

DAILY LIFE PARTICIPATION IN A RESIDENTIAL FACILITY FOR ADULTS WITH
INTELLECTUAL DISABILITIES: AN INSTITUTIONAL ETHNOGRAPHY

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ABSTRACT

Khalilah Robinson Johnson: Daily Life Participation in a Residential Facility for Adults with Intellectual Disabilities: An Institutional Ethnography
(Under the direction of Nancy Bagatell)

The overall aim of this dissertation was to determine how the daily operations and institutional structures of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) coordinate what residents and staff do. The specific aims were to (1) identify and describe the daily operations and institutional practices of the facility; (2) identify and describe the activities of the residents and staff; and (3) identify and describe how the opportunities for residents to choose and participate in meaningful activities were affected by institutional operations and culture. Institutional ethnography was applied as a social theory and methodology. Data were collected over 14 weeks with seven residents with profound ID and eight staff members. Data collection methods included participant observation, ethnographic interviewing, and text work. Conceptual mapping and narrative analysis were employed as iterative and reflexive processes to systematically extract narrative threads that depicted the complex nexus through which access to and participation in daily life activities emerged.

This dissertation is comprised of three manuscripts that form a narrative that describe the systemic ways in which front-line work and habilitative care are organized, its impact on residents' choices, and the challenges it poses on moral obligation and self-governance for staff members. Specifically, **Manuscript I** (Chapter 4) makes visible the inter-relational ways national, state, and local policies mediate the possibilities for staff to incorporate meaningful participation in occupation in daily interactions with residents; **Manuscript II** (Chapter 5)

explores how choice-making during meal and snack times is problematized and misrepresented as manipulative behavior by staff; and **Manuscript III** (Chapter 6) argues that staff participate in various circuits of accountability, and negotiating between those circuits poses significant challenges to their moral commitments to residents and their self-governance.

This dissertation interrogates the effects of institutional living on the development and participation in daily life for adults with ID and the implementation of habilitative training and personal care. This dissertation also moves forward the dialogue on choice, human rights, habilitative care, and quality of life for adults with ID; additionally, this dissertation adds to the conceptualization of occupation and challenges theoretical assumptions on participation in occupational science.

Keywords: intellectual disabilities, institutionalization, institutional ethnography, participation, occupational science

Be an advocate for the people and causes important to you, using the most powerful tool you have – your personal stories. – John Capecchi and Timothy Cage

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ASL	American Sign Language
CMS	Center for Medicare and Medicaid Services
CCDD	Community Center for Developmental Disabilities
CEO	Chief Executive Officer
CFR	Code of Federal Regulation
DHHS	Department of Health and Human Services
DHSR	Division of Health Service Regulation
DMA	Division of Medical Assistance
EI	Early Intervention
EMR	Electronic Medical Record
IHP	Individualized Habilitation Plan
IPP	Individualized Program Plan
IADL	Instrumental Activities of Daily Living
I/DD	Intellectual and Developmental Disabilities
ID	Intellectual Disabilities
ICF	Intermediate Care Facility
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
Pre-K	Pre-Kindergarten
PL	Public Law

CHAPTER 1: BACKGROUND AND STATEMENT OF PURPOSE

1.1 Introduction

Occupational Science is a discipline dedicated to studying humans as occupational beings and was established to provide the profession of occupational therapy with its own scientific and research base for informing clinical practice (Yerxa, et al, 1990). Occupational scientists posit that humans share an innate need to explore their environments, and it is through engaging in occupations that humans feed their curiosity, demonstrate competence, and achieve mastery (Wilcock, 2006). Occupations, in and of themselves, are described as ordinary, self-directed functional tasks and activities that are meaningful and purposeful to the person who engages in it (Hasselkus, 2012; Royeen, 2002), are socially constructed, and transacted through situations, spaces, and time (Dickie, Cutchin, & Humphry, 2006). Thus, the possibility for engagement in occupations is contingent upon the structures and processes that either enable or inhibit occupational participation (Rudman, 2010).

Countless sociopolitical, contextual, temporal, historical, and cultural factors affect access to and participation in occupations. Individuals are situated in societies that are hierarchically structured, and consequently, markets and systems can determine where and how one is positioned within society (Young, 1990). One key aspect of this societal hierarchy, the socio-economic position, is important as it determines individuals and groups' control over the resources that shape life experiences (Emerson & Gone, 2012). Of interest to this dissertation is how individuals with intellectual disabilities (ID) participate in occupation. Research consistently shows individuals with ID have fewer opportunities than persons without disabilities

for choosing, accessing, and participating in occupation (Johnson & Traustadóttir, 2005; Renwick, Schormans, & Shore, 2014; Wehmeyer, 2013). Across their life span, individuals with ID are more likely than individuals without disabilities to occupy a low socio-economic position and be housed in institutional settings by family members.

Emerson and Gone (2012) asserted that other social factors which limit occupational participation for individuals with ID include: barriers to forming an individual identity, gender inequalities, lack of intimate relationships and sexual autonomy, decreased recreational opportunities, and inaccessibility of employment. Renwick, Schormans, and Shore (2014) reiterated:

They [adults with ID] are often permitted little control over their own lives, even though most are [more] capable than is generally assumed....[and] lack the opportunity (more than the ability) to express preferences and make choices in their lives, including occupational participation. These constraints can affect well-being and quality of life by limiting the scope, quantity, and quality of their opportunities and participation (p. 21).

In other words, freedom to choose and participate in meaningful occupation is critical for well-being and quality of life. For individuals with ID who reside in institutions, the opportunity to exercise choice is often limited or even prohibited due to institutional practices.

1.2 Institutionalization

Institutions, hereafter referred to as developmental centers, were constructed during the early to mid-19th century as the solution to control individuals' with ID choices and segregate them from the general public (Wehmeyer, 2013). Yet, in post-deinstitutionalization America, only nine states and the District of Columbia prohibit the use of formal institutions to care for individuals with ID (Race, 2007). Further examination is needed to understand the mechanisms (i.e. institutional, political, and social structures) which allow developmental centers for individuals with ID to remain open and productive. As Scior (2011) suggested, "current policies

governing services for people with intellectual disabilities in Western countries aim to maximize their social inclusion, independence, and empowerment” (p. 2165); therefore one must ask, if developmental centers continue to be utilized for the care of individuals with ID, do these centers provide the opportunities and supports to enhance social inclusion, independence, and empower decision-making?

With deinstitutionalization comes the great social responsibility of making certain that individuals with ID have the necessary social, educational, economic, and environmental supports to engage in meaningful occupations of their choosing. However, full integration into the community has been problematic. Community housing is often costly and individuals with ID may find themselves segregated within the community. With the rise in social services expenditures for individuals who are aging, disabled secondary to mental and functional decline, or unemployed, caring for an increasing population of individuals with ID in congregate-living facilities is fiscally problematic. Although studies have found community-living to be beneficial for improving community access and participation (Chowdhury & Henson, 2011), developmental centers continue to remain the most cost-effective means for states to manage all needs for individuals with ID (Race, 2007). What this suggests is that research is needed to examine the organization of developmental centers and the experiences of individuals with ID who reside there.

Researchers have primarily used participant observation and caretaker interviews as methods for interpreting how to best support individuals with ID (e.g., Chuo, et al., 2009; Helgenkamp, Wijck, & Evenhuis, 2011; Innes, McCabe, & Watchmen, 2012; Lin & Lin, 2013). However, interviews render a narrowed scope of the experiences of caring for individuals with ID, the experience of having intellectual disability itself, and the experience of living in a

developmental center. The voices of those with ID have been all but entirely absent.

Understanding the experiences of and finding meaning in where an individual with ID lives requires conducting research that prioritizes first-person perspectives (Johnson & Traustadóttir, 2005) and examining the texts which organize their lived experiences (Smith, 2005; Townsend, 1996). Renwick, Schormans, and Shore (2014) reminded researchers that, “telling different stories - ideally, stories told by people with disabilities themselves - can work to effect new understandings” (p. 21). For researchers to understand if and how developmental centers remain effective for individuals with ID requires examining how their participation in daily life occupations is influenced by and situated within institutional living.

This study addressed this challenge posed by scholars in ID research (Hubert & Hollins, 2007; Johnson & Traustadóttir, 2005; Schalock & Luckasson, 2013; Wehmeyer, 2013). Its objective was to identify and describe the daily activities of the residents and staff and operations of a developmental center, and examine if and how a developmental center provided opportunities for residents to choose and participate in meaningful activities. It was believed that the capacity to choose and participate in daily life activities in a developmental center is greatly affected by organizational practices and social factors such as national and state health facility policies, societal perspectives and attitudes on ID, limited research on adults with ID and developmental centers, and the health policy influencing how adults with ID are characterized and classified. The rationale underscoring this dissertation was that further examination was needed to understand the mechanisms (i.e., institutional and social structures) that affect the operations of developmental centers and the implementation of habilitation programming and life skills training to enhance quality of life for its residents.

1.3 Significance of the Study

Studies about institutional living have not highlighted the experiences of and opportunities to choose and participate in meaningful activities from the perspective of individuals with ID. The lack of attention to the first-person perspective on institutional living has resulted in a narrowed scope from which researchers can understand the nuances of having ID and institutionalization. Further, limited exposure to individuals with ID and the lack of understanding of ID may translate into stigma and negative attitudes of ID from the general public (Scior, 2011). This study contributes enhanced knowledge about the experiences of adults with ID who live in developmental centers, how their opportunities to participate in daily life activities are supported by or thwarted by organizational practices, and informs clinical practices for the medical and habilitative care of adults with ID and their transition into the community.

This study is significant because it includes first-person perspectives of adults with ID who live in a developmental center, and examines how institutional living enhances or undermines their participation in daily life activities, and subsequently, their health and well-being. It also calls attention to the ways in which institutional work is organized and mediated through texts (Smith, 2005, 2006). This study is the first step in gaining a nuanced understanding of the experiences of living in an institutional setting, and how the perspectives of adults with ID contribute to that understanding. Findings from this study contribute to the conceptualization of occupation including a disability perspective, challenge theoretical assumptions within occupational science and occupational therapy, expand the contexts from which occupation is researched, and advance knowledge on the lived experiences of adults with ID. It is also anticipated that findings of this study will contribute to public policy in that it will inform how developmental centers can better address the health and well-being of its residents, and influence policy decisions which guide the habilitative programming required by the centers.

Finally, this study demonstrates the value of understanding personal experiences of institutionalized adults with ID, and how it is possible to include individuals with ID as participants and informants in research.

1.4 Theoretical Framework

I position myself as a critical social constructionist as I believe individual and group choices and engagement in daily life activities are socially organized through sociocultural processes and discourses of power. These processes affect individuals' basic understandings of the world, and social constructionists assert that understanding arises from social systems rather than from individual members of society (Allen, 2005). They contend that knowledge is derived from social discourses, which vary across cultures, place, and time, and often represent and reproduce dominant belief systems. Social constructionists also underscore the significance of language to construction processes (Allen, 2005), and question the idea of an 'objective fact' as individual and group identities and realities are constructed through multiple discourses and a multiplicity of perspectives, which all must be taken into consideration (Burr, 1998).

This study is also informed by the transactional perspective (Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry, 2006). The transactional perspective, based on the philosophy of American Pragmatist John Dewey, posits that everything people do is enmeshed in a situation or a "transactional whole." This is based on the notion of a continuity of people and the world; that is, people are in active relationships with their environments, integrating persons and situations. Situations are structured by the past and our view of possible futures, and underscore the interconnectedness of humans and environment (Cutchin, Aldrich, Bailliard, & Coppola, 2008). To be enmeshed in a situation is to be co-constituted and co-defined with the historical, social, political, economic, temporal, physical, and spatial environments (Cutchin & Dickie, 2012).

Understanding the human-context relationship provides a nuanced understanding of occupations and occupational engagement; that is, people engage in occupations through their environments in a socially constructed and socially organized manner.

To address how institutionalized adults with ID have opportunities to choose and participate in meaningful daily life activities, I draw on the evolving concept of occupational justice (Stadnyk, Townsend, & Wilcock, 2010). Occupational justice was first described as complementary to social justice; however, Stadnyk, Townsend, and Wilcock (2010) noted that these constructs differ in that social justice addresses social relations and the conditions of life, while occupational justice addresses what people do and their conditions of living. Durocher, Gibson, and Rappolt (2013) added that occupational justice emerged out of the critique of social justice as insufficient in addressing individual and collective rights to participate in occupations. Occupational justice shared the concept of equity but moved beyond to focus on rights and possibilities to participation.

Occupational justice also calls attention to the taken-for-granted notions of what people could and should do, and points to the interplay between socially contextualized structure and agency in the negotiation and enactment of occupation (Rudman, 2010). The transactions of these factors impact one's occupational possibilities (Rudman, 2010). Occupational possibilities refer to the ways of being that are viewed as ideal and possible within a specific context and that come to be promoted and made available within that context. Regarding the impact of occupational justice on institutionalized adults with ID, Rudman (2010) reminds us that "discourses shape collective perceptions regarding the 'right' ways to be, as well, as to act, and are drawn upon in justifying and developing services, programs, and policies" (p. 57).

The constructing and organizing of people's daily life activities across time and place

also points to the understanding of social constructionism inherent in institutional ethnography (Proding, Rudman, & Shaw, 2013). Institutional ethnographic methods (Smith 2005, 2006) reveal how social and institutional processes have generalizing effects from broad extra-local social and institutional structures to local practices (Proding, Rudman, & Shaw, 2013; Smith, 2005). In other words, it allows researchers to explore the systems and social relationships that structure what people do.

1.5 Research Question and Rationale for Core Chapters

The guiding research question for this study was: how do the daily operations and institutional structures of a residential facility organize what the adults with ID who reside there do? The specific aims were to (1) identify and describe the daily operations and institutional practices of the facility; (2) identify and describe the activities of the adult residents and staff, including the form, function, and meaning; and (3) identify and describe how the opportunities for adults with ID to choose and participate in meaningful activities were affected by institutional operations and culture. Chapter 2 reviews the history of institutionalization in the United States, situates current issues in ID in relation to institutionalization, and critiques the abstraction of ID in occupational science and occupational therapy.

The core chapters for this dissertation, Chapters 4, 5, and 6, are written in manuscript form and represent themes that emerged from the data including the narratives of the resident and staff participants. Specifically, these chapters discuss the systematic ways through which occupations emerge in an institutional setting, how embodied institutional practices problematize choice and participation for adults with ID, and the challenges staff participants face when

negotiating personal responsibilities and institutional accountability on the front-line.

Chapter 7 provides an integrated discussion of the core chapters and outlines the conceptual and theoretical contributions of this dissertation to occupational science and ID research.

CHAPTER 2: INSTITUTIONALIZATION, INTELLECTUAL DISABILITY, AND OCCUPATION

2.1 Historical Perspective on Institutions and Intellectual Disability

The journey of intellectual disability as a construct dates back to pre-recorded history (Race, 2007; Wehmeyer, 2013); however, for the purpose of this dissertation this literature review will begin with the 19th century. During the 19th century, individuals with ID were referred to as “idiots,” and “idiocy” became a growing specialization in the field of psychology. ID was constructed as developmental, a “perverted science of heredity” (Wehmeyer, 2013). Idiocy was believed to be incurable; however, once psychology deemed idiocy to be treatable, by connecting to the mind through the senses, legislators began establishing experimental schools or institutions. As these experimental schools emerged in the United States toward the end of the century, people with ID became segregated from the general public. The treatment of individuals in these institutions was deplorable; narratives written about institutions were pessimistic and accusatory in tone, particularly narratives written by poorer families (Wehmeyer, 2013).

The first half of the 20th century can be characterized as the mega-institution boom and the search for a new science (Harbour & Maulik, 2010). ID was believed to be inherited through a parasitic like gene; consequently, science was used to facilitate social progress by controlling the ability of individuals with ID to procreate. Eugenics became the intervention of choice as the United States Supreme Court sanctioned involuntary sterilization. There was a shift from individuals with ID being referred to as idiots to being referred to as “feeble-minded” and “morons” as they were now believed to have thoughts, but lacked adaptation of thought to action. The number of institutions increased by 50 percent after the Great Depression, with the

greatest pressure to warehouse individuals being in southern states. Institutions began to operate by economizing individuals who had the physical capacity to work the grounds and assist with caring for those most afflicted (Noll & Trent, 2004; Trent, 1994; Wehmeyer, 2013).

The second half of the 20th century saw major shifts in institutionalization. As celebrities with and without children with ID (e.g., Dale and Roy Rogers, Eunice Kennedy Shriver, Pearl Buck, and Geraldo Rivera) became vocal and active in advocating for better treatment for individuals with disabilities, legislation was written for children with ID to have access to public education. The conditions of institutions were exposed in the media and subsequently began to close their doors as individuals with ID were transitioned into group homes and other smaller congregate living facilities. A shared assumption, which was underscored in several court decisions in the United States, is that less restrictive and ‘normalized’ community-based environments are better able to meet the individual rights and developmental needs, and promote the general well-being of individuals with ID than the restrictive institutions (Chowdhury & Benson, 2011). Psychology began to use the “normalization principle,” the organizing of daily life routines and developmental experiences across the lifespan based on the activity patterns of mainstream society, as a means to define people with ID. This was accompanied by a shift from referring to individuals with ID as feeble-minded and morons to mentally retarded. Use of the term mental retardation suggested that these individuals lacked adaptive skills for normal daily life functions and social ineptness (Trent, 1994). The Bill of Rights for the Handicapped Child, the Special Olympics, and other parent-organized community programs were spearheaded as a means to include children and adults with ID in mainstream communities (Wehmeyer, 2013).

2.2 Intellectual Disability and Institutionalization: The Current Dialogue

The end of the 20th century to the beginning of the 21st century was marked by the self-determination and self-advocacy movements. Individuals with disabilities began to raise awareness about their oppression and the need to address the social conditions (e.g., societal attitudes toward education, transportation, housing, health care, and family and social life) impacting their participation in daily life (Charlton, 1998). During this time, psychologists determined that environmental modifications were critical for individuals with ID to be able to adapt to their environments and participate in daily life activities. The Americans with Disabilities Act (1990) framed disability in terms of the fit between a person's capacities and the demands of the environment, and defined intellectual disability as the "limitations of intellectual functioning, manifesting in activity limitations and participation restrictions across all life activity and human functioning domains" (Wehmeyer, 2013, p. 252). Although these advancements led to some notable improvements in the lives of individuals with ID, quality of life measures have indicated only short-term gains post-institutionalization (Chowdhury & Benson, 2011). After six months to one year, quality of life is noted to plateau or become worse. Increased leisure participation and outings to other communal places is not maintained. Therefore, true integration into the community may not be realized (Chowdhury & Benson, 2011). Nonetheless, community living remains the ideal.

For individuals with ID, realizing their potential can be stifled by socially constructed barriers that restrict the spectrum of opportunities for meaningful occupational participation, putting them at significant risk for occupational deprivation and a decreased sense of occupational competence (Charlton, 1998; Mahoney & Roberts, 2009; Renwick, Schormans, & Shore, 2014). What is known about developmental centers has provided a more historical view of their treatment of individuals with ID rather than expanding on the experiences of those who

administer and receive habilitative services in developmental centers. Academic papers continue to draw exclusively on documents written by policy-makers and providers and not from the perspectives of individuals with ID (Atkinson & Walmsley, 2010). Anecdotes and personal records from individuals who lived in developmental centers indicate that not all experiences in these centers have been negative (Johnson & Traustadóttir, 2005). Developmental centers are known to facilitate relationship building, offer educational and employment opportunities, create a safe haven for individuals to be themselves, and make health services readily accessible (Race, 2007). Therefore, it is important to understand how the operations of developmental centers are situated in the broader spectrum of policies and science that govern the care of individuals with ID and the impact on occupational experiences.

The current dialogue about adults with ID has focused on transition to community-based congregate living facilities and the renaming and reframing of ID. Specifically, Schalock and Luckasson (2013) have named five critical issues that continue to affect individuals with ID: naming ID, explaining ID, defining its class of members, classifying its members, and establishing public policy; however, these issues translate more directly to the organization of service delivery in communities, but do not necessarily address the experiences and challenges adults with ID face in developmental centers.

2.3 Occupation and Intellectual Disability

Occupational science was originally conceived as a basic science to address universal issues about occupation without concern for their immediate application in occupational therapy practice (Yerxa, et al., 1990). Therefore, occupational scientists considered occupation from a conceptual level, and did not focus specifically on the occupations of individuals with disabilities. Relatively few scholars in occupational science have considered the occupational

engagement of individuals with ID. Channon (2013) identified and analyzed 28 articles that address occupational engagement of individuals with ID. Findings indicated that individuals with ID's experience of low levels of activity could be attributed to service delivery, policy design, and the social and physical environments. Mahoney and Roberts (2009) discussed the occupational experiences of individuals with ID in an adult day program and revealed that the opportunity to choose occupations and have meaningful interaction with staff members contributed to their meaning making. Furgang's (2013) dissertation examined the construction of identities and occupations of students with I/DD enrolled in a specialized postsecondary education program, demonstrating interest in the experience of community integration. This small survey of studies contributes to the conceptualization of occupation from a minority group whose perspectives were otherwise not considered. These studies have revealed the challenges individuals with ID face in choosing and participating in occupations; yet, there is still a need for broader examination of the social systems and practices which make possible meaningful participation in daily life.

Within occupational therapy, ID has also received surprisingly little attention, particularly regarding the occupational concerns of adults with ID. An historical review of the dialogue about ID revealed that ID was initially discussed as a comorbid condition with cerebral palsy and primarily as a condition of childhood (Willard & Spackman, 1947, 1954, 1963). ID did not receive specific attention in the profession until the 1970s and 1980s, with the advent of deinstitutionalization (Hopkins & Smith, 1978); however, as occupational therapy began to specialize in sensory integration, neurodevelopmental treatment, and school-based intervention for children with developmental delay, attention given specifically to ID in occupational therapy literature waned (i.e., Case-Smith O'Brien, 2010; Chapparo & Lane, 2012; Kramer & Hinojosa,

1999). Currently, there continues to be limited research examining the occupational experiences of and interventions specifically for children with ID and even less related to adults with ID. However, with the passing of the Higher Education Opportunity Act (HEOA) of 2008, evaluating postsecondary transition needs has become an emerging area of practice for occupational therapists (Kertcher, 2014), and as adults with ID age, there is growing recognition of the need for occupational therapists to address these adults' occupational concerns (Cronin, 2013; Haertl, 2014).

Given the gaps identified, there is clearly a need for research related to individuals with ID in occupational therapy and occupational science. Whereas some studies have examined outcomes of particular interventions with children with ID (e.g., Sachs & Nasser, 2009; Wuang, Wang, Huang, & Su, 2009), understanding the lived experiences of adults with ID and the social factors influencing opportunities to choose and participate in meaningful activities remains lacking in the occupational therapy and occupational science knowledge base.

2.4 Critique of Occupational Science Literature

Occupational science scholars have critiqued the discipline for its Judeo-Christian, able-bodied, Anglo, middle-class, female perspective (Hammell, 2009a; Hocking, 2012). This unintentional discursive treatment of occupation is attributed to the fact that occupational scientists are primarily White, female, occupational therapists who work in Western academic contexts (Hammell, 2009a; Hocking, 2012; Rudman, 2008). This perspective has shaped the discipline in a way that other forms of occupation (such as how occupations are performed in other cultures or by people with disabilities) are measured against its contribution to the productivity of a particular society. Few research studies have addressed the nature of occupation in non-Western contexts or underrepresented groups beyond disadvantage (e.g.,

occupational engagement of poor youth in South Africa (Galvaan, 2012), occupations of indigenous tribes in New Zealand (Nayar, 2013)), or attend to the occupational experiences of men or children (Glover, 2009; Pierce, et al., 2010). This further evidences the need for a different perspective on occupational engagement – one that renders the point of view of individuals with a disability, who perform their occupations in institutionalized settings.

Additionally, the discipline has been criticized for its lack of methodological rigor (Glover, 2009; Pierce, et al., 2010; Rudman, 2012). Frank and Polkinghorne (2010) noted that phenomenology, grounded theory, and ethnography are the commonly used researched methods. These methods, although rigorous in their own right, have not been employed rigorously in occupational science. In particular, the authors note the discussion and application of methodological theory in occupational science studies does not consistently reflect a commitment to enhancing the political reach of the discipline and profession. In order to move the discipline forward, occupational science must be open to critique and debate (Hammell, 2009a), and rigorously apply critical perspectives to unpack the nuances of occupation and occupational engagement (Rudman, 2008, 2010). This dissertation attempts to meet this challenge by employing critical perspectives and methods to unpack the sociopolitical factors that impact how people come to do what they do in daily life.

CHAPTER 3: INSTITUTIONAL ETHNOGRAPHIC METHODS

3.1 Introduction

The purpose of this dissertation is to gain nuanced knowledge of the ways through which occupations emerged and were enacted by adults with ID and staff in a residential developmental center in the southeastern United States. Institutional ethnography was utilized as a social theory and method of inquiry as it offered ways to gather first-person perspectives on the experiences and effects of choice and occupational participation, as well as understanding the organization of “work” in an institutional setting. Perhaps more importantly, institutional ethnography provided an understanding of what institutionalized adults with ID do is mediated and how this doing is coordinated through texts (Smith, 1987, 2005).

