members consented to participate in the study when I was contacted and was provided their contact information to set up an interview. Board members had the choice whether to be audio recorded, and all but one interview was recorded and transcribed. In total, 16 board members agreed to participate in the study.

The information was triangulated with phase three, which focused on board member interview information, to ensure that the principle of trustworthiness of the data (Creswell, 2007) was adhered to sufficiently according to the participants. Board members who were interviewed were contacted in the spring of 2013 to ensure reliability of their information through member-checking procedures described later in this chapter.

## **Data Analysis**

### **Analyzing Data**

Carspecken's (1996) model was used to structure the data analysis of this critical ethnography study. The following research question guided the study: *How do community health center boards facilitate the quality of citizen participation in policy development?* To answer this question, various types of data were collected, as shown in Table 3.3. During the first phase, the primary record was constructed using the following data collection strategies: tours of specific CHC facilities, attendance and observation at two CHC board meetings for each of the three boards participating in the study, a review of the board meeting minutes for one calendar year for each of the three boards, and informational interviews with four policy experts at the state and national levels.

According to Carspecken (1996), the main analytical information of interest in the first phase is to discern evidence of bias in the collection of information about the social site of interest. To that end, Carspecken described this phase as revolving around



observations and a flexible schedule of observation to eliminate the possibility that the research or researcher affected or altered the social site. It is important in this phase to ensure that I recorded what actually occurred during observations and to record those interactions through note taking and audio recording (when possible).

According to Carspecken (1996), the second phase of data analysis involves preliminary reconstruction. The first concept of importance in this phase is that the role of the record at this point in the study is that of the *possible meaning* of the social site, because the participants' voices have not yet been incorporated as they will in phase 3 (Carspecken, 1996, p. 96). The second and third concepts of importance, *low-level coding* and *pragmatic horizon analysis*, are two types of inference employed during this phase; the idea of both of these inferences is for the researcher "to put more words onto the actions observed, as if the actor had tried to convey the entire meaning of her act verbally rather than through the complexities of vocal tone, posture, gesture, facial expression, timing, prosodic form, and so on" (Carspecken, 1996, p. 97). Additionally, Carspecken (1996) identified two key differences between low-level coding and horizon analysis. The first difference is the depth of inference because low-level coding must occur prior to horizon analysis; second, horizon analysis, or pragmatic horizon analysis, "regards action, rather than perception, to be the most primary in experience" (p. 103). Again, the goal in this phase was to reconstruct the social site within its setting and locale based on observations and other information collected in phase one; however, this was only the possible meaning, as phase three allowed for the information to be triangulated with participants of phase one.

According to Carspecken (1996), the main purpose of phase three is to allow participants entrance into the research through interviews, the main mode of data collection. Information gleaned and analyzed from phases one and two informed the probing questions asked during the interviews in the current study, thereby allowing participants the opportunity to comment, discuss, and concretely include their voices in

the data being collected and analyzed. Phases one and two are important in how they inform phase three, given that the crucial assumption by the researcher of the overall methodology is to “put more words onto the actions observed” (Carspecken, 1996, p. 97). I analyzed these actions from phases one and two and integrated them into phase three to encourage a deeper and thicker description of the social site of interest.

For Carspecken (1996), phase four involves an examination into the relationships between the social sites of interest; in the current study, this was defined by the CHC board. Phase five centers on describing the findings through critically examining the reconstruction done during phases one through three and then relating that reconstruction to the potential social system influence. Steps to address these phases are not described for the purposes of this study, but will be explored in the immediate research agenda pursued by the researcher.

Lincoln and Guba (1985) introduced concepts specific to qualitative research and described how to ensure the trustworthiness of qualitative data such as credibility, dependability, confirmability, and transferability. To check for these standards in qualitative research, Creswell (2007) presented nine criteria to assess trustworthiness. I used these criteria to ensure that trustworthiness of the data was achieved. In Table 3.5, criteria are listed and demonstrated strategies are identified that were part of the study design; tasks used to achieve each criterion are also included. Further explanation of specific steps taken to achieve trustworthiness and auditability are described in detail in the following sections.

### **Trustworthiness**

For a qualitative project, the term trustworthiness (Creswell, 2007) is used to describe a research study motivated by the meaning and the reality formed by an individual’s lives, the idea being that there are many truths instead of just one. To ensure that participants acknowledged the recorded data as their own personal experiences, triangulation of data gleaned from interviews occurred in the spring of 2013.

Table 3.5 *Nine Criteria for Characteristics of a “Good” Qualitative Study*

Criteria	Tasks and activities to achieve criteria
A. Systematic data collection procedures	A1. Carried a notebook at all times to record observations and conversation reminders. A2. Systematically conducted semi-structured interviews, adhering to an emergent design but focusing on the same categories of questions for all board members regardless of their roles. A3. All interviews were audiotaped, with permission of participants.
B. Adhered to qualitative assumptions and characteristics in the design	B1. There are multiple realities. Semi-structured interviews demonstrated an adherence to this principle. B2. Qualitative research focuses on context. Principle is realized through an ethnographic design that investigates multiple angles of community board participation, not just one.
C. Utilized a recognized qualitative approach	C1. Carspecken’s (1996) critical ethnography was the methodology guiding the project.
D. Motivation occurred from a single concept and expanded	D1. The concept of interest was quality citizen participation, and the entire study was built around understanding that concept in the context provided by community board participation.
E. Integrated rigor in all phases of research design	E1. Used multiple forms of data that included information seeking sessions with <i>gatekeepers familiar with policy</i> ; participant observation at board meetings, advocacy events, and day to day operations of the health clinics; meeting notes of board meetings; and semi-structured interviews. E2. Used multiple forms of information validation, and included member-checking, triangulation, and auditing.
F. Incorporated various levels of observation and data collection	F1. Observation occurred in a variety of settings F2. Data collection occurred in a variety of ways as mentioned above.
G. Conveyed researcher observations to give reader impression of being there	G1. Detailed notes were taken throughout study in notebook. G2. Quotes from notes were included where appropriate throughout analysis and discussion of study.
H. Research positionality was integrated throughout study	H1. Researcher positionality was explicitly discussed as well as its influence on the entire study, participants, context, and analysis.
I. Research adhered to and respected ethics throughout study	I1. IRB approval from the University of Iowa led the adherence to these criteria with extensive attention given to the protection of participants, the context, and everything included within both.

Source: Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: SAGE (pp. 45-47).

This activity is also known as member checking (Marshall & Rossman, 2011). Board members were given the option to participate in this step at the end of their interviews. Out of the 16 board members interviewed for this study, 12 members agreed to the member-checking activities. When I approached the board members and gave the option to follow through with their agreement, seven board members agreed to participate in member checking. With those who responded, I discussed the information that the participant provided either over the phone or through email exchanges to check for accuracy of the researcher's interpretation of the information. Members shared information that was incorporated into Chapters 5 and 6, including board term limits and the pathways board members took to become members of the board.

### **Auditability**

Similar to reliability in quantitative research, auditability is crucial for qualitative research. An audit trail allows for transparency in the design decisions made and data collection process followed by the researcher (Marshall & Rossman, 2011). This ensures that the reader of the research can follow the process taken by the researcher in the study. A step-by-step procedure was constructed that followed the design decisions made throughout the study and also a process was created for analyzing the data in NVivo.

Conversations with multiple committee members ensured that the steps created and conducted were consistent with the procedures approved by the IRB. In addition, a committee member most familiar with qualitative research provided feedback and consultation throughout the data collection and analysis processes to ensure the replicability of the study based on the steps recorded.

## **CHAPTER 4**

### **RESULTS OF THE PRIMARY RECORD**

This chapter presents the results from the analyses of data collected for the primary record, which was the first step in this critical ethnography using Carspecken's (1996) model. The six steps below comprise the primary record for this study. This information guides the remainder of the project and is important before the research interacts with those within the social site of interest. The purpose of this detailed description is to provide access to the information that was the foundation of inquiry for this study. These data sources included:

1. Websites of the National Association of Community Health Centers (NACHC), the Health Resources Services Administration (HRSA), the Iowa Primary Care Association (IAPCA), and the three CHCs that participated in the study. These websites were reviewed to provide the background necessary to understand the social site of interest, CHCs in Iowa;
2. Information gleaned from the interviews conducted with the IAPCA staff and the policy experts at the NACHC and the HRSA;
3. Background information on the clinics and, more specifically, on the CHC boards, gathered from the interviews conducted with the clinic directors;
4. Descriptive statistics of the seven major counties from which the three clinics drew the majority of their population to understand the community needs;
5. Descriptive statistics from each of the three clinics to capture the context in which the clinics operated. This context included the services offered by each clinic, the special populations each clinic served, the history of each clinic, and a description of the main building for each clinic. In addition, the following demographic information for the patient community of each clinic was obtained: age distribution, race and ethnicity, income distribution, and insurance status of patients; and

6. Background information obtained from interviews conducted with chairs of the three CHC boards.

The information gleaned from the primary record acted as a guide for the remainder of the project. The primary record guided the depth and breadth of inquiry through the interviews conducted with board members, which allowed the context surrounding the CHC boards to be understood prior to the interviews. The purpose of this detailed description is to allow the reader access to the information that was the foundation of inquiry for this study. The information provided the foundation because it was how I understood the social site, which adhered to Carspecken's (1996) rationale for the primary record in a critical ethnography. This chapter summarizes the information collected for the primary record from the three clinics in the study to better understand the context of the clinics that fed into the construction of the primary record (Carspecken, 1996).

### **Review of Organization Websites**

Website review was the first step in gathering information. These websites were reviewed to obtain information and to help prepare for the interviews. The websites also provided an understanding of how Iowa CHCs fit within the national and state agencies whose websites were reviewed. The researchers viewed the NACHC website (<http://www.nachc.org/>) before conducting the background interview with the NACHC policy expert to understand the role of the NACHC in CHCs in Iowa. For example, this information was used to review the statistics the NACHC compiled on health centers in Iowa, to identify where these centers were located in the state, and to understand more about the policy research analysis role of the NACHC within the structure of the CHCs.

The HRSA website (<http://www.hrsa.gov/index.html>) provided information on HRSA's role within the CHC structure in preparation for the researcher's interview with the HRSA policy expert and described how her/his work influenced the CHCs in Iowa.

For example, this website was used to gather data by reading reports compiled by HRSA on the demographics of patients served by CHCs in Iowa.

The IAPCA website (<http://www.ianepca.com/>) provided necessary background information to assist in understanding the IAPCA's role within the CHC structure. This information was used as a foundation for conducting the interview with IAPCA staff to understand the differences among the CHCs in Iowa and to help select the specific CHCs to focus on for this study. For example, this website was used in preparation for the IAPCA interviews to understand the data that had been compiled on clinics receiving support from IAPCA staff in Iowa.

Each clinic website was one aspect of the information gathered as a passive observer, as described by Carspecken (1996), to obtain information that was later compared with the data collected during the interviews with board members. Websites were viewed before further exploring each individual clinic. Websites of the three clinics were reviewed frequently during the course of the study to check, for example, the services offered or the hours the clinics were open to gain clarity about the clinic services, the information clinics provided to patients through their websites, upcoming events, publicity of the clinics in the news (radio or newspaper), and links to their social media outreach (Facebook). These reviews were helpful to understand the online presence of the clinic and how patients and other community members could access that information. Of the three clinic websites, two clinics listed the members of the board with no contact information, and the third had no information on the board members. Listed on the websites were the services offered at each clinic as well as locations of the clinics and the hours at each location. Other information on the websites included employment opportunities, history of the clinic, information specifically for patients (what to bring to first appointment, the request to arrive early for the appointment, etc.), requests for donations, resources for patients and community members at large, the latest annual

report of the clinic, information on upcoming special events, and the ability to subscribe to the clinic newsletter, to name a few.

### **Policy Expert Interviews**

#### **Iowa Primary Care Association (IAPCA) Interviews**

After reviewing the websites, I conducted semi-structured interviews with two staff members at the IAPCA (see Appendix B for interview guide). The interviews began the process of deciding which clinics in Iowa to target for an invitation to participate. A conversation was conducted with these staff members to narrow the focus of the clinics to include.

During the IAPCA staff interviews, I discussed what the study was designed to explore and how the boards of the CHCs would be a good fit. I clarified what was not of interest to the study, namely that the study was not intended to evaluate whether the boards were in compliance with the activities and duties for which they were responsible. Instead, the study focused on the quality of participation of the board members, mainly because of the unique characteristic of having a 51% patient majority represented in the board composition. The IAPCA staff was then asked to identify which three boards in the state were the most actively engaged with the policy development work of the IAPCA and with local policy development within the context of their board activities. The focus on engagement in policy development work was derived from the main research question of interest centering on the board's citizen participation element in policy development processes; thus, engaging a board that was not involved in policy development, that met the bare minimum requirement for their board responsibilities, or that had a surface level relationship with the IAPCA would not provide the rich data needed to fully explore the experience of participating on the board. The IAPCA staff was then asked to rate the 13 CHCs in Iowa as very engaged, moderately engaged, or minimally engaged. The staff identified three CHCs in different regions of the state that were very engaged. To protect the confidentiality of participants in the study, the clinics were identified as Clinic A,



Clinic B and Clinic C throughout this investigation. The IAPCA staff also commented that IAPCA had the most contact with clinic directors rather than with board chairs and that there was considerable variation in the involvement of the boards.

During one of the IAPCA interviews, the staff recommended adding a policy expert from the National Association of Community Health Centers (NACHC) to the list of policy experts to interview. The person recommended was an expert in the public policy and research division at the NACHC and had been involved with the CHC movement since the 1960s. The IAPCA staff agreed to send an email message to both the NACHC policy expert and the HRSA policy expert to introduce the project and encourage a response to the contact made (see Appendices O and P for email correspondence language).

#### **NACHC National Policy Expert Interview**

The NACHC policy expert, Mr. Dan Hawkins, agreed to be interviewed (see Appendix O for interview guide used with both NACHC policy expert and HRSA policy expert) and provided a history of the CHC movement; he had experience on the front line of the work of CHCs and, because of his position, possessed a unique perspective. This unique perspective came from his current position with NACHC and the organization's involvement with CHC board development across the nation. In addition, this perspective provided insight into the strengths, weaknesses, opportunities, and threats faced by the CHCs, their boards, and the board members in a way that was not represented in other aspects of the study.

**History of community health centers.** According to Mr. Hawkins, the community health center concept was brought to the U.S. by Dr. Jack Geiger, who as a medical student in the 1950s spent time in medical communities in South Africa. These medical communities employed a philosophy that health care should be run by the community in which it operated (Geiger, 2005). When Dr. Geiger returned to the U.S., he was swept up in the Civil Rights Movement, participated with Dr. Martin Luther King,

Jr., and others in the activities of the time, and formed the Medical Committee for Human Rights. Dr. Geiger's work was so well known that he was approached to help craft pieces of the War on Poverty legislation in 1965 related to health care. The CHCs began as a demonstration project, but health was not originally part of the mandate the Office of Economic Opportunity (OEO) was required to address (Sardell, 1988). In fact, it was not until the programs of the OEO were up and running that the problem of inadequate access to health care of the majority of consumers of the programs became an issue that policymakers felt needed to be addressed (Sardell, 1988).

According to Mr. Hawkins and corroborated by others in the CHC literature (Lefkowitz, 2007; Sardell, 1988), the health centers initially began as a demonstration project in the U.S. in the 1960s. The elements related to care revolved around creating a system that could effectively serve the poorest communities in America by assessing and responding to the unique needs of those community members where they lived. As a result of the influence of South Africa's system on Dr. Geiger, the element of a patient majority board was woven into the fabric of how the health centers would operate. Because of the connection between the War on Poverty, the Civil Rights Movement, and the social and cultural unrest of that time, a major hallmark of the CHC demonstration project was to ensure that the patient majority element of the CHC boards was preserved in the crafting and implementation of the legislation (D. Hawkins interview).

Given his long-term involvement with CHCs, the policy expert shared his perspective on the climate of political and institutional influence on the lifespan of the CHCs. The NACHC celebrated its 40<sup>th</sup> anniversary in 2005, and one of the factors discussed as a proud accomplishment of the CHC movement was its longevity, not only in terms of years but also in terms of surviving the political and social waves of change and continuing to thrive. A few factors were identified by Mr. Hawkins related to politics and government that have been, and continue to be, challenges faced by the CHC

movement, and he discussed how they have contributed to the CHCs' existence and ultimate success (D. Hawkins interview).

First, Mr. Hawkins described what he defined as the proliferation of government since the initiation of the CHC demonstration project in the 1960s. At that time, the items on the agenda of elected officials in Washington, D.C., were not nearly as complex as they are today. This point was made by the late Senator Ted Kennedy when he was interviewed by a reporter who was covering his 40<sup>th</sup> year as a member of Congress. According to Mr. Hawkins, Senator Kennedy was a champion of CHCs until his death because of the congruency with his overall ideology to provide equal access to health care for all Americans. Mr. Hawkins remembered Senator Kennedy's words when he was asked in the interview what had changed the most in his time in Congress. Senator Kennedy spoke about how busy elected officials had become, to the point where they simply did not have time to fully debate and discuss the essential issues of the day as they used to. Senator Kennedy noted how important it was to have the conversation around the patient majority characteristic of CHCs back then, and then stated that the conversation would not have happened today simply because of the shortage of time for such debate (D. Hawkins interview).

Second, Mr. Hawkins described a positive feature of contemporary politics when he discussed the bi-partisan support that CHCs have enjoyed for so many years as a factor in their continued existence. He noted very different political reasons for why each side of the aisle supports the CHC movement and continues its funding streams year after year. For Democrats, the pull is similar to Senator Kennedy's ideology to provide quality health care to all. According to Mr. Hawkins, Democrats seem to think that the rest of the U.S. health care system does not have the capacity, interest, or ability to provide care for the populations served by CHCs; more specifically, those who are low income, of color, immigrants, the working poor, etc., are ill-served by the traditional system, and the CHCs fill that gap. He noted that the view changes ever so slightly for Republicans, whose

interest is in their grassroots beginnings and governance so that big government is not necessarily making decisions at the local level. CHCs were not initiated by bureaucrats in Washington, D.C., but instead were started by a community identifying a need and pulling together the resources (government and otherwise) to make it happen. The patient majority element of the boards was cited as an interesting part of the appeal for Republicans because of the local nature with which decisions are made given the composition of the clinic boards (D. Hawkins interview).

Finally, Mr. Hawkins described another time of political turmoil and change in Washington, D.C., when President Ronald Reagan was elected in 1980. The Reagan administration brought to social policy reform the desire to shrink government and renew an interest in state's rights. Community health centers and other programs were targeted for down-sizing, including family planning services, environmental issues, child healthcare, and immunization, and the administration intended to combine them into one grant with no requirements for accountability (which the health centers had in place) or reporting of results (also already in place by the CHCs). The purpose, he stated, was not to give the money to the states but instead to defund as many programs as possible. Many advocacy groups made the "pilgrimage" to D.C. to fight for the services being provided to their respective constituency groups. The CHC boards occupied a different position because the advocacy choir was not only local community members invested in the care being provided by the health centers, but some of them were receiving care themselves because board members were part of the conversation and were present in the fight. This example points to an interesting observation on the influence that self-advocacy coupled with empowerment can have on decision makers. CHCs in the end were not block granted like many other social service and health care providers, and the policy expert attributed that victory to the power of the patient majority boards in the conversation at the time (D. Hawkins interview).

**Board charge.** A key question from the beginning of the study was what board members were actually charged with doing for the CHCs. What were their responsibilities? Mr. Hawkins described the boards as governing boards and, as such, identified the many responsibilities that fall under that purview. The board decides what services are offered by the clinic. A list from the HRSA of 19 requirements that CHCs must meet can be found in Appendix P. The board also decides the hours the clinic and its satellites will be open, within the parameter that clinics do have to offer non-business hours; this is, however, contingent on the needs of the population served by that location and what services are offered at the location. All of this information is taken into account when it comes to decisions made by the board. The board also decides the sliding fee system for the clinic, which depends on a number of factors as well.

**Consumer board member representation.** The next issue that came up in the interview was how consumer members represented their respective communities. Mr. Hawkins reiterated that each clinic and each board handles this differently depending on the needs of the community (D. Hawkins interview). He also provided tangible evidence that consumer member representation is an important element of the CHC board for an exceptional reason. He illustrated this point by describing a personal experience he had with six Spanish-speaking board members when he was a clinic director many years ago. The consumer members wanted to resign from the board because they did not feel like they were contributing anything to the work of the board, and thought instead that he, as the clinic director, should replace them with smarter people, doctors, hospital administrators, etc. At the end of their speech, the policy expert remarked that the “smart” people they mentioned were a dime a dozen and they had plenty of that experience represented on the board. He drove home the point that the consumers were coming to the table with something that none of those “smart” people had but that was crucial to the grassroots beginnings of the clinic: their experiences. He then provided

them with an example of exactly how their experiences impacted the decision making of the board (D. Hawkins, interview).

As the nuances of consumer representation were discussed in the interview, Mr. Hawkins pointed out that a role filled by the NACHC is to provide technical and educational assistance to board members and clinic staff to ensure successful consumer participation by consumer representatives on the boards (D. Hawkins interview). He mentioned the structure and resources provided by the NACHC to keep everyone on the same page as to their roles and responsibilities as CHC board members. Indeed, an interesting finding that emerged from conversations with board members and will be discussed in Chapter 5 was the pivotal role this support played in facilitating participation for board members who had attended these trainings and a desire by those who had not attended to do so in the near future.

### **HRSA National Policy Expert Interview**

When the research plan for this study was developed, the staff at the Iowa Primary Care Association (IAPCA) provided insight into conversations that were important for acquiring a complete background prior to requesting CHC participation in the study. Because of HRSA's role in many aspects of the CHCs, the IAPCA suggested speaking to someone at the HRSA Regional Office. The policy expert from HRSA was a regional office director in the Office of Regional Operations at HRSA and was suggested based on the relationship previously established between the expert and those she/he worked with as part of the collaboration on Health Care Safety Net in Iowa Post Health Care Reform (see Appendix O for interview guide).

It was not until the interview with the HRSA national policy expert that I understood the role that HRSA played in the context of the CHCs and their boards. Still believing the policy expert from HRSA was a person of interest to this study; a time to conduct the interview was scheduled. After about 20 minutes of conversation, the HRSA policy expert stated that he/she was not the best person to speak with because of her/his

actual role within the HRSA structure (HRSA National policy expert interview). She/he oversees the regional operations in four states and therefore has supervising responsibilities over the clinics in those states. Because of this, she/he was not well-versed in the day-to-day interactions between board members and clinics.

The next section details the locale surrounding the social site of interest (Carspecken, 1996), CHC boards in Iowa. This section discusses the demographics of the counties that were served by the three clinics involved in the study, the patient characteristics of the three clinics, a description of the three clinics, and the results of the interviews with the chairs of each of the boards. This information was collected and reported to provide contextual information regarding the environment in which the CHC boards functioned.

### **Demographics and Context for the CHC Clinics**

To better understand the context in which each board operated, data was collected on a variety of aspects of the clinics governed by the CHC boards. For each clinic, the following information was assembled to characterize this context: county demographic information for the counties feeding into a particular clinic, services offered by the clinics, special populations served, a summary of the clinic tour given by the clinic director, the annual report for each clinic from the year 2010-2011, the demographics of patients served by each clinic in 2011, and the expansion timeline for each clinic. Photographs of each clinic and the area surrounding the clinic as well as a blueprint or map of each clinic were reviewed but were not included in the final report to prevent the identification of clinics in this study.

### **Demographics of Counties Served**

Table 4.1 presents demographics from the 2010 census describing the seven main counties served by the three clinics in the study. Table 4.1 provides information for the counties that predominantly provided the three clinics in this study with their consumer population.

Table 4.1 *Demographics of Seven Counties Served by the Three Clinics*<sup>a</sup>

	Clinic A			Clinic B		Clinic C	
	County 1	County 2	County 3	County 1	County 2	County 1	County 2
Total Number	102,509	20,913	14,651	<b>167,095</b>	<b>147,556</b>	437,399	40,980
Clients served by age (%)							
Under 5	7.7	8.8	6.5	<b>6.7</b>	<b>6.3</b>	7.5	7.1
5-17	26.4	30	25.5	<b>24.3</b>	<b>22.4</b>	25.4	25.4
65+	12.9	11.5	14.4	<b>13.2</b>	<b>16.4</b>	11	16.3
Race/Ethnicity (%)							
Asian	2.5	3.2	1	<b>2.1</b>	<b>1.8</b>	3.7	1.6
Native Hawaiian & other Pacific Islander	0.2	0.3	0.1	<b>0.1</b>	<b>0</b>	0.1	0.2
Black/African American	2.6	3.4	0.8	<b>7.1</b>	<b>9.3</b>	6.2	1.9
Indian/Alaska Native	2.4	3.4	0.7	<b>0.4</b>	<b>0.6</b>	0.5	0.7
White	89.8	88.3	96.2	<b>87.8</b>	<b>85.9</b>	87.5	94.2
White persons not Hispanic	77.4	54.7	94.1	<b>82.9</b>	<b>75.4</b>	80.5	77.2
Persons of Hispanic or Latino Origin	14	35.9	2.3	<b>5.7</b>	<b>11.9</b>	7.8	18
More than two races	2.5	1.4	1.2	<b>2.5</b>	<b>2.3</b>	2.1	1.4
Unreported/refused to report	0	0	0	<b>0</b>	<b>0</b>	0	0
Income level 100% and below (2007 - 2011) of poverty level	14.10%	15.10%	4.90%	<b>12.80%</b>	<b>12.40%</b>	10.60%	13.50%
Veterans (total number served)	7,886	1,174	1,444	<b>12,742</b>	<b>13,078</b>	27,640	3,880

<sup>a</sup> Information obtained from U.S. Census (2010).



## Services and Special Populations

Table 4.2 presents the services offered to patients at each of the three clinics in the study. This information was used to understand the board's need to respond given the specific services offered at the clinic. It also provides insight into the topics of each board's focus given the services offered by the clinic. Table 4.3 presents the categories of special populations that each clinic served for 2011 and how many clients the clinics served who fell into those categories. Tables 4.2 and 4.3 were compiled from information obtained from the clinics' websites.

Table 4.2 *Services Offered by the Three Clinics*

Services	Clinic A	Clinic B	Clinic C
digital x-ray capabilities		x	
family practice		x	x
pediatrics		x	x
obstetrics		x	x
gynecology		x	x
internal medicine		x	x
immunizations		x	
acute and chronic illness care	x	x	x
interpreter services		x	x
homeless and housing advocacy		x	x
material/child home visitations		x	
laboratory and radiology services	x		x
primary medical care	x		x
dental services	x		
pharmacy	x		x
behavioral health and social services	x		
child health program	x		
HIV/AIDS services program	x		
health education			x

Table 4.3 *Special Populations Served by the Three Clinics*

Total served (by clinic)	Clinic A	Clinic B	Clinic C
Total Homeless	1515	5624	962
Homeless Shelter	0	380	447
Transitional	0	316	303
Doubling up	0	567	56
Street	0	34	44
Other	0	31	112
Unknown	0	4296	0
Total Veterans	107	271	406

### **Clinic A**

**History of Clinic A.** The history of Clinic A began around 1991 with a vision from a few concerned community members (Annual Report, 2010-2011; Clinic A, Board chair interview). The incorporated health center began seeing patients in 1992 and grew quickly from that point. In 1994, Clinic A acquired a larger space and began renovations to expand services to meet the growing needs served by the clinic in the community. In 1995, pharmacy services were added, and in 1997 the clinic received a grant to offer comprehensive HIV care. Dental services were first offered at Clinic A in 1997 and laboratory services were added quickly afterwards. From this point, Clinic A's history fast forwards to the ground breaking for the new facility in 2007 and further to the doubling of capacity of medical exam rooms and dental exam rooms from what previously existed in 2009; again capacity increased in 2010 when seven medical exam rooms were added. This history is summarized in Table 4.4.

At the time of the study, services offered by Clinic A included medical services (primary medical care, chronic disease management, laboratory and radiology services); dental services (dental care for children ages infant through 21 years and adults and community outreach); pharmacy services (pharmacy assistance programs geared towards providing prescription assistance to qualifying patients); behavioral health and social

Table 4.4 *History of Clinic A Expansion*

Year	Event
1992	Clinic opened, began seeing patients
1994	Acquired larger space and renovated it to serve more clients
1995	Pharmacy services added
1997	Received grant to offer comprehensive HIV care
1997	Added dental services
1997	Added laboratory services
2007	Ground breaking for new facility
2009	New facility opens
2009	Expanded medical exam rooms and dental exam rooms
2010	Expanded medical exam rooms

services (partners with local high schools to provide onsite counseling and mental health screening, partners with Legal Aid to offer assistance onsite at Clinic A); child health program (providing early screening, diagnosis, and treatment programs for kids, dental and medical treatment for kids, and resources for parents to find child care options); and an HIV/AIDS service program (providing free testing, care, prevention and other resources). As shown in Table 4.2, some of these services are common across the three clinics because all CHCs are charged with providing them; others represent the specific needs of the clinic. Types of service delivery make each clinic community based, which appeals to many stakeholders in the communities in which they are located.

**Clinic building description.** Clinic A was situated in the downtown area of the city in which it was located. The clinic first opened its doors in 1991 with a staff consisting of one medical provider and 12 staff, and at the time of the study had a staff of 170 in a 60,000+ ft<sup>2</sup> facility. A tour of this facility revealed a bright space, professional atmosphere, and attentive staff who appeared committed to fulfilling the mission of the clinic in every interaction observed. The ground floor housed the administrative offices for the clinic; mechanical, electrical, and other maintenance related spaces; the board room where the board met each month; and a large spacious area for staff. In the staff

area were encouraging posters relaying the importance of the work done in the clinic as well as a chart meant for motivational purposes related to issues of quality improvement for the clinic.

A beautiful waiting room fully equipped with seating for about 40 to 50 people and an area for kids to play while they or their parents awaited their appointment welcomed patients and guests as they entered the clinic. The front desk had three staff (who appeared friendly) waiting to assist each patient and the waiting room was full and buzzing with activity. Radiology and lab services were performed on site. Radiology was actually the motivation for the construction of the new building because Clinic A received a federal appropriation for those services to be administered onsite, allowing the clinic to expand from 19,000 ft<sup>2</sup> to over 60,000 ft<sup>2</sup>. The upper level of the clinic contained dental exam rooms, staff and business offices, additional lab space, the pharmacy and a lobby area for the pharmacy, the HIV program area, and a call center that housed the interpretative services provided by the clinic. During the tour, I was told that having the business office, which among other tasks was charged with collecting payments from clients, near the interpretation call center was a purposeful choice in the design of the new building. The staff in the business office would have to locate an interpreter when they were on the phone with a patient who spoke another language, and having the staff in closer proximity helped eliminate wasted time for both the staff person and the patient.

**Demographics of patients served.** Clinic A served a specific area on the borders of several states. As stated by many within the organization, no one is turned away because of where they live. It is for this reason that data from the patients served by Clinic A revealed that their patient population resided in an 18-county service area. The descriptive characteristics of patients served by Clinic A in 2010 are provided in the following tables: Tables 4.5 through 4.7 describe the age distribution, race/ethnicity, income distribution, and insurance status, respectively, of patients served by Clinic A.

Table 4.5 displays the age distribution of the patients served by Clinic A in 2010. The largest age group in their patient population was between 20 and 44 years.

Table 4.5 *Age Distribution of Clinic A Patients*

Age (years)	Number	%
Under 5	2,784	13.0
5-19	6,109	28.0
20-44	7,487	33.5
45-64	4,781	21.5
65+	976	4.0
Total	22,137	100.0

Table 4.6 shows the race and/or ethnicity of patients served by Clinic A in 2010. An interesting note: Of the over 22,000 patients served in Clinic A, more than 20% did not report their race and/or ethnicity.

Table 4.6 *Race/Ethnicity of Clinic A Patients*

	Hispanic/ Latino	Not Hispanic/ Latino	Unreported/ refused to report	Total	Percent total
Asian	7	824		831	4
Native Hawaiian	0	3		3	0
Other Pacific Islander	4	77		81	0
Total Hawaiian/ Pacific Islander	4	80		84	0
Black/African American	36	1527		1563	7
American Indian/Alaska Native	20	452		472	2
White	4206	10073		14279	65
More than one race	24	91		115	1
Unreported/ refused to report	4087	281	425	4793	21
Total Patients	8384	13328	425	22167	100

Table 4.7 displays the income distribution of the patients served by Clinic A in 2010. An interesting note: The majority of patients served by the clinic (51%) were at or below the federal poverty line. In addition, 35% did not report their income, which is a common survey response issue.