3.2 Institutional Ethnography

Institutional ethnography is a feminist-oriented empirical approach to inquiry developed by Canadian sociologist Dorothy Smith (1987, 2005, 2006) that combines theory and method. Its purpose is to reveal how social and institutional processes have generalizing effects from broad extra-local social and institutional structures to local practices (Proding, Rudman, & Shaw, 2013; Smith, 2005). In other words, it allows researchers to explore the systems and social relationships that structure what people do. Institutional ethnography is grounded in Marx’s theory of a political economy and ethnomethodology – the ordering and ruling of what people do and how people know and do in their specific situations as an entry point to study their position in social situations (Smith, 2005; Walby, 2007). Therefore, it is understood that knowledge is socially constituted and that whatever is brought into being is done so through the

organizing of what people do.

Like conventional ethnography, institutional ethnography begins with observing the experiences of daily life and identifies a particular area of everyday practice or specific events from which a discourse may be explored (DeVault & McCoy, 2001). However, institutional ethnography has a primary focus on the social organization of unacknowledged “work.” Work refers to both paid and unpaid activities, and in a developmental center that would include the activities of residents as well as staff and administrators. Beginning with experiences reveals to the institutional ethnographer the unacknowledged or unrecognizable work that people perform and how this work is shaped through social relations, discourses, and institutional practices. Work is understood as being nested in discourses. It is organized through systems-level institutional practices, the textually-mediated managers (e.g., words, sounds, and images) that are “set into a material form of some kind from which they can be read, seen, heard, watched” and organize daily life (Smith, 2006, p. 66). Not only does institutional ethnography examine the institutional practices and routines and their effect on local practices, it maps the relations between the two (Campbell & Gregor, 2004). Mapping here refers to a process of analyzing institutional practices and connecting them back to the coordination of people’s daily lives.

Whereas the purpose of ethnography is cultural interpretation (Wolcott, 1990, 1999), the aim of institutional ethnography is interpretation of institutional processes that organize daily life (DeVault, 2006, 2013; Smith, 2005). Institutional ethnography’s assumptions also depart from conventional ethnography in that institutional ethnography sees the everyday world as problematic. Those who perform the unacknowledged work provide a more accurate account of their social reality than the standpoint and interpretation of a researcher (Walby, 2007). Methodologically, institutional ethnography departs from conventional ethnographic methods in

that the institutional ethnographer utilizes in-depth interviews to identify which texts and artifacts to examine for the purpose of analyzing the coordination of activities and experiences (DeVault, 2013; Smith, 2006). Methods for data collection include participant observation, recurring interviews, and text work (Smith, 1995). Text work involves a thorough analysis of artifacts and documents, oral histories, and other materials. A list of texts analyzed in this dissertation is included in Appendix A.

Like all methods of inquiry, institutional ethnography has theoretical and methodological limitations, and arguably some contradictions (Walby, 2007). Walby (2007) offered a critique of Smith's (2005, 2006) claims including that institutional ethnography is void a particular theoretical orientation, departs from conventional forms of sociological research, and has a distinct method of analysis. Walby suggested all social science research is oriented toward a particular theory or meta-theory. For example, the assumption that the world provides a problematic is derived from critical ethnography, Marx's political economy, and ethnomethodology. According to Walby (2007), viewing work as nested within complex or ruling relations is grounded in Foucault and Bourdieu and not a major departure for sociology. Walby (2007) also posited that Smith contradicts herself by stating that the participants' social realities are hidden from them, which would require the interpretation of the sociological expert. Ethnography involves cultural interpretation, and part of the interpretation is the ethnographer's experience.

Whereas I appreciate Walby's critique of institutional ethnography as a social theory, the critique neither acknowledges that Smith (2005) discussed the philosophical and theoretical commitments that inform institutional ethnography, nor does it reflect the importance of the role of researcher. Smith asserted that institutional ethnographers view people as the "experts" in

their own experience and activity, but observe that they do not necessarily see the more distant sites of coordination that organize and coordinate their experiences. Analyzing and communicating about that extra-local coordination is, in fact, the primary task of the institutional ethnographer (M. DeVault, personal communication, January 18, 2015). It was evident in my experiences in the developmental center that residents, staff, and administrators were loosely aware of the ways in which organizational texts mediate the daily activities of the center and how those texts perpetuated particular practices that supported and limited choice and participation for adults with ID. Data to support these claims are discussed further in the core chapters (Chapters 4, 5, and 6).

3.3 Institutional Ethnography in Occupational Science

Ethnographic methods are suitable for occupational science in that they orient the researcher to examine the extra-local social and environmental forces which influence and organize daily life activities (Bailliard, Aldrich, & Dickie, 2012; Smith, 2003). Likewise, fundamental to institutional ethnography is an ontology that views social relations as the coordination of people's activities (Campbell & Gregor, 2004; Smith, 2005, 2006; Townsend, 1996). This is an ontology that is shared by occupational scientists. Institutional ethnography offers a social theory and critical lens from which to view the activities (occupations) people perform and how they come to choose and organize them in their daily lives (Prodinger, Rudman, & Shaw, 2013; Prodinger & Turner, 2013).

Scholars in occupational science and occupational therapy have explored the use of institutional ethnographic methods to investigate the tensions occupational therapists encounter when advocating for and implementing client-centered practice (Townsend, 1996), the ability of occupational therapists to enable empowerment in adults with mental health issues (Townsend,

Langille, & Ripley, 2003), and how occupations are identified and addressed by health care providers in the health records of women with rheumatoid arthritis and how health care practices are connected to and organized through various social policies (Prodinger & Turner, 2013). Institutional ethnography allows occupational scientists to make visible the relations between social policies and participation in daily life activities (Prodinger, Rudman, & Shaw, 2013). It problematizes how the discipline conceptualizes occupation and occupational engagement, its taken-for-granted assumptions about occupation, the discourses that organize what people are able to do, and calls attention to the language used in occupational science literature (Smith, 2003).

Institutional ethnography also lends itself to the transactional perspective (Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry, 2006) as occupations are viewed as situational wholes (Bailliard, Aldrich, & Dickie, 2012). Utilizing institutional ethnography serves as a way for researchers in occupational science to “get the story right” (Campbell & Gregor, 2004) – a story that encompasses the various ways of knowing and understanding the everyday world. As occupational scientists and occupational therapists endeavor to politicize its research and practice (Frank, 2012), institutional ethnography can serve as the catalyst for social transformation (Biklen, 2011) and expand the critical application of social science research in occupational science (Prodinger, Rudman, & Shaw, 2013).

3.4 Ethnographic Access

Establishing a relationship with a potential research site for this dissertation was not without its challenges. Hubert and Hollins (2007) emphasized that closed institutions pose some of the greatest challenges for researchers. In particular, the authors noted internal research committee approval, gaining informed consent from guardians, data collection, and the

dissemination of findings as areas of concern. Facilities with state-funded programs have their own internal research committee. As with other institutional review boards, its purpose is to ensure safe and ethical administration of research methods. Closed institution policies can be quite prohibitive in that they may require additional reports (e.g., weekly, monthly, or quarterly reports on the types of data collected) and copies of transcripts or analyses before permitting the researcher to proceed with the next phase of the study. After one year of negotiation with the center where I worked, I was ultimately denied access. Following this experience, I was denied access by two more state-funded developmental centers. As a last attempt, I contacted a private institution, the Community Center for Developmental Disabilities, that provides services for adults and children with ID.

The ease through which I was able to access the Community Center for Developmental Disabilities (CCDD) was refreshing, and by the same process, disconcerting. Having endured three denials, I was expecting to have to answer many questions and face a number of barriers for approval. Cynthia, who was appointed to manage CCDD's student research interests and projects, requested I submit a mini proposal and "if all checked out with the Human Rights Committee," my study would be welcomed at the center. One week post submission, I received notification that the center's Human Rights Committee approved the study. I do feel that their private status helped me to be able to access the site in a very different way. It is a facility that has been open to having students, they have participated in research (although not for some time), and they pride themselves on being well connected in the community. They saw me being there as a benefit to them. The center's chief executive officer stated, "Of course we want to know what we can do to better serve our residents. Any smart CEO would have you in their center." Following my data collection, the CCDD Human Rights Committee requested that I

submit a report detailing my perceptions of the strengths and areas of improvement based on my research findings.

My status as an occupational therapist, in addition to being a researcher, also affected how I was able to access the center. In particular, being a licensed clinician added another unspoken expectation that I would provide an evaluation of the habilitation technicians' performance from a clinical perspective. This, in addition to being an educated African-American female, would also prove to be an unanticipated barrier to building rapport with the habilitation technicians. It was a power dynamic that I was not comfortable negotiating, especially because direct care staff were primarily young minority females. Initial reactions from the habilitation technicians were somewhat critical. Everyone seemed to notice my attire, the type of jewelry I wore, and handbags I carried. To reduce these stares, I decided I would leave my handbag in the car and would only wear a watch and my wedding ring. I made sure that I dressed as casually as possible, including wearing scrubs on occasion. I also stopped bringing my lunches from home, and instead opted to eat fast food with staff in order to create another space through which I could become better acquainted with them. Sharing meals was a very important activity for them. I made sure I listened to the stories they shared about their families, and occasionally added my own family experiences to their narratives.

Through these efforts, over time, the staff's perceptions of me changed. I was often asked to participate in social activities (e.g., playing a game and decorating Hope House for parties) or even assist female residents with their hair. This excerpt from an exchange with a habilitation technician illustrates this point:

Ann: <laughing> We were just saying that we really like you and how down to earth you are. I told everybody you're a real sistah.

Khalilah: Uh huh.

Ann: I know we shouldn't judge people, but some of us did assume you were going to be 'saditty'. <she pauses> But seriously, we all really like you. Even the ones who tried not to like you, like you. Sometimes people like you, you know, people who have a lot of education talk down to us. You never did that. You just talk to us and listen to us. You never made us feel less than you. I can't speak for nobody else, but I really appreciate that. I wish more people were like that.

I was first viewed as an "uppity black woman" from the ivory tower, but now, I am seen as an educated and approachable woman with whom many of the habilitation technicians had many interests in common.

3.5 The Research Site and Participants

3.5.1 Community Center for Developmental Disabilities

The CCDD was founded in the late 1960s by a family-owned non-profit organization dedicated to serving families of children with special needs. The center is situated in a metropolitan area in the southeastern United States on 9.5 wooded acres generously donated by a local university. The physical campus is comprised of three residential homes, a school, a therapy and residential services center, an administrative office building, playgrounds, and a sensory garden. The center serves approximately 400 children and adults, both residentially and in the community. Services include: Intermediate Care Facility Services for Individuals with Intellectual Disabilities (ICF/IID); community residential services; day services; therapy services (i.e., psychology, social work, nutrition, and occupational, physical, speech, and developmental therapies); respite care; early childhood intervention; educational services for school-aged children (3 – 22 years); and summer camps for children with and without disabilities. Many of

the residents also have complex medical needs and receive high-level nursing services, training, and personal care 24 hours a day. The center also has three group homes in surrounding cities, each providing supported-living services for adults with intellectual disabilities.

The center receives federal, state and local government funding, as well as fees for services. Charitable contributions from individuals, businesses, foundations, civic groups and churches are a major source of funding for the center and help close the gap between what is reimbursed and the actual cost of providing services. These sources include: the state's Division of Medical Assistance (DMA), the county's Department of Human Services, the city's government assistance programs, the county's Early Intervention (EI) agency, the state's Pre-Kindergarten (Pre-K) program, United Way, private insurance, parent fees, and local fundraising. Per the Community Center for Developmental Disabilities' philosophical and mission statements, its fundamental beliefs are: that all people have the potential for growth and development and have different needs at various junctures of their lives; that physical and social supports must be in place for positive development and participation; and that strengths-based programming should be designed to meet individual needs and be offered in the least restrictive environment possible.

3.5.2 Hope House

Hope House, the home of the residents and staff participants for this dissertation, was the first of three residential homes for adults with intellectual and developmental disabilities (I/DD) established at the center. The home was named after the child of one of the center's founding families. It is situated on a hill, near the garden, at the entrance of the Community Center's campus. Hope House is home for five male and five female adults diagnosed with profound ID. More specifically, there are two African-American male residents, one Hispanic male resident, and two Caucasian male residents. Four female residents are Caucasian, and the youngest

resident is an Asian female. 22 total staff members including a house manager, three shift supervisors, a nurse, and 17 habilitation technicians provide care to the residents. 17 staff members are female and five are male.

Hope House is approximately 2,500 square feet, including a front porch and a patio for outdoor dining and activities. The house contains a full kitchen, a combined dining room and den, a multi-purpose recreation room, staff office, staff lounge, nurse's station, seven bedrooms, and two bathrooms. Three of the bedrooms are designed for two residents; two are for male residents and one is for female residents. One male and three female residents have a private bedroom. Private rooms may be provided to the resident for an additional fee. The rooms are painted with blue or coral paint. Pictures of landscapes and families adorn the walls. Bedroom floors are wood grain vinyl, while the hallway and dining room floors are beige speckled tiled. Many activities occur in the dining room and the patio. Beyond activities of daily living (ADL), other common activities of the home include playing games, arts and crafts, "Current Events," watching movies, listening to music, dancing, hosting parties, and lounging on the patio. A diagram of Hope House is included in Appendix B.

3.5.3 Staff Participants

Eight staff members – one administrator (Cynthia), one house manager (Mary Ann), one shift manager (Elijah), and five habilitation technicians (Heather, Ann, Margaret, Kena, and Niecey) – consented to participate in the study (see Appendix C). The remaining staff members did not provide consent due to lack of interest, fear of being identified, and lack of monetary compensation. The mean age for all staff participants was 35 years, with the oldest staff member being a 65-year-old habilitation technician and the youngest staff member being a 22-year-old habilitation technician. The mean number of years worked at CCDD was 6 years and 8 months. Years worked ranged from 6 months to 25 years.

The habilitation technicians are the front-line workers of Hope House. They are responsible for providing personal care and habilitative training to enhance independence and participation in self-help, domestic and leisure activities. Personal care included bathing, toileting, feeding, donning and doffing clothing, changing diapers, skin care, and medication administration. Habilitation technicians are also responsible for accompanying residents on outings, medical appointments, and other community visits.

Cynthia. Cynthia was a petite, 58-year-old woman of color. She functioned in the role of psychologist and therapy manager. She was responsible for overseeing therapy services and community-based psychological services, and establishing and coordinating the Individualized Program Plans (IPP) for all residents. She also coordinated student internships, and served as the liaison between the CCDD and the University of North Carolina for my doctoral research contractual agreement. Cynthia was the only center administrator to participate in the study. She has worked at the center for 25 years.

Mary Ann. Mary Ann was a tall, 38-year-old African-American female house manager. Mary Ann oversaw the daily functions of Hope House, and coordinated orientation for newly hired habilitation technicians for the center. Mary Ann has worked at the center for 15 years. She began working there as a habilitation technician, eventually securing a position as a shift supervisor and then a house manager. She is known across the center as a “Super Manager,” as many habilitation technicians have requested to be transferred to Hope House from their current residences.

Elijah. Elijah was a petite, 40-year-old African-American male first-shift supervisor. He was charged with making certain habilitation technicians provided quality and efficient care to the residents. Elijah was known as the Hope House “Firecracker,” as he usually demonstrated

high energy by being boisterous during activities, planned all the campus-wide parties, and was often the most vocal employee during staff meetings. He enjoyed planning lunches for the staff, as well as going to dance clubs with habilitation technicians during the weekend. He has worked at Hope House for three years. He began working at the center as a habilitation technician, until he was promoted to shift supervisor in 2015.

Heather. Heather was a petite, 22-year-old Caucasian female habilitation technician. Heather primarily worked first shift, and was often referred to as the resident hair expert. She was often observed braiding female residents' hair into various styles. As the youngest habilitation technician, Heather was often teased about being too young to be married and not being old enough to understand the politics of working in an ICF/IID. She was often quiet, but would often talk to me about her weekend adventures with her husband. Heather has worked in Hope House for nine months.

Ann. Ann was a petite, 62-year-old African-American female habilitation technician. Ann was fairly new to the Hope House first shift staff, having only worked there for six months. She had a quiet demeanor, but was always willing to assist other habilitation technicians with their assigned residents. She often talked to me about her health disorders and the types of food she ate to help her condition. She also enjoyed talking about her children, particularly her daughter, who had recently graduated with a degree in chemical engineering and was preparing to marry the son of a prominent politician.

Margaret. Margaret was a petite, 65-year-old African-American female habilitation technician. She primarily worked during first shift, and was known as the "House Mother" as she was often consulted by managers and other staff members for advice on activities for the residents, as well as advice about life. She was often observed maintaining residents' rooms

including hanging pictures and curtains. Margaret often called herself an advocate, and was not hesitant to speak up about events and activities she felt were not beneficial to the residents. She served as the primary staff informant for this study, as she often shared her thoughts about her work and led discussions with other staff about their work. She has worked at the center for nine years.

Kena. Kena was a tall, 30-year-old African-American female habilitation technician. Kena was considered the “Star” of second shift staff, and had recently been awarded employee of the quarter. She had an authoritative demeanor, as she often organized and planned second shift duties and activities. She has worked for the center for one year.

Niecey. Niecey was a tall, 32-year-old African-American female habilitation technician. Niecey worked with second shift staff. She was often observed coordinating dinner and preparing evening snacks for the residents. Niecey has worked for the center for nine months.

3.5.4 Resident Participants

Seven residents – four males (Tony, Kevin, Milton, and Lewis) and three females (Lisa, Keisha, and Marsha) – participated in the study. Verbal and written consent were provided by residents’ legal and court-appointed guardians (see Appendix C). Consent was also provided to access residents’ medical and therapy charts (see Appendix D). Due to participants’ classification of ID and status as wards of the state, only legal consent was required. I was unable to obtain consent from the remaining three residents due to difficulty establishing contact with their legal guardians. The mean age for all resident participants was 39 years, with the oldest being 53 years old and the youngest being 26 years old. The mean number of years lived in Hope House was 23 years and 8 months, with the greatest number of years being 43 years and the least number of years lived in the home being eight years.

Tony. Tony was a 32-year-old African-American male resident. He came to the center as a student in their residential school program 23 years ago. Tony required total assistance with all personal care from staff and utilized a tilt-in-space wheelchair when negotiating Hope House and the community as he also has limited dexterity skills and a severe visual impairment. He enjoyed socializing with staff and other residents, and was often heard laughing and discussing the plans for the day with anyone in his vicinity. Known as the “House Gossiper,” Tony was often observed tattling on which staff members “called out,” telling stories about staff members who he believed had recently given birth, and crafting stories about his ideal dinner at local restaurants. He also enjoyed listening to hip-hop and country music with his roommate, Kevin, and riding in the Hope House van. Tony was greatly interested in participating in the study; thus, he became a key resident informant.

Kevin. Kevin was a 38-year-old Hispanic male resident. He has lived in Hope House for eight years and shares a room with Tony. He came to Hope House from a foster home. Kevin required total assistance with all personal care from staff, with the exception of feeding. He negotiated throughout Hope House and the community independently with a power chair. Kevin used verbal speech, although his speech could be unintelligible. He had used an augmentative device prior to moving to Hope House; however, once he aged out of school-based services, the augmentative device was no longer covered by his insurer. Kevin enjoyed listening to music and assisting staff with household tasks such as wiping the dining room table and sorting linen. Kevin was known as the house “Movie Connoisseur,” as staff often allowed him to determine which movies and television shows everyone would watch during leisure time.

Milton. Milton was a 26-year-old Caucasian male who has lived in Hope House for 12 years. He came to Hope House from the center's residential school program. Milton required total assistance with personal care and received all meals via a gastrostomy tube. He also utilized a customized tilt-in-space wheelchair for all mobility. Milton does not speak and is quite lethargic. He slept during most observations, and when he was awake, he would enjoy watching 30 minutes to an hour of a cartoon mounted on his wheelchair or bed.

Lewis. Lewis was a 29-year-old Caucasian male resident. Lewis also came to Hope House from the center's residential school program and has lived there for 16 years. He required total assistance with all personal care, and utilized a tilt-in-space wheelchair for mobility in Hope House and the community. Due to self-injurious behaviors, Lewis required one-on-one attention during waking hours. Lewis enjoyed watching television and watching his housemates play board games. He was nonverbal, and enjoyed listening and waving his arms to music.

Lisa. Lisa was a 48-year-old Caucasian female resident. Lisa has lived in Hope House for 27 years. She required total assistance with all personal care and used a wheelchair for all mobility. Although she was nonverbal, she was able to make her desires known through pointing and grunting. Lisa was known as the "House Socialite," as she often greeted all visitors with hugs and would give them a stuffed animal to hold. She enjoyed watching television with Kevin and Tony, playing with stuffed animals, assisting other female residents with brushing their hair, and looking at pictures in magazines. Lisa also enjoyed assisting staff with sorting linens.

Keisha. Keisha was a 53-year-old Caucasian female resident. Keisha was the most senior resident of Hope House, having lived there for 43 years. Keisha required some assistance from the staff for self-care. She was able to assist with bathing and dressing. She also assisted

staff with preparing meals and transporting laundry. Keisha did not participate in activities in collaboration with other residents due to screaming, scratching, hitting, and spitting on others. Consequently, she also ate her meals away from other residents. Keisha was known as the “House Fashionista” as she enjoyed wearing shoes adorned with jewels and glitter. She also enjoyed looking at pictures in magazines (e.g., Southern Living, Better Homes and Garden, and Food and Wine) and playing with dolls.

Marsha. Marsha, a 49-year-old Caucasian female, was the second oldest resident of Hope House. She has lived at Hope House for 38 years. Marsha required total assistance from the staff for self-care, as well as hand-held assistance when ambulating in the home and the community. Marsha was nonverbal and used whimpering as a means to communicate with others. Marsha was affectionately known as the “House Wino,” as her mother often advocated for her to have wine at the center. She enjoyed tasting beverages, watching television, and listening to music. Marsha also enjoyed spending time with Kevin.

3.6 Standpoint of Adults with ID

The design of this institutional ethnography started from the standpoint of adults with ID who reside in Hope House. What this means is that conceptually this dissertation is designed to take up the challenges adults with ID face in institutional settings (DeVault, 2013). It was their experiences that define the starting point and not the caregiver, administrative, or professional challenges within the workings of an ICF/IID residential facility. In this respect, this dissertation is neither one of the attitudes of caregivers and administrators (Mahoney & Roberts, 2009), nor an assessment of quality of care of the individuals who reside at the Hope House. Rather, it was a study of social organization – first, in terms of what adults with ID do in institutional settings as well as how they understand their daily activities, and what they would like to do, and second,

how institutional settings function to meet, or not meet, the needs of its residents. In this context, the challenges adults with ID face in choosing and participating in daily life activities are taken up in terms of the ways in which the everyday practices of Hope House, the CCDD at large, and the regulations under which it operates, provide or impede opportunities for its residents to choose and participate in meaningful activities.

3.7 Challenges of Voice and First-person Perspectives

Ethnographers face many challenges with including adults with ID in research. Among these are recruitment and informed consent, effective and reliable communication, and balancing control and supporting participation in the research process (McDonald & Kidney, 2012; Nichols, Colyer, & Cooper, 2013). McDonald and Kidney (2012) identified several factors including personal factors (e.g., the severity of the ID, challenging behaviors, understanding risks and benefits), the unintended focus on risks resulting in overly conservative methods, lack of trust in the adult with ID as a gatekeeper or cultural broker, lack of trust from the participant that the researcher will protect their identity, participants' previous research experiences, researcher's previous experiences (or lack thereof) with participants with ID, and the fear of uncommunicated expectations to maintain close friendships. There is no consensus on best practices for including adults with ID in research (McDonald & Kidney, 2012; O'Brien, McConkey, & Garcia-Iriarte, 2014); however, a systematic review of research with individuals with ID revealed overly conservative research methods (e.g., limited responsibilities of participants with ID due to difficulties with communication and, balancing control over the research process and supporting full participation).

In addition, effective communication has been identified as an area of concern for researchers. To have an inclusive and comprehensive view of the lives of institutionalized adults

with ID would involve having participants with and without symbolic language. Thus researchers cannot rely only on the interviews with families and caregivers, but must also rely on observations and interpretations of non-symbolic forms of communication (e.g., vocalizations, gestures, eye gazes, postural changes, and object use) (Hamilton & Atkinson, 2009; Mactavish, Mahon, & Lutfiyya, 2000). I treated all forms of communication as valuable data, as it was important for the integrity of the dissertation to reveal the viewpoints of all participants. The voices of residents with verbal language were captured in observations and interviews; however, capturing the voices of nonverbal residents proved to be difficult. Often, without prompting, habilitation technicians offered their own interpretation of residents' nonverbal communication. Because I wanted to build rapport and demonstrate that I valued the habilitation technicians' input, I often allowed their voices to dominate. To manage how I captured nonverbal voices, I included detailed descriptions of how participants responded to people and situations, recounted their gestures, postures, displays of emotion, haptics, proxemics, and noted if opportunities to express themselves were presented and if such expressions were acknowledged by others.

3.8 Methods

Participant observation, semi-structured interviews, and text analysis were the ethnographic methods employed for this dissertation. Over the course of 14 weeks, I completed 46 visits (approximately 370 hours) comprised of observations and interviews at Hope House. Visits occurred during the three working shifts: 6:45am to 2:45pm, 2:45pm to 11:30pm, and 11:30pm to 6:45am. Observations took place at different times of the day to better understand what occurred during each of the three working shifts; however, most observations occurred during the day shift, as that was when most programming activities and community outings occurred.

3.8.1 Participant Observation

Institutional ethnographers, like traditional ethnographers, utilize participant observation in order to watch, listen, and ask questions regarding what people do in their everyday lives (Smith, 2006). This process takes considerable thought, extending over months of working through and reflecting over field notes and memos (Spradley, 1980), and attending to documents used by participants, which can be read for background information and before conducting formal interviews (Atkinson, Hammersley, & Gold, et al., 2004). My observations occurred three to four days per week and ranged from six to ten hours each day. Observations occurred in congregate spaces in Hope House (i.e., dining room and patio), in participants' bedrooms, and around the center's campus (e.g., day rooms in the therapeutic services building). I also observed community outings (i.e., four community parks, the state fair, and one local restaurant).

Initially, I positioned myself primarily as an observer. Doing so gave me the time and space I needed to get to know the functions of the home, as well as time for staff to be comfortable with my being there. Few staff members, primarily Elijah, Ann, Heather, and Margaret, immediately took interest in the study. Others were quite standoffish, usually looking to the head habilitation technician to determine if it was in their best interest to engage with me. Likewise, many of the residents took time to get to know me, often observing my actions with quiet interest. Tony, Kevin, and Lisa, however, engaged with me from my initial visit. Once I was able to build rapport with the residents and staff, I was able to actively participate in conversations and activities such as crafting and playing Bingo. As time went on, I assisted female residents with hair care, and assisted residents with their meals.

During observations, I recorded key words and phrases, descriptions of people and the physical environment, interactions of the participants, traffic of people entering and exiting Hope House, location and times of day activities occurred, objects and documents used, my sensory

experiences, other notable behaviors and significant events. Jottings also included which staff organized activities, which residents and staff participated in activities, and the language and dialects used in informal conversations. These jottings were expanded to full field notes at the end of each observation day. An observational guide is included in Appendix E.

3.8.2 Interviews

Institutional ethnographers often utilize semi-structured, opened-ended interviews in order to learn “how things work,” that is, understanding the coordination of activity and particular components of ruling relationships that emerge throughout the research process (DeVault & McCoy, 2001; Townsend, 1996). In institutional ethnography, informal interviews, the conversations that occur outside a scheduled formal interview are also important to understand what people are doing, why they did it just the way they did, what the documents and policies that determine what they do are, why they do it, when they do it, and where they do it (DeVault & McCoy, 2001). DeVault and McCoy (2001) assert, “‘Informal,’ on-the-spot interviewing can be combined later with ‘formal’ or planned interviews, in which the researcher brings to the longer interview a set of questions or topics based on the early observation-and-talk” (pp. 756-757). Interviewing, sometimes referred to as co-investigation in institutional ethnography, allows participants to discuss their work and related issues in a less directed but discursive manner (Smith, 2006).

During observations, informal interviews were conducted with residents, habilitation technicians, the shift supervisor, the house manager, and the psychologist. Often, Elijah requested to have time to speak with me so that he could share his perspectives on the challenges of caregiving in an institutional setting. Heather and Margaret were also eager to talk about their experiences. However, Heather did not agree to be audio recorded. Like Heather, Ann initiated conversations with me, but did not feel comfortable with audio recordings. There were other

habilitation technicians who regularly shared their perspectives with me; however, I could not convince them to consent to being in the study. Two middle-aged female habilitation technicians in particular stated they had a crippling fear they would be identified and did not want to lose their jobs. After multiple reviews of the security procedures for this study, they continued to decline participation.

Tony and Kevin initiated contact with me regularly. Tony enjoyed talking about his favorite meals, when he anticipated attending a medical appointment, whether or not family called him the previous nights, and various bodily functions. Kevin, who often spoken in single words and short phrases, shared which movies he watched and his favorite community outings. Lisa often initiated physical contact (e.g., hugs or holding hands), as well as passing a stuffed animal for me to hold. She would point and grunt at objects that were of interest to her, and propel her wheelchair towards people with whom she wanted to engage. It was difficult to engage with Milton, Lewis, and Marsha, who exhibit little initiation during activity. Occasionally, I was able to exchange single words and short phrases with Keisha about her shoe, dolls, and magazines.

Formal interviews were completed with two residents, Tony and Kevin, three staff members, Margaret, Mary Ann, and Elijah, and the psychologist, Cynthia. One group interview with five habilitation technicians and Elijah was also completed. Interviews were conversational and aimed at eliciting narratives about the participants' daily activities, relations with others, and about the texts that are important in their work. Interviewees were actively and freely probed for elaboration (Harden et al., 2004). For the residents, I used simple language and phrasing, as well as picture symbols to support their participation in the interviews (Mahoney & Roberts, 2009). All formal and some informal interviews were audio recorded. These interviews ranged in

length from 15 to 60 minutes, and occurred in a location chosen by the interviewee such as the staff lounge or staff office. Interviews were later transcribed verbatim and included as part of the field notes. An interview guide for staff is included in Appendix F, and an interview guide for adults with ID is included in Appendix G.

3.8.3 Text Work

A key tenet of institutional ethnography is the recognition that text-based forms of knowledge and discursive social practices are central to organizing what people do (DeVault & McCoy, 2001). Texts (organizational documents in the form of IPPs, policies and procedures) offered a lens through which I was able to examine the organization of work and participation in Hope House. These texts were identified through informal and formal interviews with participants (DeVault, 2006; Smith, 2006; Townsend, 1996), as well as my prior knowledge as a former contract occupational therapist working in developmental centers. Texts analyzed included the residents' chart (i.e., Habilitation Technician Worksheet, Body Check form, Communication Check List, Behavior Management Checklist, and Socialization and Leisure Form), the electronic medical record, Communication and Shift Change Book, the center's general policies and procedures, the center's personnel policies and procedures, the state's DHSR ICF/IID policies, and the national DHHS Administration statements on I/DD. I reviewed and analyzed each text and made notes of how the texts entered into and coordinated the actions of the residents and staff, including the texts that were products of the primary institutional documents and policies. Additionally, I developed a diagram to demonstrate the hierarchy through which each text was developed and implemented from national to local levels. This hierarchy of texts is discussed in detail in Chapter 4 and is represented in Appendix H.

3.9 Narrative Analysis and Mapping

In preparation for data processing, I followed First Cycle Coding and Second Cycle Coding as described by Miles, Huberman, and Saldaña (2014). First Cycle Coding (e.g., descriptive coding, process coding, protocol coding, emotions coding, value coding, etc.) involved assigning codes to chunks of data. Second Cycle Coding involved patterning or grouping codes by categories, explanation, relationships, or theoretical constructs. This allowed me to divide the data into smaller analytical units in order to focus themes as they relate to the research question. I created a provisional list of codes and definitions that were aligned with institutional ethnography prior to beginning fieldwork (Saldaña, 2013). The codes focused on groups of people and their activities, what they did individually and together, types of work, how people learned what to do, the texts they used in their work, and how those texts were “taken up.”

These codes included the following: cultural/house practices, professional practices/knowledge, experiential practices/knowledge, cognitive/meaningful encounters, emotional encounters, hierarchical/power encounters, “behaviors,” resident clique, staff cliques, administrative cliques, organizations, physical space/habitat, subculture/lifestyle, and texts/text-based practices. Codes were revised as the study progressed. Codes added included: insider knowledge, perceptions of ID, front-line challenge/work, affordance, choice, contradiction (to the center’s values), and social/dialogic participation. Narratives and salient quotes from the participants were included to elaborate on the emerging pattern of codes (Miles, Huberman, & Saldaña, 2014). In addition to coding, jottings and notes-on-notes were made throughout data collection as I reread and reflected on the field notes, interview transcripts, and texts.

Narrative analysis was utilized as a formal analytic process to review my field notes, analytic memos, interviews, and texts. Narrative analysis views narratives as social products that

are created by people in the context of specific social, historical and cultural locations (Plummer, 1997). Narrative analysis also provided a framework from which I was able to review large amounts of textual information (e.g., residents' medical records, the center's policies and procedures, and the state's DHHS and DHSR health facility policies) and systematically identify the most used keywords by locating the more important structures of its communication content, as well as focus on the ways in which people make and use stories to interpret their world (Hseih & Shannon, 2005; Plummer, 1997). I listened and looked for stories and patterns of information pertaining to daily routines or work from various perspectives, which texts organized routines, how texts were understood and enacted, how the everyday made sense to participants, and what it meant to belong to certain groups. After identifying patterns in the participants' narratives, I was able to extrapolate themes in their experiences. I then discussed those themes and my observations with members of my dissertation committee and participants to confirm my interpretations.

My second analytic process, *mapping*, was performed as a means to connect text-based institutional processes and the organizing of the residents and staff's daily activities (Smith, 2005, 2006; Townsend, 1996). Mapping gave me the ability to examine and describe the coordination of all participants' activities and work across all facets of the center. A visual depiction of the connection between institutional texts and social relations of the center is presented as a conceptual map in Chapter 4 and Appendix I. Although the diagram is not an exhaustive representation of multiple institutional complexes through which texts and participants' work coordinate, it makes visible the sequencing of participants' actions (Smith, 2006).

CHAPTER 4: BEYOND CUSTODIAL CARE: MEDIATING THE POSSIBILITIES FOR MEANINGFUL PARTICIPATION IN AN INSTITUTIONAL SETTING

4.1 Introduction

Participation in occupation has long been a unit of study in occupational science research. Scholars have conceptualized how participation in occupations is essential to well-being and quality of life (Law, 2002), how access and participation are supported and restricted (Townsend, 1996; Whiteford, 2000), theorized its social connectedness (Lawlor, 2003), and challenged the notions of individualism and the continuity of persons and their environments (Dickie, Cutchin, & Humphry, 2006). These views provided the discipline with the theoretical grounding necessary for situating and contextualizing participation, but limited participation to individuals embedded within sociocultural processes. More recent research extends this view to consider the text-based ways choice, access, and participation in occupation are mediated (e.g., governmentality and institutional ethnography) by exploring new and critical methodologies in research (Proding, Rudman, & Shaw, 2015; Rudman, 2010). This paper continues that expansion by examining the occupational concerns of institutionalized adults with intellectual disabilities (ID), a disability community with a long history of enduring grave injustices and whose voices have been largely absent in occupational science discourse.

Historically, institutionalized adults with ID in the United States were warehoused in deplorable facilities, and left to survive with minimal care and even fewer resources (Noll & Trent, 2004; Wehmeyer, 2013). National media exposure of these conditions was the impetus for the deinstitutionalization and self-advocacy movements, which began in the 1960s (Wehmeyer, 2013). With deinstitutionalization came the great social responsibility of making

certain that individuals with ID had the necessary social supports to engage in meaningful occupations of their choosing. Self-advocacy groups, whose objectives were to raise awareness about systematic oppression and the need to address the social conditions (e.g., societal attitudes toward education, transportation, housing, health care, and family and social life) (Charlton, 1998), pressured the government to address the concerns of individuals with ID and the greater disability communities. For the remaining institutions, there were legal ramifications and restructuring, which included increased oversight. Although *Wyatt v. Aderholt* 1974 determined that institutions must provide adequate habilitation and care beyond custodial care (Noll, 2005), this paper reinforces that participation in occupation in contemporary institutions continues to be based on regularities and routines rather than person-centered habilitation.

Other barriers continue to pose challenges for institutionalized adults with ID including accessing and participating in meaningful occupations, decreased spending and reimbursement on ID services, slow growth rate and growing wait lists for community-based services and supports, wage issues for direct support and ancillary professionals, and increased demands on aging caregivers (Braddock, et al., 2015). Additionally, individuals with ID “appear to be impacted by policies designed with inconsistent, and at times, contradictory, core values, impacted by the concurrent adoption of principles from different models of practice and constructions of disability” (Channon, 2014, p. 10); therefore, there is a need to better understand how opportunities for meaningful participation for institutionalized adults with ID are situated within and influenced by these systems and structures.

This paper draws on data from an institutional ethnographic study aimed to make visible the inter-relational ways national, state, and local policies mediate the possibilities to incorporate meaningful occupations into habilitation programming for adults with ID in an Intermediate Care

Facility for Individuals with Intellectual Disabilities (ICF/IID). First, this paper discusses the text-based relations of participating in occupations in an institutional setting and describes how routinization becomes standardized. Using specific examples from the participants' daily schedule, this paper will also critique the prescribed schedule and routines and their perceived effects on participation in occupation. Secondly, this paper discusses the ways in which institutional practices in an ICF/IID perpetuate the historical and ideological notions of what adults with ID should and should not do.

4.2 Institutional Ethnography: Recognizing Text-Based Ruling Relations

Institutional ethnography (Smith, 1987, 2005) is a feminist-oriented empirical approach to inquiry that combines theory and method. Its purpose is to reveal how social and institutional processes have generalizing effects from broad extra-local social and institutional structures to local practices (DeVault & McCoy, 2001; Smith, 2005). One assumption guiding institutional ethnography is that people function in the everyday world as social beings (Campbell & Gregor, 2004; Smith, 2005). Engagement in the world, whether it is in solitude or in the presence of others, is relational and purposefully coordinated through action or work. Smith (2005) defines work as “anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about” (pp. 151-152). In other words, work is the paid and unpaid activities or occupations that people perform every day.

With an ontology shared with occupational science, institutional ethnography is concerned with the contexts through which life is actually lived. More specifically, institutional ethnography begins with the actualities of daily life to reveal unacknowledged work, and how that work is situated in and shaped by social relations and discourses (Smith, 2005, 2006).

Unacknowledged work is also the entry point where participants can talk about their involvement in organizational processes (Campbell & Geger, 2004; DeVault & McCoy, 2001). Beginning with participants' everyday experiences also exposes the "problematic," a key tenet/cornerstone of institutional ethnography, which defines the major issue to be researched from the standpoint of the participants. Given the significant reform to institutional systems to restructure and instate meaningful occupation and not just custodial care, the inability of staff to provide opportunities for residents to participate in occupations of their choice due to the regulatory focus on routines and efficiency is this study's problematic.

Institutional ethnography further asserts that the ways in which human action is organized occurs through "ruling relations" – the concerted integration of extra-local texts (printed and electronic) that mediate and socially organize participation in daily life (DeVault, 2006). In other words, ruling relations occur outside of personal choice and infiltrate everyday occurrences from who participates in certain occupations, what transpires in that process, to when and where occupations occur, and how they are accomplished. By virtue of engaging in daily life, one participates in these organizational processes and unconsciously perpetuates the same ruling relations that coordinate choices and participation. Ruling relations are not static, but are dynamic and always in flux. As systems change, ruling relations change (Smith, 2005).

Occupational scientists have explored the use of institutional ethnographic methods to investigate the tensions occupational therapists encountered when advocating for and implementing client-centered practice (Townsend, 1996), and the ability of occupational therapists to enable empowerment in adults with mental health issues (Townsend, Langille, & Ripley, 2003). More recently, Prodinger and Turner (2013) studied how occupations were identified and addressed by health care providers in the health records of women with

rheumatoid arthritis and how health care practices were connected to and organized through various social policies. Institutional ethnography not only allows occupational scientists to make visible the relations between social policies and participation in daily life activities (Prodinger, Rudman, & Shaw, 2015), it problematizes how the discipline conceptualizes occupation and occupational engagement, its taken-for-granted assumptions, the discourses that organize what people are able to do, and calls attention to the language used in occupational science literature (Smith, 2003).

4.3 Research Site and Data Collection Methods

4.3.1 Hope House

Hope House, a residential facility for five male and five female adults diagnosed with profound ID, is situated within a larger ICF/IID located in a metropolitan city in the southeastern United States. Hope House employs 22 staff members including a house manager, three shift supervisors, a nurse, and 17 habilitation technicians who provide direct care to the residents. Hope House is approximately 2,500 square feet, and includes a full kitchen, a combined dining room and den, a multi-purpose recreation room, staff office, staff lounge, nurse's station, seven bedrooms, two community bathrooms, an outdoor patio, and a sensory garden. The facility is designed to resemble an ordinary home with its congregate areas and bedrooms painted in vibrant colors, bedrooms with colorful bedding and curtains, and walls adorned with pictures of residents and their families and landscapes. However, the facility also contained artifacts that were characteristically institutional including hospital and adult crib beds, beige tile floors, and industrial-style bathrooms.

Common occupations observed in Hope House were activities of daily living (ADL), instrumental activities of daily living (IADL), social and leisure occupations (e.g., birthday

parties, watching movies, listening to music, playing games, and arts and crafts), and sleep.

ADL occurred in the privacy of residents' bedrooms and the community bathroom. Many of the IADL were performed in the dining room and residents' bedrooms and included sorting linen, wiping tables, bed making, and occasional meal prep. Resident and staff group occupations (e.g., watching movies, listening to music, arts and crafts, playing games) primarily occurred in the dining room and the outdoor patio.

4.3.2 Participants

The participants included four men and three women aged 26 years to 53 years with severe to profound ID, and one male and seven female staff members aged 22 years to 65 years. All male resident participants (Tony, Kevin, Milton, and Lewis) utilized wheelchairs for all mobility. One female resident participant (Lisa) utilized a wheelchair, and two female resident participants (Keisha and Marsha) were ambulatory. Tony used verbal language and Kevin used verbal language coupled with American Sign Language (ASL). Milton and Lewis were nonverbal. None of the female resident participants utilized verbal language; however, all nonverbal participants used some symbolic form of communicating with staff. The resident participants had lived in the facility an average of 23 years and 8 months. Verbal and written consents were provided by their legal guardians.

Staff participants, who included one administrator (Cynthia), one house manager (Mary Ann), one shift supervisor (Elijah), and five habilitation technicians (Heather, Margaret, Kena, Niecey, and Ann), worked in the facility for an average of 6 years and 8 months. Cynthia served as the direct supervisor to Mary Ann and coordinated the habilitation programs for all residents. Mary Ann and Elijah oversaw the daily operations of Hope House and ensured the implementation of quality care by the habilitation technicians. The habilitation technicians were responsible for providing daily personal care and habilitative training to the residents. All staff

participants provided verbal and written consent for participation. All participants consented to having informal conversations and formal interviews audio recorded. Photography and video recording were not permitted. This study was approved by the Office of Human Research Ethics and Institutional Review Board at the University of North Carolina at Chapel Hill, and the human rights committee of the participating ICF/IID. All names used in this paper have been changed to protect the identity of the facility and participants.

4.3.3 Methods

Qualitative methods provide the researcher a way of taking stock of how people interpret their lived experiences. The researcher becomes part of those lived experiences by being an observer, participant-observer, interpreter, and developer of theories regarding observed experiences and processes (Biklen, 2011). Participant observation, ethnographic interviews, and text work were the methods utilized in this study to demonstrate how occupations come to be systematically coordinated through a complex convergence of national, state, and local policies. Conceptual mapping was employed as a systematic method of analysis.

Participant Observation. Participant observation offers an interior perspective where the researcher comes to understand phenomena in their natural settings (Hallrup, 2012). Similar to conventional ethnography, institutional ethnographers begin with observing the activities and situations people encounter every day (DeVault & McCoy, 2001; Proding, Rudman, & Shaw, 2015; Smith, 2005). Participant observations included morning and night-time routines of the residents and staff, meals, social and leisure occupations in and outside of the facility, and special occasion events (e.g., birthday parties, outings to the theater, attending the annual state fair). Observations took place over a 14-week period in congregate areas of Hope House and on community outings. Each observation ranged from six to 10 hours in length. Observational notes captured anything that may have indicated a participant's membership in a particular group

(e.g., profession, ethnicity, or social status), language and dynamics of interactions, notable behaviors (e.g., people who receive or do not receive significant attention), physical behaviors and actions (e.g., what people do, who interacts with whom, who is not interacting), how participants negotiated personal space, physical layout of Hope House (e.g., size of rooms, how spaces are arranged, and objects found in spaces), and human traffic.

Interviews. Institutional ethnographers use informal and formal interviews to capture the ways in which participants construct their world, as well as to identify the textual artifacts that mediate that process. For this study, informal interviews occurred during observations and formal interviews were scheduled during a time and place chosen by the participants. Informal interviews were completed with all participants; however, formal interviews were completed with residents Tony and Kevin, and staff members Cynthia, Mary Ann, Elijah, Margaret, Heather, and Ann. One group interview with six staff members was also completed. Formal interviews were 15 to 60 minutes in length, and were audio recorded and transcribed verbatim. Interviews were conversational and aimed at eliciting narratives about how participants' viewed their work and daily activities, relationships with others, and about the texts that are important in their work. For the residents, simple language and phrasing were used, as well as picture symbols to support their participation in the interviews (Mahoney & Roberts, 2009).

Text Work. A key tenet of institutional ethnography is the recognition that text-based forms of knowledge (e.g. policies and procedures) are central to organizing what people do (DeVault & McCoy, 2001). Campbell and Gregor (2004) stated, "...rather than being used as sources of factual information, texts are relied on as crystallized social relations. Institutional ethnographers consult them as an alternative to, and an antidote for, accepting ideological accounts" (p. 79). Active texts, the center's policies and procedures which participants stated

were important to their work, were identified through informal and formal interviews (DeVault, 2006; Smith, 2006; Townsend, 1996). Active texts functioned as the lens through which I was able to examine and document the organization of work in Hope House. An analysis of active texts also revealed the interrelation of hidden texts and higher order texts. Higher order texts refer to the guidelines and policies (e.g. state regulatory policies) that enter through active texts, which were taken up and enacted by the residents and staff (Prodinger & Turner, 2013).

4.3.4 Conceptual Mapping

Mapping was completed as a formal analytic process and involved systematically relating participants' narratives (Plummer, 1997), as well as institutional practices and connecting them back to the complex network of underlying structures through which the occupations of everyday life were constructed (Hamilton & Atkinson, 2009). First and second cycle coding (Miles, Huberman, & Saldaña, 2014) were used to categorize participants' narratives and patterns of information pertaining to their daily schedule and routines, texts that organized their routines, and how those texts were understood and enacted. The Conceptual Map of Ruling Relations (Appendix I), demonstrates the infiltration of an intertextual hierarchy and how those texts mediated the development and standardizing of participants' routines and occupations in Hope House.

4.4 Findings

4.4.1 Institutional Routinization

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and other congregate living facilities with institutional qualities, are home for many adults with ID in the United States. Although the *Olmstead v. L. C.* decision required states to eliminate segregated housing for individuals with ID, 37 states continue to maintain state-operated

institutions (Braddock, et al., 2015). Nine are southern states. Per federal regulation 42 CFR 435.1009, the purpose of these facilities is to provide quality personal care and the best available services for diagnosing, treating, and rehabilitating individuals with ID in order to enhance their functional capabilities. These services may include but are not limited to ongoing psychological and psychiatric care, nursing, occupational therapy, physical therapy, speech and language services, and vocational training. To provide personal and habilitative care in a manageable way, ICFs/IID generate schedules for the implementation of habilitative programs, referred to as Active Treatment. Active Treatment refers to the consistent implementation of an individualized training program, treatment and health services. This does not include specialized services to maintain independent residents who are able to function with little supervision or in the absence of an aggressive habilitative training program (42 CFR 483.440(a)). Components of Active Treatment include a comprehensive evaluation, an Individualized Programming Plan (IPP) or Individualized Habilitation Plan (IHP), program implementation, program documentation, and an annual reassessment.

Hope House organized its residents' daily schedule much like a typical work day. Third shift habilitation technicians began waking residents for hygiene care, grooming, and dressing at 5:30 a.m. Residents who were not awake by 6:45 a.m. completed their ADL when first shift habilitation (including Heather, Ann, and Margaret) technicians arrived. Once all residents were dressed and transferred into their wheelchairs, staff brought the residents into the dining room for breakfast at 7:30 a.m. Residents gathered around the dining room table to eat in two shifts of five. Residents who were not eating breakfast were positioned in front of the television to watch or listen to the local news. Following breakfast, residents whose IPP included goals for instrumental activities of daily living (IADL) and those who demonstrated interest would assist

with clearing the tables by placing soiled linens into a hamper and wiping the tables. Once the post-breakfast responsibilities were completed, residents participated in social and leisure programming activities (e.g., playing Bingo, Uno, or Trouble, crafting, and listening to local and world news). Residents who were not included in these group activities, by resident or staff choice, watched television, had “quiet time” in their rooms or lounged on the outdoor patio until lunch.