Table 4.7 *Income Distribution of Clinic A Patients*

Income	Number	%
100% at and below the federal poverty level (FPL)	11182	51
101-150%	1879	8
151-200%	830	4
Over 200%	406	2
Unknown	7840	35
Total	22137	100

Table 4.8 shows the insurance status of patients served by Clinic A in 2010.

Table 4.8 *Insurance Status of Clinic A Patients*

Insurance type	0-19 years	20+ years	Total
None/Uninsured	7%	27%	34%
Regular Medicaid (Title XIX)	26%	12%	38%
CHIP Medicaid			
Total Medicaid	N/A	N/A	N/A
Medicare (Title XVIII)	0	8%	8%
Other Public Insurance non-CHIP			
Other Public Insurance CHIP	1%		1%
Total Public Insurance	N/A	N/A	N/A
Private Insurance	6%	13%	19%
<i>Total</i>	8893	13244	22137

## **Clinic B**

**History of Clinic B.** The history of Clinic B expansion is an important part of the context in which the board operated. The main medical clinic and the dental clinic operated as satellite clinics while under the authority of a major medical institution in this area from the 1990s to around 2002. Because of contextual issues, the organization charged with the financial accountability of CHCs suggested that Clinic B continue as a separate organization because they wanted Clinic B to serve a unique population. The board structure under which Clinic B operated previously was different from what funding requirements suggested according to the 19 requirements of CHCs by HRSA. The decision to continue as a separate organization was one that bonded the board members who were a part of that history and continued to bond those board members still involved with Clinic B. Board members at that time met the challenge of separation by raising more funds and engaging in the financial monitoring responsibilities necessary to monitor the renovations occurring at the multiple sites and to stay within budget during that process (Clinic B, Clinic director interview).

To explain Table 4.9 in more detail, medical clinic (a) and dental clinic (a) were part of the original structure of the organization and in 2002 became the main site locations. Medical clinic (a) was renovated in 2012 and dental clinic (a) was renovated in 2007. In addition, an HIV services program that had been in existence since the organization began was also located at this site. The east side clinic location (which will be described in detail in the next section) opened in 2003 and expanded in 2011. The pharmacy opened because of a community effort that identified the need for those who did not have access to care and opened in 2003. Outreach services were in place from the beginning along with medical clinic (a), dental clinic (a), and the HIV services, but moved to the same location as the pharmacy and expanded in 2009. In 2001, a hospital in a neighboring city asked the organization to operate a site in their town, and so medical

clinic (b) and dental clinic (b) opened in 2001. Table 4.9 summarizes the way expansion occurred in the history of Clinic B.

Table 4.9 *History of Clinic B Expansion*

Year	Event
1990s	HIV Services added to main clinic (a)
2001	Medical clinic (b) Hospital in neighboring city interested in putting a site operated in this organization (b)
2001	Dental clinic (b) Hospital in neighboring city interested in putting a site operated in this organization (b)
2002	Medical clinic (a) Was part of original structure and after the split all care moved to this clinic
2002	Dental clinic (a) moved to Medical clinic (a) and expanded
2003	East side clinic opened and expanded thru grant
2003	Pharmacy services opened at East side clinic thru community effort primarily for those with no care
2007	Dental clinic (a) expanded
2009	Already in place but joined Pharmacy location and expanded
2011	East side clinic expanded again thru grant
2012	Medical clinic (a) expanded

**Clinic building description.** The original size of the clinic before the expansion was 5,510 ft<sup>2</sup>. The expansion in 2002 added 13,580 ft<sup>2</sup> for a grand total of almost 20,000 ft<sup>2</sup>. The clinic was expanded again in 2009 with a grant from HRSA. The project began in the fall of 2010 and was completed in the early part of 2012. As shown in Table 4.2, the services offered at this clinic included digital x-ray capabilities, family practice, pediatrics, obstetrics, gynecology, internal medicine, immunizations, acute and chronic illness care, interpreter services, homeless and housing advocacy, and maternal/child home visitations. As observed during the tour of this facility, the waiting room at the east side clinic was a bright space where professionals and a smiling staff were ready to



provide assistance. Each reception booth was private enough so that when patients were sharing confidential information to check in for their appointment, others around them could not hear what they were saying. Signs around the clinic in multiple languages served the clinic's diverse clientele, and the waiting room was bright and cheery with plenty of reading materials for patients who were waiting for their appointments. Two out of the three times I visited the clinic, it was early in the morning, so the waiting room was fairly empty when I arrived. When she left, however, it was prime time (around 9:00 a.m.) and the waiting room was packed.

Past the reception area and waiting room were business offices and space for files for patients, although the clinic at the time of the tour was planning on transferring everything to electronic health records by the end of 2012. On either side of the business office space, patient files, and reception area were 17 exam rooms, two labs, two shared office spaces, two nurses' stations, and two break room areas. The basement of the clinic housed the two conference rooms, a new x-ray facility paid for in part by the new money from HRSA, which was used to expand the clinic and for storage and mechanical operations. The second floor of the clinic had one conference room and open office space to be utilized as additional funds become available.

**Demographics of patients served.** According to the annual report of Clinic B, the total number of patients served by this clinic in 2010-2011 was 24,396 with a total of 92,439 patient encounters. The patient encounter number included medical, dental, and mental health services. Tables 4.10 through 4.13 describe the age of patients served by Clinic B, their race/ethnicity, their income levels, and their insurance status, respectively.

Table 4.10 shows the age distribution of the patients served by Clinic B in 2010. The majority (45%) of their patients were between the ages of 20 and 44 years.

Table 4.10 *Age Distribution of Clinic B Patients*

Age (years)	Number	%
Under 5	2,486	9.6
5-19	5,305	20.6
20-44	11,619	45
45-64	5,092	20.8
65+	1,151	4
Total	25,653	100

Table 4.11 displays the race and/or ethnicity of patients served by Clinic B in 2010.

Table 4.11 *Race/Ethnicity of Clinic B Patients*

	Hispanic/ Latino	Not Hispanic/ Latino	Unreported/refused to report	Total	Percent total
Asian	10	1097		1107	4
Native Hawaiian	4	12		16	0
Other Pacific Islander	4	34		38	0
Total Hawaiian / Pacific Islander	8	46		54	0
Black/African American	31	2386		2417	9
American Indian/Alaska Native	10	120		130	1
White	7764	11344		19108	74
More than one race	168	206		374	1
Unreported / refused to report	1959	345	159	2463	11
Total Patients	9950	15544	159	25653	100

Table 4.12 shows the income distribution of the patients served by Clinic B in 2010. Of interest is that the majority of the patients served by the clinic (57%) were at or

below the federal poverty line. In addition, 17% of patients did not report their income, which is a common survey response issue.

Table 4.12 *Income Distribution of Clinic B Patients*

Income	Number	%
100% and below the federal poverty level (FPL)	14686	57
101-150%	3804	15
151-200%	1856	7
Over 200%	886	4
Unknown	4421	17
Total	25653	100

Table 4.13 shows the insurance status of patients served by Clinic B in 2010. An interesting myth among the community mentioned by multiple board members was the perception that CHCs are free clinics. Table 4.13 shows the wide range of insurance statuses of the patients of Clinic B, thereby dispelling that myth.

Table 4.13 *Insurance Status of Clinic B Patients*

Insurance type	0-19 years	20+ years	Total
None/Uninsured	8%	43%	50%
Regular Medicaid (Title XIX)	17%	11%	28%
CHIP Medicaid			
Total Medicaid	N/A	N/A	N/A
Medicare (Title XVIII)	0.005%	4%	4.005%
Other Public Insurance non-CHIP			
Other Public Insurance CHIP	1.5%	0.004%	2.004%
Total Public Insurance	1.5%	0.004%	2.004%
Private Insurance	3%	12.99%	16%
Total	7791	17862	25653

## **Clinic C**

**History of Clinic C.** The organization began in 1975 when a group of people in the community saw a need for services. A clinic was established and the group sought funding from HRSA, and in 1976 received designation as a community health center. The clinic served patients in an area that bordered multiple states and was housed in several buildings across a multi-city area. Clinic C served a multistate area similar to Clinic A, and the history of the clinic's expansion included nine different sites where care was provided. In Table 4.14, these nine sites are depicted by letters a – i and represent clinics that are located in four cities between the two states. The expansion of the clinic as shown in Table 4.14 summarizes the growth of the organization to serve this diverse area over the last 37 years.

**Clinic building description.** I received a tour of three buildings that were identified with this organization, which were located within close proximity to one another in a busy downtown area of the city, similar to the building toured for Clinic A. For the purposes of the clinic building description, however, the main medical building of the three buildings toured is described. The three buildings toured were the main medical building, the administrative building, and the dental clinic. The main medical building was across the street from a building shared by an expanded dental clinic and administrative office space. In the entrance of the main medical building, patients were greeted immediately by friendly receptionists in a reception area; many signs in multiple languages directed patients to where they might need to go. Services at the clinic encompassed preventive, acute, and chronic care, and included family practice, internal medicine, pediatrics, and obstetrics/gynecology. On-site ancillary services included radiology, laboratory, pharmacy, and health education. Materials at the clinic were translated into Spanish and Vietnamese (Clinic C, Clinic director interview). The first floor of the clinic contained 17 exam rooms (x-ray and darkrooms included), one

pharmacy, three waiting rooms, one blood draw room, two nursing stations, two labs, 18 offices, two consultation rooms, one staff lounge, and one break room.

Table 4.14 *History of Clinic C Expansion*

Year	Event
1977	Locates to new building – Main clinic (a)
1988	Adds Homeless health care – Main clinic (a)
1990	Adds OB/GYN Department – Main clinic (a)
1994	Opens satellite site in a 2 <sup>nd</sup> neighboring city – Satellite clinic (b)
1995	Opens Virology clinic in same city as clinic (a) – Satellite clinic (c)
1996	New main clinic constructed – Main clinic (a)
2001	Opens Dental clinic in same city as clinic (a) – Satellite clinic (d)
2003	Opens new Medical clinic in a 3 <sup>rd</sup> neighboring city – Satellite clinic (e)
2005	Opens new Dental clinic in same city as clinic (e) – Satellite clinic (f)
2007	Expands clinic to include added OB/GYN, lab, dental, pharmacy and administrative services - Main clinic (a)
2008	Adds Mammography services – Main clinic (a)
2008	Electronic Dental Record added – Clinic wide
2008	Digital Radiology added – Clinic wide
2009	Opens clinic within mental health facility in neighboring city – Satellite clinic (g)
2010	Expanded facility opens – Satellite clinic (b)
2010	Opens new clinic in same city as main clinic – Satellite clinic (h)
2011	Electronic medical record introduced – Clinic wide
2011	Dental screenings offered at WIC clinics in same city as main clinic – Satellite services
2011	Expands clinic – Satellite clinic (e)
2012	Mammography services added – Satellite clinic (h)
2012	Open access scheduling implemented clinic wide – Clinic wide
2012	Opens new clinic in 4th neighboring city – Satellite clinic (i)

**Demographics of patients served.** According to the annual report of Clinic C, the total number of patients served by the clinic in 2010-2011 was 36,035 with a total of 129,800 patient encounters. The patient encounter figure included medical services, dental services, and mental health and nutrition counseling. Tables 4.15 through 4.18

describe the age, race/ethnicity, income levels, and insurance status, respectively, of the patients served by Clinic C.

Table 4.15 displays the age distribution of the patients served by Clinic C in 2010. The majority of their patients were between the ages of 20 and 44 years (31%).

Table 4.15 *Age Distribution of Clinic C Patients*

Age (years)	Number	%
Under 5	6,526	16.7
5-19	10,595	27.3
20-44	12,160	31
45-64	7,981	21
65+	1,591	4
Total	38,853	100

Table 4.16 shows the race and/or ethnicity of patients served by Clinic C in 2010.

Table 4.16 *Race/Ethnicity of Clinic C Patients*

	Hispanic / Latino	Not Hispanic / Latino	Unreported/refused to report	Total	Percent total
Asian	7	1445		1452	4
Native Hawaiian	15	79		94	0
Other Pacific Islander	52	49		101	0
Total Hawaiian / Pacific Islander	67	128		195	0
Black/African American	57	9031		9088	23
Indian/Alaska Native	19	226		245	1
White	2424	18922		21346	55
More than one race	2084	1289		3373	9
Unreported / refused to report	1905	411	838	3154	8
Total Patients	6863	31452	838	38853	100

Table 4.17 displays the income distribution of the patients served by Clinic C in 2010. An interesting note: Although 34% of the patients served by the clinic were at or below the federal poverty line, 51% did not report their income, which is a common survey response issue.

Table 4.17 *Income Distribution of Clinic C Patients*

Income	Number	%
100% and below the federal poverty level (FPL)	13034	34
101-150%	3507	9
151-200%	1496	4
Over 200%	687	2
Unknown	20129	51
Total	38853	100

Table 4.18 shows the insurance status of patients served by Clinic C in 2010.

Table 4.18 *Insurance Status of Clinic C Patients*

	0-19 years	20+ years	Total
None/Uninsured	5%	25%	30%
Regular Medicaid (Title XIX)	36%	18%	54%
CHIP Medicaid			
Total Medicaid	N/A	N/A	N/A
Medicare (Title XVIII)	0.005	5.995%	6%
Other Public Insurance non-CHIP			
Other Public Insurance CHIP			
Total Public Insurance			
Private Insurance	3%	7%	10%
Total	17121	21732	38853

### **Clinic Directors**

According to the Bureau of Primary Health Care within HRSA, the person who takes the position of executive director/Chief Executive Officer (CEO)/Clinic director is required to have the “authority, responsibilities and skills to do the following: communicate with the board and management (leadership) team, operationalize board policies, manage personnel, allocate resources and operate within available resources, identify and resolve problems, interact with the community and providers and payers in the marketplace, respond to opportunities, plan for future events, and implement board-established long-term goals and operating plans” (Retrieved from [www.nachc.com/client/documents/publications.../gov\\_2\\_03.pdf](http://www.nachc.com/client/documents/publications.../gov_2_03.pdf)). To protect the identity of the clinics in this study, all three individuals in this position within Clinics A, B, and C will be known as clinic directors, though the IRB documents located refer to them as Executive Directors.

An important part of the study design was to incorporate the multiple perspectives on the experiences of those participating on the boards. Therefore, I first interviewed the clinic directors to explore this experience from the perspective of the only employee of the CHC board (see Appendix D for interview guide). The clinic directors were interviewed during summer 2012, prior to interviews with board members of the respective clinics, and they conducted the clinic tour on the same day as the interview. The key questions asked during the interview were to gain an understanding of the day-to-day operations, the work of the board, and the perspective of the clinic director regarding the work accomplished by consumer members of the board in the policy development processes. The information obtained from the interviews with the first two clinic directors influenced the depth of the interview conducted with the third director interview approximately 2 weeks later. For example, a theme that emerged from the first two interviews that informed the third interview was the relationship between the board and the senior staff or leadership team of the clinic. This theme will be further explored



in Chapter 5 and was a new piece of information about the relation of the structure of the board to the clinic. It is important to include the perspective of the clinic directors when considering this role, however, to provide context for what emerged from the interviews with board members.

### **Role of Leadership Team/Senior Staff**

The senior staff or leadership team (clinics have different names for these individuals) played a key role in providing information to the board about the day-to-day functioning of the clinics. This relationship was different for each clinic/board. For the board of Clinic C, senior staff attended every board meeting and played a crucial role in the operations of the committees (for example, these individuals presented the finance committee report at the board meetings). For Clinic A, no senior staff/leadership team attended the board meetings and the director was the only staff who attended. For Clinic B, senior staff attended the meeting if there was a reason to attend (for example, if they had a specific report to present or specific information to share that was related to their expertise or position within the clinic).

Despite the variation among the boards as to the actual presence of these senior staff members at the board meetings, two clinic directors noted that the board “trusts” the senior staff immensely to do their job and do it right (Clinic director interviews). And although the third clinic director did not mention the issue of trust in the senior staff/leadership team’s ability to do their job correctly in a specific way, this trust was a common theme across all three boards and clinics. At each board meeting attended, the role of senior staff/leadership in facilitating board operations became clearer. By attending two meetings for each board, I could compare observations in the first board meeting with observations in the second. And as board member interviews progressed, board members were questioned about this relationship as it became clearer.

The clinic directors continued to articulate the relationship between the board and the leadership/management team when asked to discuss the role of the board in policy

development. More specifically, clinic directors identified themes such as the board sometimes directed policy making, but most of the time, staff (usually leadership team members rather than, for example, front desk attendants) brought an issue to the board for review first. The issue was then discussed by the board and, depending on the board decision, was either approved (and the staff/leadership team implemented it) or the board asked for more information. One clinic director described this process as the board “kicking the fire” (Clinic C, Clinic director interview); in other words, the board asked the tough questions that sometimes could be answered at that moment and other times more information was needed. For one board in particular, during the second observation of a meeting, the staff brought an issue to the board related to the clinic employees’ compensation package. When this issue was originally proposed to the board was unclear, but it appeared to have been discussed previously and the board had requested more information. The additional information was being presented at the board meeting I attended. Again, the role of the board in making policy decisions on behalf of employees of the clinic was a new concept because I had only focused on the board making decisions on behalf of the patients served by the clinic. So when this issue came up, it was interesting to witness the questions and points that board members posed to the staff person who presented the issue.

### **Similarity of Clinic Director Backgrounds**

One interesting similarity between the clinic directors was their backgrounds. All were promoted from within the organizations to the positions they currently held. Two of the three directors had been with their respective clinics for a combined total of almost 25 years and prior to their role of clinic director were involved in quality improvement at their clinics. The third director had been with the organization previously in the role of operations manager. As one director pointed out, the budget of the clinic was in the tens of millions (approximately \$20 million), making its management very complex. There was an advantage to hiring from within to lead the organization given that complexity.

### **Role of Strategic Planning for Clinic Directors**

When they discussed the role of the board in policy development, the clinic directors all articulated the process of strategic planning and how important it was to engage the board in that process. The director of Clinic A said that the board members' participation in this process was helpful because they offered "their guidance and suggestions." The director of Clinic B mentioned that the board's participation in the strategic planning process helped keep the board up to date on policy changes coming in the future, such as those associated with the Affordable Care Act of 2010. This director talked about the strategic planning process as a way to keep the board informed of possible changes as well as deciding whether the direction of the organization was accurate or needed to change. The director of Clinic C discussed the board's role in strategic planning as encompassing the grand view by the board, which made their participation in that process unique and valuable.

### **Issues Surrounding Consumer Member Participation**

When asked about the participation of the consumer members on the board, clinic directors again expressed similar themes. The director of Clinic A described that participation as a "balance." Consumer members are often on the board committees that deal with quality assurance issues because the consumers are able to articulate the patient experience when the committee addresses issues of quality within the clinic. The director described the balance necessary between the consumer usefully providing that input and the consumer providing that input by focusing on an issue that particular consumer might have had with the clinic in the past. The director of Clinic C described the issue of balancing consumer participation as evidence of community involvement with the fact that some consumer members are not able to contribute as other board members do to fundraising activities based on their connections in the community. The balance is part of the board culture as a whole, but the clinic director specifically had to balance the uniqueness of consumers' contributions to the board with their inability to contribute in

financial ways to the clinic's operations. This is an issue of importance to clinic directors because of their role in the fundraising activities of the board, for example, applying for relevant grants or other funding opportunities within the community or asking for profit organizations to partner with the clinic to provide a specific service. The director of Clinic B mentioned the balance that exists between the uniqueness of consumer contribution, particularly when the consumer uses the clinic as their medical home, and the intimidation some consumers feel towards participating on the board.

There was a difference among the clinic directors in how they referred to the consumer representatives in terms of their backgrounds. For example, Clinic B's director stated that some of the consumer representatives were *true* consumers because they used the clinic as a medical home; in contrast, other consumer representatives only occasionally used some of the services offered by the clinic. The directors of Clinic A and Clinic B described consumer representatives who also had professional expertise that enhanced their participation and contribution to the board beyond their perspective as a consumer. For example, some consumer members across the three boards had graduate degrees; had experience in finance, health care, or human resources; and were prominent members of their respective communities. Consumer members also represented specific target populations of the clinic's services, for example, representatives across the boards who were HIV positive or who had the experience of being homeless. There were also consumers who were recipients of safety net programs in Iowa. Each layer of experience brought complexities and complications to that consumer's participation, and each board negotiated these complexities differently. One issue was the use of acronyms and how confusing they are to consumer and nonconsumer members alike who do not have a health background. The response of the board was to include an explanation of acronyms in board meeting minutes. Another board member brought up a similar issue with acronyms, and both nonconsumer and consumer members again identified this issue as a problem. In response, the board as a whole reminded whoever was speaking in acronyms

to make sure to describe the acronym and provide more explanation for the benefit of those who may not know what it means. I observed the different ways boards maneuvered these complexities during board meetings and then confirmed those observations in interviews with board members. The third clinic director did not address this issue, but the chair of that director's board did, and the issue will be discussed later in this chapter.

Although challenges of consumer participation were identified by the clinic directors, strategies of how to deal with those challenges were discussed as well. For example, the challenge of intimidation to participate that can be felt by consumer members was mentioned by two clinic directors as well as by the policy expert interviewed. The director of Clinic A expressed this as follows: "Sometimes I think that they can be intimidated from the nonconsumer board members, so they may not speak up quite as much even though they might disagree." The two clinic directors who addressed the issue responded that the strategy to neutralize this intimidation was for the leadership of the board (i.e., the chair) to step in and address it. The director of Clinic A said that the board leadership was proactive in dealing with this situation, whereas the director of Clinic C said specifically that the chair will go around the room and provide an opportunity for everybody to weigh in on a decision to give everyone a chance to voice their opinion.

The director of Clinic A brought up an additional challenge dealt with in the past as the tendency for the chair of the board to, in essence, micromanage the director of the clinic and subsequently, the clinic. In this particular instance, the chair was a consumer member, so the chair was constantly at the clinic talking to patients about their experience and, in some cases, going directly to the director to discuss the experience and demand an immediate remedy of some sort (e.g., "what are you going to do about it?" or "at which board meeting are we going to address it?"). It was clear across all three clinic directors that none of them saw this as the role of either the chair of the board or the

board as an entity. It also seemed clear from the responses of the board members interviewed that this was not their role either. The researcher's observation of this process suggested that the strategy for addressing this type of issue was a clear articulation of the expectations of everyone's role, not just one board member, or the board chair, or the clinic director, but everyone.

Clinic directors identified the tension between consumer members representing a community or a specific population versus their representation coming strictly from their experiences as a patient of the clinic. This identification raised the question of how, if at all, information was conveyed to the patient community and the community at large about the board's work. This question stemmed from a desire to understand how in touch the board was with the community and the patients of the clinic, the assumption being that one way to maintain this connection was through contact with that community.

Surprisingly, in answer to this question, the clinic directors identified the connections of their board members to the fabric of their communities in more ways than just by being members of the CHC board. For example, the directors of Clinic B and Clinic C reported that there were some board members, both consumers and nonconsumers alike, who were very involved in their communities. The director of Clinic A indicated that the board was not enmeshed in the community; they were not that type of board. In addition, one clinic director said that the board expected that staff would collaborate in similar ways as well, and noted that HRSA required that there not be duplication of services in communities with CHCs. Two clinic directors commented that community partnerships are a two-way street, emphasizing the need for the community to engage in the work of the clinic as much as the clinic engages with the community. One of those clinic directors went even further and said that "growing and partnering is the responsibility of the staff that the board helps set the foundation for that growth and partnership to occur" (Clinic C, Clinic director interview).

## **Improve Effectiveness of Participation in Policy Development**

The multiple perspectives of people who contributed to the study allowed me to consider what could be learned from each set of people within their particular roles. To that end, the clinic directors were asked to provide feedback on how to improve the effectiveness of the board in general and of board members individually in policy development. The policy specifically discussed was the Affordable Care Act (ACA) of 2010. The director of Clinic C described how the ACA will change the landscape of the health care safety net and that their board identified the need to maintain or improve the quality of care so as to retain the patients the clinic currently serves and to recruit new patients as the health care safety net changes. According to the director of Clinic B, board members had requested information from the director to become familiar with how the legislation will impact the clinic's operations. The director said that the board had to be willing to learn and have an open mind when distributing this information. The director of Clinic A said that going forward, what would help in making the board more effective would be to have representation from all of the geographic areas that are served by the clinic. For example, all three clinics served specific counties for the purposes of their funding streams but they did not turn patients away. Given that the service area of some clinics encompassed multiple states, and multiple states bill Medicaid in different ways, it would be useful to have representatives on the board that could assist in those situations.

### **Board Chairs**

The intentions for including the chairs of the three CHC boards in the data collection plan were threefold. First, given the methodological interest in understanding a 360-degree view of the boards, it was essential to obtain from the chairs of the boards not only their permission for participation but also their perspective on the CHC board as the social site of interest. This perspective included information from the board chair about how the clinic operates and how the board operates within that context. Second, I wanted

to develop a relationship with the board chair in the interest of transparency so that the board chair fully understood the intentions and purpose of the study in exploring the experience of participation on CHC boards in Iowa. And finally, in line with Carspecken (1996), the background information gleaned from the interviews with the three board chairs was used to help build the primary record of the researcher's understanding of the social site. One important note regarding the role of the board chairs: They are members of the board as well as leaders of the board. This means that information from these three interviews will be discussed as part of the primary record and also will be analyzed in Chapter 5 with other results from board member interviews. The following section contains information from data that were consistent with previously collected data as well as new themes raised by the board chairs that showcased their unique perspective in understanding the experience of participation on the CHC boards of their respective clinics given their dual role within the board structure.

For background, the chairs of the boards had prescribed term limits separate from their position on the board as board members. Although no information was made available for Clinic C, two clinics provided clarification. For Clinic A, "Officers shall be elected for two (2)-year terms. Officers may be re-elected for two (2) additional consecutive terms, then must step down for one (1) term before being elected again" (Clinic A, Clinic director interview). Specifically, the board governance documents of Clinic B stated that "Officers shall be elected as the first order of business at the regular annual meeting of the Governing Board each year. Term of office shall be one (1) year and no member may hold the same office more than three (3) consecutive terms after the date of acceptance of these bylaws" (Clinic B, Board governance documents).

### **Background Similarity of Board Chairs**

The chairs of the CHCs boards shared similar backgrounds in a number of ways that enhanced their experience and participation on the board. First, all three board chairs had a background in finance and/or the banking industry. At the time of the study, they



either worked for a bank or in banking or they worked in a finance capacity. They had also done this type of work for a combined total of over 50 years across all three chairs. Second, the three board chairs shared a commitment and passion for the work of the CHC of which they were a part. Although each board chair articulated a different source of that passion, the commitment was clear. For example, the board chair from Clinic C stated:

I think what has held me to the organization is predominantly the work that we do with kids. Going back to when I was recruited to finance committee, the issue of the day was to explore ways of providing for dental care and the image of young kids six, seven, eight years old with an abscessed tooth or a painful cavity, not having any treatment available or avenue for treatment available to them at all, finally getting into a program where they would do an extraction just has always seemed wrong, expand that to flus and fevers and colds and all sorts of things that have such impact on their being in school, nothing like a good cold to knock him off from doing homework. (Clinic C, Board chair interview)

The board chair of Clinic A stated:

I am big believer in health care for people, so I grew up in an environment where our family didn't have a lot of money, so I had a doctor that would just come and see our family as needed and that is kind of natural fit for me. (Clinic A, Board chair interview)

Finally, the board chair of Clinic B stated:

I understand that you can try to do a political divide that says hey we need to have less handouts whatever your political affiliation is you can try to grab on to that but I think whenever it is all said and done there are basic human needs, food, clothing and water, that we need that people need. I think is kind of you can't serve a bunch of homeless people and provide really good service without providing healthcare, they kind of go hand in hand if not their going along the same parallel that is just as like hey we need to understand healthcare. (Clinic B, Board chair interview)

For one board chair, the commitment to the work of the CHC came from his/her past experiences. For the second, it was a result of a commitment to helping children succeed. For the third chair, the commitment came from wanting to provide people basic rights such as food, clothing, and shelter, and from the belief that healthcare was among the basic rights needed for people to survive.

## **Shared Perspective on CHC Board's Purpose and Chair's Role**

Given the diverse perspectives and experiences that comprise CHCs and their work, the assumption was that there would be just as much diversity in how each member of the CHC system viewed the responsibilities of the board. However, the chairs of the board shared a common view of the responsibilities of the board and also the chair's role in that responsibility. These perspectives are captured in the following quotes from the three board chairs:

Our job or my job as the board president is to oversee the board and make sure we are doing the primary functions that we need to do, which is all the committees I mentioned earlier, our interaction is that we have [clinic director] who is our employee and we made a decision a while ago that our board's function was to support the management team and to not be meddling in the affairs of the clinic, our goal is to review budgeting, reviewing clinic quality is a big one, we want to make sure our quality is up to speed, we look at one of the committees. So the board is responsible for making sure we are in compliance for federal programs. We look at grants to make sure we adhere to the terms of the grants, so all of our grants that we write we have to approve at the board level. We approve salary ranges for the employees we have to review, we set the salaries for [clinic director], and he/she is responsible for setting salaries for everyone else. (Clinic A, Board chair interview)

We have a very experienced board that is engaged and refined if you will. And you know I think probably if you are going to look at our board a need is how to help bring people along to build a community and be connected. My direct role is to be that conduit between our board and committees and [clinic director]....And as far as participation, again, not coming from the health care background, hopefully the lens I look like is how we can run this more like a business, make business decisions and help push where we need to be pushed. Again, from a non-health background, a lot of that I rely on our refined board members that are retired, either employees or people in the community that have expertise in certain business disciplines, some of them are in healthcare and some of them aren't. But I think how I lead is to lean on people who are experts in their departments so I feel that we have a good mix. I think we could always look at our board a little bit closer, research and define it make sure that we have people across business lines, so we have been trying to do that. (Clinic B, Board chair interview)

We perform oversight. We are a test of reasonableness. We can't on our own draw from either experience or expertise to make the decisions day-to-day to run this place. Some of us would like to but we're all incapable of micromanaging. We are a sounding board for ideas. We are an endorsement for changes in the way that we operate. We are the last review before publication of everything relating to finances to representations to our regulators as to how and how effectively we operate. We are also in the community to find those people and to refer those people who need us to listen at church, to listen at school, to listen at

work, and not hardcore business development, banking and some of my other careers, but to subtly suggest that there is an opportunity for care for referral for a diagnosis. And we take flack out of the system. If something or someone is misunderstood we are the buffer.... That's why at the end of the day, I hope people will always concede that it was reasonable, not perfect. For the typical patient, they have, first of all access. Secondly, cost is adjusted to their income. And third, they have respect, nobody made a project out of you or this is this type of thing. If generally our decisions can fall within those bounds, then I think we are reasonable. (Clinic C, Board chair interview)

Commonalities evident in these three quotes in terms of the responsibilities of the board include oversight and accountability and, in terms of roles of the chairs, include conduit and facilitator of the process and the assurance that all voices are heard and valued.

### **Conclusion**

This chapter presented information collected in order to construct the primary record about the social site for this study to explore the participation experience of CHC board members in Iowa. Specifically, permission for participation was requested and granted of three CHCs in Iowa and used information in multiple forms from many sources to compile the primary record for this study. This information included materials from and interviews with organizations that support the work of CHCs: the NACHCs, the HRSA, and the IAPCA. I used this background information to select which CHCs in Iowa to recruit for participation in the study and to gain perspective about the work of the CHCs in Iowa. After choosing the three CHC sites, I collected and reviewed information on the context of the three clinics that included descriptive statistics from seven counties served by the three clinics and from the patient populations of each clinic. This information was used to inform future conversations as part of additional information collected and reviewed. The additional information involved interviews with the clinic directors of the three CHCs and the chairs of the CHC boards, with parts of the interviews with board chairs as well as interviews with the clinic directors being used for the compilation of the primary record in Chapter 4. This information from the primary record informed the discussion in Chapter 5, which will center around the board

members' experiences of participating on the three CHC boards. I explored this experience through interviews with 16 CHC board members in Iowa and analyzed the themes and insights that emerged from those interviews.

**CHAPTER 5**  
**RESULTS OF DATA ANALYSIS OF BOARD**  
**MEETING OBSERVATIONS AND BOARD MEMBER**  
**INTERVIEWS**  
**Introduction**

While Chapter 4 presented the primary record, Chapter 5 will report and discuss the themes identified in the analysis of interviews with board chairs and consumer and non-consumer board members and meeting observations. The data are presented in this chapter in such a way as to maintain the anonymity of all participants. Anonymity was maintained for all participants of the study in the following ways: The participant's interview information was identified as non-consumer or consumer member interview; if the person was a consumer, he or she was further classified as a representative or non-representative consumer; and the affiliated clinic of the participant was identified only when it was relevant to that particular comment or statement. In addition, any information that identified individual participants was removed. For example, the participant's specific profession was described in general terms, and all participants were referred to by the pronouns "he/she" or "her/his" to de-identify those pieces of information. Anonymity was promised to participants when they agreed to participate, and the choices discussed above as to how participants were identified reflect that this promise was honored throughout the study.

Information from participants' interviews was corroborated through a member-checking process. As I discussed with participants during their interviews and was referenced in Chapter 3, the member-checking process was as follows:

1. Members who had agreed to be contacted and were offered the opportunity to participate in the process were contacted in February 2013.

2. Those participants were given the option again to participate, and if they were interested, they were offered the option to discuss their interview information either over the phone or via email.

3. Of the 16 total board members interviewed, 12 agreed to be contacted at a later date. Of those 12, eight agreed again to be included in the member-checking process.

4. Of those eight, one member preferred email contact and seven preferred a phone conversation.

5. A document was prepared for each of the eight participants that included information they shared during their interviews and incorporated the document into the final report. I emailed the document to those who preferred email and talked through the document over the phone with those who preferred a phone conversation. The document contained an explanation of the content of their information, and participants could agree, disagree, or clarify what they said and how it was being used.

6. Information from two board members was changed; one board member provided clarification, and another who disagreed with the information requested changes. None of the participants raised any concerns as to the information shared or how it was being used; only that clarification or changes were needed.

The results described in this chapter are based on the data collected from interviews of consumer and non-consumer board members of the three clinics, interviews of the three board chairs, observations of six board meetings, and board meeting minutes from a calendar year for each of the three boards in the study. Board chair interviews are included because of the dual role these board members filled; they were leaders of the board but also participated in the board process as board members. The goal of the analysis was to identify similarities, differences, and major themes in these 16 interviews as the themes related to understanding how three Iowa CHC boards facilitated the quality of citizen participation. The remainder of the chapter will include a description of the sample characteristics of the 16 board members who participated in the study, an analysis

of board members' participation through the lens of the socio-ecological perspective, a description of the process of quality citizen participation, an analysis of measures used to objectively and subjectively understand this process of quality citizen participation, an exploration into the board member's roles in this process of quality citizen participation, and a discussion about the impact the process of quality citizen participation had on policy development for CHC boards in this study.

### **Profile of CHC Board Member Participants**

To best understand the experience of participation on CHC boards in Iowa, it was first necessary to understand the characteristics of the board members. Sixteen board members were interviewed for this study. Although specific demographic questions were not asked of participants, the following demographic characteristics as listed in Table 5.1 were identified during the interviews: the race/ethnicity of participants (based on participant identification and researcher observation), the age grouping of participants (based on participant identification and researcher observation), the gender of participants (based on researcher observation), the retirement status of participants (based on participant identification), and the consumer or non-consumer status of participants. The definition of status provided by the Health and Resources Service Administration (HRSA) indicated that a consumer was someone who used the clinic one time for care in a 1- to 2-year period (HRSA, 2011). The categorization of a consumer's status was based on information learned from participants during the interviews; of interest is that the information from the participants did not always match the information provided in documents by specific boards. In addition to identifying consumer/non-consumer status, I used interview data to categorize the eight consumer members as either representative or non-representative consumer members. This categorization was based on a number of factors that are discussed in the next section.

Recent research on CHC boards and their board member composition has found differences in representation among consumer members. Wright (2012) discussed

representative and non-representative consumers when he examined whether CHC consumer board members represented the patient communities of the clinics served by CHC boards. Wright (2012) used HRSA's Uniform Data System Report (UDS) with information collected on 2,245 board members to classify CHC board members as non-consumer, representative, and non-representative based on their incomes and occupations. Information about the board member's occupation was listed in the UDS report, and Wright (2012) recoded board members' occupations as low status or high status based on the mean annual income for each occupation. Members in low-status occupations had an annual income of less than 200% of the FPL for a family of four in 2009, or \$44,100; members in high-status occupations had an annual income above 200% of the FPL for a family of four (Wright, 2012). Board members who had low-status occupations were categorized as representative consumer members because the majority of CHC patients fell into that socioeconomic status, and board members who had high-status occupations were categorized as non-representative consumer members. In other words, a typical patient that a board member resembled in the representative category lived in a household with an annual income of \$36,620 for a family of three.<sup>1</sup> Representative consumers were those consumers who resembled the patients of the clinic, and non-representative consumers were those consumers who did not resemble the patients of the clinic based on their occupations and presumed incomes. Therefore, of the eight consumer participants in this study, six participants were categorized as representative consumer members and two participants as non-representative consumer members.

According to Wright (2012), a combination of professional degrees and high-status occupations classified participants as non-representative; these included professionals such as doctors or lawyers. The non-representative consumer members in

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<sup>1</sup>Federal Poverty Guidelines – 2009; <http://aspe.hhs.gov/poverty/09poverty.shtml>



the current sample had professional degrees and had high-status occupations. The representative consumer members in the current sample had low-status occupations and were members of the disadvantaged minority community (i.e., race/ethnicity, insurance status, education, or age). Additionally, consumer and non-consumer board members were working in or had retired from a diverse array of professions that included human resources, health care policy, health insurance, law, nursing, education, law enforcement, nonprofit and social services sectors, health care, finance, and counseling. The consumer and non-consumer board members in this study had a wide array of experiences serving their communities, which included work on various nonprofit boards, art boards, fair exposition and conservation boards, and volunteering with local nonprofits or within their places of worship.

Table 5.1 *Demographic Characteristics of CHC Board Member Study Participants*

Characteristic	Number in study	%
Race/ethnicity		
White	12	75
Person of color	4	25
Age (years)		
45-64	9	56
65+	7	44
Gender		
Male	10	62
Female	6	38
Retired		
Yes	8	50
No	8	50
Member status		
Non-consumer members	8	50
Representative consumers	6	38
Non-representative consumers	2	12

### **Participation From the Socio-Ecological Perspective**

The socio-ecological perspective provided a unique framework through which to explore and understand the experience of participating on three CHC boards in Iowa. This perspective, highlighting multiple levels of influence, was necessary to fully appreciate the experience of participation on the three CHC boards. The socio-ecological perspective guided the researcher's interviews with the clinic directors, board chairs, and board members. As discussed in Chapter 2, the levels of the socio-ecological perspective are intrapersonal, interpersonal, organizational/institutional, community, and public policy.

The socio-ecological perspective used to guide the interviews within this critical ethnography had three specific intentions. First, the literature on citizen participation has investigated individual and community levels of the socio-ecological perspective independently (Austin, 1972; Bolland & McCallum, 2002; Brady et al., 1995; Chavis & Wandersman, 1990; Checkoway & Zimmerman, 1992; Cohen & Dawson, 1993; Foster-Fishman et al., 2007; Foster-Fishman et al., 2009; Gau & Pratt, 2010; Hardina, 2006; Huckfeldt, 1979; Kasarda & Janowitz, 1974; Lelieveldt, 2004; Marschall, 2004; Ohmer, 2007, 2010; Perkins et al., 1990; Ritter, 2008; Robinson, 2008; Swaroop & Morenoff, 2006; Verba et al., 1993; Wandersman & Giamartino, 1980), but has not yet incorporated a collective exploration to understand the phenomenon of citizen participation. Attention to context in the socio-ecological perspective provides an appropriate framework to identify how power imbalance in the policy-making process can restrict the access to quality citizen participation by marginalized or disadvantaged individuals. Second, because Arnstein (1969) conceptualized a quality citizen participation experience to involve more than the individuals participating, a perspective that included more than just characteristics attributable to an individual was necessary to fully understand the meaning of quality participation in the context of CHC boards. And third, to define and understand context, more than the perspective of those within that context was needed. Therefore, a

critical ethnographic methodology was applied to the study so that what was learned in the interviews guided by the socio-ecological framework would be complemented by documents and other information gathered from the primary record. The next section will describe evidence of the multiple levels of influence within the socio-ecological framework discovered during the interviews and will analyze their relationship to the quality of citizen participation according to Arnstein's ladder of citizen participation.

### **Intrapersonal Level Factors Influencing Participation**

Intrapersonal level factors influencing citizen participation included resources such as knowledge and skills the individual possessed and characteristics of the individual's identity, such as race/ethnicity, gender, age, and socioeconomic status. Two themes that emerged at this intrapersonal level indicated how this level influenced the participation of participants in this study. The first was the value board members placed on their own and on other board members' education and work background (learned or acquired skills or knowledge from this background) in impacting participation among board members. For those members with relevant work or educational experience, this background facilitated their participation; for example, a representative board member with accounting skills brought specific expertise to the board. The second was the way board members' personal experiences impacted their participation on the board. For those whose membership was related to their patient status, the experiences presented barriers to participation; examples are particular health conditions commonly seen at the clinic or social circumstances that qualified them as representative consumer members. Other individual characteristics of participants, such as race or ethnicity, were not specifically identified as important factors in the participation of these board members.

The education and work background of consumer board members was discussed by many participants as having multiple influences on the quality of citizen participation. Specifically, the educational background and work experience of consumer members was reported as a way to facilitate their increased participation on the board because it

assisted in their ability to contribute at board meetings when the complexities of CHC activities were discussed. The consumer members with higher educational backgrounds or more work experience were identified as bringing multiple dimensions to their consumer participation: They had the experience of being consumers of the clinic and they brought with them the additional element of education. One representative consumer member discussed having a background in teaching others about prevention and health care and, based on that background, feeling more attuned to providing information to patients of the clinic to get them involved in their own care. Specifically, this member responded, “How do we get patients involved in their healthcare? I am all about condition self-management. I teach two classes for [the local health department]” (Representative consumer member interview). Another representative consumer member, who identified as a member of the helping profession based on her/his training, stated:

But then I’m also [in the helping profession] who does frontline [work] and a lot of the people I deal with everyday also go to the [clinic]. So I think what I bring to the table is a little bit different perspective than a lot, even some of the other consumer board members, because they are not also [in the helping profession]. (Representative consumer member interview)

Conversely, for the consumer members with life experiences that qualified them as representative consumer members because they were part of a disadvantaged or marginalized group served by the clinic, elements of their background acted as barriers to their participation on the board. One non-consumer referred to this barrier when he/she described the complicated nature of the financial terms with which the CHC boards must be familiar to provide accountability to the CHC’s finances (Non-consumer member interview). Consumer members with limited work experience (because of a health condition, for example) were challenged further to understand the activities and procedures of the board. This example demonstrates that a consumer who comes to the board without additional work or educational experiences might be participating at a lower level than a consumer who comes with experiences that enhance participation.

The participation of consumer board members who had life experiences, but not work or educational experiences seemed to be at a different level. Work and/or educational experiences that complemented participation on the board facilitated a quality participation experience. Life experiences that were not mitigated by a strong educational or work background created barriers to participation, even though these life experiences were the basis for members' unique contribution to the board. One representative board member with little work or educational experience was not only viewed as unique but in many cases was referred to as a "voice of reason" (Representative consumer member interview) in the conversations of the board because he/she was the only person from that background on the board despite the high number of patients the clinic served who shared similar background characteristics. The quality of participation for consumers within this study depended on the entire circumstance of the consumer members at the intrapersonal level. When a representative consumer member was from a disadvantaged or marginalized community and also had work or educational experience that complemented the work of the board, his/her complex identity appeared to positively impact the CHC's ability to facilitate the participation of that board member.

### **Interpersonal Level Factors Influencing Participation**

The interpersonal level of the ecological perspective refers to the influence of relationships on participation (McLeroy et al., 1988), such as the relationships of individuals with family members, friends, neighbors, work colleagues, and other acquaintances. In addition, efficacy and trust, both at the individual and the collective levels, are built on relationships (Bandura 1977; Sampson et al., 1997) and impact actions taken by individuals at multiple levels. For the interpersonal level in this study, the focus was on the relationships of individuals who interacted with the CHC board. This included relationships among board members, between board members and board chairs, between board chairs and clinic directors, and between the board and the leadership/management team of the clinics. The themes that emerged within this level included two sets of

relationships that influenced board members' participation: those between the board members and the leadership/management team staff of the clinics and those between the board members and the chairs of the boards. These relationships were identified as those having the most influence on the quality of the board members' participation because of the way they facilitated the board members' ability to participate in a legitimate way in the CHC boards.

First, across all information gathered, the relationship and trust between the leadership/management team of the clinic and the members of the board facilitated and even enhanced the participation of all members of the CHC boards. Both consumers and non-consumers alike identified these relationships as important to the quality of participation for board members. For example, one consumer member commented:

And [the clinic director] makes the hard calls and is a good business manager...I think we have a great combination here. [Our medical director] does the miracle stuff and innovation and has a big, big heart and [the clinic director] with a big heart but the understanding that there if there is no money, [then there is] no mission. (Consumer member interview)

Another consumer member described how the relationship between the clinic director and other leadership team members assisted the director's ability to make decisions:

I guess when the staff and the directors provide information and provide answers and provide their opinion on what is going to be best for the organization, that makes it much easier, and when they have done their homework. (Consumer member interview)

A non-consumer member described the way a leadership team member assisted in his/her understanding of the issues in which the leadership team member possessed expertise:

And [the finance director], any time [he/she] got a question; [he/she] is very good at explaining [it] and breaking it down. (Non-consumer member interview)

These examples demonstrate the variety of ways leadership team members assisted CHC board members in Iowa with their work on the boards.

Second, the relationship between the board members and the chair of the board was identified multiple times as facilitating the quality of participation of consumer members particularly in the context of the CHC boards. For example, one consumer

member who was formerly the chair of the board described the implementation of a strategy to ensure that voice was given specifically to consumer members of the board. This strategy was an open agenda time that was incorporated into board meetings when all members, not just consumer members, had the opportunity to make a comment, ask a question, or in another way be heard in the context of the CHC board environment. In another example, when discussing the challenges of the patient majority requirement of board composition, a clinic director commented on the leadership ability of the board chair to draw out the perspectives of consumer members when their voices were not being heard in a board meeting conversation.

Collective efficacy describes how social relations impact individuals and prompts them to act collectively against unwanted behavior and towards a collective good (Sampson et al., 1997). Although this factor relies on relationships, it extends relationships to a collective perception that the group can make a difference together (Sampson et al., 1997). In the current study, the degree of collective efficacy within the culture of each of the three CHC boards influenced board members' ability to have a quality participation experience. Multiple board members across all three sites identified the importance of the collective roles of each board member in fulfilling the responsibilities of the CHC boards. A consumer member described this importance:

They [all board members] all put forth their own aspect on it so that it, it kind of each view is different...we all kind of put a little niche into it so...when it all comes to a vote it, it kind of comes out as a 100%...and or not just one person can influence the whole group. It takes all of us to make a full decision on it. So, you know, that's one person putting in a tenth, if there is 10 on the board, that one tenth kind of helps the other nine tenths to see the whole picture. So you know, with ten tenths then you get the whole picture, then it kind of makes it fall into place. (Consumer member interview)

This comment demonstrated the consumer member's belief that when he/she met with other board members, the board as a whole was able to make the best decisions possible.

## **Organizational/Institutional Level Factors Influencing**

### **Participation**

The focus on this level of the socio-ecological framework was on how the organization or institutional structures of CHC boards influenced board members' ability to have a quality participation experience as members of the board. The themes that emerged at this level described certain structures within the CHC organization as those best able to facilitate the quality of citizen participation for consumer members. Those structures were the leadership/management teams of the clinics (previously discussed) and the organizational and institutional support provided by the NACHC and the IAPCA. For board members who did not have expertise in policy and health care advocacy, this support crucially facilitated the work those members did on the CHC boards in Iowa. The information flow between NACHC, IAPCA and the CHCs in Iowa was discovered throughout the data collected to be a significant source of support for CHC board members in the policy development work they accomplished as members of the board. Examples of this information flow and the impact of the information on the board members in the study are described below.

One non-consumer board member described the support received from the IAPCA as facilitating the board's ability to affect government policy:

I don't know whether my board alone does, but collectively through the board associations [IAPCA], that's how it [our board] may contribute to the development of policy, I mean government policy. I think that having our voice in the state capital, and having a voice out in Washington collectively, that's how the board contributes [to policy]. (Clinic C, Non-consumer member interview)

Another non-representative consumer member discussed the role of the NACHC in helping the board understand the efforts of CHCs of similar size in other areas of the country and thereby improving his/her work on the board:

And so let's look at some of those [CHCs] that are [our state] or in some of the other areas throughout the country. Go to the national association of health centers [NACHC] and let's get what they are doing [and] that we're not.... [To] learn from them because we're not going to learn, [nothing] against the smaller



ones [CHCs] in Iowa but they just aren't like us. We're big, they're not. (Clinic C, Non-representative consumer member interview)

The non-representative consumer member viewed the NACHC as connecting his/her board with similar boards in other states and making comparisons that assisted the work of the board when other CHCs in Iowa were not comparable because of their size or the size of the city in which the CHC was located. Another non-consumer member discussed the way that the clinic director facilitated this information flow:

I know that [our clinic director] is very good about taking people on the board to national meetings [with the NACHC] particularly in Washington, so that they [board members] are exposed to the advocacy piece where they actually get to meet with our representatives and tell the story of the community health center. (Clinic A, Non-consumer member interview)

This example speaks directly to the impact of board members on policy when that interaction was facilitated by the clinic director directly through the NACHC to the national level of policy making. Telling the story of the CHCs is driven by the NACHC, and board members play a crucial role in that story-telling activity.

### **Community Level Factors Influencing Participation**

According to McLeroy et al. (1988), the community-level connotation most relevant to understanding how this level influences citizen participation involves a population with boundaries parallel to a political entity with one or more structures of power. Formal institutions such as local government bodies and state legislatures form the power structures at this level most relevant to the work of CHCs, and social networks impact these structures so that understanding the network associated with CHC boards becomes an important feature in understanding the impact of this level of influence on the quality of participation of the board members. For the participants in this study, the themes that emerged as imperative were the informal and formal relationships with local, state, and federal policymakers and proved to be vital to the survival and growth of the CHCs that participated in the study.

Across the information collected for this study, the relationship of clinic directors with local policymakers was identified as an crucial mechanism for funding and advocacy as described by one non-consumer member:

[Our clinic director] has always been involved [locally]. [Our city] does a big Chamber of Commerce [event] every year where a delegation from [our city goes] to Washington, DC, because we represent a [multi-state] area, and meet with [policymakers who represent that] area and [our clinic director] has always represented [the CHC] there too. [Our clinic director's] level of involvement makes us as board members all more aware of the advocacy piece. (Clinic A, Non-consumer member interview)

In this example, the non-consumer member referred to the role of the director in connecting the work of his/her CHC with a national policy conversation, and then bringing that conversation back to the board members to increase their awareness of the advocacy component of both the clinic director's job and the board member's job.

Another non-consumer member discussed the role of the IAPCA in facilitating the interaction between the board and the state legislature in response to a question about how the board contributed to policy developments at the local, state, or federal levels: “[The] Iowa Primary Care Association...in my opinion pretty much takes care of that... [for example] what the positions [are that] we're going to take at the state level (Clinic B, Non-consumer member interview). When pressed further about whether the IAPCA facilitated direct conversations between legislators and board members, the non-consumer member responded, “Yes, every year we have a [day] on the hill [with legislators]” (Clinic B, Non-consumer member interview).

### **Public Policy Level Factors Influencing Participation**

The focus of this level of influence was on how public policy impacted the quality of consumer members' participation on the board. For the context of CHCs, two crucial policies emerged as those most important to the influence of consumer members' participation: the legislation that requires patients to have a majority on the boards and the way the Affordable Care Act (ACA) of 2010 impacts the consumer member's participation. The legislative requirement was cited as having a direct impact on the

consumer's participation by how it elevated the consumer member participation to the majority; however, this impact was made more complex by the issues raised earlier that called into question the practice of how HRSA defines a consumer and that definition's ability to contribute to a quality participation experience for consumer members on the boards.

The ACA 2010 is the other policy that facilitated the quality of the consumer's participation in an unexpected way. One of the major changes that the ACA brings to the work of CHCs is that they will receive more funding to provide services to more people (Clinic C, Clinic director interview). The demographic of those people will likely be more and more like non-representative consumer members in this study: middle class, working individuals with insurance looking for a medical home (Non-representative consumer member interview and Clinic director interview). If CHCs are known in the community as quality care facilities, they will be able to recruit and serve this type of demographic. A non-representative consumer member identified this nuance that was also mentioned by board chairs and clinic directors. When asked whether the board chairs and clinic directors thought that board members generally and consumer members specifically understood this nuance of the ACA and the impact this nuance would have on the work of the board, they answered with a resounding "yes" because of the technical support provided by organizations like NACHC and the IAPCA. Information about the ACA is empowering for members of disadvantaged and marginalized groups who are directly impacted by the changes in sweeping social reform policy. This example demonstrates how important it is to understand public policy from the prism provided by a multi-level framework such as the socio-ecological framework because it highlights the interactions between levels and the influence of those interactions on the work of the whole. In addition, attention to context in the socio-ecological perspective provides an appropriate mechanism to identify how power imbalance in the policy-making process

can restrict access to the quality citizen participation of marginalized or disadvantaged individuals.

### **Understanding The Process of Quality Citizen Participation**

Analyzing the participation of CHC board members in this study through the levels of the socio-ecological perspective illustrates how interpersonal, intrapersonal, organizational and community factors influence how individuals participate on these boards but it does not provide a complete picture of quality citizen participation. The information collected and analyzed for this study revealed a complex process of the quality of citizen participation. This process is illustrated by the way CHC boards construct themselves and objective and subjective measures of how members participate on the boards. More specifically, the objective measures quantifies citizen participation of CHC board members in the study using board meeting minutes and observation data while the subjective measures understands the quality of citizen participation using the voices of participants' in the study. The subjective measures highlight participant's perceptions of the importance of other roles within the boards and their personal experiences participating as board members. An additional aspect of the process of quality citizen participation is how the process is influenced by the board member's roles and the way board members' experiences move them to different positions on Arnstein's ladder. In examining board member perceptions, I discuss how differences in participation between consumer roles (representative and non-representative consumer board members specifically) roles influences the quality of citizen participation. Finally, I discuss the way different board members move on Arnstein's ladder of citizen participation to illustrate the quality of participation gleaned from participants in the study.

### **Construction of the CHC Boards**

The process of quality citizen participation begins with a discussion of how CHC boards are constructed. Board member recruitment found in this study falls in line with

the literature that says the way in which people are asked to be a part of a policy decision-making process is important to that participation (Verba et al., 1995) and with Arnstein's (1969) belief that being asked to the table guarantees entrance to the ladder of participation. To illustrate the way the construction of the CHC boards operate in the quality citizen participation process, I describe how the CHCs used their committee process as a mechanism to recruit board members, the pathways through which different board members took to joining their respective boards, the orientation process for board members once their terms began, the role of term limits in board membership, and the barriers board members identified to their quality citizen participation.

**Committee process for member recruitment.** Across all three CHC boards in the study, committees were used as a main mechanism to vet potential board members. More specifically, located within the board governance documents of each board was a description of the tasks of these recruitment committees. In general, the recruitment committee's tasks included selecting a slate of candidates for review, reviewing orientation procedures for new members, and meeting to fill vacancies as those open spots became available (Clinic A, B, & C Board governance documents). My original assumption going into the project was that the clinic directors or the board chairs would utilize their connections to recruit members, but based on the data provided by the three boards, I found a clear governance structure for identifying new board members. An example from the governance of one of the clinic describes the role of a designated committee for board member recruitment:

Every two (2) years, not less than sixty-five (65) days prior to the annual meeting, the Board Development Committee shall convene and select a slate of candidates to fill vacancies on the Board and to prepare a slate of officers. These names shall be presented to the Board at its December meeting for its consideration. Voting will take place at the January Board meeting and installation of officers and new Board members will take place at the annual Board meeting in February. The Board Development Committee shall also identify candidates for vacancies due to death, resignation, removal, disqualification or other cause and shall present the same to the Board for consideration. (Clinic A, Board governance document, Description of board development committee)

The committee structure served as a formal mechanism for potential board members to be introduced, vetted, contacted, and eventually approved for board membership. Also, for Clinic C's board, the committee structure was a way for board members who had served their term limits to stay active and involved with the board as non-voting members (Clinic C, Non-consumer board member interview). The way names came to each CHC board and then to the committee varied, but the recruitment committees' responsibilities were uniform across the three boards.

The method by which names of potential board members arrived at the starting point for board recruitment, however, varied both by clinic and by role the potential board member would fill. For example, in some cases, clinic directors knew (from attending the board meeting and being in close contact with the board chair) that the board was in need of a specific profile to fill a particular gap, for example, a consumer member. The clinic director would then reach out to providers in their clinic network for potential names of current consumers that might be a good fit for this specific role. When names were collected by the clinic director, he or she would contact the prospective members to gauge their interest in becoming a part of the board. In some cases, clinic directors reported that they would sit down for a lunch meeting and in other cases it would be a screening phone call with the potential future members. When the clinic director "approved" the prospect, the name would then be passed on to the nominating committee chair of the board who would also schedule a one-on-one meeting or conversation to gauge interest and fit with the CHC board. If that conversation went well, the prospect would have a meeting with the nominating committee and from there, the committee would make a recommendation to the entire board for approval. During this recommendation phase, other board members plus the board chair and clinic director would have an opportunity to have a conversation about the role of this board member in the functioning of the board. Typically, they would discuss whether this person would be

a good fit, and if members around the table were familiar with the person, they shared what they knew.

As noted above, I assumed going into the study that the board chair had a lot to do with initially naming prospective board members. To test this assumption, the following question was asked during the first board chair interview: “So once you moved into the leadership position, did you use your relationships to try to recruit new members or did you have relationships with other members...?” This assumption was defused immediately. Before the sentence was completed, the board chair interrupted:

I have not done that, I don't know I just, I felt like we had a committee that was responsible for doing that and I have always believed as a manager I don't want to ... step in and do their job, [because] then they will stop doing their job, so I kind of let them do what they do. We will get input sometimes from postings for patients if they are interested in being on the board, so we just had a new consumer come on board, hopefully she is here tonight and so we try to get consumers, we need at least 50% consumers on the board so that is kind of one of the things we looked for. But I also sit on that committee when they meet so at the interview tonight [after the board meeting] I will be in that meeting [and give input]. (Clinic A, Board chair interview)

Various stages of the recommendation phase were observed across clinics at several of the six board meetings I attended. In the context of the two board meetings of Clinic A, two different stages of the process were observed. First, the chair of the board discussed in the interview that before the board meeting that evening, a prospective board member would be interviewed by the nominating committee. The chair was optimistic about this prospect as she/he had experiences (both personal and professional) that were in line with the needs of the board at that time. The chair also indicated that a few board members were familiar with the prospect, so that when the entire board discussed the prospect at the meeting that night, many people would be able to voice their opinions regarding the individual joining the board.

Second, I observed the clinic director approaching the board to alert them to the need to bridge a gap in membership when the director advised the board of the need to find a prospective board member who fit a certain demographic. This sparked a

conversation among the board members, the clinic director, and the chair of the board to determine how to go about finding someone to fill the demographic requested. The chair asked where members of that particular demographic received services among Clinic A's repertoire of services and suggested going to that specific site within the clinic network and putting up recruitment signs. Another board member suggested contacting the clinic staff members that served that population to help with recruiting a prospect. The chair then suggested having the sign in multiple languages, and a board member who was bilingual pointed out that if you do this, you must have someone at the board meetings who can interpret for the board member. If a member attended the board meetings who could not read or understand English, he/she would be unable to participate. A third board member suggested posting signs that said "we need board members" to see whom they could recruit. The discussion ended with a fourth board member asking if front line staff knew the protocol to follow if a patient approached them who was interested in joining the board. No one seemed to know the answer, and it was noted that the clinic director would follow up with the leadership team to make sure that loop was closed in case patients did approach clinic staff for information.

During the board meeting observations at Clinic C, two interesting issues were raised related to identifying prospective board members. First, at the initial meeting observed, the nominating committee was submitting names for the board to elect the executive committee. One of those being nominated was not present at the meeting, but the chair said if anyone had any questions for those being nominated, he/she could ask those board members present. No one had questions, but a consumer noted that there were no consumer members on the list. The nominating committee chair did not respond and no one commented further. The nomination of the board members to the executive committee passed. In addition to this task, the nominating committee also updated the board on the promising prospects being considered to fill the two vacancies that would be left the following month when two consumer members' terms expired.



A second interaction at Clinic C that involved prospective board members occurred at the second meeting and was a follow up from the prospects update from the previous meeting. When the nominating committee provided the update of those prospects from the previous meeting, it was reported that both prospects fell through and the nominating committee chair and clinic director were going to start the process over again. Upon hearing that update, one of the exiting consumer members suggested that one or both of the exiting members serve in an honorary capacity until their spots could be filled to avoid having two consumer member vacancies on the board. This suggestion spurred a debate, with both consumer and non-consumer members taking various sides on the issue. The clinic director said that for past members to return to the board, there would have to be an amendment to the by-laws because the current policy was that board members could return after their term was over but not for one year from the time they left the board. At one point it was suggested that the by-laws committee could vote at the meeting that night to make this change, but that suggestion was quickly dismissed as time consuming and troublesome with no notice to the by-laws committee.

The recruitment and retention of board members clarified how the CHC boards facilitated the quality of participation for their board members. Figure 5.1 illustrates how the CHC boards in this study constructs the recruitment and retention of board members and demonstrates that although names of prospective board members came into the process differently, the vetting of prospects after the name was submitted to the clinic director was standardized as the prospect moved through the channels. Specifically, the three CHC boards in the study were intentional about potential board members and relied heavily on the contacts and connections within the present board (including the leadership and management team members) to identify prospective community members. This identified intentionality provided evidence that a quality citizen participation experience was not only in the hands of individual board members but also was part of a relational and group process involving all board members.

**Members' pathways to joining their board.** Given the formal and informal methods the boards used to recruit board members as reported by the boards, the path that board members took toward board membership was of interest. Based on the conversations with all 16 board members in the study, responses revealed that all board members came to the board in one of the five ways as shown in Figure 5.1.

The five ways board members came to the board were: Path A – names come from staff at clinics in the CHC's network, Path B – names come from a “dream” list of prospects compiled by board members, Path C – names come from community members familiar with both the CHC and community residents who would be a good fit, Path D – names come from people in the community who approach the CHC interested in serving on the board, and Path E – names come from someone already on the board who was friends or acquaintances with the prospective board member. However, there were differences among both the consumer and the non-consumer members and the representative (represents the patient community and is a consumer of the clinic) and non-representative (does not represent the patient community and is not a consumer of the clinic) consumer members (Wright, 2012).

Table 5.2 lists the participants in the study according to the clinic their board was associated with, their status (consumer vs. non-consumer, representative vs. non-representative), and their pathway to board membership based on the identified paths A-E in Figure 5.1.

Based on the information in Table 5.2, of the eight consumer members, only one consumer board member, a non-representative member, took Path C as compared to all other consumer members who took Path A to membership on the board. Interestingly, this one specific non-representative consumer board member of the two in the study, although he/she had a long history in the patient community of the clinic, could be considered a non-consumer. This participant began his/her history with the clinic at a time when he/she was economically similar to the patient community of the clinic.