Prior to lunch, the habilitation technicians performed toileting hygiene (i.e. changing soiled adult protective briefs) with each resident. Once the residents completed their toileting routine, they were brought back to the dining room where they had lunch from 10:30 a.m. until 12:00 p.m. Residents and staff completed the same post-meal housekeeping and prepared for mid-day naps. While residents rested from 12:00 p.m. until 3:00 p.m., habilitation technicians completed their paperwork (e.g., electronic documentation, socialization and leisure checklist, resident communication checklist, behavior checklist, and shift change and acceptance checklist) and any remaining housekeeping tasks listed in their shift-change procedures. Habilitation technicians also checked on sleeping residents every 10 minutes until second shift staff arrived. Three ambulatory residents, including Keisha and Marsha, were permitted to stay out of bed as they were able to perform their own repositioning (e.g. independently transferring from beds and chairs). Often these residents did not participate in organized activity or group occupation, but instead, watched television in the dining room or looked at pictures in magazines. Second shift habilitation technicians, including Kena and Niecey, arrived at 2:45 p.m. Upon their arrival, all habilitation technicians gathered in the dining room for a shift change meeting. In the meeting, each habilitation technician discussed which housekeeping tasks were completed, which occupations from the checklists were performed, if there were any incidents, and signed a form

indicating which information was shared. The departing shift was permitted to leave once their reports were accepted by the incoming shift.

Second shift staff members were responsible for preparing the dining room for dinner, folding and putting away clothing and linens laundered during first shift, and completing baths before bedtime. At 4:00 p.m., habilitation technicians woke sleeping residents, transferred them out of bed and brought them to the dining room for dinner. Dinner was served at 4:45 p.m. Residents ate in the same shifts as breakfast and lunch. Two hours were dedicated to more programming activities after dinner; however, residents and habilitation technicians usually watched television or listened to music together. Occasionally, a volunteer musician would visit Hope House after dinner and sing songs to the residents. All residents remained in the dining room until their evening snack at 8:00 p.m., then had their baths before retiring to their bedrooms for the night at 9:00 p.m. Once residents were in bed, habilitation technicians completed their paperwork and shift-specific housekeeping tasks until third shift arrived at 11:30 p.m. for the shift change meeting. While residents were asleep in bed, third shift completed their shift-specific housekeeping tasks until it was time to wake residents for breakfast.

Residents' socialization and Active Treatment were bounded by meal and rest times. In other words, residents participated in group activities or Active Treatment between breakfast and lunch, and between dinner and their evening snack. Additionally, the schedule for Saturdays and Sundays included community outings (e.g., picnics in a local park, trips to the movie theater, dining in restaurants, horse shows, watching stage plays) as part of the residents' Active Treatment. It was left to the discretion of the habilitation technicians to include outings during other days of the week. Appendix J depicts how weekdays and weekends were organized as a

way to efficiently implement habilitative programs and keep habilitation technicians accountable to the prescribed schedule.

4.4.2 Ruling Relations of Participation

Analyses of interviews with staff and administrative participants revealed a number of policies and procedures influenced the daily routines of the center. Active texts identified by staff participants included the IPP for each resident, the IHP for residents who required specific services for physical, occupational, and speech therapies, socialization and leisure participation checklists, behavioral checklists, and the general and personnel-specific policies and procedures of the center. The IPP served as the parent text or “boss text” (DeVault, 2006). Parent texts function as the primary mediator and coordinator of the participants’ daily routines. The IPP included findings from comprehensive evaluations from each discipline represented on the resident’s care team, which outlined opportunities for individual choice and self-management, goals, objectives, and selected activities for each resident’s active treatment plan. Per the Center for Medicare and Medicaid Services (CMS), the IPP must also be directed toward the acquisition of functional skills necessary for an individual to participate in daily life as self-determined and independently as possible. Neither the habilitation technicians nor the residents had direct input into the IPP or IHP; however, habilitation technicians were in charge of implementing the IPP and were required to document which occupations the residents performed and if habilitation goals were or were not met. The data were read by Mary Ann and Cynthia, the manager and administrator for Hope House respectively, and were used to determine if residents’ functional and behavioral goals required modification. An annual reevaluation of the IPP is required by state’s Division of Health Service Regulation (DHSR) and the U.S. Department of Health and Human Services (DHHS); however, Mary Ann and Cynthia did not disclose how the habilitation technicians’ documentation influenced goal revisions for the residents.

Interviews further revealed the regulatory processes through which the IPP and IHP were developed for each resident, and then implemented by the habilitation technicians. Specific elements of the IPP (e.g., functional goals assigned to the residents and the objectives for meeting each goal) were dictated by the state's DHSR. These regulations stated that each healthcare profession (e.g., nursing, psychology, social work, occupational therapy, physical therapy, and speech language pathology) represented in an ICF/IID must submit a comprehensive evaluation detailing the functional abilities and limitations of each resident. At Hope House, comprehensive evaluations were compiled by the center's social worker. From the reports, members of the care team (not including the habilitation technicians), in cooperation with the manager of Hope House, developed a set of goals with specific objectives and methodologies for implementation. Once the full report was completed, the resulting IPP or IHP was implemented by the staff. None of the resident participants received direct intervention from other members of the care team.

Other texts identified by Cynthia, the administrative participant, included the DHHS regulations for ICF/IID and DHSR mandates on the responsibilities of staff working in ICF/IID. Additionally, the state's Rules for Facilities, Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402), Olmstead Act, Final Rule 76 FR 46499, and the CMS definitions and classifications of ID were identified as critical regulatory texts. The Hierarchy of Texts (Appendix H) depicts how these higher order texts (e.g., policies and regulations set for by CMS, the U.S. DHHS, and the Administration on Intellectual and Developmental Disabilities) not only define and classify ID, but filter through policies at state and local levels by setting the standards by which states regulate ICF/IID operations and implement programming and personal care for adults with ID; however, local centers must interpret these standards, along with the professional

standards guiding scopes of practice, and incorporate them into habilitative programming for the residents. The Conceptual Map of Ruling Relations (Appendix I) shows how the various active and higher order texts permeate the daily schedule and activities performed by residents and staff. The categories of activity are presented linearly to reflect how each activity occurs at specific times. Although higher order texts are important to the day-to-day functions of the center, the resulting routinization limited residents' and staff's ability to incorporate meaningful occupations of their choosing. In particular, the residents' IPP, which outlined the Medicaid and therapeutic-mandated instruction for each resident, were superseded by the need for staff to maintain the daily schedule and execute their assigned responsibilities in a manageable way.

For example, I interviewed resident participants Kevin and Tony about the activities they enjoyed:

Khalilah: What do you like to do?

Kevin: <pointing to the television> TV.

Khalilah: What else?

Kevin: Go to the store.

Tony: I like to store too.

Khalilah: Which store, Tony?

Tony: <laughing> Wal-Mart!

Khalilah: What do you like to buy at Wal-Mart?

Tony: Toys!

Khalilah: What kind of toys?

Tony: Toys.

Kevin: Trucks.

This conversation with Kevin and Tony prompted me to ask Elijah, a shift manager, questions about honoring residents' interests:

Khalilah: So when they make it known that they would like to go out to eat or go to Wal-Mart, how do you all plan for that?

Elijah: You know, they have mentioned it several times and we try to incorporate activities like shopping, but it really depends on when other outings (determined by the center's schedule) are planned. . . you know how the schedule is.

I also asked Mary Ann how staff incorporated occupations residents enjoy. She described the tension between honoring residents' individual choices of occupation with managing active treatment for a group:

One of the greatest challenges we have is individualizing activity. Not all residents want to do group activity, and they shouldn't have to. They have individual likes and dislikes. Unfortunately, we can't provide one-to-one supervision. There has to be a better way of honoring individual preferences when you have to provide care for an entire group.

Habilitation technicians had limited control in the structure of the day and were afforded few options for additional activities for residents to enjoy. Choices were constructed in the context of how they fit into daily routines and the practical constraints of managing a facility for adults with ID. An analysis of the problematization of residents' choices is presented in Chapter 5.

The administrator overseeing Hope House, Cynthia, explained that she believed, "the IPP loosely prescribes schedules and routines through programming. The habilitation technicians are allowed to deviate as needed. The goals should be integrated throughout the day..." However, it was not made clear to the habilitation technicians that they were allowed to deviate from the schedule without it being considered a violation of personnel policies and procedures of the center. When I inquired how he felt about the schedule and the ability to incorporate activities residents find meaningful, Elijah stated that he believed the daily schedule was restrictive and

did not allow staff ample time to make sure they could incorporate programming and activities residents enjoyed throughout the day. He elaborated, “We should be on their time, not the other way around. They have to get up very early and every moment of the day is dictated by ICF/MR regulation.” Although there were clear policies and procedures regulating the residents’ daily routines and activities, habilitation technicians were allowed to improvise those routines according to the contextual demands of their prescribed work. The next section will discuss how occasional adaptation to the daily schedule by habilitation technicians created distance between their work and ruling relations.

4.4.3 Work Knowledge as Improvisation: An Attempt to Create Distance from Ruling Relations

Interviews with staff participants revealed contrasting narratives regarding the provision of the daily schedule, the implementation of the IPP, and the ways through which texts important to their work were taken up. The narratives demonstrated that the habilitation technicians’ work knowledge, at times, superseded ruling relations in the daily practices at Hope House. Smith (2005) described the aspects of work knowledge as a person’s “experience of and in their own work, what they do, how they do it, including what they think and feel . . . [and] the implicit or explicit coordination of his or her work with the work of others” (p. 151). Work knowledge orients the researcher to glean from participants details about their work including what they actually do, how their work is coordinated, and their feelings about it. Habilitation technicians spoke to how they followed the schedule, the moments when they deviated from the schedule, and how in many ways the daily schedule limited what they were able to do for and with the residents. When asked about her daily responsibilities Ann shared, “We just do what is expected of us...we know they have programming and goals they have to do...whatever is planned (by Mary Ann and Elijah) we just do it . . . there just isn’t time for other stuff.” Margaret added,

“Now we all know that there are specific things that we have to do. You know, like active treatment and stuff like that; but the schedule is the schedule, and we follow it.”

It was clear there were habilitation technicians who followed the schedule as prescribed; however, there were also staff participants who stated they adapted the schedule. Specifically, Heather and others used their knowledge of the residents as well as knowledge related to how they could do work at other times as a means to deviate from the prescribed activities on the schedule. This deviation afforded the habilitation technicians the opportunity to incorporate activities that residents enjoyed, but also served as a way for staff to take breaks from work or get other things done (e.g., documenting in the medical chart and EMR, housekeeping, and doing inventory). For example, one morning following breakfast, habilitation technicians discussed among themselves which activities and time of day the residents should participate in them:

Hab. Tech. 1: So what is the plan for today?

Hab. Tech. 2: This right here! <walks to the television and turns it to the Lifetime Movie Network>

Hab. Tech. 1: No. We don't do that on this shift.

Heather: Well, we could do arts and crafts.

Margaret: They (referring to the residents) have active treatment.

Heather: Yeah, but they can do this instead. You can put it on their checklist.

Hab. Tech. 1: Does anybody need to go down?

Margaret: They all just got up.

Heather to Margaret: Well, I'm going to do arts and crafts. You can do what you want with your folks.

Margaret: Well some of them are supposed to be repositioned right now.

Heather: I know, but they just got up. They're fine. We can do that later. . . when they have down time after lunch.

Hab. Tech. 2: Well my clients are watching TV.

This type of improvisation was not a source of frustration for the habilitation technicians, but rather an issue for administrators as this was perceived as habilitation technicians choosing not to follow the prescribed Active Treatment Plan. Although there were specific policies governing and organizing the daily practices of Hope House, Mary Ann provided the habilitation technicians opportunities to adapt and prioritize the daily schedule to suit the practicalities of managing personal care, habilitative programming, and social and leisure activities for the residents. Elijah confirmed, "We have rules that we need to follow according to the center, but we do what we need to do. We have to follow the programming, but we do it in our own way." Another example of doing "it in our own way," habilitation technicians occasionally used the afternoon rest time as an opportunity for residents to choose activities that were meaningful but outside the provision of the IPP (e.g., watch reality television, visit with residents in sister facilities, spend time in the garden):

Hab. Tech. 1 to other Hab. Techs: It's time for everyone to go down (referring to resting in bed).

Mary Ann: Well Kevin wants to watch a movie.

Tony (resident): I want to watch a movie too.

Margaret: Well, I'm putting my folks down.

Mary Ann: Kevin and Tony are going to watch a movie. They're good.

Hab. Tech. 1: Well Tony needs to get out of his chair and get in a "geri chair."

Mary Ann: OK. I'll let them finish their movie and then change them before second shift

comes. They can go down after that if they want.

This suggests that Hope House staff were able to bring to consciousness the ruling relations organizing their daily responsibilities, but utilized their work knowledge in order to perform those work duties within the confines of a prescribed schedule. Ruling relations were not disembodied. In other words, habilitation technicians were not completely freed from the regulations coordinating their daily work; rather, the replication of institutional practices mediated through those regulations were, at times, rejected.

Ruling relations are significant mediators of daily life activities. The habilitation technicians' improvisation of the daily schedule at Hope House demonstrated how ruling relations are taken up in ways that are local. Replicating and adapting ruling relations reinforces its power. Applying the rules in ways that are conducive to their work, habilitation technicians embodied the same institutional processes they claimed to reject. Decisions regarding how to address participation in meaningful occupations, when to perform the occupations, how to identify the available resources, and how to document data to show adherence to the schedule calls attention to the textual-coordination of institutional work. Work knowledge did not distance the habilitation technicians from ruling relations but rather allowed them to reproduce ruling relations in ways that benefited their work.

4.5 Discussion

Institutional ethnography allows the researcher to make visible the ruling relations that bridge the categories and concepts that infiltrate and regulate daily life participation. Specific to this study, institutional ethnographic methods captured the ways national, state, and local policies systematically limited participation in meaningful occupations for institutionalized adults with ID, despite the intent of the policies. Analysis of participants' narratives revealed

that the coordination and routinization of daily activities were mediated by policies and institutional practices aimed to make staff efficient and accountable to implement individualized training programs. Likewise, text analyses and conceptual mapping exposed and reinforced participants' narratives on how work was produced and replicated. Replication is the condition of ruling relations as it legitimizes its existence (Smith, 2005). It was through replication that notions of work and participation in meaningful occupations for institutionalized adults with ID was generalized. This form of generalization is reminiscent of the sociohistorical conditions which lead to institutional routinization.

Routinization establishes the form and functions of ICFs/IID, such as Hope House, but that structuring creates tensions between self-determined participation and custodial care, and efficient spontaneity (allowing staff and residents to participate in occupations of their choice when and how they want) and accountability (adhering to performing certain occupations and specific times of the day). This may be an inevitable tension, but it is important that the residents and staff in the facilities are able to negotiate this tension. Work knowledge, as described by Smith (2005), was employed by the habilitation technicians in Hope House to negotiate through that tension. Reminiscent of Max Weber's (1968) bureaucratic routinization, the objectives of routines become more about efficiency than "efficient spontaneity." After the modernization of contemporary institutions, service delivery models were structured to provide more constructive habilitative programming. These institutional structures are well-intended, but they only allow for meaningful participation to occur in time-limited ways. In other words, institutional structures and systems were developed in order to adequately and efficiently implement constructive occupations in residential facilities, but in doing so the instructional structures became increasingly routinized. Occupations had to occur at very specific times and in

prescribed ways.

Routinization is a perpetuation of custodial care reminiscent of previous institutional models of care and constructions of disability, rather than increasing the habilitation training necessary for quality participation. In other words, it may seem that routines match the ideal that adults with ID should live self-determined lives and be able to participate in occupations of their choosing, but this is not what happens in practice. It is easy to assume adults with ID who reside in contemporary institutions are acutely affected by the regularities that result from routinization. Lopez (2007), in a study about faux routinization in nursing homes, suggested the issue is that institutionalized individuals lack the ability to object to routines effectively. Lopez (2007) stated:

Routines are reassuring and the ability to have things happen when one expects offers some sense of control over one's life . . . residents asserted their own interests in keeping to the schedule (even if in a larger sense their interests as human beings were not perfectly served by the regimentation of institutional life).

Routinization may or may not favor residents in institutions. Nonetheless, what was learned from the residents and staff of Hope House is that routinization favors efficiency and lessens the importance of the unique interests of adults with ID. Renblad (2002), in a study aimed to demonstrate how social networks and supports are essential to facilitating choice and participation for adults with ID, further reaffirmed disempowerment is perpetuated by routines maintained in facilities and lack of knowledge or institutional power by staff charged with their care. The consequences of increased surveillance by federal and state regulatory boards was a generalization of care for institutionalized adults with ID and the systematic regulation of institutional operations at the expense of residents' self-determined participation.

4.6 Conclusion

In this paper, I have discussed the need to have a deeper understanding of how opportunities for meaningful participation in occupation for institutionalized adults with ID are situated within and influenced by institutional systems and structures. Institutional ethnography provided the social theory and methodology to describe the infiltration of extra-local and trans-local policies to the standardizing of daily routines for adults with ID who reside in an intermediate care facility in the southeastern United States. It was argued that institutional routinization perpetuates the historical and ideological notions of what individuals with ID can and cannot do. For adults with ID, this translated to custodial care rather than quality habilitative training that considers their interest and choices. To date, efforts to identify and address structural and environmental barriers to participation have received little attention (Hammell, 2015), let alone the effort to address barriers to participation for institutionalized adults with ID. As social control becomes increasingly discursive and textual (Smith, 2005), it is of the utmost importance to take stock of the discipline's responsiveness to examining systematic influences of choice and meaningful participation for people in all communities.

Occupational scientists have discussed the various ways barriers to participation emerge (e.g., Hart & Shank, 2016; Law, et al, 1999; Rudman, 2010; Whiteford, 2000); but only recently has the discipline began to study the ways participation is mediated through texts (Prodinger, Rudman, & Shaw, 2015; Prodinger & Turner, 2013). Occupational scientists are well positioned to explore the depths of participation as it is perceived and subjectively experienced by people in their everyday lives in multiple ways. Institutional ethnography is a valuable social theory and methodology to understand how occupations and participation emerge through, and consequently are regulated by, texts and other extra-local influences. This study is an attempt to move the discipline's conceptualization of participation forward by acknowledging the text-based ways

through which participation is organized. This study also demonstrates utility in identifying and addressing occupational concerns that matter to groups of individuals, such as institutionalized adults with ID, who continue to face barriers to meaningful participation in daily life.

CHAPTER 5: *NO YOU CAN'T HAVE IT*: BASIC HUMAN RIGHTS AND THE PROBLEMATIZATION OF CHOICE

Marsha whimpered like a sick child who could only be comforted by being held tightly by her mother. With her gaze fixed on the red cup, she leaned forward in her chair and reached across the dining room table for her juice. The habilitation technician assisting her with her meal moved it from her reach and said, “No, you can’t have it.” Her whimpers turned into wails and seemed to fill the entire room.

5.1 Introduction

This paper takes up the concerns of institutionalized adults with profound intellectual disabilities (ID) by examining how choice-making by residents in an Intermediate Care Facility (ICF) is problematized by staff. By employing institutional ethnographic methods (Smith, 2005, 2006), this paper specifically seeks to better apprehend how understandings of behavior and meal plans passed down over time become embodied restrictive practices. These practices mediate how residents’ choices about what and when to have something to eat and drink are perceived. The actions of staff members, specifically the habilitation technicians, presented in this paper demonstrate that eating as a basic physiological and hedonic need is not considered. As a result, residents’ choices are often unacknowledged and devalued.

Extant literature on self-determination and adults with ID posits that adults with ID have fewer opportunities to make choices, are less self-determined than their nondisabled peers, and are often denied opportunities to live their lives according to their own preferences (Ward & Stewart, 2008; Wehmeyer & Abery, 2013). Yet, evidence also exists that adults with profound ID are able to display distinct preferences and interests (Lohrmann-O’Rourke & Browder, 1998; Ward & Stewart, 2008), and can become more self-determined if provided adequate environmental and social supports (Katz & Assor, 2006). The literature also indicates that

individuals who work in congregate settings, whether community based (e.g., group homes, sheltered workshops) or non-community based (e.g., institutions, work activity centers), face challenges with incorporating activities according to the interests and preferences of adults with ID (Gray & Muramatsu, 2013). Specifically, Mansell and colleagues (2008) found that direct service in institutional settings are affected by the type and size of services, staffing (including qualifications, attitudes towards caregiving, experience, training, and ratio to residents), “organizational hygiene,” and management. These organizational factors coupled with the lack of opportunities for self-determined choice-making may translate into practices that marginalize adults with ID for whom staff care.

Overall, there is a dearth of research on the opportunities for choice-making and self-determined behavior of institutionalized adults with profound ID. The following sections unpack the passed down and embodied restrictive practices that influence the ways in which habilitation technicians problematize residents’ choices and the resulting unintended obstruction to basic human rights. By using examples from meal and snack time observations, I argue that choice-making continues to be insufficiently cultivated and supported for institutionalized adults with profound ID, even for the most basic and life-sustaining activities such as eating and drinking.

5.2 Problematizing Choice

Problematization, as discussed in this paper, is inspired by French philosopher Michel Foucault and refers to the defamiliarization of common knowledge – the taken for granted discursive or non-discursive practices as problematic (Foucault, 1972, 1984). As it relates to institutionalized adults with profound ID, employing problematization as an analytic guide brings attention to the systematic processes and implementation of historical rules and practices that become “regimes of knowledge” that directly impact ways of being and doing (Foucault,

1984; Frederiksen, Lomborga, & Beedholm, 2015). For example, one objective of institutions is to provide optimal quality care that allows residents to practice choice and build independence; but what has happened in modern institutions is a perpetuation of historical practices that limit residents' ability to assert preferences. A closer examination of the familiar and accepted ways of providing custodial care is revealed as discursive to self-determination and basic human rights for institutionalized individuals.

Theoretically, problematization also relates to institutional ethnography in that it calls into question the social practices that acknowledge or do not acknowledge residents' choice-making as being intended and purposeful versus manipulative and problematic. This allows new or unheard viewpoints on choice-making to emerge and focuses on the context and details of the exchanges between residents and habilitation technicians. During my analyses, problematization provided useful ways of thinking about and situating choice-making in institutionalized adults with ID (e.g., attending to those making the statements and gestures, why specific statements are stated or are not stated, the context of the statement, who it benefits, and who it harms).

Attending to those exchanges made visible the connections between choice as a human right and the habilitation technicians' mandated responsibilities and preferences in caring for the residents. Fyson and Cromby (2013) affirmed:

Other studies have suggested that 'choice' is invoked as a right only when it suits the needs of service commissioners and providers. Involvement in choices is often thereby limited to the mundane and everyday – so, for example, individuals with ID may be encouraged to make choices about what to wear or what to eat, while being excluded from participation in more fundamental choices about where or with whom to live. In this sense, talk of a 'right to make choices' enables services to adopt a veneer of respect for human rights without challenging more fundamental injustices (p. 1168).

However, examples presented in this paper demonstrate that even mundane choices are often not granted. Residents' meal and snack time choices are circumvented by habilitation technicians who perceive their choices as manipulation, inconveniences, and inappropriate; and as it relates

to rights for the intellectual disability community, this is a departure from the self-determination discourse.

5.3 Intersecting Choice and Rights in an Institutional Setting

This paper draws on data from an institutional ethnographic study with adults with profound ID and habilitation technicians in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). Institutional ethnography served as the guiding social theory and methodology as it allows the researcher to reveal the social practices and discourses that textually mediate how choice-opportunities emerge in an ICF/IID (DeVault & McCoy, 2001; Smith, 2005, 2006). The ICF/IID for this study, referred to as the Community Center for Developmental Disabilities (CCDD), is situated in a wooded enclave in a metropolitan city in the southeastern United States. The CCDD provides daily personal care and habilitative programming for approximately 400 children and adults with ID through residential state-funded programs, day programs, and educational services. Hope House, one of the oldest residential facilities at the CCDD, is the primary residence for the participants of this study. Hope House is home to five male adults and five female adults with profound ID and 22 staff including a house manager, three shift supervisors, a nurse, and 17 habilitation technicians.

Seven residents (four males and three females) use wheelchairs for all mobility. They require total assistance from habilitation technicians to transfer to and from their wheelchairs via a Hoyer lift. Three residents (one male and two females) are able to ambulate throughout Hope House with supervision from all staff for safety. All residents require assistance for self-care including bathing, grooming, toileting and dressing. Three residents (one male and two females) are able to feed themselves independently, whereas seven residents (four males and three females) are fed by habilitation technicians. Eight residents (three males and five females) are

nonverbal, but are able to indicate choices with prolonged eye gaze, gestures, and verbalizations. One male resident uses verbal language, and one male resident is able to use some verbal language together with American Sign Language (ASL). 21 staff members are African-American and one staff member is Caucasian. 17 staff members are female and five are male. The habilitation technicians are charged with maintaining a daily schedule, which includes morning self-care and breakfast routines, mid-morning habilitative programming followed by lunch. Following lunch, residents have a rest period when they are taken back to bed for naps or to have private individual time in their rooms. The evening routine consists of additional habilitative programming, dinner, and structured leisure time before baths and going to bed.

Data were collected over 14 weeks utilizing participant observation, recurring informal and semi-structured interviews, and text work. Observations occurred for six to 10 hours per day, four days per week. Residents and staff were observed in congregate areas (e.g., multipurpose room, dining room, patio, garden), as well as in residents' bedrooms and staff-specific spaces (e.g., staff lounge) in Hope House. Informal conversations occurred throughout participation observation, whereas formal interviews convened at a time and location chosen by the participants. Informal conversations and formal interviews between the participants and myself were audio recorded and transcribed verbatim. Texts identified by participants as important to their work included the residents' Individualized Program Plans (IPP), Individualized Habilitative Plans (IHP), socialization and leisure checklists, behavioral checklists, staff Communication and Shift Change log, and the policies and procedures of Hope House. These documents dictated the roles and responsibilities of the staff, as well as the habilitative programming for each resident.