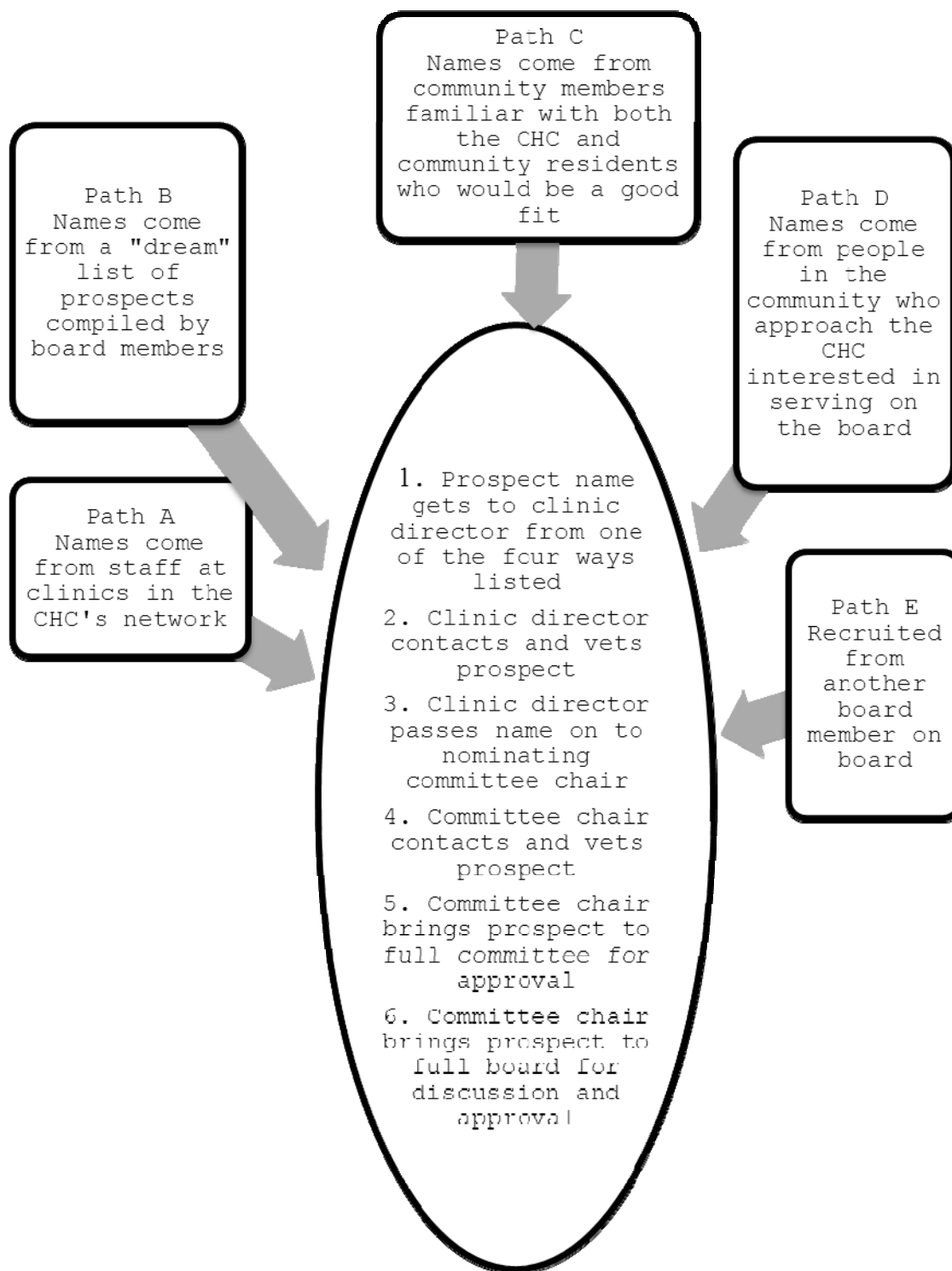


Figure 5.1 Prospective board member recruitment process

Table 5.2 *Participation by Clinic Board, Member Status, and Path to Board Membership*

Clinic Board	Member Status	Path (A-E)
B	Consumer / Representative	A
B	Consumer / Non-representative	C
B	Consumer / Representative	A
B	Consumer / Representative	A
A	Consumer / Representative	A
A	Consumer / Representative	A
C	Consumer / Non-representative	A
C	Consumer / Representative	A
B	Non consumer	C
B	Non consumer	C
B	Non consumer	E
A	Non consumer	C
A	Non consumer	B
A	Non consumer	C
C	Non consumer	C
C	Non consumer	A

However, at the time of the study, he/she had a professional degree and employment, which called into question his/her consumer status. It was through connections at his/her job that he/she was approached to become a member of the board. When asked about this path, he/she stated, “I got in the board because I was recommended by [someone] who was directing [a nonprofit in town that I worked with through my job] at that time. It was interesting because [this person] and I were actually [working in opposition] pretty regularly but he recommended me, and they asked me to join” (Non-representative consumer member interview). Although this participant was considered a consumer member, his/her employment and education might have suggested otherwise. This participant’s experience of board recruitment contrasted with experiences of the other consumer members who were recruited to the board by a service provider in the clinic in which they were patients. For example, another consumer member stated, “And then it might have been [a provider at the clinic] who said you know, there is a place on the board, but I think it would be really good – that it would be a really good fit for you” (Representative consumer member interview).

Compared to the consumer members, who mostly took similar paths to board membership, of the eight non-consumer members, there was considerable variation. This variation was evident in the non-consumer members' descriptions of their paths to participating on the board. For example, one non-consumer member described his/her experience as follows:

Well, I came to the Board because of a fellow coworker. She was a staff member for me and they were looking specifically for somebody that has the technology experience and would be interested, and so she you know, asked me if I would consider it and then shared my name with the CEO and then he contacted me and interviewed me and I felt this would be a good deal and that's how it came about, so it was a referral from somebody else. (Non-consumer member interview)

Demonstrating the variation in non-consumer member paths to board membership, another non-consumer member described how he/she found the board:

Well, I was recommended by the director of [a local nonprofit]...I've worked with youths for probably 30 plus years and he knew me through working with my youth program. And I've been involved in the community; I mean here beyond [a city in the area]. So I've just been involved in the community for a long, long time. He knew that. He was retired, so he thought I might be a good fit. (Non-consumer member interview)

There was only one member in the whole sample that arrived at the board via the path of being identified as being on the "dream" list constructed by current board members and clinic directors. The majority of participants with non-consumer status were connected to the CHC by community members who were familiar with the clinic and with the particular person and believed that the person would be a good fit based on that familiarity. One non-consumer member was identified by the then clinic director when that person took over the job, because the clinic director was familiar with the non-consumer member in his/her previous work context. These results of five different pathways to board membership, as identified in Figure 5.1, are consistent with citizen participation literature suggesting that those from communities with traditionally less power (lower SES status, little or no health insurance, racial/ethnic/gender minorities) are more likely to participate when their participation is solicited by another individual whom

they trust (Bolland & McCallum, 2002; Verba et al., 1995). In the case of the consumer members in this study, the person they trusted most often was a service provider of the clinic of which they were a consumer.

**Board member orientation.** To help board members acclimate to the climate and culture of the CHC boards, it was assumed that they would undergo a formal orientation process upon joining the board. However, across the three boards, this was more of an informal process than a formal one. One strategy used was a process of informal mentoring between members (not necessarily consumers paired with non-consumers) in order to be available to answer questions as needed. Another informal strategy used was that board members had a grace period before they had to decide which committees to join in order to give them time to get used to the board and see where they might best contribute based on that initial assessment. This grace period lasted anywhere from a few months to a year, depending on the member and the clinic. This grace period also existed for both consumer and non-consumer members equally. A formal strategy used by one clinic was to have the clinic director sit down with new board members and walk through the board member packet of information and provide an overview of the services provided by the clinic and the responsibilities of the board. It appeared that much information was shared during the interview process of potential board members so that they knew just what they were getting into with joining the board, which might have contributed to the lack of a formal process across all three CHC boards.

In terms of how board member orientation related to the quality of the participation experience for board members, again there was overlap with other issues mentioned. In particular, if barriers for a quality experience of participation derived from new board members not feeling comfortable in the climate or culture of the board or prepared for their immediate participation in board meetings, for whatever reason, it is easy to see how a formalized board member orientation might eliminate those barriers by assimilating new board members joining to the board in a standardized way. A newer

representative board member referred to the benefit of an orientation and stated: “This is the first board I have ever been on that had an orientation and then had an orientation acclimation period. I had not encountered that before, I had been on two other boards in the past” (Representative board member interview). The board member was discussing the orientation as a way for her/him to feel comfortable on the board, and although the orientation had not happened yet, he/she was looking forward to it. This issue in particular points to potential best practice suggestions within the way CHC boards are constructed that the boards could alter to improve the quality of citizen participation, and is worth further investigation to see if in fact other boards have these types of processes in place and to explore how well they are working.

**Board member term limits.** Board member term limits varied among the CHC boards, with some boards having stricter term limits than others. There also appeared to be a difference in how board members, clinic directors, and board chairs understood and applied these term limits. The issue of board member term limits impacts the quality of participation of board members in a crucial way. Turnover affects the culture and climate of the board when a number of members are rotating in and out, a number of members have been a part of the board for many years while others are brand new and do not know anyone. Members rotating in and out challenges group cohesion and members’ staying on the board prevents new members with new ideas from joining. If quality citizen participation is related to the bonding of board members, then board members’ not knowing one another will impede this bonding from occurring. Conversely, when board members remain on the board for years, they prevent others from joining and bringing a new fresh perspective to the board. The next section will review term limits and turnover for each clinic, address them as either strengths or challenges for the clinic, and discuss the implications of these issues for quality participation.

In the case of each CHC board, board member term limits shed interesting light on how the particular CHC board was constructed. Although each board consistently had

term limits for the members of the board, there was variation in board adherence to those term limits. Each board handled the issue in a different way, and this difference could contribute to a variation in a quality participation experience for board members who are a part of that particular board. Based on the researcher's observations and data obtained from interviews, the decisions each board made regarding term limits were a source of both strength and challenge regarding the quality of participation among all board members.

For Clinic A, the term limits were 4 years but a member could be re-instated at the end of that time if requested (Clinic A, Board chair interview). According to a non-consumer board member, who quoted the by-laws for Clinic A's board, "a board member term is four years and a board member cannot serve more than three consecutive four-year terms" (Non-consumer member interview). One representative consumer member responded, "I am not sure if we have term limits, if we do I am not aware of them" (Clinic A, Representative consumer member interview). Another representative consumer member replied, "To my understanding, you are allowed to stay if you choose for up to 12 years, which is three 4-year terms. I know four people who stayed the full 12 years and recently had to leave the board" (Clinic A, Representative consumer member interview).

Interestingly, Clinic A had experienced considerable turnover recently (Clinic A, Board chair interview), with a number of board members joining the board and leaving within a short time. The ambiguity around the term limits could be a factor in the amount of turnover experienced by Clinic A's board. Because the board members who were no longer on the board were not around at the time of data collection, it is not certain if they were consumers or non-consumers, but presumably such turnover creates other issues important to quality. For example, the board has to spend time in the prospective board member recruitment process which, if they are trying to fill four slots, could take a significant amount of time away from other board activities. In addition, the time



required to get board members orientated to the board, or up to speed, could delay the adjustment of newer board members and their finding a comfort zone of participation on the board, which could impact the quality of participation for those new board members. However, according to a non-consumer member, the board term limits were unclear, and there were board members who had been on the board for six, seven, eight, and even 11 years (Clinic A, Consumer member interview).

Clinic B board members served a 3-year term, no board member could serve more than three consecutive terms, and the term could be renewed under exceptional circumstances at the board's discretion (Clinic B, Board governance document, By-laws). According to a non-consumer member, Clinic B had 3-year term limits that could be reinstated at the end of that 3-year time period (Non-consumer member interview). A large percentage of board members (over 50% of current members) had been on the board 10+ years (Clinic B, Board chair interview). One representative consumer member noted that he/she was unaware of term limits for board members (Representative consumer member interview). In addition, Clinic B's board had experienced minimal turnover in the last 5 to 10 years, with seven of the 13 members serving a third term or longer. Based on information collected, there did not seem to be an example of a board member who wanted to stay on the board as a voting member who was not able to do so because of the term limits of the board.

Board members were elected in staggering terms of 3 years from July 1 to June 30 (Clinic B, Board chair interview). According to Clinic B board's by-laws, "no director [also known as board member] may serve more than ~~two~~ three consecutive terms" (Clinic B, Board governance by-laws), and the "two" was crossed off and replaced by "three." Based on information gathered for this study, it is unknown why this change was made or when. When asked about his/her time on the board and the term limits which govern that time, a non-representative consumer member replied:

...the bylaws allow us to after like two I think two or three terms they [the board] can vote somebody back in but they have to actually discuss it on board and discuss why that person is a benefit to the board. And I mean, if they ever decided that I wasn't a benefit [they could vote me out and replace me with someone better]. (Non-representative consumer member)

This example illustrates that this particular board member was aware of this restriction and accepted leaving the board if the board decided he/she was no longer useful, or that there was someone of more use to take his/her place. The board chair, however, expressed perplexity regarding this issue when he/she was discussing board members who had been on the board a number of years: "We have a board that needs some generational turn...just from, you know, looking at it from another angle, because at some point people have kind of missed touch and we need to refill that" (Clinic B, Board chair interview). This comment was made as part of an example of a specific issue the board dealt with in which people with different skills might be the ones to help direct the board through the future needs and directions of the health care industry. This issue could impact the quality experience of participation for board members in that the people serving on the board are taking seats where others with a new perspective could contribute to the future direction of the board. Conversely, those on the Clinic B board who had been on the board for a number of years provided institutional knowledge that was important to the vitality of the board.

Clinic C's board had a 3-year term limit that could be renewed once, for a total time served of 6 years, which was strictly adhered to. If a board member wanted to return as a voting board member after the two 3-year terms were served, he/she could do so after a 1-year wait period. One non-consumer member stated that he/she did not know that remaining on the board for a second 3-year term was optional and not mandatory: "I thought my term was 6 years total, not two 3-year terms. Had I known that, I might have gone off the board after the first 3- year term because the board is a lot of work" (Non-consumer member interview). Another non-consumer member added to the 3-year term discussion that he/she did not know of members who asked to be re-instated as full board

members after they had served their terms, but did know that past board members interested in remaining on the board did sometimes stay involved with the committees as non-voting members (Non-consumer member interview). Interestingly, Clinic C had experienced considerable turnover as well. Each year beginning in 2006 through 2012, one to three new board members joined the board (Clinic C board governance documents).

The way Clinic C's board handled term limits for their members' impacted quality in an important way. First, although board members were given the option to leave after 3 years, it did not seem to be the norm on this board. So you have board members who serve for six years and based on my observation, this seems to have been the norm for many years. Given the information collected for this study that showed many board members felt comfortable on the board with their responsibilities after 1 or 2 years, being on the board for 6 years provided ample time for board members to understand their roles and responsibilities on the board and to increase the likelihood that they would speak up and participate. When people are speaking up and expressing their views, their voices are being heard.

For Clinic C, the issue of board member term limits in practice looked different from Clinics A and B. Clinic C strictly adhered to their board member term limits. This was evident when one of the two consumer members leaving the board requested to remain on the board in an unofficial capacity until the open position could be filled. This consumer's offer was blocked by a vocal non-consumer member during a board meeting observed by the researcher. There was evidence of this adherence to the rules in the pattern that emerged of the years board members joined the board. The board chair described a deliberate plan to have one or two members join the board each year in an attempt to rotate board members on and off in a timely fashion. So when two board members were rotating off the board, another two were rotating on. In theory, this was a strength because it avoided a potential problem faced by Clinic B with a large number of

board members entering their ninth year or higher on the board. If a great number of those board members leave, that will leave many seats to fill instead of just one or two which could potentially be problematic. The strategy in practice could create a challenge if they are not able to fill those spots, and there is a gap in representation on the board. Another challenge presented by this strategy is that the board runs the risk of losing dedicated and worthy board members whose shoes might be next to impossible to fill, which is a practical loss when those board members want to stay on the board but are unable to because of the board term limits.

**Board member participation barriers.** Consistent with previous research (Checkoway et al., 1984; Sleath & Rucker, 2001), barriers to participation by consumer and non-consumer members were identified across all three clinics. If consumer members are prevented from participation due to barriers at any level, the quality of that participation becomes a moot point because the participation is disputed to begin with. For participants in this study, one barrier in particular was discussed by non-consumers, consumers, clinic directors, and board chairs: The board member's knowledge of health care and financial terms used frequently in board meetings created barriers for consumer and non-consumers members' participation. The fact that this same barrier existed for both consumer members and non-consumer members was an interesting finding in the data collected. The boards in this study dealt with this barrier in a variety of ways, although an important first step to addressing this issue was the identification that this barrier existed.

Knowledge levels of health-care related terms as well as financial terms varied among both consumer and non-consumer members. The root of this variation was easily understood during observations of the board meetings. The language used by the clinic directors and, where applicable, the leadership/management team was heavy in jargon and acronyms and could lead to the creation of barriers to participation if not addressed. From the perspective of some participants in this study, this barrier had improved over

time with a greater number of board members drawing attention to it repeatedly. From the perspective of other participants, however, this barrier continued, and in the case of one consumer member, he/she was tired of being the one to raise the issue repeatedly so he/she chose not to and instead was lost or confused in meetings (Representative consumer member interview). As previously described, one CHC board requested an explanation of acronyms in their board meeting minutes to help alleviate this barrier for board members and relieve them of the having to bring it up during board meetings. Only one board had implemented this solution, however, and it would be interesting to see if other boards would implement it as well if the suggestion was made.

Another barrier related to financial terms was cited by clinic directors, board chairs, and some non-consumer members as being a challenge specific to consumer member's inclusion on the CHC boards. Because, generally speaking, consumer members have little experience with the financial industry, it creates a challenge to not only acclimate them to that industry but also expect them to have a high enough working knowledge of the terms and relationships in the industry to make the informed decisions they must make as a member of a board who governs a clinic that has a budget in the millions of dollars. As is the case with previously discussed issues, this issue was intertwined with others and could therefore benefit from solutions already suggested to improve the quality of participation for consumer members who experience these barriers. For example, if a formal orientation process was implemented, there could be an explanation of commonly used terms and acronyms to acclimate members to this specific language. Potentially during board meetings, board members could have a one- page "cheat sheet" of important acronyms and terms that are quickly accessible by members who need assistance with them.

This section reviewed how CHC boards are constructed and included a description of the way boards recruit and retain members, the pathways taken by board members to join the board, the orientation process board members experience upon

beginning their time on the board, the term limits which dictate the board members participation on the board, and the barriers to quality citizen participation identified by board members. This construction is a necessary element to understanding the process of quality citizen participation for CHC boards in this study because it provides a useful foundation on which to build the experience of participation on the boards. The foundation is a part of the complexity existing around participating on CHC boards. The next section describes objective and subjective measures of the process of quality citizen participation using board meeting observation data and board meeting minutes alongside interview data with board members.

### **Measures of the Process of Quality Citizen Participation**

The process of quality citizen participation is further explored using objective and subjective measures to understand the process of quality citizen participation. For CHC boards, the patient majority requirement of board composition originated from the idea that those with less power needed a legislatively required majority seat at the decision-making policy table in order for their voices to be heard (Boone, 1972). However, simply placing consumers of services at the table was not enough, because there was no guarantee of the quality of their participation (Alinsky, 1971; Arnstein, 1969). Therefore, both objective and subjective measures of the process of quality citizen participation were used based on the multiple levels of data collected for this study, and were analyzed to examine the attendance of board members as well as identify the quantity of participation for both consumer and non-consumer board members and their level of participation.

**Objective measures quantifying participation using board meeting minutes and observation data.** Across the data collected, an issue that was raised repeatedly was the attendance of board members at full board meetings and the smaller committee meetings that occur with varying frequency depending on the charge of the committee. In an analysis of the board meeting minutes for the year 2010-2011 revealed a small difference in the absences by consumer and non-consumer members; consumer members

were absent a total of 42 times and non-consumer members were absent a total of 50 times. The number of absences for consumer members across the three clinics was: Clinic A – 17, Clinic B – 12 and Clinic C – 13. The number of absences for non-consumer members across the three clinics was: Clinic A – 12, Clinic B – 21 and Clinic C – 17. These absences were excused in eight instances. Based on observations, for an excused absence, the particular board member had to contact the clinic director's administrative assistant (whose job it was to remind board members about the meeting) and let the assistant know of the planned absence. The term "excused absence" was discussed by two board members who shared that some members of their boards had been excused from participating on the board for a few months or up to a year because of health complications (Clinic B, Non-consumer member interview; Clinic C, Representative consumer member interview). The use of an excused absence in this case reflected a board member's having a long-standing health issue but not wanting to leave the board, so their place was held indefinitely.

The issue of variation in board member attendance was seen as a weakness for all boards as they all experienced this issue, and examples of these feelings from participants are discussed below. However, the way boards addressed this issue varied and therefore a strength or weakness depending on that variation. One strategy used by all three clinics was to have administrative staff of each clinic make contact with each board member prior to each board meeting to gauge whether the meeting would have a quorum of attendees. This helped remind members to attend the meeting and presumably cut down on absences.

Another strategy used by Clinic A and Clinic C to encourage attendance at meetings was to provide a meal at each board meeting. Clinic A appeared to struggle with the issue of attendance, as there were board members who, because of their work schedule, had difficulty getting to meetings when they began. There seemed to be no move toward adjusting the start time, although the board meeting start time appeared to

be informally delayed during both meetings observed by the researcher, presumably because board members could not arrive on time.

Clinic B held their meetings at an unusual time, though it appeared that this did not make a difference in facilitating the attendance of non-consumer members who had the highest incidence of absences. Participants from Clinic B reported that when board members were unable to attend due to illness, efforts were made to facilitate those members' presence through the use of technology. An interesting note regarding attendance issues with Clinic B: The one consumer member who might have had the most difficulty attending meetings because of his/her personal experiences had the best attendance overall, only missing three meetings in the 60 meetings since he/she joined the board (Representative consumer member interview). This is a testament to the extraordinary dedication of this particular board member and also a testament to the role he/she felt that he/she played on the board. Clinic C's attendance rate was in the middle of the two clinics for both non-consumer members and consumer members. The reason for this was unclear from the information collected, although this is an area to explore in future research.

Board attendance issues influence the quality of the participation because it contributes to the overall climate and culture of the boards. When absences are accepted as the norm, it is not difficult for certain members to miss meetings and for other members not to notice, or if members do notice, not to say anything. If this occurs, the legitimacy of consumer's voices is absent and therefore challenges the quality of the participation experience. In one of the more emotional interviews conducted, a non-consumer member directly connected the absence of two consumer board members consistently throughout the years as being detrimental to the consumer representative voice on the board. In this interview, I asked about board members' attendance and requested clarification about how many meetings board members could miss. The non-



consumer member replied, “You can miss up to three” (Non-consumer member interview). She/he then added:

Now we have a lot of the exceptions to that. And [consumer member x] is one, if he/she is at one meeting a year it’s remarkable. That disturbs me. And they have tried to find someone else to take his/her place and it’s been extremely difficult. (Non-consumer member interview)

The non-consumer member identified the absence of a consumer member as important in the discussion of how consumer’s voices are heard on the board, presumably because if a consumer voice placed on the board to represent the experiences and needs of the patient community is consistently absent, that voice is silenced as are the needs of the patients that person represents. In addition, the question of how power can be redistributed in an environment where the mandated seats in the process are constantly unfilled is justifiable and speaks to the quality of the citizen participation of those absent from the table and needs further exploration.

The next objective measure used to understand the process of quality citizen participation is located in Table 5.3. This table shows the number of times a specific board member participated at a board meeting by clinic, member status (consumer vs. non-consumer), and source of data. In order to count as participation, members had to have their names listed in board meeting minutes as doing any of the following five actions: making a motion, seconding a motion, asking or answering a question, and/or delivering a committee report. Board meeting minutes reflected the discussion as recorded by the person taking the minutes, and the board meeting observation data came from the researcher’s observations at the six board meetings (two meetings each) for the three clinics from June 2012 thru October 2012.

Table 5.3 *Quantifying Participation by Clinic, Member Status, and Source of Data*

Clinic	Member status	Source of data	# of times participated
A	Consumer	Observations	10
A	Consumer	Meeting minutes	77
A	Non-consumer	Observations	2
A	Non-consumer	Meeting minutes	33
B	Consumer	Observations	5
B	Consumer	Meeting minutes	162
B	Non-consumer	Observations	6
B	Non-consumer	Meeting minutes	91
C	Consumer	Observations	22
C	Consumer	Meeting minutes	52
C	Non-consumer	Observations	27
C	Non-consumer	Meeting minutes	74

Closer inspection of the information in Table 5.3 reveals interesting patterns. First, it appears that for Clinic A and Clinic B, consumers participated more than non-consumers according to the board meeting minutes. At Clinic A, consumers participated 44 more times than non-consumers, and at Clinic B, consumers participated 71 more times than non-consumers. But for Clinic C, non-consumers participated 22 more times than consumers. The observation that consumers were participating in this way more often than non-consumers on two of the three clinic boards suggested that the spirit behind the patient majority requirement was present in the environment of board participation based solely on the quantification of their participation. In other words, there were more consumers on the CHC boards because of the requirement, so it was expected that consumer participation would be higher than non-consumer participation. However, this was not the case for Clinic C, which raises the question of why this difference existed. A possible explanation could be that Clinic C had either more timid consumer members or very vocal non-consumer members who disrupted the intention behind the patient majority requirement. This possibility was supported by interviews with board members of Clinic C. In these interviews, both consumer and non-consumer members identified feeling intimidated by speaking up, and they also identified a variety

of strategies used to overcome this intimidation. One consumer member described the initial impression of her/his participation on the board:

I was just so fearful. I didn't say anything and I just – probably the first year... I was just so afraid to say anything. And just because I was intimidated, I didn't know how these people work and... I didn't know that really how the board worked and I've never been on such a formal board before.... I mean now I feel like I have more voice on the board and so I'm not afraid to speak up a lot of different things, but it's taken me a lot to get to the point where I felt comfortable talking.... Well, it's just time. (Representative consumer member interview)

Another consumer member noted that current consumer members were not speaking up in the board meetings like they could, saying when asked about this timid behavior specifically that “I think it is by those that have had some experience on that board. I look at our two or three new consumer board members and I'm not seeing that they quite got that feeling ground into them yet” (Non-representative consumer member interview). For the representative consumer member, his/her timid behavior was a direct result of his/her lack of experience on the board, which corroborated the statement made earlier by the representative consumer member that he/she felt better as time went on to vocalize opinions on the board. The non-representative consumer member's statement agreed with both of these representative consumers in relating a lack of experience to more timid behavior early in the participation experience on the board.

A non-representative member articulated this difference in consumer members and the ability those members had to be vocal versus those who were not vocal as attributable to their experiences beyond their role as a consumer member. When asked if he/she could describe a time when he/she expected a consumer member to raise an issue at a board meeting and the consumer member did not, he/she stated, “Because you think – now remember, the ones that I've been on there with the last [few] years, they've been there for almost [the]whole time too. Like we all came in together, they were pretty outspoken [from the beginning]” (Non-consumer member interview). And when pressed further to respond to specifically what might cause a consumer member to be less vocal, the member addressed the issue of professional experience with the following example:

Well, again going back to finance, finance is a whole different world. I mean you got a bunch of terms there. What do they mean debt ratio, etc...? I think a person that's from a professional world would understand it a lot better than somebody that's never seen that stuff before. (Non-consumer member interview)

Another possibility also evolving from these examples when comparing the three clinics is that the consumer members on the boards of Clinic A and B were non-representative members, meaning that they came to the table with occupations of higher status requiring more education and work experience than the representative consumer members who more closely resembled the demographic of the patient community served by the clinic. The consumer members of Clinic C, with the exception of one current non-representative member, were representative of disadvantaged or marginalized groups, whether on the basis of economic, health, or social disadvantage.

The previous section provides objective measures of the process of quality citizen participation by examining the attendance of non-consumer and consumer members as well as the quantity and level of participation by both non-consumer and consumer members. While the quantity of member participation provides some illustration of the contribution of consumer and non-consumer board members to the work of the board, Arnstein (1969) suggested that merely quantifying the activities and behaviors of citizens who participate on boards does not go far enough to understand the quality of the experience participating on boards. How members describe their contribution is needed to complete this picture.

**Subjective measure of the quality of citizen participation using participant's voices.** To understand board members experiences on the boards in greater depth I used semi-structured interviews with board members, board chairs, and clinic directors to construct a thick description (Carspecken, 1996) of what quality citizen participation looks like from the perspective of those doing the participating. As previously described, quality is best understood not only from the perspective of the consumer members but also from the perspective of others who interact with and work with the consumer

members: the chairs of the boards and the directors of the clinics. First, Mr. Hawkins defined the consumer member on the CHC boards in the following way:

[The consumer member's] job isn't to be a healthcare expert. If we need healthcare experts, we got a dozen of them okay? Or a finance expert or a politician. They are a dime a dozen. We can get more of them all the time. Your job on this board is to represent the different areas of our community that you come from. We have to make sure that what the health center does is in align with the needs of your neighbors and the people in your community, and there's no one...no one who can do that job better than you can. (D. Hawkins interview)

This quote illustrates how consumer members *should* be defined on CHC boards. The main responsibility of the consumer members from this perspective is to ensure that the work of the CHC is connected to the needs of the community that is served by the clinic. The educational background does not necessarily matter, because the consumer members from this perspective are viewed as experts on their own experiences, making them experts on the role of consumer board member.

The importance of consumer member expertise was confirmed in the perspectives of clinic directors interviewed in this study. The three clinic director participants defined the consumer members of the CHC boards in the following ways:

I mean, I can think of a couple of the consumer board members that, you know, they'll make comments about, "Well, I'm not an expert, I don't know." and "Why do you need my opinion?" But, we do want to hear from them and we try to encourage them if it's a topic that we really [want] to discuss that they share what their opinion is. (Clinic A, Clinic director interview)

Those (consumer members) relying on [the clinic] as medical home they have experience, (the) constant patient satisfaction feedback what is working, what is not working. (Clinic B, Clinic director interview)

Consumer members will ask tough questions, they provide information related from their own experience. I see the board members as telling their story of the (clinic) how they have benefited from the clinic, that message is best given by consumers. Some focus on their own care and experience and bring that voice. (Clinic C, Clinic director interview)

Not only do these perspectives represent the view that consumer members are the experts in telling their story, but the clinic directors identified additional attributes that consumers' experience brought to the board. For example, the Clinic C director stated that "consumers members ask tough questions" and the Clinic B director stated that

consumers discuss “patient satisfaction feedback, what is working, what is not working,” which demonstrates that the perspective consumers bring to the board is not only from an expert opinion but is unique given that they are patients of the clinic the board is charged with managing.

Although there were commonalities between the national policy expert and the clinic directors within the study regarding the role of the consumer, such as the consumer members’ expertise is in their experience, the consumer members interviewed revealed nuances beyond those already mentioned. The perspectives of several consumer members, both non-representative and representative, revealed these nuances:

I always get a little weird with [being] a patient but...part of my belief in this [the work of the board] is that if I am going to advocate, if I am going to support it and work for and tell how great it is, I shouldn’t have a problem being a person that relies on it myself. (Non-representative consumer member interview)

I think to be able to present the types of barriers and problem that seniors have and what we would expect or like or need from the health center and I’m not saying that that would all be one shot at one meeting. (Representative consumer member interview)

No, I’m not one that just sits there and doesn’t do anything; I speak my mind. And then so I just speak for others that weren’t able to be heard at that point you know, because they are not on the board. (Representative consumer member interview)

I mean I advocate for the clients I serve to the board and I advocate for [clinic]. (Representative consumer member interview)

I really want to be the voice for folks who would normally not have a voice; I just want to make sure that things are okay, healthy if you want to put it that way. Initially, when I was asked to be on the board, I had some idea that I was going in as someone who has a unique experience with actually being homeless, and I knew that going in. (Representative consumer member interview)

If it’s [the work of the clinic] geared more toward patients then you know, how (we) can increase patient participation especially, you know, with the medical home model. How do we get patients involved in their healthcare? (Representative consumer member interview)

Most consumer members in this study agreed that they came to the table with the unique experience of being patients of the clinics. The consumer members who did not were typically those who were not distinguished by the representative versus non-representative label, but instead only used the clinic for minor care (e.g., seeking services

from the clinic once a year for an annual check-up). The consumer members who viewed themselves as uniquely positioned to speak on behalf of patients of the clinic also saw themselves as advocates for those people who were patients of the clinic but did not have a seat at the table. These board members truly saw themselves as using their experiences as consumers to best represent the patients of the clinic.