Data were analyzed using first and second cycle coding (Miles, Huberman, & Saldaña,

2014) in order create smaller analytical units for analysis. For this paper, meal and snack time narratives were extracted and analyzed through an iterative and reflexive process (Srivastava & Hopwood, 2009). “Food/drinks as a social tool or tool of power” and “Denial of choice” were themes that were prevalent in the data. These specific narratives were analyzed to contextualize and give meaning to what was happening during meal time exchanges between habilitation technicians and residents. I examined what was said, how it was said, where and when it was said, and participants’ reactions. I also looked at transcripts of interviews with habilitation technicians and explored explanations of actions/reactions. I then discussed each narrative with my dissertation advisor. I revisited my data and repeated my analysis after the discussion. I recoded each narrative as needed, as additional meanings emerged. Again, the new discoveries were discussed and unpacked, adding deeper focused connections between what transpired between participants throughout meal and snack times as it related to basic human rights.

The following narratives were extracted from field notes and reveal the misappropriated control and lack of choice-opportunities for two residents, Kevin and Marsha. Kevin is 38 years old and has lived in Hope house for eight years. He came to CCDD’s residential education program from foster care after a report of physical abuse. Kevin uses a wheelchair for all mobility and requires total assistance with all personal care from staff, with the exception of eating. He is able to use simple words and phrases coupled with ASL. Kevin enjoys watching television, listening to music and assisting staff with housekeeping tasks. According to staff, Kevin has a history of “harassing” people for things he wants. He also has a history of only eating sweet foods during meals. Marsha is 49 years old and has lived in Hope House for 38 years. Marsha is ambulatory but requires total assistance from staff for personal care. She is nonverbal but uses gestures and vocalizations such as whimpering to communicate with others.

Marsha enjoys watching television and listening to music. According to staff, she also enjoys drinking wine with her mother during her visits home. Marsha has a history of rumination, the regurgitation of food and beverages, and has her caloric intake monitored by a dietician. Kevin and Marsha are an unofficial couple at Hope House. Kevin states that Marsha is his girlfriend. Marsha does not demonstrate opposition to his claims.

These narratives were chosen because they illustrate the complexity of meal and snack time negotiations between residents and habilitation technicians, and because of the frequency in which the exchanges were observed. These examples also reveal the key issue argued in this paper – residents’ rights to choose what they eat and drink, and when they eat and drink as a basic human right are attributed to manipulative behaviors and restricted by staff through practices that have become standardized over time.

5.3.1 “Work for it”

I arrived to Hope House early one sunny afternoon to spend time observing second shift staff and the residents. I entered the dining room through a back door at the patio, and deposited my notebook and bottled water on the green sofa near an area where residents were gathered. From this vantage point, I was able to observe five residents, including Kevin, seated in their wheelchairs in a semi-circle around a large 40-inch television. Kevin’s concentration was not broken by my entrance as he focused intensely on the program, Dr. Phil. His roommate Tony announced my arrival – *Hey it’s Khalilah* – and proceeded to ask me questions about my day. Staff members Margaret, Heather, and Elijah were seated around a large oak dining room table and discussed which residents would be taken to their rooms for naps and which would be allowed to continue watching Dr. Phil. It was decided that Kevin and Tony would remain in the dining room since they had only been out of bed since lunch. Elijah and Margaret assisted three residents to their rooms, while I remained in the dining room with Heather, Kevin, and Tony.

While Kevin and Tony watched television, Heather decided she would begin her daily documentation. She walked over to a bookshelf containing the residents' charts and retrieved three large black notebooks. Heather returned to the dining room table, and I joined her.

Kevin turned on his motorized wheelchair and made his way to the dining room table. He positioned his wheelchair in front of me and said, "Hey!" I responded, "Hey, Kevin. How are you?" He slowly brought his left hand to his mouth and with a large grin mumbled, "I want . . . <long pause> . . . I want . . ." I interrupted, "What do you want?" With urgency he was able to get out "a drink." I further probed, "What kind of drink do you want?" Kevin answered, "Juice." Margaret reentered the dining room and heard our exchange. She interjected, "Kevin you cannot have a drink right now." I was puzzled by this and asked why. Margaret responded, "That's the way his meal plan is set up. . . it's not in his plan to have [juice] now." I was quite baffled by this. I asked Margaret if there was a medical contraindication that limited what he could have to drink. She confirmed that he did not have medical restrictions. Heather lifted her head from her notes and added, "Usually the drink he has after lunch is served by second shift. I'll ask Mary Ann (the house manager) if he can have it." To which I responded, "So if he wants it, he has to wait until second shift?" Heather clarified, "Well they're not usually up right now. So we really don't have to worry about it." Heather left the dining room. Her sneakers squeaked against the tile floor as she made her way down the hallway to Mary Ann's Office.

When Heather returned, she informed Kevin that getting juice would be a reward. In other words, Kevin had to "work for it" in order to quench his thirst. Heather retrieved the resident notebooks from the dining room table and asked Kevin to return them, one by one, to the bookshelf. Smiling, he answered, "OK" and reached forward with both hands for the notebooks. Heather helped him position each notebook in his lap. Kevin transported the three

notebooks across the dining room to the bookshelf. Upon completion, Heather said “Thank you so much, Kevin,” walked into the kitchen, and prepared a cup of thickened grape juice for him. He watched and smiled.

Heather’s admission that serving Kevin an afternoon drink was often left to second shift spoke to serving snacks during this time of day being a matter of convenience. Kevin wanting a drink did not fit the afternoon routine; therefore, asking for a drink was perceived as an inconvenience. For Kevin to make multiple requests was viewed as harassing (requests are made at times outside of their routine) and manipulative (he asks multiple people until he gets something to eat or drink). Staff perceptions were based on his behavioral history rather than viewing the functions of his behaviors in the present. One must question why is it an issue for Kevin to have something to eat or drink when he wants it? It is a natural, physiological need; however, even the most basic need is problematized. When asked about Kevin’s food and drink requests during informal conversations, habilitation technicians stated, “he’s looking for attention” and “he really doesn’t want anything.” They dismissed his behaviors as trivial.

The aforementioned observation was not an isolated incident with Kevin. There were a number of instances when staff did not honor Kevin’s food and beverage requests or preferences. Another example involved the sequence in which Kevin was allowed to receive his food. Since he preferred sweet foods and beverages, staff reported that he would not eat the rest of his meals or drink water. Therefore, staff decided to leave sweet foods off his plate and present them to him only after he ate his other food. Sometimes he would eat, but there were also examples when he would not eat until he received fruit or some other sweet food item. As a result, it became common practice not to put dessert or fruit on his sectional plate and to offer him juice

or a sweet snack as a reward. The following excerpt demonstrates how infantilized views of the residents are negotiated when Kevin exerts his will to have what he desires.

5.3.2 A Battle of Wills

I sat around the television to watch *The Wendy Williams Show* with Kevin and six other residents while staff members gathered place mats, plates, bibs, napkins, and flatware for lunch. Margaret and Kena poured pureed spaghetti, spinach, and fruit cocktail into Tupperware, gathered pitchers of water and milk, and placed them on the table for family-style dining. One resident, Keisha, hummed and circled around the table watching as if she were supervising the how lunch was arranged on the table. All staff members began preparing plates for the residents, carefully scooping serving spoon sized helpings. Kena prepared Kevin's plate with pureed spaghetti and spinach; however, the fruit cocktail was poured into a bowl and placed out of reach. Kevin would only be served the fruit cocktail after Kena determined he had eaten enough of the main course. A standardized method was not used to determine whether Kevin had consumed enough food. Instead, the staff member assigned to Kevin on any particular day decided if he or she felt he had eaten an adequate amount of lunch to reward him with his dessert or fruit. Kena asked Kevin to come to the dining room table. He turned on his motorized wheelchair, turned away from the television, and slowly made his way to the table.

Kena placed a lap tray and his sectional plate onto the arms of his wheelchair. Kevin glanced down at the sectional plate. His gaze stayed on his food as if he were studying its composition. Kena said, "Go ahead Kevin. Eat your spaghetti. You like spaghetti." Kevin retrieved his Mothercare spoon from the table and used it to point to the fruit cocktail. Kena repeated, "Kevin, go ahead and eat now." He responded, "Hey, hey, hey I want that." Kena encouraged him again to "go ahead and eat." Kevin, not accepting her answer repeated, "I want that." Kena did not offer him the fruit cocktail. Instead she told him, "You have to eat all your

food before you eat your fruit cocktail.” Kevin, with his gaze fixed on Kena, dropped his spoon onto the table. He did not attempt to eat his spaghetti or spinach. Rather, he sat at the table and watched other residents consume their meals. Kena offered Kevin the cup of thickened milk positioned in front of his plate. He drank his milk and asked, “Fruit?” Kena responded, “Not until you eat.” Kevin continued to sit in his wheelchair without attempting to eat his food. In quiet protest, he continued to watch staff members feed other residents their spaghetti, spinach, and fruit cocktail. Kena continued to encourage Kevin to eat, “Kevin you really need to eat.” Kevin did not turn his head to acknowledge she was speaking to him nor did he make any gestures indicating he was interested in eating.

Eventually, Kena asked Kevin to go to his room because he was choosing not to eat. He looked at her, and without vocalizing or gesturing in protest, he turned on the power to his wheelchair and left the dining room. I was not quite sure what to make of the observation, so I inquired about the particulars of Kevin’s meal plan. I wanted to know why staff did not serve fruit with the rest of his meal as a method to getting him to eat other portions. After all, Kevin knew what he wanted to eat; however, staff would not honor eating sweets first as an appropriate choice. When asked about serving the fruit last, Margaret and Kena stated, “this is how we have to do him or he won’t eat.” I probed further, “does he do that all time?” Kena responded, “Well not all the time, but we have to make sure he eats.” Symbolically, Kevin was viewed as a child who did not understand nutrition and the habilitation technicians were the parents who knew what was best for him. Kevin protested staff’s decision by not eating, and the habilitation technicians responded by waiting out his protests. It became a “battle of wills” – manipulation by Kevin in order to get his fruit cocktail and manipulation by the habilitation technicians to get Kevin to consume the rest of his lunch; however, sitting and waiting became a “time out” for

Kevin because he would not comply with Kena's instructions. The result was that Kevin did not eat at all. The habilitation technicians did not acknowledge that not eating, in and of itself, was a dire consequence.

5.3.3 The Phantom Meal Plan

I observed Margaret prepare Marsha's sectional plate during breakfast. Marsha was assisted to the table from the plush recliner where she patiently waited in front of the television until her turn to eat. She was presented with portioned pureed pancakes, sausage, and chopped strawberries. Margaret fed her each food item, one by one, from a teaspoon. Marsha did not attempt to feed herself independently. Margaret waited 30 minutes before scooping a second serving of the pancakes, sausage, and strawberries onto Marsha's plate. While she waited, Marsha whimpered and rubbed her fingers over the edge of the plate. She stared at the Styrofoam containers holding the extra servings and alternated gazing at the pitchers of juice and milk sitting in the center of the table. Periodically, she reached for the containers of food. Margaret blocked her hand and told Marsha, "No, not yet." The longer Marsha waited, the louder her whimpers became. Once her 30-minute wait was over, Margaret scooped another serving of pureed pancakes and chopped strawberries onto Marsha's plate. The whimpers subsided again. Once she completed her second serving, she was required to wait another 30 minutes before she was offered something to drink. Again, Marsha waited, and the whimpers crescendoed with each passing minute. Margaret retrieved a cup from the center of the table, removed the lid, poured milk into it, and offered it to Marsha. She was not offered juice as an option although the pitcher was positioned next to the milk. Rather, Margaret chose which beverage she thought Marsha should drink with her meal. Marsha would not drink the milk and dropped the cup onto the floor.

Marsha's ability to access food and beverages of her choice was impacted by practices

passed down through staff members over a number of years. Marsha had a history of rumination. Per staff interviews, she periodically regurgitated food and liquids she had consumed and rechewed them. Marsha was not given a specific diagnosis of Rumination Disorder; however, an individualized meal plan was devised by her care team (i.e., physician, psychologist, speech language pathologist, occupational therapist, house manager, and her mother) to decrease ruminating behaviors. Specifically, staff members were required to institute a staggered meal plan which involved presenting food and drinks in 30 minute increments during meals. Although it was not explicitly stated, it could be implied that the goal of the meal plan was to associate rumination with a negative consequence (i.e., not being able to have food and drink all at once). This meal plan was instituted more than five years prior to this study, and was not part of her formal Individualized Program Plan (IPP) during the time of the study.

This phantom meal plan is an example of how practices are passed down and continue to be instituted even when they are no longer warranted. It is also important to note that Marsha's specific meal plan was not formally documented in her IPP or meal time procedures and goals. I questioned the habilitation technicians about the implementation of Marsha's meal plan. Ann verbalized that she carried out the meal plan as instructed, although she did not fully understand its intended use:

Ann: I know she wants something to drink, but I just can't give it to her.

Khalilah: Does the meal plan allow you to give her something when she's not ruminating...rechewing? I haven't seen her do that.

Ann: All I know is that we have to wait 30 minutes. They really don't let us do it differently. You can tell she's still hungry and she wants something to drink. <Ann shrugs her shoulders>

Khalilah: Does she have a plan in the [electronic record]? I looked for one but didn't see it.

Ann: They just tell us what we need to do. I don't see that she really needs it.

Khalilah: Have you expressed to the team that she seems to do fine without the plan, or suggest that they do a trial of eating and drinking in one meal sitting?

Ann: I just do what they tell me to do. I don't know. It doesn't make sense to me.

This dialogue demonstrates that Ann recognized this meal plan may no longer serve its original purpose for Marsha, and instead inhibits her ability to enjoy her meal. Although Ann did not feel empowered to offer an alternative to Marsha's staggered meal plan to the care team, she does offer an alternative to serving water to another habilitation technician in the following example.

After lunch, I joined Niecey, Ann, Marsha, and five other residents on the patio to enjoy the sun and warm breeze under the trees. We sat along a brick wall facing the gardens so the trees would provide much needed shade from the summer sun. For additional protection, Niecey applied sunscreen to the residents' faces, ears, arms, and hands. Everyone sat in their respective lawn chairs and wheelchairs, resting the backs of their heads against the chairs. One by one, the residents began to fall asleep. Rustling of the leaves, chirpings, and the occasional roar from a jet engine flying over the CCDD provided a break from the silence. Ann glanced down at her watch and said to Niecey, "It's about time for a snack." Niecey responded, "OK, I'll go grab some juice and water. We may have some animal crackers too." Niecey entered the building to retrieve juice and animal crackers for the residents while Ann wiped off a picnic table. Niecey returned only with cups and pitchers of water and apple juice. Residents were woken up and asked if they wanted something to drink.

I focused my attention on the interaction between Niecey and Marsha. Marsha was not

asked if she wanted water or apple juice. Rather, Niecey presented her with a cup filled with water. Marsha took the cup, sipped from the straw, and dropped the cup onto the patio. Niecey said, “Marsha! You have to hold your cup.” She took the cup and replaced the soiled lid. Again, Marsha took the cup from Niecey, took a sip, and dropped the cup onto the patio. She began to rock back and forth in her lawn chair and whimper. In disbelief, Ann said to Niecey, “She’s just going to keep spilling that water everywhere. Maybe give her some juice. That’s what she wants anyway.” Niecey responded, “She can’t have juice.” Ann responded, “Maybe give her some Crystal Light in her water. She not gonna drink that water.” Niecey argued, “Well she supposed to get the water.” Ann rebutted, “But it’s Crystal Light. Ain’t no calories.” The staff members continued to debate whether to offer Marsha an alternative to water. Niecey attempted to give her water one more time. Not surprisingly, Marsha sipped the water and dropped the cup onto the patio. Her whimpers turned into wails.

This example demonstrates again how residents’ preferences are not honored by staff. The habilitation technician did not offer Marsha a choice of water and juice, but gave her what they thought she was supposed to have; however, Marsha made it known to the habilitation technicians that she disapproved of the water by dumping it onto the ground and whimpering. There was some obvious tension between Ann and Niecey as they determined whether or not to offer Marsha an alternative to water. There was some recognition of preference, followed by a blatant refusal to honor it – Ann and Niecey know that Marsha does not want water but Ann communicated they rely on the “old way of doing things.” Ann challenged the embodied practice by offering Crystal Light as an alternative, but Niecey was unable to see it as a viable solution. The passed down meal plan called for Marsha to have water. Neither were able to see the situation from Marsha’s point of view, ultimately denying her the right to choose.

5.4 Discussion

Individuals with ID are characterized by having limitations in intellectual functioning and adaptive behavior (Schalock, et al, 2010), which includes difficulties with choice-making (Devi, 2013). This characterization can directly impact how professionals and non-professionals recognize and acknowledge choice-making in adults with profound ID. As seen with Kevin and Marsha, caregivers can often assume that individuals with profound ID are eternal children, are unable to communicate on their own behalf, and therefore not competent to make their own decisions (Ward & Stewart, 2008). This narrowed view of adults with ID is deficit-focused and a conduit for the perpetual log jamming to the most basic human rights. Crowson, Brandes, and Hurst (2013) suggested the prejudice and discrimination that all people with disabilities encounter on a continual basis raises the question of whether or not these individuals are perceived as deserving of the rights that most citizens take for granted. Further, it has been repeatedly argued in the literature that historically individuals with ID were excluded from a consideration of their rights. They were confined to various forms of group living (e.g. farm colonies) away from mainstream communities and behind the walls of institutions (Johnson, Walmsley, & Wolfe, 2010).

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 recognized the freedom to exercise personal choice in the decisions that influence daily life as a foundational concept and a basic human right in American and international perspectives on human rights (Tichá, et al., 2012). Likewise, Articles 12 (Equal Recognition Before the Law) and 21 (Freedom of Express and Opinion, and Access to Information) of the United Nations Convention on the Rights of Persons with Disabilities (2006) addressed the need to recognize the legal right to communicate interests through all means for all people, even those with significant intellectual limitations. Rights have a direct impact on quality of life, and are insufficient if they are not

accompanied by opportunities to exercise them (Verdugo, Navas, Gomez, & Schalock, 2012).

The UK Parliament's Joint Committee on Human Rights (2008) listed the following reasons as to why individuals with ID may be vulnerable to violations of their human rights:

1. People with intellectual disabilities may not be aware of their human rights due to the lack of accessible information.
2. Expectations have traditionally been low for people with intellectual disabilities.
3. The existence of negative attitudes, e.g. people with intellectual disabilities are somehow worth less than other people.
4. People with intellectual disabilities are often marginalized and isolated.
5. People with intellectual disabilities are often dependent on carers.
6. Difficulties in understanding and communicating with people with intellectual disabilities (Hall & Yacoub, 2012, pp. 466 – 467).

Although these reasons for the maltreatment of individuals with ID are valid, they provide only a superficial glimpse into how it is possible barriers to basic human rights for individuals with ID still exist. The data presented here show that the barriers individuals with ID face are more nuanced than awareness of rights, historical expectations, and perceived functional dependence. This paper highlights that the complex and restrictive nexus in which they live is also influenced by the historical understandings of behavior as aimless and manipulative, the systematic defining and classifying those with ID as infantile, and the application of marginalizing policies and practices that become embodied and standardized over time.

In Hope House, choice-making was inconsistently supported and often problematized, as residents' actions and communication were perceived as manipulative behavior aimed to circumvent staff's control over their daily life choices. Historical narratives drove interactions

between the residents and habilitation technicians in the present. Specifically, habilitation technicians evaluated situations based on their histories with the residents or passed down histories or narratives (e.g., “This is how Kevin is. He harasses.”), versus contextualizing the functions of verbal and nonverbal behaviors as choices in the moment. Likewise, historical programs guiding meal time practices, such as Marsha’s staggered feeding program, are carried over without reason or examination. The unintended result is an embodied practice of misinterpreting “choosing behaviors” as manipulation or “calling your bluff,” thus, eliminating choice becomes a tool of power to combat perceived manipulation. Although habilitation technicians perceived some behaviors as manipulation, they also used food and beverage as an element of control – the carer having power over the cared for. As noted with Kevin, habilitation technicians’ decisions were based on what they thought was best for him or reflected decisions they might make for themselves (Fyson & Cromby, 2013), versus making decisions immediately aligned with his interests. In addition to viewing the residents as manipulative, the habilitation technicians at Hope House viewed the residents as adults who do not have needs and desires. Residents were also infantilized and characterized as individuals who are unable to make decisions that are in their best interests. The actions of the habilitation technicians revealed a cultural ambivalence toward residents’ desires and interests and their having to live in a restricted life space (Hallrup, 2012).

Cultures, including the culture of adults with profound ID, create their own *emblematic gesture vocabularies* (Matsumoto & Hwang, 2013; Matsumoto, 2006) to communicate choice. Institutional cultures standardize ways of interpreting how residents communicate via eye gaze and visual attention, the use of voice and various forms of vocalization, and use of signs and physical gestures (Matsumoto & Hwang, 2013). In other words, it is the institutional culture that

influences how unconventional forms of communication are interpreted in specific ways. Matsumoto and Hwang (2013) also related cultural meaning to social coordination – the negotiating between communicating needs and preferences between residents and staff based on the cultural norms and expectations of the institution. Adults with profound disabilities develop unconventional and highly individualized or idiosyncratic means to communicate with others (Brady, et al., 2016). Yet, the ways in which staff interpret these forms of communication is often misrepresented and embellished as challenging behavior. Staff's misinterpretations are influenced by their roles in the institution, their history and experiential knowledge, embodied beliefs of stereotypes and attitudes toward individuals with profound ID (e.g., the abled versus the disabled) (Dovidio, Hebl, Richeson, & Shelton, 2006). Staff may have viewed residents as incapable of making sound decisions, and subsequently their choices are seen as nonsensical. Therefore, in order to have a deeper understanding of the relationships between human rights, choices, and embodied restrictive practices one must consider the intersection of these ideas as the unit of study – the point where these constructs meet.

For adults with profound ID, the opportunities to exercise the right to communicate needs and interests can be obstructed by institutional practices that perpetuate the infantilization and marginalization of institutionalized people. The need for a fundamental change in institutional culture and attitudes toward cultivating and supporting residents' choice (Roberts, et al., 2013), as well as advocacy in support work is paramount (Brolan, et al., 2012). Bigby and colleagues (2009) in their study of staff working with individuals with severe and profound ID suggested that staff provided general care rather than facilitating and developing independence. The authors also noted better functional outcomes for individuals with ID were associated with increased facilitative assistance from staff. Meal time studies with individuals with ID have also

supported increased staff training and facilitative support to improve meal time interactions (Zoder-Martell, et al., 2014). Burton, Cox, and Sandham (2009) in their reference for nurses working with individuals with ID recommend staff engage in specific training on the fundamentals of nutritional care in relation to the needs and desires of individual clients. The authors also note the need for professional and nonprofessional staff to recognize their role with assisting in maintaining nutritional balance; habilitation technicians should balance supported decision making by being sensitive to and honoring their food and beverage preferences. Ultimately, the enjoyment of meals and encouragement of pleasures of eating should be the objective of dietary plans and staff's focus at all times. Incorporating individuals' choices and their favorite meals and snacks into dietary planning can significantly enrich meal time experiences and quality of life (Burton, Cox, & Sandham, 2009).

5.5 Conclusion

In this paper I have argued that choice-making, even for the most basic and mundane activities such as eating and drinking, continues to be insufficiently cultivated and reinforced for institutionalized adults with ID. Problematization was employed as an analytical framework and provided the starting point from which to understand and analyze staff's actions during meal and snack time negotiations and residents' choice-making. Present literature suggests that adults with profound ID can make choices with the proper environmental supports; however, examples from this study revealed that choice-making by residents in an institutional setting is often problematized as manipulative or without purpose, if their choices are even acknowledged. Problematizing choice was influenced by staff's historical understandings of residents' behaviors and passed down restrictive practices that became standardized over time. Staff's ignorance to these practices as a violation to basic human rights demonstrates an ongoing tension between

providing quality nutritional care and honoring residents' right to have nutritional preferences.

Declarations in the Developmental Disabilities Assistance and Bill of Rights Act (2000) and the United Nations Convention on the Rights of Persons with Disabilities (2006) move forward the idea that all individuals with disabilities have a legal right to live their lives according to their own interests and preferences; yet, the sociohistorical impacts of institutionalized care continue to influence how adults with profound ID are able to exert their interests and preferences. This bears weight on the application of 'least restrictive' in nutritional planning, as well as all other habilitative programming in institutional settings. There are also implications on staff training, particularly providing instruction on contextualizing interactions with residents and how to offer opportunities for choice-making using regimented as well as organic methods. Relationships between staff and residents are more than simply providing care. The staff – resident relationship should develop and support all facets of the everyday that improves the quality of institutionalized lives.

CHAPTER 6: MORAL OBLIGATION, SELF-GOVERNANCE, AND ACCOUNTABILITY ON THE FRONT-LINE

6.1 Introduction

The examination of front-line work in institutional settings for adults with intellectual disabilities (ID) has primarily been limited to understanding the authorization of unskilled custodial care, abuse and exploitation (Noll, 1995; Trent, 1994; Wehmeyer, 2013). Present research in ID continues to focus on stigma, disability rights, and habilitative training necessary for community transition (Nielsen, 2012); yet, little has been added to the knowledgebase on the nature of work and care in the contemporary institution. This paper calls attention to the implementation and challenges of front-line work for staff members in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). These front-line workers, referred to hereafter as habilitation technicians, work within institutional complexes that they must encounter, enact, challenge, and sometimes reject (Grace, Zurawski, & Sinding, 2014). These institutional complexes include, but are not limited to, the guiding principles of the institution and regulations that define interactions between all staff members and the execution of care to adults with profound ID. Various forms of accountability circuits (the cyclical processes through which extra-local bureaucracies and the standards and procedures of local agencies are produced and front-line work implemented) fall within these complexes. Accountability circuits are officially represented through the material documentation and technologies habilitation technicians complete in order to fulfill that accountability (Griffith & Smith, 2014).

Juxtaposed to accountability circuits is the notion of self-governance, which refers to the

ability to exercise the functions of power and self-determined decision making without intervention from an outside authority (Sørensen & Triantafyllou, 2016); however, habilitation technicians' self-governance, as discussed below, is not divorced from institutional oversight. Their self-governance is aligned to and mediated through accountability circuits by enacting the personnel and regulatory texts that specify particular roles, responsibilities, or procedures and their associated documentation. These texts are bound by state and national mandates that color front-line work in ICFs/IID in a particular way that can come into conflict with the habilitation technicians' sense of obligation to the residents. This moral obligation – the duty or responsibility a person feels compelled to perform because of personal values and beliefs about right and wrong (Skorupski, 2010) – to residents is different from text-based forms of accountability. The habilitation technicians are oriented to accountability circuits through texts, but oriented to the residents by their personal commitments; and this moral obligation to residents compels them to prioritize “moral work” – work that brings meaning to residents' lives.

Data presented here illustrate that “moral work” is not aligned with or valued within the textual complexes organizing front-line work. The absence of work that brings meaning to the lives of residents by elevating the monotony of day-to-day living implies that habilitation technicians are not able to exercise self-governance. Examples from institutional ethnography literature suggest that front-line workers can negotiate these circuits using self-governing strategies that benefit them (e.g., Griffith & Smith, 2014); however, I argue that by participating in these circuits, habilitation technicians set aside their moral obligations and perpetuate limitations to their own self-governance.

6.2 Institutional Ethnography: A Theoretical Framework

6.2.1 Regimes of Knowledge and Constructing Work in the Everyday

Institutional ethnography (Smith, 1987, 1990) is a feminist approach to inquiry that directs the researcher's attention to the ways knowledge regimes are linked to and influence institutional processes that structure what people do every day (Prodinger, Rudman, & Shaw, 2015; Prodinger & Turner, 2013; Smith, 2005). In doing so, the researcher is able to identify particular social practices or specific events from which a discourse may be explored (DeVault & McCoy, 2001). Institutional ethnography places special interest in examining "work" – the paid and unpaid activities of the individuals being investigated. Work is understood as being nested in discourses, and attending to these discourses reveals the unacknowledged or unrecognizable work that people perform, and how this work is shaped through discourses and institutional practices (Smith, 2005, 2006). Specific to this study, management of the daily operations and plans of care for the residents and staff in an ICF/IID is determined by a complex hierarchy of regulatory texts and mandates set forth by a number of local, state, and governmental agencies. These texts give way to an operation of institutional circuits (a broad term that accountability circuits fall under) that align staff to the institution (DeVault, Venkatesh, & Ridzi, 2014). That is, textual hierarchies form the conduit through which institutional circuits emerge.

6.2.2 Accountability Circuits and Self-governance

An accountability circuit is a form of coordination that brings front-line work into alignment with institutional objectives through the activation of texts. In general, its purpose is to "bring together people who have – or at least appear to have – shared interests" in certain outcomes in an institutional setting (Grace, Zurawski, & Sinding, 2014, p. 254). Texts impose specific expectations for acting or being, and front-line workers account for those ways of acting and being through documentation. Griffith and Smith (2014) theorized that front-line workers'

self-governance is drawn into accountability circuits through their documentation. Therefore, workers' participation in these circuits is immediately aligned with prescribed reporting requirements and ways of doing work. The mere act of documenting their work and being assessed by managers and administrators directly shapes the actual doing or representation of front-line work (Wagner, 2014). Sørensen and Triantafyllou (2016) also agreed that the desires of those who execute work, on the front-line or otherwise, are commensurate with institutional objectives. However, what is not accounted for are actions or duties that are not explicitly defined in texts. For instance, the ability to make decisions and adaptations to individualized care to the residents, as well as habilitation technicians' values and moral obligations are not divorced from their work.

The following sections describe and analyze the impact accountability circuits impose on moral obligation and self-governance in front-line work for five habilitation technicians and one shift supervisor in an ICF/IID.

6.3 Research Site, Participants, and Methods

This study took place at an ICF/IID, hereafter referred to as the Community Center for Developmental Disabilities (CCDD), in the southeastern United States. The CCDD provides state-funded programming, day and respite care, and educational services to 400 children and adults with mild to profound ID. Hope House, the primary residence for the staff participants of this study, is one of the oldest residences at the CCDD. Hope House is home to five men and five women with profound ID. Hope House employs 22 staff members including a house manager, three shift supervisors, and 17 habilitation technicians who provide 24-hour direct care to the residents. Specifically, staff participants included one administrator (Cynthia), one house manager (Mary Ann), one shift supervisor (Elijah), and five habilitation technicians (Heather,

Margaret, Kena, Niecey, and Ann). Six of the staff participants are African-American, one is Caucasian, and one is Indian-American. Their mean age is 43 years, with the oldest participant being 65 years old and the youngest 22 years old. They have worked at the facility for an average of 6 years and 8 months. Cynthia has the most experience having worked at the CCDD for 25 years; Ann has least amount of experience having worked only six months.

Administrators and upper level managers (e.g., Therapy Manager, Director of Education, and Director of Nursing) at CCDD were typically college educated, middle-aged, and Caucasian. Upper level managers supervised house managers, shift supervisors, and habilitation technicians. House managers, shift supervisors, and habilitation technicians typically had some college education (an Associate of Arts or Associate of Science degree or less), were female, under 40 years of age, and primarily African-American. These positions were also comparatively low-paying (less than 30,000 US dollars for annual income per year), and considered relatively unskilled by administrators and upper level managers.

Cynthia served as the direct supervisor to Mary Ann and coordinated the habilitation training programs for all residents. Mary Ann managed the daily operations of Hope House including the implementation of habilitation, behavioral, and educational programming, and medical care. Elijah, as a shift supervisor, ensured the execution of quality care, as well as housekeeping and maintenance by the habilitation technicians. The habilitation technicians were responsible for providing daily personal care (e.g. bathing, dressing, toileting), creating opportunities for residents to complete habilitative and behavioral goals, planning community outings, and accompanying residents on medical appointments. Although the habilitation technicians spent the most time with and were the most knowledgeable about the residents' particular needs and wants, they were often left out of the care planning process. Overall, there

was little interaction between administrators and upper level managers, and house managers and habilitation technicians.

All staff participants provided verbal and written consent for participation and consented to having informal conversations and formal interviews audio recorded. The remaining staff members did not formally provide consent, but participated in informal conversations and were observed as they worked throughout data collection. This study was approved by the Office of Human Research Ethics Institutional Review Board at the University of North Carolina at Chapel Hill and the human rights committee at the CCDD.

6.3.1 Methods

Data were collected over a 14-week period. Participant observation, formal semi-structured interviews and informal conversations, and text work were the methods utilized in this study to demonstrate how staff's self-governance and moral obligation to the residents were reorganized and aligned to the institution through a circuit of accountability.

Participant observation. Observations occurred for six to 10 hours per day, four days per week. Staff were observed in congregate areas of Hope House (e.g., multipurpose room, dining room, patio, garden), as well as in residents' bedrooms, staff-specific spaces (e.g., staff lounge), CCDD-wide events, and community outings. I also observed Mary Ann and Cynthia during staff meetings, administrative meetings, and Individualized Program Plan (IPP) review conferences. I recorded key words and phrases, descriptions of people and the physical environment, interactions of the participants, traffic of people entering and exiting Hope House, location and times of day activities occurred, objects and documents used, and my sensory experiences. Jottings also included which staff organized activities and which staff participated. I functioned primarily as an observer while I built rapport with the participants. As staff became more comfortable with participating in the study, I became more of a participant as staff would

ask to me to assist with activities, invite me join them during lunch, and include me in group conversations concerning their work in Hope House.

Interviews. Informal conversations occurred throughout each observation visit, whereas formal interviews convened during a time and location chosen by each participant. Formal interviews occurred with Cynthia, Mary Ann, Elijah, Ann, and Margaret. Informal group conversations transpired, and well as one formal group interview with eight habilitation technicians. Interviews were conversational and aimed at eliciting narratives about the participants' work responsibilities and daily activities, relations with residents and other staff, and about the texts important to their work. Informal conversations were either included in the field notes or recorded and transcribed. All formal interviews were recorded and transcribed verbatim.

Text work. Text work refers to the identifying, reading, and linking of everyday action to material and nonmaterial texts (Campbell & Gregor, 2004; Smith, 2005). I reviewed the texts staff identified as important to their work. Texts included the electronic medical record, the residents' (IPP), the Individualized Habilitative Plans (IHP), the socialization and leisure checklists, the behavioral management checklists, the staff Communication and Shift Change logs, and the policies and procedures of Hope House and the CCDD. These documents outlined the roles and responsibilities of the staff, as well as provided the necessary documentation to hold staff accountable to their institutional responsibilities.

6.3.2 Analysis

Excerpts from field notes and interview transcripts were analyzed using first and second cycle coding (Miles, Huberman, & Saldaña, 2014) in order create smaller analytic units. For this paper, data segments related to staff work and staff relationships were extracted, constructed into narratives, and analyzed through an iterative and reflexive process (Srivastava & Hopwood,

2009). I discussed each narrative with my dissertation advisor, revisited the data, and developed more focused connections between staff responsibilities and self-governance, and their immediate alignment to institutional objectives. Themes within the narratives included obligation to residents and coworkers, inter-professional and trans-professional power, positional politics (e.g. leveraging political power in the institution based on position), and textual work/alignment. Analyses revealed a paradox in which self-governance through accountability circuits shifted responsibility from the organization level to habilitation technicians while simultaneously negating professional judgment and moral obligation at the front-line.

6.4 Negotiating Moral Obligation, Self-governance, and Accountability

6.4.1 An Institutional Account of Work

There are two levels of texts that frame the operations and direct care services at the CCDD: the national and state standards that govern the form and functioning of an ICF/IID (e.g. Olmstead Act, Rosa's Law, Final Rule 78 FR 46499, Developmental Disabilities Assistance and Bill of Rights Act, Rules for Facilities) and the local agency-based mission and objectives that define standards for the delivery and management of therapeutic, educational, and personal-care services (see Appendix H). Together, this intertextual hierarchy establishes the accountability circuit that dictates all aspects of work at the CCDD. Outlined in national texts are the Code of Federal Regulations and Conditions of Participation for ICFs/IID. These texts establish the requirements these facilities must meet in order to participate in Medicare and Medicaid programs, as well as health and safety requirements, client protections, facility staffing, facility environment, delineation of services, and surveyor guidelines (CMS, n.d.).

State level texts – based on the state's department of health and human services and health service regulation agency – prescribe the licensing and regulating of ICFs/IID. These

regulatory bodies are also responsible for surveying and evaluating programmatic and personnel matters in ICFs/IID. Included in their survey and evaluation are the rules and regulations for all healthcare personnel, the rights of those receiving services, treatment and habilitation rights, scope of treatment, criteria for admission and discharge, safety, and quality assurance. For ICFs/IID to consistently achieve a standard of quality care and compliance, all personnel must document procedures using a system informed by and created through these regulations. Front-line work at the CCDD is also defined and governed by these rules and systems and is maintained through regulatory texts.

The official job description for a habilitation technician at the CCDD lists the following as daily responsibilities:

Provide personal care including toileting, changing diapers, skin care, bathing, dressing, feeding, etc.; implement habilitative training to children and adults with severe/profound intellectual and developmental disabilities (I/DD) such as self-help, domestic, and leisure skills; complete light housekeeping assignments, medication administration, and routinely lift 40 pounds independently and 41 – 140 pounds with assistance; accompany residents on outings; and complete all relevant medical and habilitative documentation.

Habilitation technicians are also expected to read and decipher the regulatory texts that guide their work. This requires that they become knowledgeable readers of texts, make sense of its structural and linguistic complexities, and apply that knowledge in novel and practical ways.

The next section describes the specific accountability texts habilitation technicians must enact and their influence on their self-governance and moral obligation to residents.

6.4.2 Aligning Accountability through Texts

Habilitation technicians at Hope House document on a number of forms that provide evidence that individualized training for each resident is completed daily. These forms are also used to provide the care team with data to determine if and when amendments to habilitation training plans are required. The resident chart is the primary text where habilitation technicians indicate which activities and habilitation goals were performed. Included in the resident chart is the IPP, which habilitation technicians reported to be the primary document influencing their work. The IPP contained the comprehensive evaluations of each discipline represented on the care team (i.e., psychiatry, psychology, social work, nursing, nutrition, physical therapy, occupational therapy, speech language pathology, and education), which defined the habilitation goals and interventions required for active treatment. The IPP also indicated ancillary program plans such as meal/nutrition, behavioral and socialization supports. Meal plans specified the types of adaptive aids required for safe assisted self-feeding, as well as suggested verbal instructions habilitation technicians may employ for meal time participation and compliance. A behavioral support plan included specific strategies for deescalating targeted problematic behaviors and reinforcing desired behaviors during habilitation training. Also included in the behavioral support plan, the socialization plan provided methodologies for improving quality engagement between residents and others at the CCDD and during community outings.

Habilitation technicians are also required to initial and sign a *Body Check* form located in the front of the chart, acknowledging that they were the habilitation technician assigned to the resident on any particular day. They must date, provide a description of how each resident was found (e.g. was the resident soiled, clothed or unclothed, asleep or awake) when their respective shifts began, and sign their initials. Each habilitation technician must also complete a *Communication Checklist* by indicating a plus sign if an opportunity for residents to

communicate with staff was given or minus sign if an opportunity was not given.

Communication goals included “responds to name,” “responds to or uses sign,” “participates in group activity,” “activates a switch,” “follows direction with object or sign cues,” and “makes a picture or object choice.” Likewise, each habilitation technician was to place a plus or minus sign on skills performed on a *Socialization and Leisure Activity Program* form, which is designed to enhance social and leisure skills by engaging residents in active treatment and leisure participation. This form includes 19 activities: listens or reads; listens to music; watches television; participates in arts and crafts; plays table games, videos, or exercise; swings; ball play; activates switches; walks; participates in cooking activity; interacts with peers; visits with other residents; plays musical instruments; attends outings; participates in bowling; starts VCR; and uses microwave for snack. Residents are expected to perform a minimum of three activities each day. Although each resident received habilitation goals, all residents received the same *Communication Checklist* and *Socialization and Leisure Activity Program* forms.

Habilitation technicians are also required to complete a *Behavioral Management Checklist* for residents who require specific interventions to deescalate unwarranted or undesired behaviors. At the time of this study, three male and four female residents required behavioral management program plans. This form includes the resident’s name, psychological or psychiatric diagnoses, and behavioral methodologies. Should a habilitation technician be required to utilize an intervention from the behavioral program, he or she must document the date, time the behavior occurred, description of the behavior, frequency, duration, interventions used, quality of the implementation, and the resident’s response. Habilitation technicians also complete a *Communication and Shift Change Acceptance* form, which includes a list of daily housekeeping duties for each working shift. Each shift pens four entries in the communication

log – when the shift started, during two staff breaks, and when the shift concluded. All logs must be accepted and checked off by all habilitation technicians working on each shift. The final form of documentation habilitation technicians were required to complete was the electronic medical record (EMR). The EMR was a web-based log containing information on each resident including their medical history, current diagnoses and treatment plans, vital signs log, elimination log, and programming goals. The EMR was maintained on two wall-mounted computer stations. Habilitation technicians were required to complete each assigned resident's EMR before the end of their respective shifts.

All documentation was reviewed by the house manager, Mary Ann, and the director of habilitation, Cynthia. Mary Ann utilized the data to provide a comprehensive report to the care team during residents' annual IPP care conference. Specifically, Mary Ann noted whether residents have met or have not met habilitation goals as outlined in the IPP, if frequencies of challenging behaviors increased or decreased, changes in the medical status, and changes in levels of care. Cynthia used their documentation to justify maintaining or updating residents' behavioral management and socialization plans and their habilitation training program. It is important to note that habilitation technicians were not directly involved in the care planning of the residents. They were not invited to attend care conferences, or offered methods for amending habilitation goals. Therefore, decisions made by the care team were abstractly applied to the habilitation technicians' daily tasks. This directly impacts, and arguably undermines, habilitation technicians' self-governance.

The aforementioned texts produce material documents and technologies that keep habilitation technicians in compliance with the CCDD, which then allow the CCDD to be in compliance with state and federal regulatory agencies; however, analyses revealed that these

texts do not account for the work that is most important to habilitation technicians such as ensuring residents are able to live their lives according to their own interests and preferences, celebrating special moments and events (e.g. birthdays and national holidays), and building meaningful relationships. These represent the elements of daily living habilitation technicians feel obligated to address and advocate for on behalf of the residents. The following section presents narratives on how habilitation technicians leveraged their moral obligation and self-governance by creating experiences for the purpose of enhancing residents' quality of life.

6.4.3 Self-Governance and the Perceptions of Work

The roles and responsibilities of habilitation technicians are written in accordance with the national and state regulatory standards that delineate care in ICFs/IID. These standards provide a framework for the execution of daily tasks with residents and the maintenance of the facility. Specifying habilitation technicians' daily tasks is maintained through accountability circuits. Habilitation technicians are liable to these circuits through various forms of documentation that produce and are being produced through extra-local knowledge regimes and institutional circuits. Juxtaposed to the institutional demands on the habilitation technicians are their personal commitments to the residents. In particular, habilitation technicians highlighted advocacy as a critical aspect of their work. When asked specifically about their job requirements and other important responsibilities, one habilitation technician, Margaret, shared what she considered to be important responsibilities:

Basically, what we do, we are supposed to be advocates for the clients. Definitely advocate first. We do the medical appointments with them too. We're supposed to make sure that their goals are run. Which they're supposed to do their goals every day. Whatever the goal is, that's what they're supposed to do. Like Kevin has a goal where he will take his clothes to put it in the hamper, and stuff like that. So basically, we're supposed to teach them their goals; and you know we have to do like their personal care stuff, which you definitely have to do what you're supposed to do for their personal care. Like you do to yourself you know.

It is interesting to note that Margaret's first stated responsibility is to be an advocate for residents. Margaret elaborated that advocacy included honoring residents' preferences, ensuring those preferences were considered for inclusion in their habilitation plan by relaying that information to the house manager before each resident's annual IPP conference, allowing residents to experience typical activities people in mainstream communities enjoy, as well as providing opportunities to develop meaningful relationships with staff and other residents. Yet, after she first mentioned advocacy, she did not refer to it again. Instead, she listed the responsibilities outlined in the official personnel texts of the CCDD. In other words, Margaret discussed the tasks most valued by the institution as tasks important to her work.

As a way to better understand how habilitation technicians commit to advocacy, I probed further. Margaret added:

I try to advocate for them because if I see stuff that's not right for the client, I will address it with the manager or the supervisor. And they (the supervisors) have to take action from there . . . they have to you know . . . You need to the best job that you can possibly do. You should want the clients' home to look nice and clean for when visitors come in. You should want the clients to look nice so when people come in and see the clients and stuff they will say, 'oh that's, wow, that's really nice.' We do things for them. The clients are well maintained, dressed, and they seem like they are happy. Their home is beautiful, the clients live in a beautiful environment, and stuff like that.

Providing residents with a clean home and nice attire were viewed as essential elements of normal living. The habilitation technicians' views of normalcy were measured against their own experiences (e.g. having a well maintained home, dressing in nice clothing, enjoying community events, and celebrating special days); however, normalcy, as experienced by the residents, is constructed through the texts governing work and the implementation of care at the CCDD.

These texts emphasize safety and prevention, treatment, and rehabilitation rather than enhancing the experience and quality of life of residents. Therefore, in order to bring meaning to the everyday, habilitation technicians must provide extraordinary experiences that go beyond the

center's basic operational standards while simultaneously adhering to the center's expectations.

The following anecdote from a conversation with Elijah, a shift supervisor, illustrates the importance of bringing meaning to the lives of residents as important to the habilitation technicians:

We treat our clients like family, because that's what's right. Some of them don't even have family. Like Kevin. He came to us from the foster care system. Supposedly his mom died and his dad couldn't take care of him, but you know how it is with foster care. You never really know. He had been abused and everything. So really, this is the first place he's been where he's really being taken care of. We make sure his birthdays are really special. Like, every shift does something for him. But you know first shift really does the most. We have to <he laughs>. We'll have a barbecue and buy him new movies. Sometimes we go overboard. Like at Christmas time, we really have to do it up. You can tell he feels bad because he sees everybody else family coming and visiting. No one comes to visit him. Not even his guardian. One time Tony (Kevin's roommate) went home for two weeks. Kevin wouldn't hardly come out of his room. I asked him what was wrong with him. You know what he said? He missed Tony. That's his buddy! After that I said I will never let him feel bad during Christmas ever again. No one wants to be sad during the holidays.

This anecdote describes the importance of taking up the concerns and well-being of residents beyond providing basic needs. Habilitation technicians value their relationships with the residents and are committed to care for them not as clients, but as family, even when it requires extra work and spending personal money. The commitment to care for residents in this way is not accounted for within the texts guiding their daily responsibilities; however, habilitation technicians sought to make these experiences part of the operational fabric of Hope House.

Throughout my time at Hope House, I informally inquired about how habilitation technicians created extraordinary experiences for residents. Elijah, Ann, and Heather shared reasons why they provided care beyond what is prescribed for the residents:

Elijah: We reject labels. It doesn't matter what their disability is. We want them to have lives like us . . . we try to make life seem as what society sees as normal as possible for them. Like we throw them barbeques. We throw them the big birthday parties,

Halloween parties, Christmas parties. We do the whole nine yards! We, we – like Christmas morning, Christmas Day, we get up, we unwrap the gifts with them. You know? Why can't they share in all this? We do it!

Ann: We have to do for them. This is their home, not ours.

Heather: Yes! We want them to have normal lives just like us.

The habilitation technicians did not define the residents by their level of ID. They did not consciously allow the classification as “severe/profound” to color their interactions or decisions to engage them in certain activities. It is clear that the habilitation technicians incorporated the residents into their own interpretations of the good life based on their personal experiences, hopes, and expectations. They valued the residents as people and wanted them to be able to have the same or “normal” experiences as other adults their age; yet Ann says, “this is their home not ours.” This implies that habilitation technicians can envision caring for residents in their actual homes, but they do not quite feel as “at home” at Hope House.

The following excerpt from a field note written on Halloween also demonstrates the level of care and detail habilitation technicians took in organizing the holiday for the residents of Hope House:

In the dining room, two habilitation technicians (Ann and Heather) and three residents (Lisa, Kevin, and Tony) were making spider webs from cotton cosmetic supplies. Cutouts of spiders, bats, pumpkins, ghosts, and skeletons adorned the walls and windows. Niecey, a habilitation technician, was in the kitchen pouring bags of candy into a large Halloween decorated bowl. One habilitation technician (Margaret), the shift supervisor (Elijah) and three residents (Marsha, Keisha, and Lewis) sat in a semi-circle around the television. Growls and moans from zombies intermittently filled the room. Mary Ann, the house manager, entered the dining room with Halloween costumes draped over her left arm. She held up a sailor's costume and said, “Oh my goodness. They are going to have so much fun today! I can't wait.” Heather placed decorations on Kevin's lap and asked him to assist her in the hallway with the decorations. He smiled and nodded as he powered on his wheelchair, turned from the table, and followed her out of the dining room. Ann, Elijah, and Margaret assisted residents to their rooms to change into their costumes. Niecey gathered sausages, hotdogs, and hamburger patties from the

refrigerator and took them out to Kena, who was manning the grill on the patio. I was fascinated by the assemblage of decorating, food preparation, and dressing that was happening, all so that the residents could celebrate Halloween. As Elijah walked past me he said, “Khalilah, one day we’ll be able to take them downtown so they can do Halloween right!”

Since holiday parties, barbeques, and other social functions only occurred for special occasions, they became extraordinary rather than ordinary; and because these extraordinary occurrences were not included in the institution’s circuit of accountability, they were not always well received by administrators or the care team.

In fact, habilitation technicians’ efforts to create these experiences for residents had been criticized by administrators at CCDD. For example, one administrator, Cynthia, described the habilitation technicians as being unaware of residents’ abilities to value or understand their efforts to celebrate birthdays, religious holidays, and other national observances due to their level of ID:

They [habilitation technicians] overestimate the residents’ abilities . . . what they understand . . . I know they think they’re really high level and can do more than they actually are able to . . . They all function in the profound range.