Moving from how consumer members defined themselves and their role to examples of how the voices of consumer members were heard within CHC boards is the next link in understanding the quality of citizen participation for consumer board members. Examples of times when consumer members described their voices being heard follows:

For instance they decided they were going to move one of their segments [of services] because it's...being offered by another provider [in the area] who is actually doing a better job of it than [we] are. And so there was a board decision to cut that particular department. And I wish I had been with the board longer at that period of time because one of the questions that popped into my head was as we make decisions...if there is anybody considering what's going to happen to the people [staff of the clinic] who are losing their jobs. Having been there and done that recently...I'm kind of sensitive to that. And you know, is there an effort made to find them a position within the organization or are they simply told, man your department is no longer needed, so see you. You know, how are they [at the clinic level] handling that piece of it? I have no background about that particular decision. I don't know if they had already discussed all of that, you know two or three meetings in advance for that and...So, I've been involved in some of those sorts of things. (Representative consumer member interview)

With this example, the representative consumer member was describing how he/she felt his/her voice could have made a difference, based on her/his experience losing her/his job, had he/she been with the board longer. The example also demonstrates what could be lost when a consumer member joins a board and is not brought up to speed regarding what discussions were like in the previous two or three meetings prior to the new member's joining the board. This next example was a response to the question of an example where the consumer felt his/her voice was heard as well as how he/she prepares for decisions as a consumer member prior to the board meeting. The example involves the annual review of Clinic A's clinic director:

I said also one thing [the clinic director has going for her/him] is he/she has worked here, he/she is quite familiar with the health center with what's going on in this building, with the doctors. I said, why would we want to take thousands of dollars to interview and give somebody money to move here or fly up here for the interview and then move from here [if] she/he is already here. I said, to me it's a waste of money... anyway I try to really have a logical reason why I'm either for or against something, and I don't have to listen to it or like it or not that's my right as the consumer to sit on that board. You better have your own reason for why you are making a decision that you're making or siding with one decision versus another. You feel like you really have to come prepared in order to voice that opinion. (Representative consumer member interview)

The next example describes a non-representative consumer member basing a decision on his/her professional experience and feeling comfortable being the only voice with that concern because of his/her professional experience.

As [a medical professional], I'm really quite anti having chiropractors as caregivers and every time that a chiropractor has been brought up for approval by the board to become a caregiver, I voted no. And every time I've been the only board member that does it. Said I – say you know, you could make up your own mind, so I'm not going to tell you, but in my opinion a chiropractor does not belong as a caregiver for medical patients. (Non-representative consumer member interview)

The examples provided by these consumer members illustrate the notion that consumer board members come to the table with unique characteristics that facilitate their voices being heard on the board. Those characteristics include the consumers being patients of the clinic and basing their perspectives on that experience; however they also include the backgrounds of the consumer members. From the previous example, that one representative consumer member reported that when a decision was being discussed to eliminate a department in the clinic structure, the member thought about his/her own experience losing his/her job and when she reflected on the situation, mentioned that she wanted to raise questions in that discussion based on that experience. However, because of the limited time on the board, this member in this example did not feel comfortable speaking up. Another example was discussed by a non-representative consumer member who said his/her opinion was based on his/her educational training and this training allowed the consumer member to have a strong voice when this particular issue was raised.



The examples above suggest that the quality of the participation of consumer members was facilitated by the CHC structure in that their participation built on not only their experience as a patient of the clinic but also their individualized background or experiences. The examples demonstrate that board member participation began before a board member attended their first board meeting. In other words, board members relied on their experiences and backgrounds to inform their participation, which are processes that began prior to their physical attendance at their first meeting. Prospective board members were recruited based on multiple aspects of their experiences which included their identity, their background, their social networks, and their community connections. They were also recruited based on the role they filled within the CHC board structure. However, as the examples demonstrate, the quality of participation is influenced by the level of comfort different board members feel upon beginning their participation process within the board.

### **The Influence of Roles on the Process of Quality Citizen Participation**

The theoretical foundation for this investigation is Arnstein's ladder of citizen participation crafted as a response to the interest of War on Poverty policy creators, implementers, and evaluators in engaging consumers with the services they were receiving in a policy development context but only to a certain extent and not in a legitimate way (Arnstein, 1969). In other words, Arnstein called into question the quality of the participation, given the absence of a legitimate voice by those in the process with less power. She was not questioning the quantity of that participation because consumers were at the table, which is a helpful distinction to make given the literature on citizen participation's focus on quantifying participation in multiple contexts as referenced in Chapter 2. Mainly, the participation of the disadvantaged and marginalized members of the community who were receiving the services of War on Poverty programs and organizations was the focus, and it was the quality of their participation Arnstein called into question.

With CHC boards, those theoretically with less power (the consumer members of the boards) hold the majority of seats on the board and presumably have the loudest voice. However, what is illustrated by the socio-ecological perspective that guided the interviews with board members is that the board members themselves were not the only factor influencing the quality of participation on the boards. Participants in the study discussed the ways roles impacted the quality of the citizen participation experience, which is not an element of Arnstein's ladder. Participants discussed their own perceptions of the consumer role's importance in the functioning of the CHC boards. Those discussions led to an identified difference in the quality of citizen participation between the consumer members in the study, specifically the representative and non-representative consumer members. The next section discusses the perceptions articulated by participants as well as the disconnect between participant's identifying how important the consumers were with how that importance translated to consumers comfort levels once they began their time on the CHC board.

**Participant's perceptions of the importance of roles.** In interviews with board members, it was clear that all board members understood their roles and the roles of other board members. First, board members consistently understood the roles of others within the board throughout the three sites. Information collected suggests that whether the board members were the manager of a bank, a worker for the state, a retired human resources professional, a retired medical professional, a retired retail worker, an advocate for a disadvantaged population, or filled any role not mentioned in this list, they all understood what they were bringing to the board as well as what their colleagues were bringing to the board. The board members articulated this role clarification in the following ways:

Going around the table they are convinced that, I'll use myself as an example, that I read that 990[tax form being discussed at the board meeting]. There is an expectation out there that if I raised no objection, there isn't anything objectionable, but the same token of one of our board members, has been a patient on our virology clinic from many years and I respect a great deal of the protocols

and the way that he is treated that the process takes shape. So, we each have our stronger suits. (Board chair interview)

I mean when we sit in our board meetings we all know what the others bring in the table, and we have, you know, we have ex-nurses that are really, I mean they understand, you can't blow the medical stuff by them when people started talking, and that's great. (Non-representative consumer member interview)

I think everybody on the board is pretty open about who they are and what they represent. (Representative consumer member interview)

Well, you know when they did the interview and stuff being that I was a patient of the clinic and stuff and that's what they were looking for someone that was a consumer so that they could help voice what was going on. I think I, I knew right away that, that's what my role would be as a consumer; I would be able to speak on behalf of other patients in the clinic. I mean that, that was right off that, I knew that part of it and I knew where I would be playing my role in that so I would be able to speak for others in the clinic. I knew that, that's my role and I knew that, that would be a good part for me and I knew that my voice would be heard. (Representative consumer member interview)

I think for all the board there has been mostly what we can do we come into the board with no position on it, and then we start seeing what committee we can serve, if we have experience and/or background, and our jobs and so that's when we start serving on those committees. You can start during the committee and then you can, you know, give your advice on it and based on your experience and based on your knowledge. (Representative consumer member interview)

I think roles are very important. (Non-consumer member interview)

The board members articulated a number of issues of role clarification. These issues identified agreement with previously presented information about the importance of what each person brings to the board and how for consumer members, that expertise is their experience. This experience is just as crucial as what others bring based on their experience, whether that experience is a history of working in health care or in finance. Not only did they identify these roles as valuable, but they also stated that the roles of the board members were articulated to them from the beginning of their prospective membership process.

Even though I am in health care, I am in a very different type of healthcare and a different part of the delivery system, every part is different and you have to learn the dynamics of that and understand what are the major issues that as a board you have to deal with. Some of them are the same, they are basic financial performance and quality and patient care but there are always nuances depending on where you are in the delivery system, so it was a learning curve again coming back. (Non-consumer member interview)

Well, I think primarily they were interested in my background in finance. As you [are] aware, the Board has certain guidelines as to its makeup in terms of how many consumers, but it also has a need for educated people that have knowledge in certain areas of expertise, you know its career in the world of finance. Of course there are a lot of other professionals on here too. And in my case, it's the technology experience with on the board. They kind of needed to have somebody with that knowledge and understand the technical lingo and that kind of stuff, so I think it's my primary role, but at the same time I have connections... some connection to the community, and then also my knowledge of how different things in the community operate. (Non-consumer member interview)

My background in accounting and being able to analyze and write reports, analyze where we stood financially.... [and in addition] that people, they all had a lot to offer, and you better listen because there's nobody there that knows everything and they certainly can add your knowledge and your background, so I'm saying to that extent I learned. (Non-consumer member interview)

I used an example of talents and we all have talents we must bring; yours are different from mine, that's a strength. (Non-consumer member interview)

In the examples provided above, board members noted that roles were effective and also acknowledged that the different talents, experiences, and training of those board members was how the diversity of the board represented strength. The individual people were invaluable because they composed the board; however, their strength was also in the diversity of perspectives and experiences they represented as a collective.

#### **Difference in the quality of citizen participation between consumer roles.**

There was a distinction found in the data that articulated a difference in consumer roles on the three boards. This difference was consistently noted throughout the three sites as well. Specifically, as Wright (2012) pointed out, there was a difference between non-representative and representative consumer board members that impacts the quality of citizen participation for these board members. In other words, non-representative consumer members had higher status occupations and economic situations whereas representative consumer members more closely represented the population served by the clinic. This difference could be a result of the power difference between non-representative and representative consumer members in this study, though this was not explored explicitly with this research design but begs for investigation in the future. The question is what is the origin of this difference and how might it impact the quality of

citizen participation for CHC board members. As noted above, the population that is typical of the patient community of CHCs in Iowa is more commonly uninsured, below 100-200% of the Federal Poverty Level, and lives in a rural area compared to the general population. Additionally, these board members were more likely to be enrolled in Medicaid but less likely to be enrolled in Medicare as compared to the overall state or national population<sup>2</sup>.

This difference in representation by non-representative and representative consumer members was articulated by both consumer and non-consumer board members as well as by the chairs of the boards from each clinic. The difference was not mentioned by the national or state policy experts, however, or by the directors of the three clinics. Here are a few examples of board members and board chairs articulating this difference:

Well, like for consumer member X, he [has professional training in the medical field]. Now, how many people go on to the clinic everyday are [in the medical field as patients], ever? And now, consumer member Y, I don't know what she did, but she was not the same – I don't know how you put it, same level or same place that consumer member X is. (Non-consumer member interview)

So that patient can be defined as any, you know, an active patient with a record. I am a unique patient because I don't need to go, I think I have a wart on my foot, I don't have anything I need to go for, so it is hard to answer that question because the hope is that our patients are average day people. (Board chair interview)

In answer to the question, “How do you see the role of the consumer member?”, this participant responded as follows:

I think that's a real hard question and I think, yeah, I have to say this, I think we don't have a consumer that reflects the economic status of the majority of our clients. (Non-consumer member interview)

This board member provided a few examples to articulate her/his point:

And the young women had and she was a single mom and she had a [child] who had [a learning disorder], so [this] was a child that needed lots of attention and it would be difficult for the young women [to participate], many times she had to do phone conferencing...And the time of our board [meetings] -- she is trying to get the kid ready for school and getting and have some kind of structured environment for the kid. So, I thought that and I think that time impacted her ability [to participate]. So, but now we have people like consumer x, [they] are a

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<sup>2</sup> Source: <http://www.nachc.org/client/documents/IA10.pdf>; [http://www.nachc.org/client/state\\_X\\_key\\_facts\\_2009.pdf](http://www.nachc.org/client/state_X_key_facts_2009.pdf)

consumer [and] consumer y, [they] are a consumer. I think one is a consumer and they're well educated people. So they contribute to the board by virtue of their background where this young woman I mean was really willing to serve but the circumstances for her [made it hard]. (Non-consumer member interview)

This board member articulated a difficulty of the board in engaging representative consumer members in the board's activities because of their social, economic, or health circumstances. In addition, it also reflected the board's unwillingness to accommodate a specific need of a representative consumer board member in order to facilitate his/her participation. Another board member commented on the difference between a wealthy and a non-wealthy consumer:

Well I mean, let's say you have someone who was homeless and became incredibly wealthy somehow they might need not to go through all the hoops, well if you want to call it, or being a representation or applying but as someone who gets a scholarship (in order to go to a meeting). (Representative consumer member interview)

These comments demonstrate an interesting divergence in the agreement many participants identified regarding the definition of a consumer member as well as the role of the consumer in the structure of the CHC board with who those consumer members actually are. This seems to represent a difference between the theory of a consumer member and the application of that theory, which both non-consumer members and consumer members discussed. This difference between theory and application will be discussed in greater detail in Chapter 6.

### **Board Members' Movement on Arnstein's Ladder**

To revisit the absence of roles within Arnstein's ladder, as mentioned previously in this section, a discussion of board member's movement on the ladder rounds out the discussion. Through the information collected and analyzed it was discovered that there was movement of members on Arnstein's ladder, not only across the clinic's board, but also within each board member. I assumed entering into this study that board members would finitely describe their experience as being at one place or another on Arnstein's ladder and that finding would be consistent enough to determine the position the entire board might have on the ladder. Interestingly, when information from the interviews was

analyzed using Arnstein's ladder, evidence from individual board members was concentrated in the top grouping.

This finding suggests that board members experiences more closely resemble quality citizen participation given their high positioning on the ladder. In this grouping, collectively called the degrees of citizen power and represented by *partnership, delegated power, and citizen control*, 24 pieces of evidence were identified. The next highest concentration was in the middle grouping, called degrees of tokenism and represented by *placation, consultation, and informing*. Only five pieces of evidence were identified in this grouping. Finally, in the lowest grouping, called non-participation and represented by *therapy and manipulation*, only three pieces of evidence were identified. Using Arnstein's ladder alone, the findings demonstrate that participants in the study place their experience high on the ladder of citizen participation suggesting that they feel they have legitimate voice on the CHC board. However, what is less clear is whether this finding means that power has been redistributed amongst board members.

More specifically, the same board members, both consumer and non-consumer members, provided information that placed them at different points on the ladder when they discussed different issues. For example, a non-representative consumer member shared the following information that placed him/her in all three groupings of the ladder:

*Degrees of citizen power – citizen control:* My input has more weight, especially on matters [related to his/her profession].

*Degrees of tokenism – placation:* [It is] difficult to locate someone in the patient community who has their act together that they can be relied on [to participate on the board] (noting that the board really only has one person who truly fits the description of a consumer).

*Non-participation – manipulation:* Under [the different board structure], we [as a board] we could make recommendations but really couldn't do much other than that. (Non-representative consumer member interview)

Another non-representative consumer member provided information that placed him/her on different points within the degrees of citizen power grouping and the degrees of tokenism grouping, but she/he had a high educational background similar to the non-

representative consumer member mentioned above, suggesting that something else explained this difference. For example, this member described the following examples to demonstrate a presence in all three areas in the grouping:

*Degrees of citizen power – delegated power:* My primary committee has been the quality improvement committee, I've been on that forever since I became a board member and I was chair of that committee until I became board chair and then [as] board chair, I don't feel should be a committee chair. The committee chair has to sign off on that as the board chair, this is ridiculous now I mean signing two places, no, I'm not – that's not right. I think that it should be a separate individual.

*Degrees of tokenism – placation:* [The weight of my participation] varies sometimes I am taken at value and other times questioned. (Non-representative consumer member interview)

Board members did not specifically identify moving from grouping to grouping and level to level within Arnstein's ladder because they were not asked to specifically place themselves on one level or another. However, I assumed that within one interview, all information would point to the presence of that board member on a certain consistent place on Arnstein's ladder, and generally speaking that was not the case.

The previous section discusses the influence of roles in the process of quality citizen participation by reviewing both the participants' perceptions of their roles as well as the identified difference between representative and non-representative consumer members on how the importance of the consumer role is translated into action for those particular board members. Participants positioning on Arnstein's ladder is discussed to demonstrate that the influence of roles is absent within the ladder's configuration, and illuminates the complexity of the quality citizen participation process.

### **Outcome of Interest: Quality Citizen Participation and Its Influence on Policy Development**

The above sections in this chapter discuss the process of quality citizen participation according to the participants in this study on CHC boards in Iowa. An important outcome of this quality citizen participation process which addresses an interest identified by the main research question guiding this study is how the quality



citizen participation influences policy development. More specifically, I will address (a) the general role of the board in influencing clinic level policy, (b) the role of non-board members on clinic policy development and (c) the factors that influence participation at the state and federal levels of policy. The data analysis demonstrated a clear difference between the articulation of the board's role in policy development for the clinic and what factors influenced that board participation at state and federal levels of policy development.

Because of the nature of the CHC board's work, it was important to get a sense from multiple perspectives what role the board had in policy development. First, the national policy expert stated:

Well, it [the CHC board] is the governing body. There are a set of services that every health center is required to provide, but they're pretty straightforward services—preventative medical care, treatment for injury and illness, radiology x-ray that is appropriate, and voluntary family planning, that's a required service on the health centers, and there are other services like oral health. The only thing in dental care that is required is preventive dental care. The health centers are permitted to provide restorative dental care and other kinds of oral health services. Mental health is not even mentioned as a required service. Substance addiction treatment is an allowable, but not a required service. (D. Hawkins interview)

So when asked about the role of the board in policy development, Mr. Hawkins first mentioned the services decisions the board had to make in order for the clinic to provide the most relevant services needed based on their community. Mr. Hawkins then focused on the other clinic-level policy decisions made by the clinics, which included:

So, health centers do all of this stuff, and the governing boards are the ones who decide, you know, what services will be offered beyond those that are required, what hours clinics will be open. There's a minimal statement in the law that they must have evening and weekend hours, but there's no rules.... They have to hire and fire the executive director. But the Board is and must be the only organization level that selects the director of the health center or the CEO. [The Board makes decisions about the]...annual budget. [The board] receives regular financial reports on their operation. [The board] oversees the annual agency-wide audit that's performed in accordance with federal cost-accounting principles called A-133, and it's an agency-wide audit, so whether that health center has the senior citizens home or housing or daycare... I mentioned. While the law says that patients below 100% of poverty must be charged no fee or at most a nominal fee, and that patients over 200% of poverty must pay the full amount of what would be a cost-based charge system or fee system. The law allows those in between 100 and 200% poverty to pay on what's called the Sliding Fee System, but there

are no hard rules for that, and the boards decide what the nominal fee will be, whether there's any nominal fee at all for the lowest income folks, and they decide what the sliding fee will look like. (D. Hawkins interview)

The expert then described the other policy decisions about the CHC the board has to make that are both in compliance with federal regulations and match the needs of the community. This was a helpful perspective to begin this examination of the boards' influence on policy because it provided background on the letter of the law that governed the CHC boards.

### **General Role of the Board in Influencing Clinic**

#### **Level Policy**

Each clinic's leadership identified roles for the board in policy development that were strikingly similar. These roles included financial checks and balances, approval of grants, hiring and firing of the clinic director, choosing the services the clinic will offer, maintenance of high-quality service and fiduciary responsibility, and ensuring that the clinic is in compliance with federal guidelines governing the clinic. For Clinic A's board chair, the job of the board chair is to "oversee the board and make sure we are doing the primary functions that we need to do" (Clinic A, Clinic director interview). Those functions included overseeing the committees, maintaining the relationship between the board and the board's one employee, the clinic director, reviewing the budget, maintaining high quality, overseeing fundraising to support various activities at the clinic, and making sure the board was in compliance with the requirements of HRSA. When this question was asked of Clinic A's director, the same information was conveyed. The clinic director also described a tight working relationship between the leadership and management team to "really assess and review whether or not we need policies and to write them...so [the board] will review contractual type situations, whether we should enter into a contract for something, the day to day policies and procedures, they review or approve them" (Clinic A, Clinic director interview). The leadership/management team of the clinics consists of individuals who oversee the various departments in each clinic. For

example, these individuals include the medical director, the Chief Operating Officer, and the finance director. The director mentioned that the board does not review all of the policies because of the board's trust in the management/leadership team. The clinic director finally mentions a big piece of policy development at the clinic level that the board has a hand in and that is strategic planning. The director described it as follows:

Every two years we do strategic planning, and so to have them [the board] involved in that process, you know, they can offer their guidance and suggestions there, but again, it's the leadership and management that come together to really work with the consultant (whom they hire to help in the process as well) to, you know, fine tune that plan and then we take it to the Board for their approval after that. (Clinic A, Clinic director interview)

This articulation of the role of the board in strategic planning demonstrated that in this process specifically, the clinic director viewed the board as important in offering guidance and suggestions to develop a plan that then gets vetted by the leadership and management team before coming back to the board for approval. This process worked for this clinic because of the aforementioned trusting relationship between the leadership/management team and Clinic A's board. The relationship was reinforced in other interviews with board members, so it appeared that all agreed that this relationship existed.

One board member at Clinic A articulated this relationship in his/her response to the inquiry of the role of the leadership/management team in strategic planning. The member stated that when it comes to who is accountable for meeting the goals made during the strategic planning session, the staff of that specific department was identified. The member then said that "the board holds [those] employees accountable" (Non-consumer member interview). Another board member agreed that during the board member's initial interview in the process of becoming a board member, she/he asked explicitly about the chair of the board's view of board governance and the chair responded that it was oversight and not operations because operations was the responsibility of the staff. A third board member at this clinic commented that within the

health center, the board “plays a very active role because we have to approve policies or changes to policies” (Non-consumer member interview). So the distinction was made in Clinic A’s board between the day-to-day operations of the board and who was accountable for meeting goals and who was the one who set the policies that govern those day-to-day operations. However, this process most likely worked because there seemed to be a trusting relationship between the leadership/management team for this clinic. Although other clinics handled this relationship and this division of labor differently, similarities still existed.

The clinic director of Clinic B identified a number of activities and responsibilities of the board within their clinic. More specifically, she/he recognized that “the board did additional fundraising, understanding what is needed and engaged in financial monitoring thru renovations (of the clinic) and stayed within the budget. Sometimes (the) board directs policy making” (Clinic B, Clinic director interview). The clinic director went on to say, in terms of the board *occasionally* directing policy making, that most often the staff identified a need and developed something that was sent to the board for approval (Clinic B, Clinic director interview). This is the process that started the conversation, and then the board read the proposal prior to the meeting and came prepared at the meeting to ask questions. This interaction was made possible because, according to the clinic director and board meeting observations, “senior staff participates in board meetings” (Clinic B, Clinic director interview). Another key feature that made this interaction possible was the relationship between the clinic director and the chair of the board.

The chair of Clinic B’s board was very clear as to the board’s role in facilitating this process between the clinic director, leadership staff, and the board. More specifically, he/she described it as follows:

My direct role is to be that conduit between our board and committees and (the clinic director). I really see this [role] as an additional sounding board to be able to connect with, whether it be with an employee, a board member, a committee

member, hear their concerns, comments, feedback, ideas, hear that from (the clinic director) as well as staff and try to allow people either step in or step back and encourage our (clinic director). So (the board) [are] amazing in that sense, but (the board) knows...where does our organization need to grow and it needs to grow from the developmental side. The developmental side is finance; funding, marketing, etc. and so we are trying to address that. (Clinic B, Board chair interview)

The board chair of Clinic B had finance experience and so was skilled in the financial aspect of the work of the board, which complemented nicely the skills and strengths of the clinic director and the experience of the board members. The role of the board members in this process was unique to this clinic given the number of board members with a great deal of experience on the board and also the various board members with experience in policy making. In the case of Clinic B's board, there were a number of board members who had been with the organization in some capacity or another for many years. Although the clinic director identified that the board's policy development interactions for the clinic's operations typically began with the staff, the board was very active in the process once the proposals were made to the board. The role of the board chair as a "conduit between our board and committees and the clinic director" was unique given the characteristics of the chair alongside the longstanding relationship of the clinic director with the majority of the board given their history with the clinic and each other; this uniqueness was articulated by board members during several interviews.

One non-representative consumer board member referred to both the experience with the organization and the retired status of the more vocal board members as contributing to that board member's involvement in policy development. This board member also identified another entity of influence, the IAPCA, as a driving force in the involvement of board members in policy development by keeping them informed and providing opportunities for that involvement with policymakers. For example, the board member said:

We have people they are very involved like [retired non-consumer member] is really a policy expert who is out there. And I guess... the people that are retired they have more time [on] their hands are more involved with that part of it. We are interested but as far as pushing the policies a lot and just going up to capital

do that kind of stuff, we do it sometimes [when the IAPCA organizes it]. (Non-representative consumer member interview)

A representative consumer member also noted the more veteran board members on the board as an asset in policy development, when he/she said, “There are three board members that have been on the board for years, even when I started they were there, and they are really, really good on doing policies” (Representative consumer member interview). Another representative consumer member reported that the clinic director is crucial in the board’s level of involvement. Specifically, the consumer member said:

A good deal [of the work comes from] [the clinic director]. But those [board members and leadership team members who do not go to Washington] will just answer [to] the chair person for the Executive Committee and interact in the Washington fully [by having] complete contact with the head of the health centers nationally and [they] would meet with these people. Yeah, but they are on their toes. They keep informed and they keep us connected and informed about needs. (Representative consumer member interview)

Clearly, for these two consumer members, the process of the board having a hand in policy development was facilitated by resources located outside the board: the IAPCA and the leadership team within the clinic.

For Clinic C, many of the same ideas emerged regarding how the board was involved in policy development. From the perspective of the clinic director, the board acted as a “backstop” to make sure what was happening with the clinic was legitimate. In addition, the clinic director indicated that a signal to the leadership team (including the clinic director) that the policy needed to be tweaked to be clearer were instances when board members did have questions. This idea was a check and balances notion not raised by other clinics, but it spoke very directly to the unique interest in community governance that the CHCs possess.

There were similarities between the clinic director and the chair of the board for Clinic C. More specifically, the chair listed the following responsibilities that characterized the board:

We perform oversight. We are a test of reasonableness. We are a sounding board for ideas. We are an endorsement for changes in the way that we operate. We are

the last review before publication of everything relating to finances to our regulators as to how effectively we operate. (Clinic C, Board chair interview)

Another comment that confirmed this unique characteristic regarding the board's role in policy development was the clinic director's statement that the board was "the eyes and ears out in the community." This comment was made to describe how the clinic ensures it is meeting the needs of the community, but was also made in terms of quality of services at the clinic. The clinic director pointed out that consumer members in particular acted as advocates for the clinic in the community. This advocacy role was identified by board members as well. As one representative board member articulated, "I mean I advocate for the clients I serve to the board and I advocate for [the clinic]. I'm quick to bring out hey, these are the changes that [they] are doing [to make things better]" (Representative consumer member interview). A non-consumer member described the advocacy ability of a representative consumer member who was no longer a member of the board as follows:

[H]e was very – he kind of looked out for the Hispanic community. I remember him because he was so outspoken, he represented the Hispanic consumer very well. He spoke to issues that normally someone in that may not see as it relates to the Hispanic population and things like that. (Non-representative member interview)

This advocacy characteristic made the CHC board relevant to the communities they served and distinguished them from other organizations who service communities where the majority of the consumer population comes from low-income, under or uninsured, minority populations because of the presence of consumers at the policy development decision-making table. Moreover, this characteristic was evident in the experiences of not only board members but also clinic leadership and staff.

### **The Role of Non-board Members in Clinic Policy**

#### **Development**

The participation of board members in policy development at the clinic level aligned with the perspective that not just one level of influence shapes this experience, but many. Accordingly, non-board members influence board members, which in turn

influence clinic policy development. As discussed in previous sections, the leadership/management team appears to have a significant role in facilitating the board's influence and participation in clinic-level policy, however, these teams' influence cannot be directly examined in this study since these team members were not a part of the study sample. However, the leadership/management team's influence on clinic policy development was confirmed by board members across all clinics:

Our Board I think is probably typically a little bit more hands off [than other CHC boards], but they rely on the leadership and the Management Team to really assess and review whether or not we need policies and to write them. (Clinic A, Clinic director interview)

They bring things to us whatever it is that they as the leadership team need to change, they have a great leadership team and I think they have the [community health clinic's] best interest in mind. (Clinic C, Representative consumer member interview)

We really have an excellent staff, [the clinic director] (and the other members of the leadership and management); they have my confidence completely and if I have questions and so forth, they for sure get them answered. (Clinic B, Non-consumer member interview)

Leadership staff provides great leadership; this is an improvement over the past. (Clinic C, Non-consumer member interview)

Highly qualified leadership staff; leadership team understands that role (Clinic C, Clinic director interview)

We made a decision (as a board) a while ago that our board's function was to support the management team and to not be meddling in the affairs of the clinic. (Clinic A, Board chair interview)

Where the clinics differed regarding the way the leadership/management teams interacted with the board was through their level of involvement or participation at monthly board meetings and within the committee structure. According to the board meeting minutes analyzed and the board meetings observed for Clinic A, the clinic director was the only leadership/management team staff who attended the board meetings. The clinic director commented that he/she communicated frequently with the leadership team of the clinic and acted as the conduit of necessary information between the board chair and other board members and the leadership team. The interactions of the



staff at the committee level were unclear, but the presence of staff during the committee meetings was not mentioned in any data analyzed for this study. Also, board members presented committee reports at the board meetings, which suggested that the involvement of staff in the committees was supplementary.

For Clinic B, the situation was a bit different. Leadership/management team staff attended board meetings frequently, with variation contingent on the topics being discussed and what that particular staff person brought to the conversation. For example, if a financial issue was “hot” on the agenda, the head accountant of the clinic attended the board meeting to give a report and answer any questions relevant to the discussion at hand so that board members were as informed as possible. The level of involvement of staff at the committee level in this clinic was unclear, but board members also gave committee reports, which suggested involvement that was similar to Clinic C.

For Clinic C, the situation was quite different. Leadership/management team members attending board meetings and, in some cases, presented reports for the committees on which they served. The exception to this was in the case of the quality committee report, which was given by a non-consumer member who had been the chair for a while and seemed to command great respect among the board members. Leadership/management team staff seemed very involved with multiple aspects of the committee structure, not only presenting the committee reports but also attending committee meetings.

Overall, the policy development process at the clinic level is influenced by multiple factors which include non-board members privy to board activities. As demonstrated above, the three clinics in the study varied as to the level of involvement of the leadership/management team in the work of the CHC boards. Due to the exclusion of these non-board members in the information collected for this study, however, it is not known what factors influenced this variation on involvement. As is discussed in Chapter 6, a future endeavor with this line of research would be to include these non-board

members in an exploration of the CHC board participation experience to hear various perspectives as to the variation of this involvement.

### **Level of Involvement of the CHC Boards in State and Federal Policy Development**

Although the level of involvement of the CHC boards in state and federal policy development varied among the three sites, consistencies emerged. These consistencies included the external factors that influenced board member participation in these policy-development processes, such as the existing relationships between clinic staff or board members and policymakers and the support provided by outside organizations such as the IAPCA and the NACHC. These consistencies also emerged from an analysis of the primary record of data as well as through interviews with board members; the clinic staff or leadership/management team were not part of the study design so their perspective on this issue was not solicited.

Across all three sites, the clinic directors were identified in other places within the data as having relationships with local, state, and federal policymakers in their areas. For example, when Clinic B expanded in their city, they organized a ribbon cutting ceremony and a member of the congressional delegation of Iowa attended and spoke (Non-representative consumer member interview). In another example of this relationship, board members of Clinic C noted that the clinic director facilitated the relationship skillfully between the work of the clinic and a number of policymakers in their area (Non-representative member interview). And when Clinic A was recently awarded a grant to expand their work, board members and the clinic director alike noted that a congressional delegate member had a hand in the clinic's being awarded the grant (Clinic A, board member, and clinic director interviews). A board member from one of the clinics had this to say about the clinic staff and their relationship with local policymakers:

I think [medical director] is very active in making those kinds of connections. I think [clinic director] was also very active in making those kinds of connections,

because of wanting to access grant dollars. (Representative consumer member interview)

Across the clinics and in multiple ways, it was clear that those involved with the work of the CHCs valued relationships with policymakers at various levels and that those relationships were cultivated and maintained from multiple directions.