Cynthia’s counternarrative reveals a belief that habilitation technicians may not realize or acknowledge that they are providing experiences that the residents may not fully comprehend or even value. This counternarrative also brings to light the assumption that adults with ID are unable to experience these activities in similar ways as other people; however, the habilitation technicians see it as their moral obligation to ensure these special events/occasions are deemed appropriate and feasible occurrences in Hope House.

Literature consistently shows that feasibility in direct care or front-line work is contested (Bigby, Clement, Mansell, & Beadle-Brown, 2009), as regulatory decisions are made by individuals who do not participate in direct care. At the CCDD, habilitative training and daily life planning are determined by a care team who utilized abstract knowledge, rather than

deferring to the knowledge of those directly involved with residents in the day-to-day.

Habilitation technicians reported that their work often goes unacknowledged in the planning and care of residents. The following scene illustrates the disconnect habilitation technicians identified between themselves as knowledgeable self-governed advocates and those who represent and reinforce the regulatory system in which they work:

Four habilitation technicians (Heather, Ann, Niecey, and Kena) were sitting outside on the patio while residents were in their rooms in bed for afternoon naps. I sat around the picnic table with Ann and Heather, Kena and Niecey rocked in chairs alongside the patio wall beneath the trees. Kena said, “You know what? Those people down the hill [pointing towards the CCDD administration building] have no idea about dealing with our adults (referring to the residents).” “What do you mean?” I asked. She responded, “We are the ones working with them. We work with them all day every day, but they try to tell us what to do. That shit is crazy don’t you think?” Niecey added, “The ones across the street (referring to CCDD administrators) have always made the decisions about what we do.” I further probed, “How do you all provide your input?” Ann turned toward me with surprise, “Input?” Her question was followed by Kena yelling, “The hell you say? Input?” Heather sat quietly but shook her head. I clarified, “So are you saying you do not provide input?” Niecey explained, “We have to tell Mary Ann (the house manager) what we think should happen and then she will relay it to everyone else in the meeting; but we’re never asked to attend a meeting to give input directly. It’s so ridiculous. We work with these folks eight hours a day, but you’re going to tell me how to do my job? Fuck out of here.” Kena agreed, “Right! Like, if you want us to use certain words to get them to do something, I know if they will work or not and not them. They come up here for two minutes. You know.” Niecey conceded, “That’s right! We’re here for hours. Hours! That should matter, but it doesn’t.”

Habilitation technicians saw themselves in many practical ways as the 'real' family members who were the experts on the residents, and yet they were not included in the decision-making, which invalidated their work and expertise. They acknowledged that they are powerless in their own self-governance because they are not invited to the “care planning table.” They made exceptions for their house manager, Mary Ann, who communicated their concerns and suggestions to the care team; however, they recognized that this is passive participation. Elijah, a shift manager asked, “Shouldn’t it (referring to care planning) start with us anyway?” Schwarzkopf and Kiger (2012) confirmed that leadership and care planning often begins with middle and executive level

management, rather than the front-line. The lack of interface between the care team and habilitation technicians may lead to the perpetuation of barriers limiting how they enhance residents' quality of life.

6.5 Discussion

Habilitation technicians are charged with providing quality care and habilitation training to adults with profound ID at the CCDD. To do so, they must decode and decipher the language of a number of policies and regulations coupled with the institutional texts of their local agency that outline the particulars of their daily job duties. These texts are informed by knowledge regimes that establish and organize a complex hierarchy of regulations and procedures that set standards by which people must conduct themselves and their work. Habilitation technicians adhere to and maintain those standards by engaging in circuits of accountability. These circuits tie their work to institutional objectives through a system of documentation. That is, habilitation technicians are required to log, both in material and electronic form, that specific tasks are completed every day. Analyses revealed that this documentation is a reflection of both horizontal accountability (demands for the habilitation technicians at the local level), as well as vertical accountability (demands for the CCDD at the state and national level). Equally important to their work was the moral obligation to adults with profound ID; however, their commitment to improving residents' quality of life was not directly aligned to, or sometimes was in conflict with, these standards as determined by accountability circuits.

Grace, Zurawski, and Sinding (2014) in their analysis of the Australian Vocational Education and Training sector, the use of "human resource development" as a strategy to improve job performance, and of patient decision-making in cancer care argued that front-line workers utilize a range of strategies to negotiate accountability circuits, while simultaneously

attending to their own work needs. In other words, by virtue of participating in these accountability circuits, front-line workers accept their participation as inevitable. Belanger and Edwards (2013) also suggested that workers are able to harness power that allows them the ability to negotiate the relationships and forces coordinating work in order to produce particular outcomes. I argue that whereas habilitation technicians have accepted their participation in accountability circuits as inevitable, they do not possess the necessary power or professional leverage required to accrue sustainable benefits to themselves or the residents through their participation in these circuits. Although habilitation technicians are able to create experiences that are not prescribed as part of the residents' IPP, their efforts to make these experiences an institutional practice has not yet been realized. Doing "moral work" as a means to bring normalcy and enhance quality of institutionalized living has not been recognized as a sufficient measure of habilitation in the governing of ICFs/IID.

Skorupski (2010) argued people make personal commitments to others based on a moral assessment of their actions. This assessment is reinforced by their own personal and social experiences, which then become embodied. Skorupski also argued that these commitments are inextricably tied to self-governance in that an individual's acts of self-governance must also reflect those commitments. They must "assess whether they have sufficient reason to believe, or feel, or act—or whether they must investigate further before they have sufficient reason...to act [based on] their conclusions" (p. 159). The ability to act on those conclusions is influenced by a person's capacity to be self-determined. The analyses presented in this paper challenge the idea that habilitation technicians, and others who engage in front-line work, have the power to act on their own conclusions. The extent to which habilitation technicians are able to fulfill their commitment to enhancing residents' quality of life is limited by procedures and checklists

framed within the structural complexity of federal and state legislation (Smith, 2005).

Habilitation technicians' work is systematically aligned to a regime that deems institutional life to consist of prevention, treatment, and habilitation, rather than building a sense of community and belonging through meaningful relationships and experiences. However, the institution is a dynamic system. It creates and recreates opportunities or marginalization through policies and the social encounters of its people (Bjerregaard & Jonasson, 2014). These are qualities that cannot be written into policy or driven by administrative abstractions. They have to be instituted with sincere engagement with individuals with ID (Johnson, Walmsley, & Wolfe, 2010).

Habilitation technicians' alignment to these institutional regimes impacts their ability to significantly influence a legislative system that has not yet recognized the range of experiences that constitute quality life for institutionalized individuals with ID. Arguably, moral obligations and self-governance appear to be incompatible with accountability circuits because circuits require habilitation technicians to compartmentalize their morality/moral obligations, which is essentially dehumanizing for them, and indirectly dehumanizing for the residents. Habilitation technicians harness passion to provide the utmost care for the residents but none of the power, which makes them feel unvalued. As noted during their discussion on the perceived value of their position within the organization, their lack of participation in decision-making for direct care and the habilitation of residents not only undermines their moral obligation, it can contribute to job dissatisfaction (Gray & Muramatsu, 2013). This calls attention to the need for advocacy support in direct care and other front-line work (Brolan, et al., 2012). I argue that this goes beyond support but also valuing habilitation technicians as knowledgeable contributors. In many ways, habilitation technicians serve as the voice of the residents. Their exclusion from care planning ultimately affects how habilitation is prioritized and care implemented. Honoring

habilitation technicians as integral, self-governing members of the care team brings to the fore and systematically aligns an institution's moral obligation to prioritize the quality of life of residents with ID to accountability circuits.

6.6 Conclusion

In this paper, I have argued that habilitation technicians who perform front-line work in an ICF/IID must enact and negotiate various accountability circuits. These accountability circuits are products of a complex hierarchy of national and state legislative texts that outline standards of operation and care for institutionalized adults with ID. The net effect of this alignment negatively impacted habilitation technicians' ability to exercise self-governance and fulfill their moral obligations to residents to ensure an improved quality of life. This paper also highlights the need to recognize and acknowledge how habilitation technicians are situated within these circuits, not because they demonstrate valuing people as people as novel; instead, they personify the move away from applying abstract ideas of what enhances quality of life to committing to understanding the nuances of engaging with individuals with ID. Findings from this study also have implications for management and implementation of direct care services in other settings with institutional qualities, and underscores the importance of moral obligation and self-governance to front-line work.

CHAPTER 7: DISCUSSIONS, IMPLICATIONS, AND CONCLUSION

7. 1 Overview of the Study

Individuals with intellectual disabilities (ID) have a long history of enduring grave injustices within and outside of institutionalized settings. From maltreatment in hospitals for individuals with mental illness and unlawful sterilization, to difficulty in accessing post-secondary educational services and community transition, individuals with ID continue to face barriers to access and participation in meaningful activities (Mahoney, Roberts, Bryze, & Parker Kent, 2016; Wehmeyer, 2013). Although placement of individuals from state-run and private institutional settings for 16 or more people has fallen over time (National Council on Disability, 2012), 5.7% of individuals with disabilities continue to live in institutions or are housed in facilities with institutional qualities (e.g., nursing homes, hospital facilities, correctional and juvenile institutions) (Americans with Disabilities Act Participatory Action Research Consortium, n.d.). Specifically, 29, 576 individuals with ID continue to live in state-operated institutions for individuals with ID (Braddock, et al., 2015). This shifting in institutionalization calls attention to the impact of policies designed with inconsistent and contradictory values influenced by the concurrent adoption of constructions of disability that depict individuals with ID as requiring custodial, regimented, and rehabilitative care, which are used as justification for institutionalization (Barken, 2013; Channon, 2014); therefore, it is important to have a deeper understanding of the functioning and nuances of contemporary institutionalization, and how opportunities to choose and participate in meaningful occupation for adults with ID are situated within and influenced by these systems and constructions of disability.

The purpose of this dissertation was to examine how national and state-mandated health facility regulations coordinated the daily activities of residents and staff in one Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). More specifically, this study sought to identify which types of activities occur in an ICF/IID, how choice and participation in meaningful daily life activities emerge through and are mediated by these regulations, and how these regulatory texts organize the operational structure and coordinate habilitation training and personal care by staff members. Critical social constructionism (Allen, 2005), the transactional perspective on occupation (Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry, 2006), occupational justice (Durocher, Gibson, & Rappolt, 2013; Stadnyk, Townsend, & Wilcock, 2010; Whiteford, 2000) and occupational possibilities (Rudman, 2010) informed this study by providing a theoretical perspective; however, institutional ethnography (Smith, 1987, 1990, 2005, 2006) was utilized as the primary guiding social theory and methodology as it draws the researcher to discover and examine the problematic or puzzles through which to better understand a particular phenomenon.

By applying institutional ethnographic methods, I was able to identify and describe how the historical constructions of ID infiltrate the policies and regulations governing ICFs/IID, and their effects on residents' choice-making in everyday mundane tasks and habilitation technicians' ability to perform meaningful work in a system designed to keep their work routine and aligned to institutional objectives. Together, these findings were developed into three manuscripts (Chapters 4, 5, and 6) and answered the research question: how do the daily operations and institutional structures of a residential facility organize what the adults with ID who reside there do? The next section integrates these manuscripts and discusses how they relate to and challenge existing literature. Specifically, I illustrate that the three papers are

consistent with the current dialogue on the disadvantages encountered by adults with profound ID, and the necessity to recognize the unique needs of individuals in institutional settings through effective implementation of person-centered habilitation plans. I also show how the three papers explore the tensions or double-consciousness habilitation technicians must negotiate within institutional complexes. Additionally, I discuss how this dissertation, in and of itself, brings forth a discussion not consistent with the dominant literature related to ID and transition as there are adults who reside in ICFs/IID who will spend their later years of life institutionalized and not in mainstream communities.

7.2 Integrated Discussion

The core chapters of this dissertation described and analyzed the systematic processes and embodied practices that define the specific operations of ICFs/IID, the opportunities for adults with profound ID to exercise self-determined choice-making even for the most mundane activities, and staff's ability to negotiate systems in order to enhance the quality of life of those for whom they provide care. Specifically, Manuscript I (Chapter 4) emphasized that the institutional systems through which staff work was coordinated created a systematic regulation of access to and participation in meaningful activities. The policies and procedures governing the operations and habilitative programming in ICFs/IID placed greater value on routinization and efficiency over self-determined participation. These findings not only highlight the lack of opportunities for adults with profound ID and staff to incorporate activities of their choosing, they call attention to the ways institutional routinization is a perpetuation of the historical notions of what adults with ID should do.

Manuscript II (Chapter 5) moved the discussion of textual-coordination (Smith, 2005, 2006) from the agency level to its impact on choice for the residents and its implication on basic

human rights. Michel Foucault's (1972,1984) problematization offered a theoretical lens through which to better apprehend how understandings of behavior and meal plans that are passed down over time become embodied restrictive institutional practices. Using examples from the data of meal and snack negotiations between staff and residents, the paper emphasized staff's infantilization and misrepresentations of residents' choices as manipulation. The data also suggested that past experiences with residents and historical meal plans color how they acknowledge and interpret residents' choices. This paper also called attention to the textually mediated ways barriers to adults with ID living life according to their own preferences become perpetuated.

Manuscript III (Chapter 6) completed the narrative triad by unpacking the ways institutional systems and processes generate challenges for staff in advocating for and doing "moral work" with adults with profound ID. Specifically, this paper revealed that staff's inevitable alignment to institutional processes reflected that text-based accountability superseded their moral obligation to adults with profound ID. As participants in these circuits of accountability, they perpetuated limitations to their own self-governance. Findings presented in this paper have implications for management and implementation of direct care services and underscore the importance of aligning moral obligation and self-governance to front-line work.

Together, these manuscripts demonstrate that institutional living for adults with ID remains problematic, and the ability to institute sustainable changes to policies and practices to enhance the quality of life is increasingly textual and discursive. These chapters narrate how the historical understanding and depictions of ID established a need for legislative oversight in order to prevent the level of abuse and exploitation institutionalized individuals experienced in years prior to deinstitutionalization. The resulting regulatory frameworks for ICFs/IID, instead of

creating a system that supports the unique needs and interests of adults with ID, produced institutional practices that generalized and routinized care. Consequently, these institutional practices restricted self-determined decision-making and the implementation of care that accounted for residents' personal preferences. Likewise, habilitation technicians' inevitable alignment to these institutional practices created an environment that caused them to perpetuate these old regimes and limited their ability to do work that was most meaningful to them and the residents. In other words, the adults with ID and the staff who provide daily care for them endeavor to thrive in a system that continues to place more value on routinized custodial care than on health and quality of life.

The narrative triad presented in this dissertation is also consistent with other arguments that adults with ID continue to be at risk for occupational deprivation and social exclusion, as well as educational, vocational, and economic marginalization (Johnson, Walmsley, & Wolfe, 2010; Mahoney, et al., 2016; Wehmeyer, 2013). This triad is also consistent with the notion that quality habilitative training is critical for adults with ID to develop skills necessary for participation in residential facilities as well as in the community, and that improving the quality of this training and inclusion into mainstream society should be prioritized. Equally important, this dissertation adds to the person-centered, individualized-care planning debate. Although person-centered planning, which is championed as the ideal method to determine the unique needs and proper supports for individuals with ID, is utilized in ICF/IID, the plans are created by professionals who do not perform front-line work. The application of abstract ideas about what individuals with ID should or should not do has translated to care that is restrictive, regimented, and lacking meaning. Legislative and regulatory frameworks are in place to support individualized care that address choice-making in meaningful activities that are not regimented

or restrictive; however, this dissertation underscored that efforts to include all personnel who care for adults with ID as essential to creating true person-centered planning (Hopp, 2014) may not be fully realized.

Findings also indicated that habilitation technicians are uniquely positioned members of the institution in that they are the primary executors of care and are often the closest thing to family residents encounter. This means habilitation technicians often have to negotiate between two groups who at times have opposing demands. This is evident in Chapters 5 and 6, where we see two versions of habilitation technician work. In Chapter 5, habilitation technicians personify the embodied restrictive practices institutions have historically enforced on individuals with ID. They limited residents' choice-making during meal and snack times as a result of adopting and implementing plans of care and ideals that are informed by historical notions of what people with ID should and should not be able to do, and did not honor residents as self-determined adults with interests and preferences. Yet in chapter 6, we see habilitation technicians as family – the advocates, the paternal protectors, and the defenders of the residents.

Habilitation technicians demonstrated that they also value the residents as family and see their primary role as bringing normalcy and meaning to their lives by going above and beyond to create meaningful experiences that were not “normal” to the institution. The habilitation technicians' behaviors are indicative of the tensions they must negotiate in order to fulfill their duties as employees of the center, as well as advocate on behalf of the residents. As employees, they are under the control of the institution; however, as front-line workers in Hope House, they are able to exert control over the residents. This bargaining of consciousness confirms that control texts can have over the ways people perform work as well as interact with each other. Although habilitation technicians have to negotiate these demands, one of the most salient

revelations about their perceptions of work was the emphasis on advocacy. Advocacy, as a tool to marry moral obligation with institutional accountability, not only allowed the habilitation technicians to challenge the duties and responsibilities imposed on them by institutional policies, it called attention to importance of aligning moral obligation, and maybe justice, to the care of individuals with ID. By attending to their moral obligations to residents, habilitation technicians prioritized enhancing their quality of life in their work responsibilities.

7.3 Conceptual Implications for Occupational Science

The utilization of institutional ethnography (Smith, 1987, 2005; DeVault, 2006) as theory and methodology has many implications for occupational science. Most salient is that it views the everyday world as a matrix of experiences that are organized by relations bound by larger processes, as well as by locally organized practices (Campbell & Gregor, 2004; Griffith & Smith, 2014; Smith, 1987, 1990), and that the control of human action is becoming increasingly discursive and textual (Smith 2005). This theoretical stance in institutional ethnography is complementary to the transactional perspective (Cutchin & Dickie, 2012; Dickie, Cutchin, & Humphry, 2006), governmentality (Rudman, 2012, 2013), and occupational justice (Nilsson & Townsend, 2010; Stadnyk, Townsend, & Wilcock, 2010; Whiteford, 2000). It is also useful in deepening the discipline's conceptualization of occupation.

7.3.1 The Transactional Perspective

A transactional perspective on occupation posits that individuals are co-constituted and co-defined with their environment, and that occupations offer a means through which individuals become functionally coordinated with their indeterminate or unstable environment (Dickie, Cutchin, & Humphry, 2006; Cutchin & Dickie, 2012). In other words, individuals' experiences of the environment are constituted by their interrelationship with it and occupation is used to

understand how human action emerges in that relationship. This perspective is holistic in that it unpacks the richness and complexity of occupation – deepening the discipline’s understanding that the act of doing (occupation), individually and collectively, is influenced by an amalgam of the physical, social, cultural, temporal, political, economic, and historical ideals. Institutional ethnography complements the transaction perspective on occupation in that its theoretical approach includes the historical, socio-cultural, socio-political, and temporal aspects to understanding contexts through which human action unfolds. In its concept of the problematic, institutional ethnography also seeks to discover and understand the uncertain and unacknowledged work or “action” that is occurring within a dynamic world.

Institutional ethnography is also complementary to the notion that the individual as the unit of study is necessary to understanding these processes but insufficient (Dickie, Cutchin, & Humphry, 2006). This dissertation serves as an exemplar that institutional ethnography can be utilized to examine phenomena that occur with groups or populations. Additionally, institutional ethnography also recognizes that past experiences can infiltrate and shape the expectations and constructions of present action, as well as connects possibilities of future action; however, it adds that these constructions of action are also tied to institutions and discourses of power. This tenet of institutional ethnography complements the understanding of action that is inherent in governmentality studies (Rudman, 2013).

7.3.2 Governmentality Studies

Rudman (2013) stated, “...governmentality studies provide a way to consider how such perceptions are shaped through technologies of government which enact power in accord with broader systems of thought regarding how best to govern populations and individuals” (pp. 52-53). In other words, governmentality consists of the ways various institutions – such as national and state health care system (public and private) in this dissertation – shape the conduct of

individuals by prescribing specific ways of doing or being in everyday life. The practices of governmentality also include the shaping of discourses that influence how people construct reality, themselves, and the needs of groups they serve (e.g. the habilitation technicians and adults with ID), in ways that align with the interests of those authorities (Rudman, 2013).

Institutional ethnography is complementary to governmentality studies in that it considers how power and ruling relations are infiltrated and perpetuated textually. These ruling relations come to be seen as “true” as they are linked to sources of power that construct and circulate particular discourses and texts that serve to align people to particular objectives.

Institutional ethnography is also complementary in that it emphasizes that perceptions of reality are shaped over time and that these perceptions are in flux – they serve a purpose in a specific socio-historical context (Rudman & Molke, 2009). Both governmentality and institutional ethnography assert that as ruling relations change, perceptions of reality change. Whereas governmentality and institutional ethnography attend to the ways power and discourse are perpetuated through texts, institutional ethnography makes visible and problematizes work that is hidden or unacknowledged within discourses.

7.3.3 Occupational Justice

Scholars in occupational science and occupational therapy offered occupational justice as a model to critique of access and participation in occupation because they believed social justice did not adequately address the right to participation in daily life activities (Stadnyk, Townsend, and Wilcock, 2010). Social justice addresses the issues of equal worth of all citizens, rights, and opportunities; occupational justice theorists suggest that occupational justice moves beyond the equity of individuals and groups and addresses the rights to occupation (Durocher, Gibson, & Rappolt, 2013). A theory of social justice encompasses rights to and opportunities for engaging in daily life activities (occupation). It acknowledges the social and structural barriers to equality

for all individuals and can result in the following injustices: alienation, apartheid, imbalance, marginalization, and deprivation. Institutional ethnography adds to the evolving theory of occupational justice as it allows the researcher to make visible to complexes through which phenomena (e.g., barriers to accessing occupation) emerge. It provides the political leverage linking what people are able to do or not able to do back to material texts and technologies. This dissertation offers empirical evidence to demonstrate how institutional ethnography addresses issues of power with systematic and social practices, opportunities and possibilities for engagement in daily life activities from a critical perspective informed by theory originating outside of occupational science.

7.3.4 Reflections on Occupation

Findings from this dissertation have challenged my conceptualizations of occupation and participation. In particular, it challenged the idea of occupation being defined in the lexicon of the culture (Yerxa, et al, 1990); that is, the dominant beliefs, customs, and values in society that determine what is or what is not considered occupation, when occupations are performed, spaces occupations occur, who participates, tools used, and their duration. Occupational science has been critiqued for its Judeo-Christian, able-bodied, Anglo, middle-class, female perspective, which has served as the dominant purview of the discipline (Hammell, 2009; Hocking, 2012). Additionally, this dissertation critiqued pluralism in the discipline by arguing that the standpoints of those who are unable to provide phenomenological perspectives or those who may not perform occupation in conventional ways (i.e., institutionalized adults with ID) have not been taken up in occupational science discourse. Taking up the standpoint of institutionalized adults with ID who are not able to exert control over their lives is perhaps the best example of a commitment to pluralism. While few scholars in occupational science have taken up the occupational concerns of nonverbal individuals (see Spitzer, 2003), relatively little attention has

been paid to understanding the occupations of institutionalized individuals with ID.

The concept of work in institutional ethnography (Smith, 1987, 2005) is also complementary to occupation in that it constitutes the paid and unpaid everyday activities that people perform. Much like the discipline's focus on understanding the micro, meso, and macro level influences on occupation (Rudman & Molke, 2009), the concept of work also has utility across multiple contexts and for making connections between those contexts through an examination of texts. This adds to the discipline's conceptualization of occupation as trans-contextual and orients occupational scientists to critically evaluate how occupations emerge across contexts in textually mediated ways. In essence, institutional ethnography bridges important concepts from the transactional perspective and governmentality in its ability to critically evaluate how situations come to be, and thus, aligns to the discipline's current focus on critically situating occupation as embodied action (Aldrich & Cutchin, 2012; Farias & Rudman, 2016).

7.4 Implications for Future Research in Intellectual Disabilities

Findings presented in this dissertation indicate the need for ongoing research in ID in relation to institutionalized persons. The following sections describe the implications for expanding the conceptualizations of choice-making and its impact on human rights and how policy influences the care implemented in institutional settings.

7.4.1 Choice: A Way Forward with Human Rights?

Article 12 in the Convention on the Rights of People with Disabilities states that it is mandatory to "recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life," and stresses the importance that access to the necessary supports be provided to ensure all persons can exercise their legal capacity (United Nations, 2006). This

international treaty was adopted by the United States in 2009 and utilized to make recommendations for national legislation, regulations at the local level, and models of practice that ensure equality, inclusion, and justice for all people with disabilities (National Council on Disability, n.d.). Although Article 12 explains that protections for the right to choose are essential, it neither provides specific guidelines for achieving this nor offers solutions to situations in which individuals are unable to make autonomous decisions (Werner, 2012). This lack of clarity has direct implications for legislators, disability advocates, service providers and direct care workers. Findings presented in this dissertation affirm that choice-making for institutionalized adults with ID remains an issue. There is a need for ongoing research that provides evidence for the reconstruction of institutions and institutional practices to enhance choice-making. Likewise, findings indicate the need for training in supported decision-making modeling with all personnel in ICFs/IID.