The support provided to CHC boards by outside organizations such as the IAPCA and the NACHC was another consistent finding across all three sites. As stated in Chapter 4, the IAPCA “provides technical assistance and training to Iowa community health centers to support their ongoing commitment to provide quality, affordable primary and preventive health care to the underserved in Iowa” (IAPCA website, <http://www.ianepca.com>). The IAPCA provides assistance through policy analysis of legislation that has a direct impact on the work of the CHC boards and through data collection and interpretation that assists the CHC boards in their work. The various types of support were mentioned repeatedly across all three sites as being crucial to the work of the boards from the perspective of board members, board chairs, and clinic directors. For example, one non-representative consumer member discussed this role in the following way: “The biggest impact we’ve had on policy probably is through the association... [Iowa Primary Care Association]” (Non-representative consumer member interview). The board member also described instances when the IAPCA organized lobby days at the state capitol so that different board members could meet with their legislators to discuss the work of the CHCs. Not all board members participated at this level in policy development. However, the board members who did not were able to contribute in other ways, which led to the conclusion that nonparticipation in these activities did not lead some board members to believe the nonparticipating members were not pulling their weight.

The second external organization that supports the work of the CHC boards in Iowa is the NACHC. According to the NACHC website:

...works with a network of state health center and primary care organizations to serve health centers in a variety of ways: provide research-based advocacy for health centers and their clients, educate the public about the mission and value of health centers, train and provide technical assistance to health center staff and boards and develop alliances with private partners and key stakeholders to foster the delivery of primary health care services to communities in need. (NACHC website, <http://www.nachc.org/about-nachc.cfm>)

As evident by their mission, the NACHC works closely with the IAPCA to provide state-level support to the work of the board.

Another key form of support from the NACHC to the Iowa CHCs is their annual conference and the events that occur during that time. Boards send one board member along with the clinic director and/or the board chair to the event each year, and during the conference these individuals receive training, attend meetings with those who are in their position in other parts of the country, and also arrange to meet with the Congressional delegation to discuss issues on Capitol Hill (D. Hawkins interview). During this conference, called the Community Health Institute & Expo, the NACHC also hosts a series of trainings specifically for board members. The board members who attended these trainings reported that they were a significant aspect of their membership on the board that facilitated the quality of their participation. Specifically, board members discussed this experience in the following ways:

I love going to that and I love going to DC and lobbying and going to different community healthcare, it's just a good way to meet people and see what's going on nationally.... So yeah, you go to Washington DC and it's such a great energy because there are these people from all over the country... I would recommend it to anybody. I think every board member should go.... Yeah and it's just such a great time to just talk to the legislatures and kind of get your need out there and just meet up with other board members and others because it mostly board members. (Representative consumer member interview)

I think part of it just all the time I have been on the board, but also this past March I went with the board president and the CEO to Washington DC. They were doing some lobbying but I was also at that time I was able to attend a board member boot camp so when I did that it made more sense to me and I felt more empowered. (Non-consumer member interview)

These comments from one consumer member and one non-consumer member from two different clinics demonstrate the effect of attending this conference on their

understanding of their work and how it fueled the passion they felt toward what the CHC was doing for their community.

This last section in this chapter discusses the outcome of the quality of citizen participation on policy development. The section discusses the difference among participants to the general role of the board in influencing policy, the role of non-board members (e.g. leadership/management staff) in facilitating the participation of board members through their varied levels of involvement with the board and the level of involvement of the CHC boards in state and federal policy development. Relationships were found to be crucial to facilitating the participation of CHC boards in policy development at both the state and federal levels, and the relationships specifically of the leaders of each clinic were identified across the information collected as important. However, it is difficult to surmise whether these strong relationships by the leadership of the clinics mean that board members have a quality citizen participation experience in their role as board members. The organizational support provided by the Iowa Primary Care Association and the National Association of Community Health Centers did appear to have an impact on board member's ability to engage in policy development, which suggests that these entities could be places of intervention in order to improve the quality of citizen participation for CHC board members across the state.

This chapter focused on the board meeting observations and interviews with clinic directors, board chairs, and consumer and non-consumer board members to explore the question of how CHC boards facilitate the quality of citizen participation in policy-development processes. This exploration included a description of the sample characteristics of the 16 board members who participated in the study, an analysis of board members' participation through the lens of the socio-ecological perspective, a description of the process of quality citizen participation, an analysis of measures used to objectively and subjectively understand this process of quality citizen participation, a discussion of board member's roles in the process of quality citizen participation using

Arnstein's ladder of citizen participation and the impact the process of quality citizen participation has on policy development for CHC boards in this study. Chapter 6 will provide a deeper analysis of the information presented in Chapters 4 and 5, present the limitations of this study, and conclude with implications of the study for social work education, community, and policy practice.

## **CHAPTER 6**

### **DISCUSSION AND IMPLICATIONS**

#### **Study Summary**

This study explored the experience of consumer members who participated on the boards of CHCs in Iowa. CHC boards were chosen because of the unique requirement that their board composition have a 51% patient majority. The aim of the study was to understand how three CHC boards in Iowa facilitated the quality of citizen participation in policy development processes. Using a critical ethnographic methodology, the entire context of the CHC boards who participated in the study was examined with data obtained from interviews with national and state policy experts; from general descriptive demographic statistics of the counties served by the clinics and demographics of the patient communities for the three clinics; and from interviews with clinic directors, board chairs, and consumer and non-consumer members of the three boards.

The conceptualization of quality citizen participation was derived from Arnstein's (1969) ladder of citizen participation, which suggested that for those with less power to have a legitimate voice in policy development and decision making, those in power must relinquish that power. This relinquishment of power results in power redistribution and privileges the voices of disadvantaged and marginalized citizens. The 51% consumer majority is a unique feature of CHC boards and provides a structure to facilitate the quality of participation of board members. However, the data showed that the picture of a quality citizen participation experience was more complex than what is reflected in Arnstein's ladder and suggests that quality participation is about more than the redistribution of power.

The present chapter will synthesize all information gathered and analyzed for this research and, in the first section, discuss the following topics: (a) the inconsistencies between the spirit of the 51% on CHC boards and the reality, (b) the limitations of Arnstein's ladder of citizen participation, and (c) the missing links to understanding the

quality of citizen participation. This chapter will then conclude with the implications of the study findings for future research on citizen participation and the implications for community policy and practice and the strengths and limitations of this research

### **Inconsistencies Between the Spirit of the 51% and the Reality**

This section synthesizes the primary record information of Chapter 4 with the board meeting observations and board member interview information of Chapter 5. Three themes emerged from this synthesis that are relevant to understanding the quality of citizen participation within the three CHC boards: 1) evidence of the spirit behind the 51% patient majority in the work of these boards; 2) the definition and representation of consumer board members; and 3) the challenges faced by CHC boards to match their consumer members with the community (both county and patient) served by the clinics.

The spirit that motivated CHC program designers to require that service consumers make up the majority of board members stemmed from a commitment to legislatively require giving voice to disadvantaged or marginalized communities typically excluded from these processes (D. Hawkins interview; Geiger, 2005). The purpose of requiring a majority was that those previously excluded voices would not only be at the table but also have legitimacy in the decision-making process because of their experience as consumers of the services.

**The spirit behind the 51% majority.** The first person interviewed for this study told many stories about the intention behind the patient majority characteristic of CHC boards (NACHC policy expert, D. Hawkins interview). CHC boards were chosen as the setting for this research because the 51% patient majority/consumer requirement presumably meant that CHC boards had, as part of their structure, a mechanism to provide a legitimate voice for disadvantaged and marginalized CHC consumers. However, a question remained despite the fact that CHC boards had met the 51% patient/consumer requirement on paper: Did this requirement legitimize the voice of



consumers on the three CHC boards in the study? The data analyzed across Chapters 4 and 5 present a complex picture of not only whether the CHC boards met the majority requirement but also how they infused the spirit behind the requirement within the work accomplished on the boards. This complexity suggests that CHC boards contributed to the consumers' ability to have a legitimate voice in the policy-making processes of these boards. This conclusion stems from multiple sources of information demonstrating their saturation within the material collected.

First, clinic directors expressed the spirit behind the majority requirement when they described the strengths and benefits of having patient majority participation on the CHC boards. For example, one clinic director indicated that the consumers who relied on the CHC as a medical home had experience with the programs of the CHC (Clinic B, Clinic director interview). This same clinic director related the consumer members' experience as a crucial factor in the CHC's ability to meet the needs of the overall patient community. The clinic director also identified the benefits the consumers brought to the board that were in line with the spirit behind the patient majority requirement (Geiger, 2005; D. Hawkins interview; Lefkowitz, 2007; Sardell, 1988).

Another clinic director referred to a discussion about increasing the sliding scale fee for low-income consumers and the ways in which having input on this issue from consumers on the board was particularly helpful: "...having their input in that particular situation of what the reality is of what they can afford and can't afford, you know, when you have them telling us, 'Well, if I have to pay \$50 I'm probably not going to come because I don't have that money because I need it for groceries'" (Clinic A, Clinic director interview). As evident by these examples from clinic directors, there was evidence to support the notion that having a consumer perspective on the board was important and contributed in significant ways to the work of the board, a sentiment that is in line with the spirit behind the consumer members' positioning on the CHC boards.

However, the clinic directors who held leadership positions within the CHCs did not acknowledge the importance of consumers having a majority opinion on the boards, only that the consumers' perspective contributed in a unique way to the CHC board's work. According to Arnstein (1969), it would appear that the conceptualization of a legitimate voice in the policy processes the consumers are there to provide is absent. The spirit of participation found in this study was more in line with findings from Checkoway, O'Rourke, and Bull (1984). In their review of literature on the importance of consumer participation within CHCs, Checkoway et al. (1984) reported that although consumer participation was "intended to enhance participatory democracy and improve health planning" (p. 296), the "record of participation in [health] planning has been mixed" (p. 296). Checkoway et al.'s review of the consumer participation literature questions the accuracy of equal access to participation and fits with this study because it calls for more information regarding the process of participation for those whose voices represent traditionally excluded communities.

The CHC board chairs in this study shared a perspective about the spirit of consumer participation similar to that of the clinic directors. Board chairs' acknowledge the consumer's contribution to the overall work of the CHC board. For example, one board chair described consumer participation in this way: "I would say, for the most part, it [consumer majority piece of the board] is a huge plus, having people who are in the clinic gives you a natural pulse on what is really happening operationally" (Clinic A, Board chair interview). There was a shared sentiment among the board chairs that consumers contributed in significant ways to the board's ability to have an accurate pulse on the effectiveness and quality of care of the clinic. Their comments, however, did not reflect consumer board members empowerment. Such comments seem to provide evidence that are contrary to Arnstein's (1969) contention that power redistribution is necessary for consumers to have a legitimate voice in the policy development processes of the board. Instead, it appears that evidence was not found to support the notion of

Arnstein's requirement that there be power redistribution in order for those with less power to have a legitimate voice. The evidence from interviews with board members, both consumers and non-consumers, supports the notion shared by clinic directors and board chairs that consumers made a unique contribution to the board that was equal to the contribution made by non-consumers on the board.

Both consumer and non-consumer board members identified the benefits of having consumers represented at the decision-making table for the CHC boards. When asked about the role of consumers on the board, one non-consumer member responded, "The consumer can tell you about their experience, [and they] might make it more in a positive [light] or that they might not have a lot to say [depending on the circumstance]" (Non-consumer member interview). A representative consumer member, when discussing his/her experience with representing the consumer perspective, stated: "When I go to the [clinic] to get a service, you know I look at the facility, I look at how we, when you come in, how they treat you, and how things are done, so how was the experience in how [I] was treated and how was the service?" (Representative consumer member interview). This consumer articulated what was described by the previous non-consumer about how the consumer members contributed from their experiences to give input about the facility's services. This consumer member did not view him/herself as a voice for all consumers but rather was sharing his/her experience as a patient of the clinic.

A second representative consumer member described representation on the board by consumers as being a part of a whole:

It takes all of us to make a full decision on it. So, you know, that's one person putting in a tenth, if there is 10 on the board, that one tenth kind of helps the other nine tenths to see the whole picture. So you know, with ten tenths then you get the whole picture then it kind of makes it fall into place. (Representative consumer member interview)

This consumer agreed with what other board members shared about the role of consumers on the board, which is that the consumer voice is one of many in the mix, but did not articulate that the benefit of consumers' presence was related to the patient

majority that consumers are required to hold on the board. This finding questions whether the existence of the patient majority element on the boards makes a difference in the legitimate voice consumers has on the board, and instead draws attention to the necessity of the patient majority element to ensure that any consumer voice is present at the decision-making table in the first place. Although this finding supports the importance of having a patient majority requirement on the board, what is less clear is whether this importance translates to a legitimization of the consumer voice on the board.

**Consumer board member definition.** The definition of “consumer” on the board was another theme that emerged from the data presented in Chapters 4 and 5 that shed light on the patient majority requirement of the CHC boards and its ability to ensure quality participation as defined by Arnstein (1969). This definition might contribute to the consistent findings in this study that seemed to overlook the importance of the patient majority factor in power redistribution within the CHC boards. As discussed previously, the clinic directors, board chairs, and representative consumers as well as non-consumers identified the unique importance of the consumer presence on the CHC boards. What is less clear from the data is whether having a 51% consumer majority accounted for or contributed to quality, despite the requirement that these traditionally excluded voices be the majority on the board. This inconsistency reflects a strand in literature on CHC boards that deals with representation and revolves around the way consumers are defined.

To better explain the theory of the consumer definition, the definition’s origin is important. This definition, which was derived from the Health Resources and Services Administration (HRSA), indicated that a consumer was someone who used the CHC as their usual source of care for one visit within the last 2 years (NACHC, 2005). Absent from this definition is how to decide which consumers of the clinic should be involved in the policy-making processes of CHC boards (Singer, 1995). The question which comes to mind is whether those who are representative because of their experience should be targeted for inclusion, or those who are non-representative because of their complex

identities and the multiple attributes they bring to the board be the focus of recruitment? This question leaves room for subjective interpretation of whom these consumer board members are and how they might represent the patient population of their respective clinics.

As discussed in Chapter 5, Wright (2012) explored this issue of representativeness with CHC board members across the country and divided board members into three categories: non-consumers, representative consumer members (who resemble the majority patient community economically), and non-representative consumer members (who, although consumers of the clinic, have an economic background that does not resemble the patient community). Wright (2012) found that out of the 2,245 board member profiles included in his analysis from Uniform Data System (UDS) reports, 31% were non-consumers, 26.5% were representative consumer members, and 42.5% were non-representative consumer members.

Wright's (2012) distinction is an important consideration given that across the data gathered for this study, the application of HRSA's definition of a consumer resulted in the presence of non-representative consumers on the three boards. Because not all board members from each of the three CHC boards participated in the study, it is difficult, if not impossible, to match Wright's findings with the board composition of the three CHC boards in this study. However, the finding that non-representative consumer board members are present on CHC boards in Iowa and that there could be a difference in these board members' participation when compared to representative consumer members has implications for the quality of participation of consumers. More specifically, it suggests that, despite the consumer members of CHC boards holding the majority of board positions, the legitimacy of voice by those meant to represent the patient community of the clinics are not at the table in the same way that the patient majority characteristic requires them to be.

Chung, Grogan, and Mosley (2012) explored the idea of representativeness in local health decision-making processes with 14 African-American and Latino residents on the South side of Chicago. The authors found that although the participants could articulate what activities a representative might participate in during health decision-making processes, they had difficulty identifying what a good quality representative would look like. For example, Chung et al. noted that participants believed that community representatives should distribute information to the community and become involved with community activities. However, when they were given a list of potential representatives, the participants chose those with technical expertise (e.g., doctors) over those who might have a more accurate pulse on the needs of the community (e.g., community organizers). Although Wright (2012) questioned the ability of non-representative consumers to accurately represent the patient community of CHC clinics because those members did not align with that community, Chung et al. (2012) discovered that the preferred choice of those who would be represented by these community representatives was someone with health-related expertise rather than someone with local community knowledge. This discrepancy in the literature on representativeness in health decision-making processes speaks to the need for further exploration of patient communities being represented in order to clearly understand how to define an accurate representative for those patients.

The theoretical definition of a consumer was consistently encountered in interviews with clinic directors, board, and consumer and non-consumer board members. However, within the definition, and not necessarily divided between representative and non-representative consumers, a difference was noted between consumer members who met the minimum threshold of the consumer definition and those who exceeded it. Of the consumer members in the study, those who met the minimum definition used a few services every 1 to 2 years (n=5), and those who exceeded the threshold used a multitude of services offered by the clinic (n=3). The utilization of multiple services by some

consumer members meant that they were physically at the clinics more often, interacted with more clinic staff, and might have demonstrated greater need as compared to the consumer members who met the minimum threshold.

These differences articulate the theory and application of the consumer definition because those who visit the CHC once every 1 to 2 years have a different relationship with the CHC, its staff, and its services than those who visit the CHC multiple times per year and/or use a multitude of services offered by the clinic. The difference also suggests that those consumers who visited the CHC on occasion might have been chosen because of areas of expertise that they brought to the board. For example, one of the non-representative consumer members who held a professional degree had been called upon in multiple situations over the years of his/her involvement with the board because of his/her expertise. The ways this difference impacts the quality of the participation experience for board members is through a consumer's ability to accurately represent those patients who are not at the decision-making table but who also utilize the services of the clinic from multiple angles. If the traditionally marginalized patients, who make up the majority of patients at the CHCs, are being represented by those who receive services from the CHC once or twice a year and who bring additional expertise to the board above and beyond their consumer identity, the accurate representativeness of that marginalized consumer voice and the quality of the participation are called into question.

**Challenges for boards to find consumer members willing to participate.**

Research has explored the difficulties in finding representatives who can speak to the experiences of disadvantaged and marginalized communities in health policy decision-making processes (Checkoway et al., 1984; Chung et al., 2012; Sleath & Rucker, 2001). Indeed, participants in this study identified barriers to finding consumers who were willing and able to serve on the boards, suggesting that CHC boards need to think strategically and creatively when engaging consumer members in order to have consumer representatives who reflect the experiences of the majority patient population served by

the clinic. Some suggestions of imaginative solutions CHC boards could integrate include flexibility of the board meeting times and creativity in incorporating multi-lingual consumer members within the boards. These suggestions address issues that CHC boards in this study faced and solutions that were offered by CHC board members during interviews, and provide interesting ideas for future work with CHC boards across the country.

To integrate consumer board members who accurately represent the majority patient communities of the clinics served, board members have to be flexible in scheduling their board meetings. For example, the majority of patients served by the three clinics were in the age range of 20 to 44 years. It is likely that many patients in this age range had children, and meeting times over the dinner hour might be difficult for consumers who are parents of small or school-aged children. If CHC boards want to engage this particular group of consumers, they will have to be flexible regarding when the board meets to facilitate these consumers' participation rather than creating a barrier to their participation.

Similarly, if CHC boards are interested in incorporating consumer members who are multi-lingual or speak a language other than English, the boards must adjust what resources are available during board meetings as well as over the course of the board member's tenure to facilitate these consumers' participation. For example, as presented in Chapter 5, Clinic A board members discussed the changes that would be necessary to accommodate the participation of a consumer member on the board who spoke another language, such as Spanish. It was suggested that recruitment signs could be posted in multiple languages, but to incorporate this type of participation, translators (who are not board members) would need to be available for bilingual board members during the meetings and information would have to be translated into the consumer's language to ensure full participation. This challenge was faced by all three CHCs in the study because the population of non-English speaking patients for each clinic had grown in the last 10



years, with different communities experiencing an influx of different languages and cultures. Because of the multiple languages represented by all three clinics (Clinic A, B, C Clinic directors interviews), this issue is multiplied. The clinics in the study were addressing these needs, evident by the multiple languages present in the clinics' day-to-day activities; the next step is for CHC boards to incorporate these changes as well.

The quality of participation on CHC boards is impacted when consumer members are not representative of the experiences patients can relate to who are served by the CHCs. When there is no voice at the CHC board table representing these specific experiences, those patients whose lives are impacted by the experiences are absent from the decision-making process. To ensure that the work of the CHC board represents the majority patient experience of those served by the clinic, the voices of that experience must be represented at the table and the barriers to their participation must be removed to ensure a quality participation experience.

Dividing consumers in this study according to the frequency with which they utilized the services of the CHC spoke to one aspect of what consumers rely on as a foundation for their participation, and is an added dimension to Wright's (2012) representative versus non-representative distinction which was only based on a consumer's occupation and household income. The division potentially differentiates between the consumers whose participation reflects a voice based on the frequency with which they use the CHC services versus the consumers who are recruited by clinic staff to join the board based on other aspects of their identity. This division does not necessarily fall along representative and non-representative consumer distinctions, however. Additionally, how this differentiation impacts whether power is redistributed to ensure an empowering experience for board members is less clear. According to Arnstein (1969), power must be redistributed if those from disadvantaged and marginalized communities are to have a legitimate voice, and a clear path toward empowerment is paved when power is redistributed to those impacted by policy when those impacted are a

part of the decision-making process (Boehm & Staples, 2004). As the data have shown, the consumer perspective is one of many voices worthy of consideration in the work of the CHC board where consumers' opinions are not privileged over others' perspectives. Given the information presented, one remaining question is whether empowerment processes are at work for consumer board members in this study which improve CHC board participation?

### **Limitations of Arnstein's Ladder**

Arnstein's ladder of citizen participation (1969) served as a theoretical touchstone for this study because the ladder focuses on citizens from disadvantaged or marginalized communities participating in decision-making processes that directly impact their lives. The CHC boards demonstrated this focus because of the emphasis on consumer participation within the structure of the CHC boards, which was why Arnstein's ladder was chosen as a mechanism to examine what the legitimate voice of those consumers were in the CHC board structure. However, data gathered and analyzed for this study revealed that Arnstein's ladder fell short in understanding the quality of citizen participation for CHC board members. Although the ladder provided a good foundation, more research is needed that reaches beyond the scope of Arnstein's ladder to understand the quality of citizen participation for CHC board members for one important reason: Passion was identified as a crucial motivator for board member's participation and dedication to the work of the CHC board, but how this passion for the work of the board impacted board members' perception of the quality of their participation experience is not represented in Arnstein's ladder. This omission excludes the importance board members place on the work they do, and how their participation fulfills the desire to help others in need. This passion was demonstrated across data gathered for this study and is illustrated in the following statements by two board members:

I felt that it's been a very worthwhile volunteering. And I would hope that other people feel the same way. I've enjoyed the last six years. (Non-representative consumer member interview)

Another board member discussed the motivating aspects of serving on the board:

I think it's a real privilege [to serve on the board]. I mean I really love it. I love all the different people, I like the way they bring and yeah I look forward to go on with those meetings. I mean honestly I try to definitely make it a priority and a commitment to at least be to the board meeting and just see what's happening.  
(Representative consumer member interview)

These board members articulated that this passion is a large part of what motivates them to participate on the board, and signals the importance of passion to these board members. However, it is unclear the role passion would play in Arnstein's ultimate goal of power redistribution other than to note that possessing the passion in the first place is a required first step towards the redistribution of power. In other words, if consumer board members do not have that passion for the work they are doing, they will eventually lose interest in the work of the board and become disengaged from participation. This disengagement causes silence at the decision-making table. Therefore, further exploration of how passion factors into the experience of disadvantaged and marginalized citizens participating in decision-making processes such as that provided by the CHC boards is important to understanding the quality of that participation experience.

Arnstein (1969) appeared to suggest that for power to be redistributed, both individual and collective empowerment must be present. Participants interviewed for this study discussed the impact of individual empowerment (for example, board members described numerous times where they felt their voices were heard) where the impact of collective empowerment on decision-making processes within the CHC boards was mentioned less frequently. Discussions about how to ensure that patients pay their bills and whether to increase the sliding fee scale were examples of how collective empowerment and the majority voice were present in policy decisions that had a direct impact on the consumers of the clinic.

A sliding fee scale is used for patients of CHCs who are between 100% and 200% of the Federal Poverty Level (FPL); those who are at or below 100% of the FPL receive a full discount (NACHC, 2005). Despite this sliding fee and the discount it provides, the

clinics still had difficulty collecting payments from patients (Clinic A, B, & C Clinic directors, Board chair interviews). In fact, one of the issues discussed by the board members across all three clinics was how to collect fees from patients who were overdue on their bills. In this instance, consumers and non-consumer members were aware of the need for the clinics to generate revenue, particularly given the high percentage of patients who were between 100% and 200% of the FPL and were also uninsured. In addition, both consumer and non-consumer members recognized that for some patients, even the reduced sliding fee was too much to pay; this issue resulted in overdue patient accounts and the clinics' loss of even the minimal amount of money generated by the reduced sliding fee scale. The boards considered how patients on a tight budget would be impacted if they were asked to pay a \$50 fee rather than a \$20 fee and how this might create a barrier to care for those patients. When non-consumer members addressed this issue in their interviews, they deferred to the particular expertise of consumers to make this decision. This example, therefore, provides evidence of the influence of a consumer majority in the decision-making activities of the CHC boards. It also suggests that the consumer members found this to be empowering for themselves and their experience on the board (Gutiérrez, 1990), thereby speaking to empowerment that comes from a quality citizen participation experience.

Evidence in the data gathered for this study suggested that both representative and non-representative consumer members experienced various aspects of empowerment through their participation on the board; however, these aspects were not always formal, but were sometimes informal. An example of informal empowerment was provided by two consumer members from the same board, one who was a representative consumer and the other a non-representative consumer. The non-representative consumer illustrated a collective empowerment experience (Boehm & Staples, 2004) by describing the ways in which he/she intentionally supported another representative consumer member of the board in facilitating that board member's quality participation experience. This non-

representative consumer described meeting regularly with the representative consumer member outside of board meetings to discuss the activities and issues of the board, which supported the representative consumer member's comfort level on the board (Non-representative consumer member interview). The representative consumer member discussed this same relationship during his/her interview as well and described it as assisting him/her to improve his/her engagement on the board (Representative consumer member interview). This exchange provides evidence of a non-representative consumer member joining with another consumer member on behalf of a disadvantaged or marginalized minority to assure that this voice was heard on the board. However, there were no responses that suggested any formal planning among consumer members occurred to support each other or to vote as a block.

This information suggests that from the perspective of participants in this study, sometimes the patient majority contributed to the legitimization of the consumer voice and sometimes it did not. For example, in the policy example of the sliding fee scale and how to collect delinquent payments, non-representative and representative consumer members united to influence a policy decision conversation that addressed changing the sliding fee scale to collect on delinquent patient accounts. In this example, the non-consumer members deferred to the consumer members. This deferment could have been the result of non-consumer members feeling it was an appropriate issue to privilege consumer voices, but did not necessarily mean that if this collective empowerment process were to occur again, the non-consumer minority would listen in the same way. In other instances, informal processes between different consumer member categories facilitated the participation experience for representative consumer members who faced barriers that non-representative consumer members assisted in transcending. In the example used, a non-representative consumer member informally checked in with the representative consumer member and provided support by answering his/her questions about activities of the board. In both examples, perhaps the complexity of the consumer

definition (representative versus non-representative) was a strength that facilitated the quality experience for representative consumers that otherwise would have been absent.

### **Environmental Influences: Missing Links Necessary for Understanding the Quality of Citizen Participation**

As illustrated by Arnstein's ladder (1969), to understand how power is redistributed in boards where disadvantaged or marginalized citizens are traditionally excluded, it is necessary to understand how multiple levels of influence impact participation, as was discussed in Chapter 5 using the socio-ecological perspective. In addition to the interpersonal, intrapersonal, organizational/institutional, community, and public policy levels described in the socio-ecological perspective, the environmental influences on the CHCs and their boards were vital to understanding how disadvantaged citizens gained a legitimate voice. The environmental influences included (a) the economic environment - the influence of the economy on the CHC and ultimately on the CHC board; (b) the political environment - the influence of local, state, and federal policy makers in facilitating CHCs' access to funding, which relied heavily on relationships between the CHCs and those policy makers; and (c) the cultural environment - the influence of the different patient populations and needs based on the various cultures served by the different clinics. In the literature on citizen participation in general and CHC boards specifically, the environmental influences are a missing link to understanding citizen participation and will be reviewed in the next section.

Data collected across this study revealed that environmental influences were important in the work of the CHC boards and that they contributed to the board's ability to facilitate a quality citizen participation experience for board members. Because of this impact, CHC boards must take stock of these environments and be mindful of them in serving the CHC to whom they are accountable. Attempting to understand the work of the CHC boards without considering the influence of these environmental factors would be like exploring the CHC boards in a vacuum. Carspecken's (1996) critical ethnographic

method was used in this study to investigate the economic, political, and cultural environmental influences of CHC board members in Iowa. Factors within economic, political and cultural environments were found to influence the work of the CHC boards in this study and are therefore important to facilitating the legitimate voice that signals a quality citizen participation experience for traditionally excluded citizens and communities.

**Economic factors influencing the work of the CHC boards.** The economic crisis of 2007/2008 was reported by participants interviewed for this study as having a multi-layered impact on the work of the CHC boards. For some participants and their clinics, the economic crisis resulted in cuts in funding at the local, state, and federal levels. For other participants and their clinics, the economic crisis was equated with the closing of a major employer in the area. These two outcomes had a domino effect on the CHCs and their boards. For example, when there is a cut in funding for a clinic, it reverberates through many aspects of that clinic. A cut in funding can result in having to lay off staff and cut services, and can mean that patients go elsewhere for care because of a decline in the quality of services. This example impacts not only the clinic, but the clinic's staff and the clinic's patients. In another example, if a major employer lays off workers in a community whose residents are patients of a CHC, the impact is felt throughout the clinic as well. If workers are laid off, they lose their employee insurance, which means they have to go elsewhere for care or they continue as a patient of the CHC but are not a source of revenue from insurance.

To illustrate this point from the data collected, one consumer member discussed the economic crisis as a consideration of Clinic B's board because of the domino effect the crisis had on funding at the local, state, and federal levels:

One of the difficult parts has been where there's funding issues and finance issues for the organization, and then we ...had to cut expenses and without doing any cutting to the services....And, as you know, with the economic situation it [funding] has been cut and cut and cut, and how we do that, and then without, or being able to fill up the positions that are vacant within the organization. You

know, and putting the burn on the employees that had to do a [lot] of extra work... And the position that we have to maintain in order to continue to do the services that we have done for years and being able to stay focused on healthcare part of the organization even if there are different services. (Clinic B, Representative consumer member interview)

In addition, participants discussed the impact of the economic crisis on employment in their clinic's area and the effect of the crisis on the clinic's bottom line. In this instance, a major employer had laid off a number of workers in the clinic service area who were patients at the clinic and who had paid for services with their employee health insurance. When the workers were laid off, their health insurance was terminated. Although they were still able to receive services from the clinic, the care was no longer a revenue source for the clinic. The board chair of this clinic described the impact: "There is a big plant here in town, [and they] closed their plant and that was about 1000 patients who were paying consumers that we lost so a lot of our efforts have been trying to make sure we have the money to keep open" (Clinic A, Board chair interview). The participant not only identified the issue, but also described the impact of that event on the work of the board for Clinic A.

The economic environment of the CHC boards affected their work in an important way. In the initial example above, when funding was cut, CHC boards had to make difficult decisions as to which services to keep and which to eliminate. Sometimes, specific funding was associated with specific services, which made the decision easier. Other times, CHC boards had to consider if other organizations in the community were providing similar services and, if so, the decision was again made easier. In more difficult instances, the particular CHC was the only provider in the area, and the board had to decide what to do about the service. Moreover, when funding was cut and CHCs had to lay off workers, the boards had to decide how to continue a high level of care with fewer resources. A representative consumer member of Clinic B described this decision as "being one of the toughest he/she had to make as a board member" (Clinic B, Representative consumer member interview), which speaks to the impact of this type of



environmental factor on the work of the boards. These economic factors are necessary to consider when exploring the complete experience of CHC board members, because these factors influence the work of the board.

As demonstrated, economic factors influenced the work of the CHC boards in this study. Given this influence, it is important to consider how these factors could impact the quality of participation on the CHC boards. If CHC boards have to make funding decisions such as eliminating services and/or staff as a result of economic factors (such as those mentioned above), while there is a question as to the representativeness of a legitimate voice from consumers, access to services vital to the care of disadvantaged and marginalized patients of the clinic patient community could be lacking. This example demonstrates how an outside factor under the direct influence of board members could potentially impact the legitimacy of the consumer voice within the CHC board structure.

**Political factors influencing the work of the CHC boards.** A consistency across clinics and across participants of the same clinic was the influence of politicians or policymakers in the work of the CHC boards. This consistency was the predominant response given regarding this influence when the participants were asked how CHC boards were involved in local, state, or federal policy development. More specifically, this consistency was the relationship between these individuals and others associated with the CHCs in order to influence decision-making processes. For example, one way participants described this involvement was through relationships between the clinic directors and local, state, or federal politicians in their areas. One board chair responded, “We have people, who to their credit grew relationships with elected officials [at multiple levels], in particular. [A senator from our area] is probably one of the most outspoken of advocates for [CHCs]. And he is well-received in our community... [A representative from our area] has been very good” (Clinic C, Board chair interview). Another consumer member for Clinic B replied, “I think [the clinic director] was also very active in making those kinds of connections, because of wanting to access grant dollars” (Clinic B,

Representative consumer member interview). And another consumer member from Clinic A stated, “I know that one of the board members along with [the clinic director] had gone to Washington, D.C., for some conference or something...it was...one of those conferences that they had gone to and there were some legislators there that listened to [them] and different clinics [spoke] on behalf of their clinics’ board” (Clinic A, Representative consumer member interview). The relationships described in these comments were with members of the U.S. Senate or U.S. House of Representatives. All clinic directors had been affiliated with their clinics for many years, which presumably contributed to the depth of these relationships and hence the impact of political contextual factors on the work of the CHC boards.

These political factors can affect the work of the boards in two ways. First, when clinic directors have relationships with policymakers, they are able to quickly and efficiently access opportunities for funding. The boards, in turn, must respond promptly to the requests of clinic directors to apply for funding and, in some cases, must make completing the funding application a priority. Second, clinic director’s relationships with local, state, and federal policymakers facilitates support for the CHC’s work, which for some clinics has yielded good press for that clinic and, by default, for the board. This good press makes the CHC board’s work easier in some instances because when their work is well known in the community and supported by this Representative or that Senator, that good work could speak for itself.

With regard to the issue of how these political factors could influence quality, however, no board members noted that being on the board increased their own personal access to politicians. Acknowledging the power in that political influence could have been an indicator of board members’ increased voice as a part of the CHC boards. The absence of this connection suggests that the political factor influence does not go beyond the CHCs leadership, and points to a potential opportunity for CHCs interested in increasing the legitimacy of the consumer voices of their boards.

**Cultural factors influencing the work of the CHC boards.** An interesting characteristic of CHCs across the country is that they are a community-based way to provide access to quality healthcare for everyone in that community. The cultural environmental factors that impact the CHCs and their boards revolve around the cultural communities who utilize the services of the CHCs. The clinics must respond to those communities by the services offered and the way those services are offered.

Recent research exploring the ways in which CHCs are similar and how they are different illustrates that one size does not fit all in the CHC model, but there are similar practices that high performing CHCs utilize. Gurewich, Capitman, Sirkin, and Traje (2012) investigated high performing CHCs in California, Massachusetts, and Texas and found that there were four similarities among the CHCs in their study: (a) They took steps to enable access to care for patients, (b) they assisted patients in securing referrals for specialty services, (c) they provided support to providers to better serve patients, and (d) they paid intentional and consistent attention to quality improvement measures within the clinic. However, the differences discovered by Gurewich et al. (2012) were the result of a “difference in patient populations served by each clinic, what resources were available to different clinics and the different provider preferences of different clinics” (p. 455). The authors attributed these differences not to incorrect practices of the different CHCs but to the emphasis that CHCs place on community-based primary care service (Gurewich et al., 2012). Understanding this particular environmental factor for CHCs and their boards demonstrates that just because CHCs look different in terms of how the clinic serves different populations does not make one clinic better or more effective or efficient than another clinic.

The ways CHCs operationalize how to provide the community-based primary care service needs for their patients looks different because they are responding to the specific needs of the community they serve (Gurewich et al., 2012). This idea was articulated early in the information gathered for this study from the interview with the policy expert

from the National Association of Community Health Centers, Mr. Hawkins, when he stated:

[This important community based feature of CHCs are in place]... to make sure that each health center is responsive to the needs of the community it serves, and that's why...by the way, when you go to those three health centers, I dare say you will see similarities, but you will see differences that make each health center unique. And those differences are reflective of what the community board has decided that that specific health center should be doing for its community. (D. Hawkins interview)

Mr. Hawkins provided an example based on the area of the country where he lived:

I've got a health center up the street from me here in [the city where I live] in what is a growing Latino community. You walk in the front door of the health center and... [there are] many notices above the wall in both English and Spanish. You go to that same organization's health center down in southeast [part of the city, which is an] African-American community, there is very little, you know, in Spanish. There is some Spanish-speaking, but you know, you...can feel the culture from the community and the people getting care at the health center when you walk in the door, and that's true pretty much everywhere. (D. Hawkins interview)

One example of this difference in the cultural environment of each of the clinics was the discovery that each clinic served very distinct racial/ethnic/cultural populations. For example, Clinic C incorporated several different strategies to meet the translation needs of the population served by the clinic. The clinic addressed the needs of patients who spoke Spanish in the clinics through a bi-lingual staff presence. Clinic C also had Vietnamese translators in place at a few locations because of the influx of this refugee population into the area. Via telephone, the clinic provided access to multiple languages. In fact, in a recent quarter, Clinic C requested interpretation services in over 20 different languages at that location alone (Clinic C, Clinic director interview). However, the non-English speaking population served by Clinic A is slightly different. Languages besides English spoken at the clinic include "Spanish, Vietnamese, French, Somali, and Oromo" (Clinic A, Clinic director interview), and materials are printed in Spanish and English (Clinic A, Clinic director interview). While the clinic may have access to translators on a

case-by-case basis, Clinic A does not have staff in house on call to handle the situations as they arise.

The cultural environment of the CHCs and their boards are an important consideration when studying participation on the CHC boards. Paying attention to the cultural environment surrounding the CHCs suggests that needs for services are specific to certain populations enmeshed within that cultural environment. Further, because CHC boards make decisions about services based on the needs of the patient population, it is crucial that this environmental factor is considered when exploring the work of the boards. In addition, when the board is aware of the cultural environment of the clinic and the influence it has on their work, identified gaps in board representation can be remedied promptly to reflect the needs of the patient community served by the clinic.

The connection between understanding the cultural environment and having accurate representation on the board is related to the ability of board members to have a quality citizen participation experience. For example, in the case of Clinic C, the clinic director mentioned that in recent years, more refugees had begun to seek services from the various clinics in Clinic C's network. To accurately represent the needs of this new patient community, a board member should join the board who is representative of this patient community. If Clinic C's board is not aware of this demographic trend, they cannot fill the anticipated gap on the board. When the gap is left unfilled, it results in a lack of voice for this particular patient community within the decision-making processes of the board.

The way board members perceived how well the board understood these elements of the cultural environment demonstrates a specific example of how these elements of the cultural environment could impact the quality of citizen participation. For example, one non-representative consumer board member stated, "Some members, I don't think they have any knowledge of what goes on with the patient. Some are very concerned about patient care, but really don't know all that much about them, say the financial parts"

(Non-representative consumer board member interview). A second board member agreed with the first non-representative consumer member mentioned earlier, when he/she stated:

I think some board members have more, are more in tune to the people that we serve than other board members. I don't think any of them are insensitive to the need of the people that go to [our clinic]; I don't ever get the impression that they're not compassionate and empathetic but do they really know the exact nature of their need? Maybe not. (Descriptive consumer member interview)

A third board member, a representative consumer member, mentioned that the knowledge of the board about the patient community derives from the monthly reports given by the leadership team and centers on demographic statistics. The board member stated:

You know we get those every month from the previous month, what the patient encounters and the medical provider encounters and our dental encounters and the pharmacy scripts dispensed. We get those every day, premature report maybe we get one of those, so in that aspect (our board) knowledge is pretty good on that. (Representative consumer member interview)

This board member was more focused on the demographic statistics and the fact that board members received those reports every month as an indicator of the board's familiarity with the patient community. A fourth board member, a non-consumer, also made this link when they stated, "I would say, I couldn't rattle off percentages by any means, but I think we have a good sense for the population being served" (Non-consumer member interview). A fifth board member referenced the reports received at each board meeting as well, but noted that this report did not give good enough information to be able to say that the board adequately knew the patient population. The board member stated,

I would say on a scale of 1 – 10 I think it is a 5. I haven't gotten a real good profile and we see [the monthly report at each meeting] but as far as really understanding the demographics there used to be a lot of people with insurance that went to the CHC, it is not as much as it used to be, but it is still the demographics as a board we are pretty well distanced from that. (Non-consumer member interview)

Interestingly, the variation follows either previous distinctions made between consumer or non-consumer members, or the distinctions made between representative and non-

representative consumer members either. This variation also calls to question how to ensure a quality experience which legitimizes the voices of disadvantaged or marginalized members of the clinic patient community given the identified discrepancy between member's perceptions of that exact patient community and their circumstances.

### **Implications for Social Work: Education, Community Policy, and Practice**

Given the missing links identified during this study, this section discusses what this new information means for social work education, community policy and practice. Social work educators and practitioners will benefit from the advancement of knowledge about what factors facilitate the quality of citizen participation in policy development processes. The results of this study suggest that practitioners interested in empowering consumers to have a role in the provision of services need to understand what facilitates the quality of citizen participation to ensure that consumers have a legitimate voice in policy development and implementation processes. Because of this role, it is important for social work educators to incorporate concrete lessons of empowerment into the classroom to facilitate the learning process of this role with their students. This can be done through hands-on activities meant to simulate processes where consumers might feel disempowered, such as role playing conversations between students to simulate an exchange between a practitioner's client and a legislator on a faux lobby day, for example. The activity could involve having students brainstorm ways to facilitate the empowerment of these consumers through knowledge and skill building tasks. The next step with the activity could involve a legislator visiting the class and students being afforded the opportunity to try out their new skills in a real life situation. This type of activity is decisive to facilitate students' knowledge of empowerment and also to build the student's confidence that they can make a difference in these types of exchanges.

A driving force of the idea of legislatively requiring citizen participation of those representing marginalized and disadvantaged communities in policy development

processes is that this type of participation must be legislatively required or else it does not happen, hence the traditional exclusion of certain groups and individuals from the processes. The implications of this study for this type of social policy suggest that it is necessary to understand such a legislative mandate in theory and practice in order to evaluate whether it facilitates a quality citizen participation experience for those the policy is meant to impact. For the participants of this study, there were additional factors influencing the quality of the experience and this finding is important to consider when policy-makers evaluate current solutions to remedy the exclusion of disadvantaged and marginalized members of society in policy making processes which directly impact their lives. This finding suggests that social workers must be aware of potential discrepancies between how a policy benefits a group of people in order to ensure that the evaluation of that policy is accurate and adequately represents the situation in question.

To that end, research has addressed the possibility for inconsistencies between consumers and practitioners on abstract concepts such as empowerment, which is a goal of many social policy solutions, including the consumer majority requirement of CHCs (Sleath and Rucker, 2001). Boehm and Staples (2004) discovered a discrepancy between focus groups composed of consumers and social workers as to how each viewed and conceptualized empowerment. This finding speaks to the necessity of evaluating a concept as abstract as empowerment from the perspective of those who will most directly benefit from its incorporation into policy development processes. One suggestion social work practitioners could incorporate into their practice based on the findings of this study is for practitioners to think of ways to incorporate the voices of the consumers they serve in the evaluation of programs and the effectiveness of policies meant to empower them and improve their lives. This suggestion falls in line with the NASW Code of Ethics views on client self-determination and empowerment which believes that social workers should not do for their clients what their clients can do for themselves (NASW Code of Ethics, 1999).



Given the research on inconsistencies between consumers and practitioners, this study has implications for social workers' role in practice when organizations, agencies, or institutions rely on, or desire, a consumer voice in their work. Because of social work's values of social justice, self-determination and empowerment, we as professionals are well positioned to assist organizations, agencies and institutions in facilitating quality participation for consumer voices. For example, social workers in these contexts could help boards of directors evaluate the participation of consumer members on boards and provide suggestions, based on the best practices revealed in this study, to improve that participation. Social workers would also be able to conduct trainings with entire boards of directors to improve that participation. Training might focus on the identification and elimination of barriers to quality consumer participation or strategies to facilitate consumer's participation in board processes. If consumer participation did not exist a social worker could work with the board to recruit and retain consumer members to participate in policy decision making processes to improve the relevancy of the services offered and ensure that marginalized persons were represented.

An implication specific to the CHC context is what a social worker could bring to the experience of board members if they were a permanent part of the staff of the CHCs. For the three CHCs in this study, Clinic A had four licensed clinical social workers on staff, Clinic B did not have any social workers on staff, and Clinic C had two openings available at the time of data collection for master's level social workers. Services provided by social workers are not required by HRSA (see Appendix P for 19 guidelines laid out by HRSA for CHCs), but if a clinic identifies the need and obtains specific grant funding to hire a social worker they are on staff. They are not permanent positions, however. If other CHCs around the country have social workers on staff, one of their roles should consultation with the clinic and the board to facilitate a quality citizen participation experience for the board and board members.

The results of this study also inform our understanding of citizen participation in multiple policy development processes. For example, because legislators will benefit when barriers to the quality of citizen participation are identified, educators teaching social work students about macro practice will have concrete lessons to draw from. In addition, practitioners who work with non-elected members of boards will benefit from barrier identification of those with less power serving in the context of these boards. Practitioners could then assist in the empowerment of future board members engaged in policy development on a wide variety of boards through skill building and barrier identification in order to facilitate the empowerment of board members with less power. And finally, for actual board members serving in a multitude of contexts but especially those representing traditionally disadvantaged or marginalized communities, the benefit of knowledge gained from similar experiences in a variety of contexts will provide insight for those board members into their own experience and assist them in making that participation more effective.

### **Strengths and Limitations of the Study**

Two strengths stand out as contributions to the literature on citizen participation research as a result of this study. First, previous research studied independently how multiple levels, including interpersonal, intrapersonal, organizational/institutional, community, and public policy, impact citizen participation. However, research has not simultaneously examined these multiple levels within the same study. The current study utilized the socio-ecological perspective to guide the interviews conducted with clinic directors, board chairs, and board members, which allowed me to gather information on multiple levels of influence. By gathering information on multiple levels which influence the participation experience of CHC board members, I was able to glean the complexity of that experience and the factors which impact the experience in order to make concrete suggestions for places CHC boards could alter their practices in order to facilitate a quality participation experience for their members. For example, had I only explored the

individual characteristics of the board members such as their work experience, I would have missed the influence of broader CHC board policies on the board member's experience.

Second, the methodological design choice of Carspecken's (1996) critical ethnography was a strength of this study. This design choice examined and appreciated not only the CHC boards and therefore not only the CHC board members alone, but also included information on the clinics themselves and the environmental influences that structured their existence. Research on CHCs has not yet combined these multiple levels of influence to understanding the experience of participation on CHC boards. Therefore, a specific contribution is made to the research on citizen participation suggesting that in order to fully understand a quality citizen participation experience; researchers must explore multiple aspects of that experience to uncover the nuances of these multiple levels and their impact.

As with any research, limitations to the design of a study as well as the data collected are present because no research design or study is perfect. The next section reviews these limitations and also discusses how some of them can be addressed in future research. One limitation was derived from the quality of the data made accessible to the researcher. Although all information requested was provided by the clinic directors or board chairs, depending on the information, there was unexpected variability in that information. For example, a great deal of analysis was conducted on the board meeting minutes obtained for one calendar year for each of the three CHC boards. However, some minutes contained greater detail than others, leaving gaps in information that were difficult to fill. While the researcher has no control over the context, it is important to acknowledge that the information collected was not equal.

The second limitation of this study involved the logistics of setting up interviews with clinic directors, board chairs, and eventually board members. This limitation revolved around not only the complicated and busy lives of individuals who volunteer

their time for community responsibilities but also the schedule of the CHC boards during the months of May 2012 to October 2012 when data were collected. More specifically, two of the three boards did not meet at least twice during this time frame, which delayed the data collection phases and made for some anxious days waiting for contact to be established early in the study's data collection. In addition to the timing of data collected, situations arose that were out of the researcher's control and even out of the control of the participants. For example, in the process of setting up an interview with a representative consumer member, the only time the member was available was after a board meeting. This time was the only one available because the member worked a job where he/she was on call most evenings and had limited availability during the day to schedule an interview. This limitation could possibly have affected the quality of the data because the participant's state of mind during the interview could have been altered or he/she might have been distracted in some way. These possibilities were also outside of my control and were handled as best they could be in each situation with each participant.

Another logistical limitation that arose because of the time constraints of busy members was where interviews would take place. Some participants were happy to set up in-person interviews in a quiet location so that the audio-recording of the interview was clear. Other participants were more comfortable conducting the interviews over the phone. In some of these cases, the interview was conducted over the phone while the participant was in their car, running errands, on a bus, and so on, making the quality of the recording poor. It is also reasonable to advise future researchers interested in conducting interviews with consumer and non-consumer board members that they will be very busy, so flexibility and ingenuity is important when interviews are scheduled. In these and other situations, patience and perseverance was crucial to successfully recruiting board members to participate and was rewarded with a rich and diverse pool of board member interviews to analyze.

A third limitation of the study design originated with the clinics that were approached for participation. Given the criteria of only those clinics and subsequent boards that were engaged in policy development work with the Iowa Primary Care Association (IAPCA), the question arises regarding what might be learned about quality of citizen participation from those clinics and boards who were not as engaged in policy development work with the IAPCA. Because of this, it is difficult to know what the results of the research would have been had there been a lower functioning and less engaged board in the study, or if the three CHCs had all been low functioning or less engaged. Future research to expand this body of knowledge even further would include both “engaged” and “non-engaged” boards to explore the quality of participation experience and compare and contrast the findings between engaged and non-engaged boards.

A fourth limitation centered with the participants was the fact that not all board members of each of the three CHC boards agreed to an interview. For Clinic A, there were five board members interviewed out of a total of 11 (minus 1 for the board chair), for Clinic B, there were seven board members interviewed out of a total of 12 (minus 1 for the board chair), and for Clinic C there were four board members interviewed out of a total of 12 (minus 1 for the board chair). Based on these numbers I interviewed 45% of the total possible board members out of these three clinics. It is difficult to know what the results might have been like if there had been a different 16 members interviewed, or if in addition to the 16 I interviewed an additional 10 agreed as well. And this unknown is a limitation in the results, because I speculate that different voices in the study would have altered the results.

### **Future Research**

A limitation that suggests a direction for future research is the omission of interviews of leadership/management team staff at each of the three clinics. As has been previously mentioned, the relationship between these clinic staff and board members was

a crucial piece of how these boards facilitated the quality of participation for both consumer and non-consumer members across the three clinics. This relationship was discussed repeatedly during interviews; it became clear that a flaw in the design of the study was not interviewing this group of people who seemed to be crucial to not only the day-to-day operations of the clinic but also to the board members' ability to do their job of governing the clinics. These CHC individuals should be incorporated into future research conducted to understand the quality of the citizen participation experience for board members of CHC boards and will no doubt reveal additional complexities related to this experience.

An additional issue to be addressed in future research involves which board members of the three CHC boards decided to participate in the study and whether there was a difference in the conceptualization of quality from the perspective of board members who did not participate in the study. If given a longer time frame it is possible others might have participated, and if the time frame was during a different part of the year (in other words, not the summer), others might have participated as well. A future challenge for researchers is to understand who chooses to participate, and how that decision could impact the results of future studies. Future researchers could address these issues by conducting research over a longer period of time, maybe a full calendar year, to account for these seasonal differences and could also provide incentives for participation to encourage participants to give their time to the study.

A second limitation that suggests directions for future research is the way in which participant recruitment during this study's process followed a top down approach. This approach was a necessity given the time limits of completing the research as well as the association between an already existing project and this current study. However, I was unable to build my own relationships with study participants, because the relationship trust was built on previously existing relationships. In future research with CHC boards, the design could incorporate tenets from a participatory action research

framework that would dissolve the researcher/participant paradigm and instead put participants on the same research team as the researcher to develop the study, implement the data collection, analyze the data, and disseminate the findings in a way that spurs social change (McIntyre, 2008). For example, I could approach board members in a variety of CHCs and ask them what they would like to explore related to their participation on the CHC boards. In this example, I would bring my abilities and skills as a facilitator and researcher, and they would equally bring their roles as board members and the skills and knowledge they carry with them and we would work as a team to explore aspects of their participation that are important to them. This would be in direct contrast with the current study because I would not be the leader; I would be a member of a team. Future research using tenets from a participatory action research framework provides many opportunities to privilege the voice of those typically studied in the creation, implementation and dissemination of knowledge.

An additional future research direction evolved from the limitations presented by a qualitative research design in general. Qualitative research does not alone answer all the questions posed by the challenge of understanding the process of quality citizen participation and whether citizen's have legitimate voice and redistributed power in that process. To address this in future research, a key change could be implemented. A qualitative design could be combined with other methods, for example a case study approach, because of the approach's utility to appreciate how contextual conditions impact certain issues (Hentz, 2012). This combined approach could include the added benefits of both qualitative and quantitative data collection and would presumably yield a more complex and complete picture of the experience of quality citizen participation.

Future research could also incorporate different theories in order to delve deeper into the relationships of power which exist within the CHC structure. While at the heart Arnstein's ladder was the redistribution of power (1969), the socio-ecological perspective does not specifically address this issue of the role of power. Given the perspective's role

in crafting the interview guides utilized throughout the study, it was only if participants mentioned power on their own in the interview that the dimension was entered into the analysis. Future research which utilizes theories specific to power's examination and understanding would be an appropriate direction to explore in order to discern this complex picture.

### **Conclusion: Lessons Learned**

To revisit the main research question that guided this research: Do CHC boards facilitate a quality citizen participation experience for CHC board members in Iowa? One assumption made was that a quality citizen participation experience could occur only at the top of Arnstein's ladder of citizen participation. After collecting and analyzing all of the data for this study, however, this assumption was proven to be misguided. To recap, Arnstein's (1969) idea of full citizen control in policy decision-making processes stemmed from the approach of the War on Poverty program administrators to incorporate traditionally excluded voices into processes making implementation and evaluation decisions for War on Poverty programs, because this approach revealed a multifaceted view of participation for those traditionally marginalized and excluded voices and not voices with legitimate participation. Arnstein viewed power redistribution to the point of full citizen control as being the root of legitimate participation for marginalized voices. Arnstein's ladder was part of the conceptual framework of this study because in the context explored (three CHCs in Iowa with boards composed of 51% patient majority), it appeared that this board structure would create an environment in which the expertise of consumers could potentially impact policy decision making through CHC boards.

Because for Arnstein (1969), legitimate voice was not only about an individual's ability to influence policy-making decisions but also about the environment surrounding that decision-making process, this study applied a multi-dimensional, qualitatively conducted, critical ethnography design. This design was chosen because to identify the layers of influence at the individual, relational, institutional/organization, community,



and public policy levels, data must be collected and analyzed from a 360° vantage point to understand how the multiple levels influence the experience of power redistribution and empowerment for members of the CHC boards. What the data revealed were more in line with previous work (Salber, 1970) specific to CHCs that called for a blend of citizen control and partnership in power in citizen governance to most effectively and justly represent the needs of communities served by this primary health care delivery system. Wondolleck, Manring, and Crowfoot (1996) agreed with Salber, but digressed slightly when they recommend that this type of partnership worked only if it was in the correct circumstance with the right amount of support. For Wondolleck et al. (1996), correct circumstances included examples where not only citizens understand what is expected of them during the decision-making process, but those in power (government officials or business partners) understand the expectations and are supportive of citizen's involvement. Tritter and McCallum (2006), in an interesting critique of Arnstein's focus on power, stated that with a focus on power comes an omission of other forms of knowledge and expertise. These other forms of knowledge and expertise, such as the unique experiences consumer members bring to their membership on the board, were certainly discussed in the data collected for this study.

The data presented in this study support the notion that a blended approach to governance within the CHC structure facilitates true consumers participation within the CHC boards in Iowa; however, a question unanswered from the data collected is how to address the high number of non-representative consumer board members who were part of the CHC board structures in this study. This question speaks to how CHC boards can capture the uniqueness of expertise from representative consumer members in a way that empowers them to legitimately impact policy decision-making processes that not only impact their primary health care, but the health care of others in similarly disadvantaged and marginalized communities who also utilize the services of the CHC that the board governs. In addition, the question of whether this high number of non-representative

consumer members makes a difference in the quality of citizen participation and, more importantly, the legitimacy of voice representing the disadvantaged and marginalized communities those consumer members are charged with representing remains as a clear next step in research on legitimacy of voice for disadvantaged communities in policy development processes.

The topics presented in this chapter weave a complex story of the ways CHC boards facilitate the quality of citizen participation for their board members. This story is complex because the information suggests that there are elements inherent in the CHC board participation experience which impact the quality of that experience, but that there is variation on this impact depending on a number of factors. The factors which influence a CHC board's ability to facilitate a quality citizen participation experience are reviewed in detail in the previous section, and include: The way CHC boards operationalize the consumer definition given to them by the Health Resources and Services Administration; CHC boards consideration of the role passion plays in motivating board members to participate in and engagement with the CHC boards; How CHC boards consider the environmental influences within their work, and how those influences impact individual board members and the board as a whole; And how the policies of the board which engage board members in the CHC board process are implemented within the structure of the CHC board.

These factors suggest that CHC boards have the ability to in fact facilitate a quality citizen participation experience for the disadvantaged and marginalized board members. However, addressing any one of these four factors without addressing all four could hinder the board's ability to facilitate a quality experience for consumer members. This conclusion suggests that future research on how to facilitate a quality citizen participation experience must reflect on multiple facets of that experience to identify the gaps and make improvements. The synthesis of this information as to whether the three CHC boards in this study facilitate a quality citizen participation experience for their

board members suggests that in some respects the boards do accomplish this facilitation and in some respects they do not.

An analysis of the factors presented above coupled with the information reviewed for this research yield two thought-provoking questions: 1. Does the consumer definition used by the CHCs from the Health Resources Services Administration need revision, and if so, in what ways? 2. Given the findings of this research, is the 51% consumer majority needed in order to facilitate quality citizen participation, and if so, should it be implemented in other contexts? These questions have implications for both social policy and for contexts which social workers find them because of the impact it could have on how to improve consumer participation.

First, does the consumer definition need revision and if so, how? Based on the information presented in this study, I would say that the definition does need revision. The issues to consider in this revision are varied, and are as follows. Consideration must be given to how the patients of clinics are represented on the CHC boards. If there is a certain population that is increasing in the community served by the CHC, the board must do all it can to make sure services of the clinic reflect that demographic switch. Second, the classify a consumer as one who visits the clinic once in a one to two year period, by the admission of those who fall into this classification in this study, does not accurately portray the experience of a patient who uses the CHC has their medical home. Utilization of the CHC as their medical home would mean they receive multiple health care services from the CHC including dental services, pharmacy services, etc. And by using a wide variety of services offered by the CHC the consumer member is able to draw on multiple experiences as evidence for their consumer participation. Third, given the difficulty boards face with recruiting and retaining consumer board members, boards should expand the way that consumer representation and voice reaches the board in order to impact policy. For example, the board could hold public education events or listening posts for patients to attend and speak their mind, similar to the open forums many local,

state and federal representatives use to solicit opinions from those they represent. This could be a first step to identifying those patients who would be appropriate consumer advocates and assist the board in identifying those individuals. And in the meantime allow the board to field requests and suggestions from the patient community.

The second question prompted by this research is whether or not mandating a 51% consumer majority is necessary anymore to ensure that the voices of those from disadvantaged and marginalized communities are heard, and if it is necessary, should that mandate be expanded to other contexts where members of these communities are receiving services. Based on the information analyzed in this research, mandating participation still ensures that the voices have a seat at the table. The question of whether or not that seat ensures legitimacy of voice, at least from the data collected, was negated by the confusion and grayness centered on the issues with the consumer definition. What is needed is an enforced and relevant consumer presence on all boards interested in making sure their services are accomplishing what they want them to accomplish and those interested in a level of accountability to those service recipients. If this is the structure of the consumer participation mandate, I do think all contexts who serve those from disadvantaged and marginalized communities should implement some type of mandate. But this mandate should be accompanied by a social worker's presence to evaluate and improve the participation experience as needed. Providing this evaluation and monitoring the participation of marginalized persons ensures that the social work profession continues to advocate for all persons at all services levels. A crucial component of the social work profession is to strive for social justice; facilitating a citizen's ability to have a voice in policy processes which directly impact their lives will move society closer to this ultimate goal, and it is the social work profession's responsibility to advocate for such opportunities for all citizens.

**APPENDIX A****GLOSSARY OF ABBREVIATIONS**

ACA – Affordable Care Act of 2010

CAPs- Community Action Partnerships

CEO – Chief Executive Officer

CHCs – Community Health Centers

COPC – Community-oriented primary care

FPL – Federal Poverty Level

FQHCs – Federally Qualified Health Centers

HRSA – Health Resources and Services Administration

IAPCA – Iowa Primary Care Association

IRB – Institutional Review Board

MFP – Maximum Feasible Participation

NACHC – National Association of Community Health Centers

OEO – Office of Economic Opportunity

PPC – Public Policy Center at the University of Iowa

UDS Report - Uniform Data System Report

**APPENDIX B**

**INTERVIEW GUIDE FOR IOWA PRIMARY CARE**

**ASSOCIATION (IAPCA)**

Note: These questions will be used to identify the most engaged boards of the 13 total in Iowa.

1. I am looking to understand which FQHC boards are the most engaged in Iowa. I acknowledge that boards are required to do the following activities:

- Is comprised of a majority (at least 51%) of individuals (“consumers”) who are being served by the health center and who as a group, represent the individuals being served by the health center;
- Meets at least once a month;
- Selects the services to be provided by the health center;
- Schedules the hours during which such services will be provided;
- Approves the health center’s annual budget;
- Approves the selection of a director (Program Director or CEO) for the health center;
- Establishes general policies for the health center, except in the case of a governing board of a public center (a public entity may be allowed to retain the responsibility for establishing general policies i.e. fiscal and personnel policies, for the health center); and
- Approves applications for subsequent grants for the health center.

\*Source: <http://www.ask.hrsa.gov/downloads/fqhc-rhccomparison.pdf>

Given that this project is not interested in evaluating a board’s consistency with the above activities but rather the quality of the participation of community board representatives, I am seeking to identify the boards in the project that are the most actively engaged with your legislative advocacy work of the IAPCA and engaged with local policy development within the context of the FQHC board. Could you rate the 14 total clinics as either very engaged, moderately engaged or minimally engaged?

2. Of the 5 boards you mention, have you discussed the PPC / Commonwealth project with any of the executive directors or board presidents of any of these FQHCs? If so, what have the conversations generally been about? Did executive directors and/or board presidents seem enthused about the collaborative project?

3. Do you primarily work with the executive directors of the FQHCs? Do you have secondary contact with the board presidents of the FQHCs? For each, how frequently would you say you are in contact with them?

4. To your knowledge, what role do the community boards you mention have in policy development? For example, do they attend meetings or education events in Des Moines with policy makers (such as legislators)? Do they hold educational events back in their towns regarding policy decisions?

**APPENDIX C**  
**EMAIL CORRESPONDENCE BETWEEN EXECUTIVE**  
**DIRECTORS AND IAPCA**

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201202734 APPROVAL DATE: 04/12/12 EXPIRATION DATE: N/A
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Email correspondence with Executive Directors of FQHCs identified by IAPCA staff

Good morning/afternoon Mary Smith, [replace name with name of clinic Executive Director]

My name is Kristi L. Law and I am a PhD candidate at the University of Iowa's School of Social Work. I understand you have been contacted by the staff at the Iowa Primary Care Association providing you with information regarding my research which is interested in understanding participation on community boards of Federally Qualified Health Clinics in Iowa involved in policy development processes.

I also understand that you have contacted me so that I may follow up on that initial contact to request your permission to set up a time and date for me to make a visit to your clinic to better understand the daily activities of the clinic and talk with you about the role of the board in governing and structuring those activities. I think the visit could be completed in two hours or less, but will be guided by your schedule and suggestions.

If you are interested in participating in my research project, please reply to this email with which of the following dates and times work best for your schedule. If none of these dates will work for you, please suggest others. **Three dates will be proposed.**

- 1.
- 2.
- 3.