7.4.2 Texts, Policy, and Front-line Work

For more than two decades, advocacy groups have focused on the closing of state-run institutions (Braddock, et al., 2015; Charlton, 1989; Hopp, 2014; Nielsen, 2012). Although research in ID has consistently affirmed that community-placement is the “best fit” to ensure individuals with ID are provided with the best supports and care, and opportunities to participate as valued members of mainstream communities, it is important to acknowledge that a substantial number of people with intellectual disabilities and developmental disabilities (I/DD) continue to live in institutional settings. This includes 26,695 in large (more than 16 residents) non-state DD facilities and 29,608 in nursing homes (National Council on Disability, 2012). This dissertation indicates the need for ongoing research to examine the conflicting beliefs about the necessity for large institutions such as ICFs/IID, as well as the community-based congregate facilities that adopt – or appear to adopt – institutional models (Barken, 2013). Findings from this dissertation

also indicate the need for ongoing examination of policies and practices in ICFs/IID and ways to fundamentally shift their current practices toward a model that values and embodies interests and supported decision-making of residents and honors the self-governance and autonomy of front-line workers.

7.5 Contributions to Occupational Therapy Practice

Although there has been debate on the utility of occupational science research in occupational therapy practice (Clark, et al., 1991; Hocking & Wright-St. Clair, 2011), this dissertation highlights an important implication for occupational therapy practice: institutionalized adults with ID have significant occupational needs. Occupational therapists are well suited to address and advocate for access to and facilitate meaningful participation in occupations that enhance health and quality of life of adults with intellectual disabilities; however, there are observable deficiencies in the occupational therapy knowledgebase as it pertains to practice and research with institutionalized adults with ID. This dissertation demonstrates that research that deepens the understanding and strengthens the theorization and conceptualization of how selection of and participation in daily life activities can also expand how frames of references are applied in occupational therapy practice.

Occupational science research can also provide the theoretical foundation to address justice and human rights within practice (Hocking & Wright-St.Clair, 2011). Hocking and colleagues (2015) suggested documenting human rights concerns into patient records to make visible the social conditions impacting patients' health and participation, and to embed human rights into practice. Although I do not believe documenting human rights concerns is feasible in practice, I appreciate the implications of leveraging occupational therapists' accountability to insurance companies and other healthcare regulatory agencies to bring attention to issues of

justice. In addition to Hocking & Wright-St.Clair's recommendation, findings from this dissertation suggest the need to address issues of justice and rights in the policies regulating how health-related services are provided and received for all people.

7.6 Conclusion: The Big Picture

This dissertation represents progress toward enhanced knowledge on the impact regimes of knowledge and institutional processes have on participation in everyday activities. It also moves the fields of occupational science and intellectual disability to developing a deeper conceptualization of access and participation in meaningful activities for individuals with ID, and how barriers become textually perpetuated in institutional settings. Additionally, aspects of this knowledge can also be directly applied to occupational therapy practice; however, future research is warranted to expand upon this body of knowledge to contribute to the development of improved legislation governing habilitative programming and service delivery in institutional settings that include occupational therapy services, management of front-line work with individuals with ID, and care that enhances quality of life by supporting self-determined decision-making for individuals with even the greatest intellectual limitations.

This dissertation also moves forward the notion that institutionalized adults with ID are valuable contributors to ID research, and calls attention to need for diverse perspectives from various communities of individuals with significant disabilities. Probably the most important implication is the call to do “moral work” in research. This dissertation served as a reminder that as a researcher, I have a moral obligation to complete relevant work that brings to the fore issues that directly impact communities I serve. Although considerable progress has been made, there remain many hurdles to overcome to ensure basic human rights and opportunities to live “the good life” are protected for institutionalized adults with ID.

APPENDIX A: ANALYZED TEXTS

Texts	Description	Implementation
US DHHS & CMS	Conditions of Participation and Conditions of Coverage in Medicare and Medicaid programs; definition and classification of ID	Federal and state legislation; center policies and procedures
State DHHS	Facility environment and staff requirements; client safety; treatment/habilitation training criteria.	Federal and state legislation; center policies and procedures
State DHSR	ICF/IID program evaluation and surveyor guidelines	Federal and state legislation; center policies and procedures
Center General Policies and Procedures	Mission statement and objectives; facilities and maintenance guidelines; descriptions and operational guidelines for private and state-funded programs provided by the center.	Admin.; mid-level managers and directors
Center Personnel Policies and Procedures	Job descriptions and safety guidelines for therapeutic and personal care.	Admin.; mid-level managers and directors
Individualized Program Plan	Habilitative goals and objectives developed from comprehensive evaluations by care team members.	House managers; Habilitation Technicians
Hab. Tech. Acceptance Form	List indicating which staff members are assigned to residents each shift.	Habilitation Technicians
Body Check Form	Checklist indicating the state/condition in which residents are found at each shift change.	Habilitation Technicians
Communication Checklist	Record of opportunities and communication attempts made by residents.	Habilitation Technicians
Socialization and Leisure Checklist	Record of social and leisure activities performed by residents.	Habilitation Technicians
Electronic Medical Record	Record of vital signs, medication administration, nutrition plans, and bladder/bowel functions.	Nurse; Habilitation Technicians
Behavioral Management Form	Record of behavioral episodes requiring specialized intervention from staff.	Staff Psychologist; Habilitation Technicians
Shift Change and Acceptance Form	Guide for exchanging pertinent information regarding residents, housekeeping, and maintenance.	Habilitation Technicians

APPENDIX B: HOPE HOUSE MAP



APPENDIX C: INFORMED CONSENT

University of North Carolina at Chapel Hill Consent to Participate in a Research Study Adult Participants

Consent Form Version Date: February 23, 2015

IRB Study # 15-0434

Title of Study: Daily Life Participation in a Residential Facility for Adults with Intellectual Disabilities

Principal Investigator: Khalilah Johnson, MS, OTR/L

Principal Investigator Department: Allied Health

Principal Investigator Phone number: 678-617-6491

Principal Investigator Email Address: Khalilah_Johnson@med.unc.edu

Faculty Advisor: Nancy Bagatell, PhD, OTR/L

Faculty Advisor Contact Information: 919-843-4463

What are some general things you should know about research studies?

You or your ward is being asked to take part in a research study. To join the study is voluntary. You or your ward may refuse to join, or withdraw consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You or your ward may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you or your ward understand this information so that you or your ward can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to understand how residents and staff of a developmental center come to do what they do. The objects are to identify and describe the daily routines, the coordination of activities between residents and staff, and the opportunities for residents to choose and participate in meaningful activities. You or your ward are being asked to be in the study because you provide direct care to individuals with ID and are able to give an important and distinctive perspective on the daily life of residents with intellectual disabilities.

How many people will participate in this study?

15 participants (residents and staff) will be recruited for this study.

How long will your part in this study last?

The study will last up to four months (16 total weeks). It is anticipated that the study will begin in late April, 2015 and end by the end of October, 2015. More specifically, the investigator will be present in the unit with you or your ward for six hours, two to three days per week for the duration of the study.

What will happen if you take part in the study?

The investigator will use participant observation and interview methods for this study. The investigator will “hangout” with residents and staff three days per week for two six to eight week blocks. Each observation session will last up to six hours. The investigator will observe and participate in activities in the unit, dining rooms, classrooms, and community outings as appropriate. You or your ward will be asked to go about your usual routines and the investigator will not interfere in any way.

If you or your ward decide to participate you will be asked to discuss what it is you do at the center with the investigator. This will include informal conversations and formal interviews. Formal interviews will take 30 minutes to one hour, and will take place in a private location within the cottage. You may choose not to answer any question for any reason. If you or your ward is unable to verbally communicate, alternative communication will be utilized.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. The benefit of this research is that you or your ward will be helping us to understand the experiences of living in and working in a developmental center. This information should help us identify and describe the work the staff do in caring for residents with intellectual disabilities. However, you or your ward will not personally experience benefits from participating in this study. Others may benefit in the future from the information we find in this study.

What are the possible risks or discomforts involved from being in this study?

Some people may find it uncomfortable to be observed or to answer questions about their work. You or your ward may choose not to answer any questions or ask not to be observed. There may be uncommon or previously unknown risks. Any problems should be reported to the investigator.

What if we learn about new findings or information during the study?

You or your ward will be given any new information gained during the course of the study that might affect your or your ward’s willingness to continue your participation.

How will information about you be protected?

All data gathered for this study will be collected, encrypted, and stored in a way that protects your or your ward’s privacy and anonymity. The following procedures will be used:

- You or your ward will be assigned a pseudonym, and numbered codes will be created to de-identify all identifiers and other protected information.
- The key that matches pseudonyms to names and explains each code will be stored in a password protected file.

You or your ward will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your or your ward's information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

- All observation notes and audio recordings will be documented in a password protected file.
- At any time during the study, you or your ward may request that an audio recording be turned off.
- Each file will be maintained in a password protected external drive and stored in a digital combination locked box.
- Observation notes and audio recordings will be kept for five years after the study has ended. After five years, the key to the codes, all notes and recordings will be destroyed.
- Only the investigators listed on this form will be permitted to access the files.

Check the line that best matches your choice:

_____ OK to record me or my ward during the study

_____ Not OK to record me or my ward during the study

What if you want to stop before your part in the study is complete?

You or your ward can withdraw from this study at any time, without penalty. The investigator also has the right to stop your or your ward's participation at any time. This could be because you or your ward is unable to fully participate, or have failed to follow instructions, or because the entire study has been stopped.

Will you receive anything for being in this study?

Incentives to participate are not offered for this study.

Will it cost you anything to be in this study?

It will not cost you or your ward anything to be in this study.

What if you have questions about this study?

You or your ward has the right to ask, and have answered, any questions about this research. If you or your ward has questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your or your ward's rights and welfare. If you have questions or concerns about your or your ward's rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Date

Printed Name of Research Participant

Signature of Legally Authorized Representative

Date

Printed Name of Legally Authorized Representative

Signature of Research Team Member Obtaining Consent

Date

Printed Name of Research Team Member Obtaining Consent

APPENDIX D: HIPAA AUTHORIZATION FORM

University of North Carolina at Chapel Hill

HIPAA Authorization for Use and Disclosure of Health Information for Research Purposes

IRB Study # 15-0434

Title of Study: Daily Life Participation in a Residential Facility for Adults with Intellectual Disabilities

Principal Investigator: Khalilah Johnson

Mailing Address for UNC-Chapel Hill Department: CB: 7122

This is a permission called a “HIPAA authorization.” It is required by the “Health Insurance Portability and Accountability Act of 1996” (known as “HIPAA”) in order for us to get information from your medical records or health insurance records to use in this research study.

1. If you sign this HIPAA authorization form, you are giving your permission for the following people or groups to give the researchers certain information about your ward (described below):

Any health care providers or health care professionals that have provided health services, treatment, or payment for you such as physicians, clinics, hospitals, diagnostics centers, laboratories, treatment or surgical centers, including but not limited to the UNC Health Care System, health insurance plans, and government health agencies.

2. If you sign this form, this is the health information about your ward that the people or groups listed in #1 may give to the researchers to use in this research study:

Any information in your ward’s medical records that relates to participation in this research. These records might include information about medical diagnoses, mental health, communicable diseases, or genetic testing. Other information includes: personal history, physical examination reports, therapeutic interventions such as behavioral intervention plans, consultation reports, and habilitative programming goals.

3. The HIPAA protections that apply to your ward’s medical records will not apply to their information when it is in the research study records. Your ward’s information in the research study records may also be shared with, used by or seen by collaborating researchers, the sponsor of the research study, the sponsor’s representatives, and certain employees of the university or government agencies (like the FDA) if needed to oversee the research study. HIPAA rules do not usually apply to those people or groups. If any of these people or groups reviews your

ward's research record, they may also need to review portions of your ward's original medical record relevant to the situation. The informed consent document describes the procedures in this research study that will be used to protect your ward's personal information. You can also ask the researchers any questions about what they will do with your personal information and how they will protect your personal information in this research study.

4. If this research study creates medical information about your ward that will go into their medical record, you or your ward may not be able to see the research study information in your ward's medical record until the entire research study is over.

5. If your ward wants to participate in this research study, you must sign this HIPAA authorization form to allow the people or groups listed in #1 on this form to give access to the information about your ward that is listed in #2. If you do not want to sign this HIPAA authorization form, your ward cannot participate in this research study. However, not signing the authorization form will not change your ward's right to treatment, payment, enrollment or eligibility for medical services outside of this research study.

6. This HIPAA authorization will not stop unless you stop it in writing.

OR

This HIPAA authorization will stop November 30, 2015.

7. You have the right to stop this HIPAA authorization at any time. You must do that in writing. You may give your written stop of this HIPAA authorization directly to Principal Investigator or researcher or you may mail it to the department mailing address listed at the top of this form, or you may give it to one of the researchers in this study and tell the researcher to send it to any person or group the researcher has given a copy of this HIPAA authorization. Stopping this HIPAA authorization will not stop information sharing that has already happened.

8. You will be given a copy of this signed HIPAA authorization.

Signature of Research Subject

Date

Print Name of Research Subject

For Personal Representative of the Research Participant (if applicable)

Print Name of Personal Representative: _____

Please explain your authority to act on behalf of this Research Subject:

I am giving this permission by signing this HIPAA Authorization on behalf of the Research Participant.

Signature of Personal Representative

Date

APPENDIX E: OBSERVATIONAL GUIDE

Specific responsibilities include:

- to observe participants as they engage in activities that would probably occur in much the same way if I was not present
- to engage to some extent in the activities taking place, in order to better understand the participants' perspective or so as not to call attention to myself
- to interact with participants socially outside of a controlled research environment, such as community outings
- to identify and develop relationships with key informants and stakeholders

<i>Categories</i>	<i>Components</i>	<i>To Note</i>
Appearance	Physical appearance, clothing, age, gender,	Anything that might indicate membership in groups or in sub-populations of interest to the study, such as profession, social status, socioeconomic class, religion, or ethnicity
Language and Interactions	Who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice	Gender, age, ethnicity, and profession of speakers; dynamics of interaction
Physical Behavior	What people do, who does what, who interacts with whom, who is not interacting	How people use their bodies and voices to communicate; what individuals' behaviors indicate about their feelings toward one another, their social rank, or their profession
Personal Space	How close people stand to one another; how close caregivers stand or sit to residents	What individuals' preferences concerning personal space suggest about their relationships
Physical Space	Sizes of rooms, distance to walk to desired destinations, physical layout of the observation site	What objects are found in rooms, social spaces, and the around the observation site. Are spaces conducive the activities performed in them?
Human Traffic	People who enter, leave, and spend time at the observation site	Where people enter and exit; how long they stay; who they are (ethnicity, age, gender); whether they are alone or accompanied; number of people
Notable Behaviors	Identification of people who receive a lot of attention from others	The characteristics of these individuals; what differentiates them from others; whether people consult them or they approach other people; whether they seem to be strangers or well known by others present

Adapted from: <https://assessment.trinity.duke.edu/documents/ParticipantObservationFieldGuide.pdf> and Spradley, J. (1980). *Participant Observation*.

APPENDIX F: INTERVIEW GUIDE (STAFF)

Daily Life Participation in a Residential Facility for Adults with Intellectual Disabilities Interview Guide

Opening Statement to Staff:

Hello, my name is Khalilah. I'm going to talk with you about your daily routines. For example, I will ask you to tell me about your job responsibilities and the tasks you perform during your shift. I will also ask you which tasks you enjoy and which tasks are challenging. I also want to know how you prioritize what you do. I am interested in hearing your thoughts and opinions about the supports you need, and how those needs may be met. There are no right or wrong answers. You can choose not to answer any question at any time. Do you have any questions about how your answers will be used? Do you have any other questions about what we are doing here?

Interview Questions for Direct Care and Ancillary Staff Members

Question Type	Questions asked and probes
Opening	Question: Tell me about yourself. Probe: Where are you from? How long have you lived here? Question: How long have you worked here? Have you always worked in your current role? Probe: Have you worked with adults with ID before?
Introductory	Question: What would you like to know about me and about my research? Probe: How do you feel about me being here? How do you feel about participating in research?
Transition	Question: Tell me about your responsibilities. What types of activities is your shift responsible for? Probe: Tell me more. What else do you do?
Key	Question: How do you prioritize what to do? How do you prioritize when to do it? Probe: Who makes those decisions? Question: Can you describe what you enjoy about your work? Are there any challenges to your work? Probe: What supports do you need?
Summary	Question: Based on what you have told me, it sounds like....Is that right? Probe: Tell me more.
Closing	Question: Is there anything else you would like to tell me? Probe: Tell me more.

APPENDIX G: INTERVIEW GUIDE (ADULTS WITH ID)

Daily Life Participation in a Residential Facility for Adults with Intellectual Disabilities Interview Guide

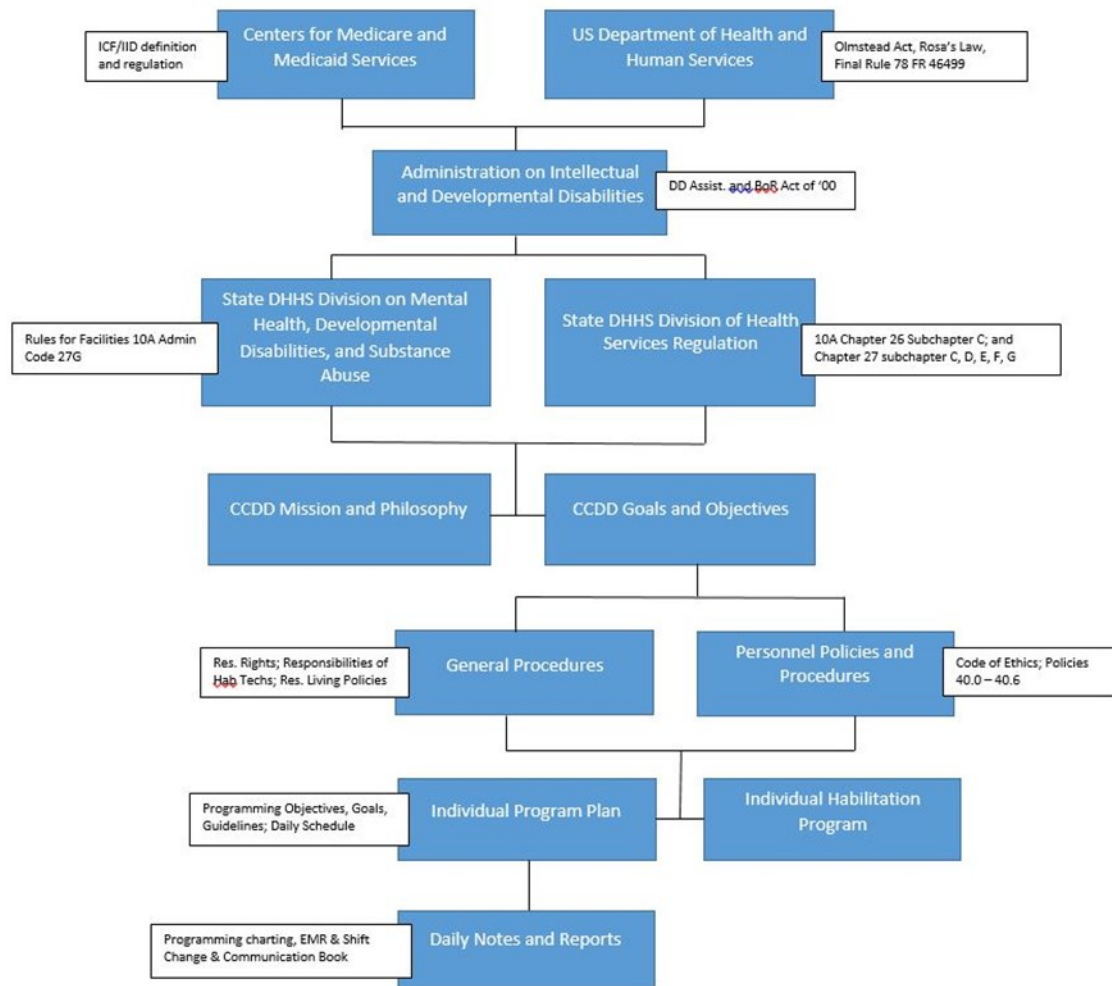
Opening Statement to Residents:

Hello, my name is Khalilah. I'm going to talk with you about your daily routines. For example, I will ask you to tell me about what happens in the morning or before bed time. I will also ask you which activities you like and which activities you do not like. I also want to know how you decide when and where to do them. I am interested in hearing your thoughts and opinions about the supports you need, and how those needs may be met. There are no right or wrong answers. You can choose not to answer any question at any time. Do you have any questions about how your answers will be used? Do you have any other questions about what we are doing here?

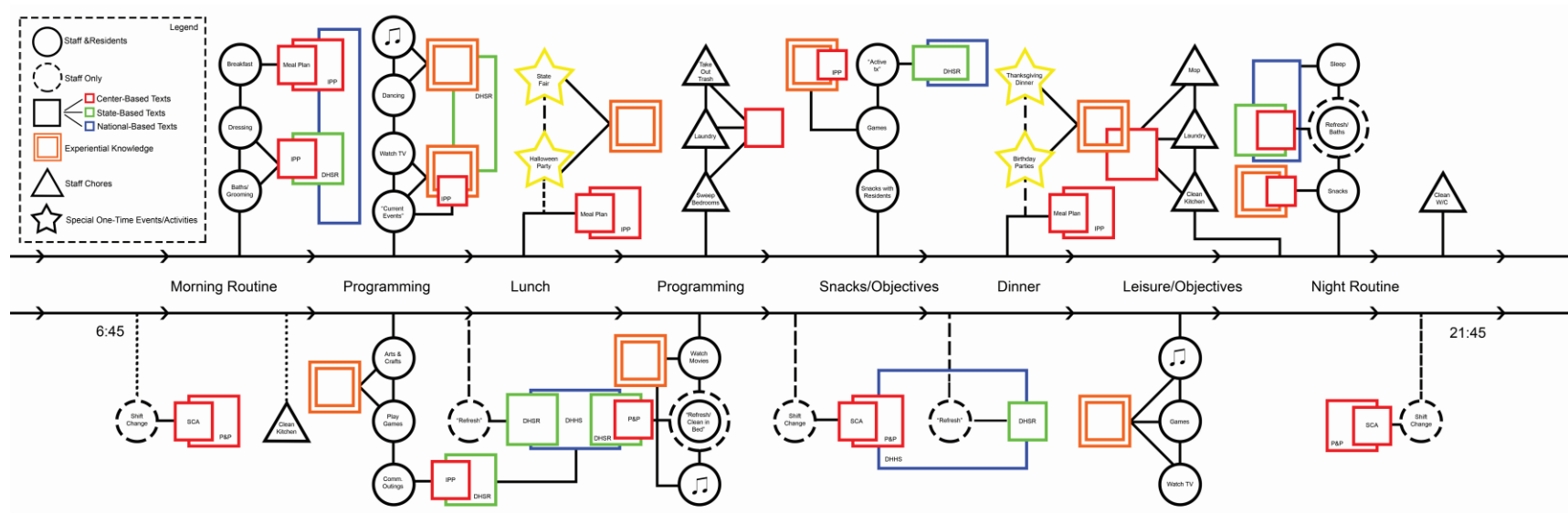
Interview Questions for Residents

Question Type	Questions asked and probes
Opening	Question: Tell me about yourself? Probe: How old are you? What do you like to do?
Introductory	Question: What would you like to know about me? Probe: Do you remember my last visit?
Transition	Question: Tell me about your day? What happens in the morning? Afternoon? Evening? Probe: What do you do after breakfast? Where do you do [named activity]? Question: Where do you go around campus? Probe: What do you do at the [named locations]?
Key	Question: What are some of your favorite things that you do during the day? Who do you do them with? Probe: Are you able to do the things you want to do? How come? How does that make you feel? Question: What are some of your least favorite things about your day? Probe: How come? How does that make you feel?
Summary	Question: Based on what you've told me, it sounds like.....Is that right? Probe: Tell me more.
Closing	Question: Is there anything else you'd like to tell me? Probe: Tell me more.

APPENDIX H: HIERARCHY OF TEXTS



APPENDIX I: CONCEPTUAL MAP



APPENDIX J: HOPE HOUSE DAILY SCHEDULE

Daily Schedule			
<i>Time</i>	<i>Monday – Friday</i>	<i>Saturday</i>	<i>Sunday</i>
5:30 am	Awake	Awake	Awake
7:00 am – 9:00 am	Morning Routine and Breakfast	Morning Routine and Breakfast	Morning Routine and Breakfast
9:00 am – 11:00 am	Day/Home Program	Outing	Outing
11:00 am – 12:00 pm	Lunch	Lunch	Lunch
12:00 pm – 3:00 pm	Rest/Private Time	Outing	Outing
3:00 pm – 5:00 pm	Snacks and Objectives	Snacks and Objectives	Snacks and Objectives
5:00 pm – 6:00 pm	Dinner	Dinner	Dinner
6:00 pm – 7:00 pm	Objectives and Leisure	Objectives and Leisure	Objectives and Leisure
7:00 pm – 9:00 pm	Snack and Baths	Snack and Baths	Snack and Baths

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