If you have any questions, comments, or concerns regarding this project, you can contact me at [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu), or my academic advisor and dissertation committee chair Dr. Jeanne Saunders at [Jeanne-saunders@uiowa.edu](mailto:Jeanne-saunders@uiowa.edu) or (319) 335-1276.

I look forward to your response and appreciate your time assisting with this project.

Sincerely,

Kristi L. Law, MSW  
PhD Candidate, School of Social Work  
University of Iowa

**APPENDIX D**  
**INTERVIEW GUIDE WITH EXECUTIVE**  
**DIRECTORS**

1. Please describe your role within the FQHC of which you are the executive director.
  - Original motivation for involvement
  - Active in community
  - Your understanding of the role of this board in policy development prior to your involvement
  - Participation on these boards makes a difference in your community? Can you provide an example?
  - Level of knowledge regarding the activities of the board in the daily activities of this FQHC
  
2. What role do you see FQHC community boards having in policy development? Does the perspective shift when thinking about state and federal policy development?
  - If so, how? If not, why not?
  
3. In what ways is the work of the FQHC board distributed to the community at large and to patients of the clinic specifically?
  
4. What information has the FQHC board distributed to the community at large regarding the ACA? What information has been distributed to patients of the clinic?
  
5. What ways could boards or board members more effectively engage in policy development related to the ACA, particularly as the 2014 deadlines of the legislation approach?



**APPENDIX E**  
**EMAIL CORRESPONDENCE TO BOARD CHAIRS**

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201202734 APPROVAL DATE: 04/12/12 EXPIRATION DATE: N/A
---

Email correspondence with Community Board Presidents of FQHCs

Good morning/afternoon Mary Smith, [replace name with name of president of FQHC community board]

My name is Kristi L. Law and I am a PhD candidate at the University of Iowa's School of Social Work. I understand you have been contacted by the Executive Director of the Federally Qualified Health Clinic (FQHC) of the community board in which you are the current board president providing you with information regarding my research, which is interested in understanding participation on community boards of FQHCs in Iowa involved in policy development processes. I also understand that you have contacted me so that I may follow up on that initial contact to request your permission to set up a time and date for us to further discuss this project in detail, request your permission to observe (2) board meetings in the near future, and to request permission to recruit board members for participation in the project. I think the visit could be completed in two hours or less, but will be guided by your schedule and suggestions.

If you are interested in participating in my research project, please reply to this email with which of the following dates and times work best for your schedule. If none of these dates will work for you, please suggest others. **Three dates will be proposed.**

- 1.
- 2.
- 3.

If you have any questions, comments, or concerns regarding this project, you can contact me at [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu), or my academic advisor and dissertation committee chair Dr. Jeanne Saunders at [Jeanne-saunders@uiowa.edu](mailto:Jeanne-saunders@uiowa.edu) or (319) 335-1276.

I look forward to your response and appreciate your time assisting with this project.

Sincerely,

Kristi L. Law, MSW  
PhD Candidate, School of Social Work  
University of Iowa

## APPENDIX F

### INTERVIEW GUIDE WITH BOARD CHAIRS

The main questions are in **bold** and prompts for each question are underneath the main question.

**1. Please tell me about yourself and your involvement on this board.**

- Original motivation for involvement
- Active in community
- Your understanding of the role of this board in policy development prior to your involvement
- Participation on these boards makes a difference in your community? Can you provide an example
- Level of knowledge regarding the activities of the board in the daily activities of this FQHC

**2. How would you describe your role and contribution on the board?**

- Understanding of the general board purpose
- Purpose impacts day to day activities of clinic
- Activities of the board, including decision-making process and individual and group participation
- Weight of your opinions in decision-making with regard to other members on the board

**3. Tell me about your experience as the board president of this board.**

- Relationships with individuals on board prior to your involvement and what that was
- Length of time on board and length of board term
- Definitions of community you representative
- Methods you use to convey information to your community
- Geographic area your board represents – live within this area?
- Experiences that translate into helpful knowledge for your role on the board

**4. How do you see your role as a community representative on this board?**

- Reports made to community to engage them in policy development
- Communications with others outside the FQHC board regarding information of board activities

**5. Tell me how you believe this FQHC board contributes to policy development both locally and at the state level?**

- Decision-making processes regarding policy development
- Processes of implementation of the board's decision – Example?

**6. What is your perception of your personal influence within the board on policy development?**

- Value of decisions by other board members
- Resources or strategies used to assist in policy development
- Agenda and priorities within policy development

## APPENDIX G

### OBSERVATION GUIDE FOR BOARD MEETINGS

**Note: These are subject to change depending on information gleaned from initial conversations regarding background information of FQHC community boards.**

#### **Interactions**

- Between board members with different roles
- Within board members of both different and similar roles
- Between board members (including president) and patients served by clinic
- Between board members (including president) and community at large

#### **Information sharing**

- Between board president and other board members
- Between board members (both president and community members) and patients served by board
- Between board members (both president and community members) and community at large within which the FQHC is located

#### **Process of policy development**

- Setting the agenda
- Decision making
- Task assignments
- Discussion process

#### **Policy references to ACA**

- Board member / president concern
- Board strategies to disseminate information regarding ACA

## APPENDIX H

### BOARD MEMBER INTERVIEW GUIDE

**1. Please tell me about yourself and your work on this board.**

Prompts include:

- Original motivation for involvement
- Active in community
- Role of this board in policy development prior to your involvement
- Role on the board in policy development prior to your involvement
- Participation on these boards makes a difference in your community? Can you provide an example?
- Level of knowledge regarding the activities of the board in the daily activities of this FQHC

**2. How would you describe your role and contribution on the board?**

- Understanding of the general board purpose
- Purpose of the board impacts day to day activities of clinic
- Activities of the board, including decision-making process and individual and group participation
- Weight of your opinions in decision-making with regard to other members on the board
- Weight of your opinions in decision-making with regard to the board president

**3. Tell me about your experience on this FQHC board.**

- Relationships with individuals on board prior to your involvement and what that involvement was
- Length of time on board and length of board term
- Definitions of the community you represent
- Methods you use to convey information to your community
- Geographic area your board represents – live within this area?
- Experiences that translate into helpful knowledge for your role on the board

**4. How do you see your role as a community representative on this board?**

- Reports made to community to engage them in policy development
- Communications with others outside the FQHC board regarding information of board activities

**5. Tell me how you believe this FQHC board contributes to policy development both locally and at the state level?**

- Decision-making processes regarding policy development and *possibly ACA?*
- Processes of implementation of the board's decision
- What would an example be of what decision-making processes are within the board?

**6. What is your perception of your personal influence within the board on policy development?**

- Value of decisions by other board members
- Resources or strategies used to assist in policy development
- Agenda and priorities within policy development

**APPENDIX I**  
**INSTITUTIONAL REVIEW BOARD APPROVAL**



**Human Subjects Office/  
Institutional Review Board (IRB)**

105 Hardin Library for the Health Sciences  
600 Newton Road  
Iowa City, Iowa 52242-1098  
319-335-6564 Fax 319-335-7310  
irb@uiowa.edu  
<http://research.uiowa.edu/hso>

**IRB ID #:** 201202734

**To:** Kristi Law

**From:** IRB-02            DHHS Registration # IRB00000100,  
Univ of Iowa,        DHHS Federalwide Assurance # FWA00003007

**Re:** An exploration into the quality of citizen participation

**Approval Date:** 11/16/12

**Next IRB Approval  
Due Before:** N/A

**Type of Application:**            **Type of Application Review:**            **Approved for Populations:**

New Project  
 Continuing Review  
 Modification  
Fetuses, Neonates

Full Board:  
Meeting Date:  
 Expedited

Children  
 Prisoners  
 Pregnant Women,

Exempt

**Source of Support:**  
York Community Trust

Fahs-Beck Foundation for Research and Experimentation in the New

This approval has been electronically signed by IRB Chair:  
John Wadsworth, PHD  
11/16/12 0936

**IRB Approval:** IRB approval indicates that this project meets the regulatory requirements for the protection of human subjects. IRB approval does not absolve the principal investigator from complying with other institutional, collegiate, or departmental policies or procedures.

**Agency Notification:** If this is a New Project or Continuing Review application and the project is funded by an external government or non-profit agency, the original HHS 310 form, "Protection of Human Subjects Assurance Identification/IRB Certification/Declaration of Exemption," has been forwarded to the UI Division of Sponsored Programs, 100 Gilmore Hall, for appropriate action. You will receive a signed copy from Sponsored Programs.

**Recruitment/Consent:** Your IRB application has been approved for recruitment of subjects not to exceed the number indicated on your application form. If you are using written informed consent, the IRB-approved and stamped Informed Consent Document(s) are attached. Please make copies from the attached "masters" for subjects to sign when agreeing to participate. The original signed Informed Consent Document should be placed in your research files. A copy of the Informed Consent Document should be given to the subject. (A copy of the *signed* Informed Consent Document should be given to the subject if your Consent contains a HIPAA authorization section.) If hospital/clinic patients are being enrolled, a copy of the IRB approved Record of Consent form should be placed in the subject's electronic medical record.

**Continuing Review:** Federal regulations require that the IRB re-approve research projects at intervals appropriate to the degree of risk, but no less than once per year. This process is called "continuing review." Continuing review for non-exempt research is required to occur as long as the research remains active for long-term follow-up of research subjects, even when the research is permanently closed to enrollment of new subjects and all subjects have completed all research-related interventions and to occur when the remaining research activities are limited to collection of private identifiable information. Your project "expires" at 12:01 AM on the date indicated on the preceding page ("Next IRB Approval Due on or Before"). You must obtain your next IRB approval of this project on or before that expiration date. You are responsible for submitting a Continuing Review application in sufficient time for approval before the expiration date, however the HSO will send a reminder notice approximately 60 and 30 days prior to the expiration date.

**Modifications:** Any change in this research project or materials must be submitted on a Modification application to the IRB for prior review and approval, except when a change is necessary to eliminate apparent immediate hazards to subjects. The investigator is required to promptly notify the IRB of any changes made without IRB approval to eliminate apparent immediate hazards to subjects using the Modification/Update Form. Modifications requiring the prior review and approval of the IRB include but are not limited to: changing the protocol or study procedures, changing investigators or funding sources, changing the Informed Consent Document, increasing the anticipated total number of subjects from what was originally approved, or adding any new materials (e.g., letters to subjects, ads, questionnaires).

**Unanticipated Problems Involving Risks:** You must promptly report to the IRB any serious and/or unexpected adverse experience, as defined in the UI Investigator's Guide, and any other unanticipated problems involving risks to subjects or others. The Reportable Events Form (REF) should be used for reporting to the IRB.

**Audits/Record-Keeping:** Your research records may be audited at any time during or after the implementation of your project. Federal and University policies require that all research records be maintained for a period of three (3) years following the close of the research project. For research that involves drugs or devices seeking FDA approval, the research records must be kept for a period of three years after the FDA has taken final action on the marketing application.

**Additional Information:** Complete information regarding research involving human subjects at The University of Iowa is available in the "Investigator's Guide to Human Subjects Research." Research investigators are expected to comply with these policies and procedures, and to be familiar with the University's Federalwide Assurance, the Belmont Report, 45CFR46, and other applicable regulations prior to conducting the research. These documents and IRB application and related forms are available on the Human Subjects Office website or are available by calling 335-6564.

**APPENDIX J**  
**CONSENT FORM – EXECUTIVE DIRECTOR**

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201202734 APPROVAL DATE: 07/31/12 EXPIRATION DATE: N/A
---

**Project Title:** An exploration into the quality of citizen participation

**Principal Investigator:** Kristi Law

**Research Team Contact:** Kristi Law – Kristi-law@uiowa.edu  
**OR**  
 Academic adviser Dr. Jeanne Saunders –jeanne-saunders@uiowa.edu or (319) 335-1276.

We invite you to participate in a research study. The purpose of the study is to understand the experience of participation on community boards of Federally Qualified Health Clinics in Iowa involved in policy development processes.

You were notified by the Iowa Primary Care Association to participate in this study because you are the executive director of a Federally Qualified Health Clinic in Iowa. You were then provided our contact information and asked to contact the research team if you were interested in participating. Approximately 50 people will take part in this study at the University of Iowa.

If you agree to participate in this study, we will meet with you to conduct a visit / interview which will last around two hours and the PI will be taking hand-written notes. The PI will sit down with you and ask a series of questions revolving around your experiences with FQHC boards in policy development. You are free to not answer any questions you would prefer not to answer or are uncomfortable answering. At the end of the interview, the PI will request that you provide information of the project to the community board president of your FQHC, given the study's interest to discuss the experience of citizen's participating in policy development. The PI will also request that you provide the contact information (including mobile phone number and email address) to the community board president so that, if he/she is interested, they might contact the PI to participate in the study. Once the interview is complete, the PI will transcribe the interview and give you the opportunity to check that the information is accurate. No additional follow-up is required.

The interview will take place at the clinic of which you are the executive director at a time and date convenient to your schedule.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. To help protect your confidentiality, we will assign a numeric code which will be used to identify your study information as well as the audio-tapes of the interviews.



The list linking your assigned code and your name will be kept in a secure place which will be different from the data and which is accessible only to the researchers on this project. We will store all study data in password protected computer files. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify. If we obtain any new information during this study that may affect your willingness to continue participating in the study, we'll promptly provide you with that information.

We would also like to inform you that this research study is supported in part by a grant from the Fahs-Beck Fund for Research and Experimentation from the New York Community Trust.

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Kristi L. Law at [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu). If you experience a research-related injury, please contact Dr. Jeanne Saunders at [Jeanne-saunders@uiowa.edu](mailto:Jeanne-saunders@uiowa.edu) or 319-335-1276

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail [irb@uiowa.edu](mailto:irb@uiowa.edu). To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

If you agree to be in the study, please tell me now and we will begin the interview.

If you do not wish to be in the study, please tell me now or at any time and our time together will stop.

Thank you very much for your consideration.

Sincerely,

Kristi Law  
Principal Investigator  
School of Social Work  
The University of Iowa

**APPENDIX K**  
**CONSENT FORM – BOARD CHAIRS**

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201202734 APPROVAL DATE: 07/31/12 EXPIRATION DATE: N/A
---

**Project Title:** An exploration into the quality of citizen participation

**Principal Investigator:** Kristi Law

**Research Team Contact:** Kristi Law – Kristi-law@uiowa.edu  
**OR**  
 Academic adviser Dr. Jeanne Saunders –jeanne-saunders@uiowa.edu or (319) 335-1276.

We invite you to participate in a research study. The purpose of the study is to understand the experience of participation on community boards of Federally Qualified Health Clinics in Iowa involved in policy development processes.

You were notified by the executive director of the FQHC of which you are the board president to participate in this study because you are the president of that FQHC community board. You were then provided our contact information and asked to contact the research team if you were interested in participating. Approximately 50 people will take part in this study at the University of Iowa.

If you agree to participate in this study, we will meet with you to conduct an interview which will last between 60 – 90 minutes and where the PI will be taking hand-written notes. The PI will sit down with you and ask a series of questions revolving around your experiences as the president of a FQHC board involved in policy development. You are free to not answer any questions you would prefer not to answer or are uncomfortable answering. At the end of the interview, the PI will request that she attend the next board meeting of the FQHC in order to engage board members with the research project. You are free to deny the request of the PI to attend the meeting, and the involvement of your FQHC community board in the current research project will cease. Once the interview is complete, the PI will transcribe the interview and give you the opportunity to check that the information is accurate. No additional follow-up is required.

The interview will take place at the clinic at a time and date convenient to your schedule.

You will also be observed in two public board meetings related to your participation on this board. The data collected will involve interactions among board members, between you and other board members, and conversations around policy development. The PI will record those interactions using a field journal and hand-written notes. You will know when you are being observed because the PI will alert you to her presence and intention of observing interactions.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. To help protect your confidentiality, we will assign a numeric code which will be used to identify your study information as well as the audio-tapes of the interviews. The list linking your assigned code and your name will be kept in a secure place which will be different from the data and which is accessible only to the researchers on this project. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify. If we obtain any new information during this study that may affect your willingness to continue participating in the study, we'll promptly provide you with that information.

We would like to inform you that this research study is supported in part by a grant from the Fahs-Beck Fund for Research and Experimentation from the New York Community Trust.

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Kristi L. Law at [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu).

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail [irb@uiowa.edu](mailto:irb@uiowa.edu). To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

If you agree to be in the study, please tell me now and we will begin the interview.

If you do not wish to be in the study, please tell me now or at any time and our time together will stop.

Thank you very much for your consideration.

Sincerely,

Kristi Law  
Principal Investigator  
School of Social Work  
The University of Iowa

**APPENDIX L**  
**CONSENT FORM – BOARD MEMBERS**

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201202734 APPROVAL DATE: 07/31/12 EXPIRATION DATE: N/A
---

**Project Title:** An exploration into the quality of citizen participation

**Principal Investigator:** Kristi Law

**Research Team Contact:** Kristi Law – [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu)  
**OR**  
 Academic adviser Dr. Jeanne Saunders [\\_jeanne-saunders@uiowa.edu](mailto:_jeanne-saunders@uiowa.edu) or (319) 335-1276.

We invite you to participate in a research study. The purpose of the study is to understand the experience of participation on community boards of Federally Qualified Health Clinics in Iowa involved in policy development processes.

You were notified by the community board president of the FQHC of which you are a member of the community board to participate in this study because of your role as a member of that board. You were then provided our contact information and asked to contact the research team if you were interested in participating. Approximately 50 people will take part in this study at the University of Iowa.

If you agree to participate, we will meet with you to conduct an interview at a date, time, and location that are convenient for you. The type of questions asked during this interview will only revolve around describing your experience as a board member and you are free to not answer any question you would prefer not to answer. The interview will take between 60 and 90 minutes. Once the interview is complete, the PI will transcribe the interview and give you the opportunity to check that the information is accurate. No additional follow-up is required.

One aspect of this study involves making audio recordings of you. The interview is being audio recorded as a way for the PI to record the interview at the same time that it is being conducted, and to ensure no details are excluded. The only person who will have access to them is the PI and chosen members of the research team. You are still eligible for the study without being audio-taped. We will ask you at the start of the interview whether or not you agree to the recording.

You will also be observed in two public board meetings related to your participation on this board. The data collected will involve interactions among board members, between certain board members, and the conversations the board has around policy development. The PI will record those interactions using a field journal and hand-written notes. You

will know when you are being observed because the PI will alert you to her presence and intention of observing interactions.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. To protect your confidentiality, we will assign a code number that will be used to identify your study data. The list linking your assigned code and your name will be kept in a secure place which will be different from the data and which is accessible only to the researchers on this project. The link between your study code and your name will be destroyed once the study is over. We will store all study data in password protected computer files. If we write a report about this study we will do so in such a way that you cannot be identified.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify. If we obtain any new information during this study that may affect your willingness to continue participating in the study, we'll promptly provide you with that information.

We would also like to inform you that this research study is supported in part by a grant from the Fahs-Beck Fund for Research and Experimentation from the New York Community Trust.

If you have any questions about the research study itself, please contact Kristi L. Law at [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu) or Dr. Jeanne Saunders, the faculty advisor at [Jeanne-saunders@uiowa.edu](mailto:Jeanne-saunders@uiowa.edu) or 319-335-1276.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail [irb@uiowa.edu](mailto:irb@uiowa.edu). To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

If you agree to participate in an interview with the PI, please fill out and return one of your information sheets provided in the self-addressed stamp envelope provided.

If you do not wish to be in the study, please tell me know or at any time and our time together will stop and you will not be penalized for that decision in any way.

Thank you very much for your consideration.

Sincerely,

Kristi L. Law, MSW  
PhD Candidate, School of Social Work  
University of Iowa

**APPENDIX M**  
**CONSENT INFORMATION FORM FOR ALL FQHC**  
**BOARD MEMBERS**

**Description of Study:**

Kristi L. Law, a PhD candidate at the University of Iowa - School of Social Work, is interested in exploring the experience of participating on FQHC community boards with community representatives of the boards in a research study. The researcher is conducting ethnography and will collect many different types of data including reviewing content related to the FQHC board, observing activities and behaviors of board members in the context of facilitating policy development, and interviewing board members about their experiences from their perspective of participating on the FQHC board. She is inviting board members to participate in the study.

**Participant requirement:**

If participant agrees to participate in the study, the following next steps will take place:

1. If you are interested in hearing more about the study, please fill out the contact information at the bottom of this form and return to the researcher in the distributed self-addressed stamped envelope within the next two weeks.
2. The researcher will contact you directly and set up a time to meet with you, provide you additional information about your participation, and answer questions you may have about the study. If you agree to participate, the interview may be conducted at that time or scheduled at a mutually convenient time for the interview to take place. The interview can be at a location of the participant's choosing and will last from 60-90 minutes.
3. Upon completion of the interview, the researcher will transcribe the interview and send the transcription to the participant so that the participant may verify the information.

In addition, with the participant's permission, the researcher will conduct observations relating to the participant's involvement on the board. These will include legislative advocacy events, community education events, and activities or events where the board member publicly represents either him/herself or the board. You will not be compensated for your participation in this research project.

**Consent:**

**Please check one of the following two boxes to indicate whether or not you consent to be contacted by the PI.**

I agree to be contacted regarding this study, please use the information provided below.

I do not agree to be contacted regarding this study, please do not contact me.

**Contact information:**

**Name:** \_\_\_\_\_ **Telephone Number:** \_\_\_\_\_

**FQHC Board:** \_\_\_\_\_ **City & Zip Code:** \_\_\_\_\_

**Email address (if applicable):** \_\_\_\_\_

**Thank you for your time. If you have any questions please do not hesitate to contact me, Kristi Law at [Kristi-law@uiowa.edu](mailto:Kristi-law@uiowa.edu).**

**APPENDIX N**  
**TELEPHONE SCRIPT FOR BOARD MEMBERS**

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201202734 APPROVAL DATE: 04/12/12 EXPIRATION DATE: N/A
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Script for telephone conversations with board members interested in participating in study

Hello. My name is Kristi L. Law and I am a PhD candidate at the University of Iowa's School of Social Work. I understand you have been contacted by the community board president of the community board at the \_\_\_\_\_ clinic here in \_\_\_\_\_ providing you with information regarding my research which is interested in understanding your participation on community boards of Federally Qualified Health Clinics in Iowa involved in policy development processes. I also understand that you are contacting me so that I may follow up on that initial conversation in order to provide information about the project, answer any questions you might have, and ask for your participation.

If you agree, I will contact you in the way you request to schedule an interview. I anticipate the interview to take no more than 2 hours (probably less than that) and the interview can take place at a public location of your choice. You will not be compensated for your participation.

If you have any questions, comments, or concerns regarding this project, you can contact me at Kristi-law@uiowa.edu, or my academic advisor and dissertation committee chair Dr. Jeanne Saunders at Jeanne-saunders@uiowa.edu or (319) 335-1276.

Thank you for your time and again, if you have any questions I am happy to answer them now.

Are you interested in participating in this research project?

If yes – Great! Now let's talk about the date and time and location most convenient for you to schedule an interview with me. **Propose times and dates, and then set up a location in their town.**

If no – I do appreciate your time and if you should have any questions in the future please do not hesitate to contact me. Have a good day!



**APPENDIX O****INTERVIEW GUIDE FOR NACHC AND HRSA**

1. Please provide a description of your official title and role within the HRSA/NACHC.
2. Please describe the similarities and differences between the FQHCs and the CHC/MHC program from the 1960s and 1970s.
3. What is the official role or charge of the FQHC board in policy development? Is there a difference in state-level policy development and federal policy development? If there is, how? If not, why?
4. How do the board members act as community representatives?
5. What is the official charge to FQHC boards as to how to distribute information from the HRSA/NACHC? What information has the HRSA/NACHC distributed to FQHC boards regarding the ACA? What have FQHC boards done with this information, or in what ways have they used it?

## APPENDIX P

### 19 HRSA REQUIREMENTS FOR CHCS

According to information provided by <http://bphc.hrsa.gov/about/requirements/index.html#services1>, and document the program requirements of health centers include an established need, services offered, and how they are managed, financed and governed. This is all according to Section 330 of the Public Health Service Act (42 U.S.C. §254b). These requirements are listed below:

#### **NEED**

1. Needs Assessment: Health center demonstrates and documents the needs of its target population, updating its service area, when appropriate. (Section 330(k)(2) and Section 330(k)(3)(J) of the PHS Act)

#### **SERVICES**

2. Required and Additional Services: Health center provides all required primary, preventive, enabling health services and additional health services as appropriate and necessary, either directly or through established written arrangements and referrals. (Section 330(a) of the PHS Act)

Note: Health centers requesting funding to serve homeless individuals and their families must provide substance abuse services among their required services. (Section 330(h)(2) of the PHS Act)

3. Staffing Requirement: Health center maintains a core staff as necessary to carry out all required primary, preventive, enabling health services and additional health services as appropriate and necessary, either directly or through established arrangements and referrals. Staff must be appropriately licensed, credentialed, and privileged. Section 330(a)(1), (b)(1)- (2), (k)(3)(C), and (k)(3)(I) of the PHS Act)

4. Accessible Hours of Operation/Locations: Health center provides services at times and locations that assure accessibility and meet the needs of the population to be served. (Section 330(k)(3)(A) of the PHS Act)

5. After Hours Coverage: Health center provides professional coverage for medical emergencies during hours when the center is closed. (Section 330(k)(3)(A) of the PHS Act and 42 CFR Part 51c.102(h)(4))

6. Hospital Admitting Privileges and Continuum of Care: Health center physicians have admitting privileges at one or more referral hospitals, or other such arrangement to ensure continuity of care. In cases where hospital arrangements (including admitting privileges and membership) are not possible, health center must firmly establish arrangements for hospitalization, discharge planning, and patient tracking. (Section 330(k)(3)(L) of the PHS Act)

7. Sliding Fee Discounts: Health center has a system in place to determine eligibility for patient discounts adjusted on the basis of the patient's ability to pay.

°This system must provide a full discount to individuals and families with annual incomes at or below 100% of the Federal poverty guidelines (only nominal fees may be charged) and for those with incomes between 100% and 200% of poverty, fees must be charged in accordance with a sliding discount policy based on family size and income.\*

◦No discounts may be provided to patients with incomes over 200 % of the Federal poverty guidelines.\*

◦No patient will be denied health care services due to an individual's inability to pay for such services by the health center, assuring that any fees or payments required by the center for such services will be reduced or waived.

(Section 330(k)(3)(G) of the PHS Act, 42 CFR Part 51c.303(f), and 42 CFR Part 51c.303(u))

8. Quality Improvement/Assurance Plan: Health center has an ongoing Quality Improvement/Quality Assurance (QI/QA) program that includes clinical services and management, and that maintains the confidentiality of patient records. The QI/QA program must include:

◦a clinical director whose focus of responsibility is to support the quality improvement/assurance program and the provision of high quality patient care;\*

◦periodic assessment of the appropriateness of the utilization of services and the quality of services provided or proposed to be provided to individuals served by the health center; and such assessments shall: \*

□be conducted by physicians or by other licensed health professionals under the supervision of physicians;\*

□be based on the systematic collection and evaluation of patient records;\* and

□identify and document the necessity for change in the provision of services by the health center and result in the institution of such change, where indicated\* (Section 330(k)(3)(C) of the PHS Act, 45 CFR Part 74.25 (c)(2), (3) and 42 CFR Part 51c.303(c)(1-2))

## **MANAGEMENT AND FINANCE**

9. Key Management Staff: Health center maintains a fully staffed health center management team as appropriate for the size and needs of the center. Prior approval by HRSA of a change in the Project Director/Executive Director/CEO position is required. (Section 330(k)(3)(I) of the PHS Act, 42 CFR Part 51c.303(p) and 45 CFR Part 74.25(c)(2),(3))

10. Contractual/Affiliation Agreements: Health center exercises appropriate oversight and authority over all contracted services, including assuring that any subrecipient(s) meets Health Center program requirements. (Section 330(k)(3)(I)(ii), 42 CFR Part 51c.303(n), (t)), Section 1861(aa)(4) and Section 1905(l)(2)(B) of the Social Security Act, and 45 CFR Part 74.1(a) (2))

11. Collaborative Relationships: Health center makes effort to establish and maintain collaborative relationships with other health care providers, including other health centers, in the service area of the center. The health center secures letter(s) of support from existing health centers (section 330 grantees and Look-Alikes) in the service area or provides an explanation for why such letter(s) of support cannot be obtained. (Section 330(k)(3)(B) of the PHS Act and 42 CFR Part 51c.303(n))

12. Financial Management and Control Policies: Health center maintains accounting and internal control systems appropriate to the size and complexity of the organization reflecting Generally Accepted Accounting Principles (GAAP) and separates functions appropriate to organizational size to safeguard assets and maintain financial stability. Health center assures an annual independent financial audit is performed in accordance

with Federal audit requirements, including submission of a corrective action plan addressing all findings, questioned costs, reportable conditions, and material weaknesses cited in the Audit Report. (Section 330(k)(3)(D), Section 330(q) of the PHS Act and 45 CFR Parts 74.14, 74.21 and 74.26)

13. Billing and Collections: Health center has systems in place to maximize collections and reimbursement for its costs in providing health services, including written billing, credit and collection policies and procedures. (Section 330(k)(3)(F) and (G) of the PHS Act)

14. Budget: Health center has developed a budget that reflects the costs of operations, expenses, and revenues (including the Federal grant) necessary to accomplish the service delivery plan, including the number of patients to be served. (Section 330(k)(3)(D), Section 330(k)(3)(I)(i), and 45 CFR Part 74.25)

15. Program Data Reporting Systems: Health center has systems which accurately collect and organize data for program reporting and which support management decision making. (Section 330(k)(3)(I)(ii) of the PHS Act)

16. Scope of Project: Health center maintains its funded scope of project (sites, services, service area, target population, and providers), including any increases based on recent grant awards. (45 CFR Part 74.25)

## **GOVERNANCE**

17. Board Authority: Health center governing board maintains appropriate authority to oversee the operations of the center, including:

- holding monthly meetings;
- approval of the health center grant application and budget;
- selection/dismissal and performance evaluation of the health center CEO;
- selection of services to be provided and the health center hours of operations;
- measuring and evaluating the organization's progress in meeting its annual and long-term programmatic and financial goals and developing plans for the long-range viability of the organization by engaging in strategic planning, ongoing review of the organization's mission and bylaws, evaluating patient satisfaction, and monitoring organizational assets and performance;\* and
- establishment of general policies for the health center.

(Section 330(k)(3)(H) of the PHS Act and 42 CFR Part 51c.304)

Note: In the case of public centers (also referred to as public entities) with co-applicant governing boards, the public center is permitted to retain authority for establishing general policies (fiscal and personnel policies) for the health center. (Section 330(k)(3)(H) of the PHS Act and 42 CFR 51c.304(d)(iii) and (iv))

Note: Upon a showing of good cause the Secretary may waive, for the length of the project period, the monthly meeting requirement in the case of a health center that receives a grant pursuant to subsection (g), (h), (i), or (p). (Section 330(k)(3)(H) of the PHS Act)

18. Board Composition: The health center governing board is composed of individuals, a majority of whom are being served by the center and, this majority as a group, represent the individuals being served by the center in terms of demographic factors such as race, ethnicity, and sex. Specifically:

◦Governing board has at least 9 but no more than 25 members, as appropriate for the complexity of the organization.\*

◦The remaining non-consumer members of the board shall be representative of the community in which the center's service area is located and shall be selected for their expertise in community affairs, local government, finance and banking, legal affairs, trade unions, and other commercial and industrial concerns, or social service agencies within the community.\*

◦No more than one half (50%) of the non-consumer board members may derive more than 10% of their annual income from the health care industry.\*

Note: Upon a showing of good cause the Secretary may waive, for the length of the project period, the patient majority requirement in the case of a health center that receives a grant pursuant to subsection (g), (h), (i), or (p).

(Section 330(k)(3)(H) of the PHS Act and 42 CFR Part 51c.304)

19. Conflict of Interest Policy: Health center bylaws or written corporate board approved policy include provisions that prohibit conflict of interest by board members, employees, consultants and those who furnish goods or services to the health center. ◦No board member shall be an employee of the health center or an immediate family member of an employee. The Chief Executive may serve only as a non-voting ex-officio member of the board.\*

(45 CFR Part 74.42 and 42 CFR Part 51c.304(b))

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