


May 2014

# "They're Our Bosses": Representations of Clients, Guardians, and Providers in Caregivers' Narratives

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“They’re Our Bosses”: Representations of Clients, Guardians, and Providers in Caregivers’ Narratives

by

Dina Vdovichenko

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Department of Sociology  
College of Arts & Sciences  
University of South Florida

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Date of Approval:  
March 4, 2014

Keywords: caregiving, characters, disability, narratives

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## ACKNOWLEDGMENTS

I would first like to thank my committee members for making this endeavor a reality. Dr. Green, you have been an immense source of support since day one. Your guidance as chair has proved invaluable. You believed in my research and helped turn my thoughts into a focused thesis. Most importantly, you believed in my efforts when my own faith faltered. Thank you immensely both for the academic and personal advising you gave. You truly are a remarkable caregiver. Dr. Loseke, you brought so much enthusiasm into this project – the conversations we had greatly nurtured the development of my study into a workable thesis. I also want to thank you for cracking the whip when it needed to be done. Dr. Mayberry, I am incredibly appreciative of the support and feedback you gave me during this process. You are an amazing cheerleader and for that, I am ineffably grateful.

I want to also thank two other significant individuals that have assisted me since the early stages of this project. Christina Partin, thank you for willing to discuss my concerns, aspirations and ideas with genuine interest and reflection. You've been an extraordinary source of emotional and academic support. Jeffrey Hilbert, I am deeply thankful for our interactions. You always provided so much encouragement. I am grateful to call you a friend. Finally, I would like to extend immense gratitude to my family and my West coast friends for their support and love throughout this process. I love you all very much.

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## ABSTRACT

The purpose of this study is to examine how various characters are portrayed within the self-narratives of women who are employed to care for adults with disabilities. This research looks at how these women's personal narratives construct characters-their clients (the individuals they provide services for), clients' guardians, and how these women portray themselves as caregivers. Interviews were conducted with eight women who provide paid care services to physically and/or cognitively impaired adults who receive services through the Florida Developmental Disabilities Home and Community Based Services Waiver Program. This program endorses specific expectations about the nature and purpose of caregiving. According to their stories, clients were perceived as diverse and in control; relationships with parents and legal guardians were described in terms of helpful and challenging qualities; and, "good" caregivers were perceived as maintaining client choice, and were expected to know their clients. Given the disparate narratives of care that exist in the Waiver, the work these study participants do requires careful balancing of often contradictory expectations. Their accounts indicate how at the ground level, these narratives of care become "muddled" as caregivers interact with clients and other significant individuals.

## **Chapter 1**

### **Introduction**

The purpose of this study is to examine how various characters are portrayed within the self-narratives of women who are employed to care for adults with disabilities. Caregiving is a multifaceted experience comprised of contested narratives regarding “proper” notions of care. Disability is similarly contested and the appropriate roles and responsibilities of people who provide care for individuals with impairments is a matter of considerable debate (Shakespeare 2006). Scholarly work typically has focused on experiences of women who provide paid child or elder care or unpaid care to family members with impairments. Less is known about the experiences of women who are paid to provide care to unrelated adults with physical and/or cognitive impairments. Grounding my work in a narrative framework, this project will examine the experiences of such paid caregivers. My research looks at how these women’s self-narratives construct three types of characters-their clients (the individuals for whom they provide services for), clients’ parents or legal guardians, and caregivers.

In order to examine these character depictions, I conducted open-ended in-depth interviews with eight women who provide paid care services to physically and/or cognitively impaired adults who receive services through the Florida Developmental Disabilities Home and Community Based Services Waiver Program (Medicaid Waiver for short). This program endorses specific expectations about the nature and purpose of caregiving. The purpose of the program is to protect the health and safety of individuals with disabilities while also maximizing their independence and respecting their freedom of choice. Hence, this program lies at the intersection of divergent narratives regarding the appropriate role of caregiving in the

lives of people with impairments- caregivers as “protectors” and caregivers as “supports for independent action.” These caregivers are all employed by agencies funded by the Medicaid Waiver. Thus, by exploring the narratives of caregivers, this research aims to add a new dimension to the divided discourses on caregiving and disability.

The current research is concerned with how women who are employed to care for individuals with cognitive and/or physical impairments make sense of their experiences. Before describing how I will use a narrative framework for this exploration, I will provide an overview of the literature on caregiving and narratives of care.

### ***Caregiving***

Both paid and unpaid caregiving can be conceptualized as a process that entails not only caring for bodies that necessitate washing, dressing and feeding, but also caring *about* an individual, providing attentive care that responds to the person’s needs (Parks 2010). In the United States, a majority of care provided to the elderly, disabled and ill is informal and unpaid, performed by family and friends (Nakano Glenn 2010). Furthermore, roughly 70 percent of informal caregivers are *women* (Duffy 2011, Lee and Singh 2010, Nakano Glenn 2010, Stacey 2011). *Paid* caregiving is similarly gendered, which is specifically relevant to and influenced by the current ‘care crisis’ that is transpiring in United States. This crisis pertains to the large and developing gap between the demand and supply in caregiving (Nakano Glenn 2010, Parks 2010, Duffy 2011). As the care crisis develops, there is a parallel increase of *women*, especially women from racial-ethnic minority groups, who become concentrated in *low-wage*, often-exploitative paid care jobs (Nakano Glen 2010, Duffy 2011, Stacey 2011). Thus, despite pay, care work is economically undervalued and still primarily performed by women, especially by minority women.

Literature depicting the lived experience of *paid* caregivers who work with young adults with impairments has not been adequately addressed and this current project is designed to help fill that gap. What we know about caregiving of individuals with impairments largely comes from studies on informal

family caregiving, and such research highlights the complex experience of caring for individuals with impairments. Considerable evidence demonstrates that over time, fulfilling numerous expectations of caregiving can become overwhelming (Nakano Glenn 2010). A study on informal caregiving of children with impairments found an association between long-term informal caregiving and various health consequences (Murphy et al. 2007). Lilley's (2001) research also suggested that some caregiving mothers began to view their children through the lens of diagnostic criteria, while Skinner, Bailey, Correa and Rodriguez (1999) found that others viewed their children's conditions as punishment from God. This is important to the current study as paid caregivers may also perceive care recipients through a medical or moral lens or in ways that are shaped by their own unique backgrounds.

However, a number of primary caregivers report a positive experience. Results from a survey study of 175 parents and other biological primary caregivers, indicated that a significant number of families displayed resilience and described becoming stronger as a result of having someone with impairment within the family (Bayat 2007). Furthermore, despite experiencing a "burden of care," a study examining the social experience of 81 mothers caring for children with disabilities showed that most mothers acknowledged valuable benefits of mothering and informally caring for a child with impairments (Green 2007). Other mothers offered counter-narratives to dismantle their child's identification from the diagnostic process and focused on individual strengths of their child (Jacobs, Lawlor and Mattingly 2010; Lilley 2011). Thus, informally caring for a child with impairment is multifaceted. Though the aforementioned studies pertain primarily to mothers of children with physical and/or cognitive impairments, it is important to gain a perspective of these experiences as they may parallel or diverge from the experiences of paid caregivers.

Literature on the experiences of *paid* caregivers tends to focus on child care workers or workers within the eldercare industry. Comparable to informal family caregiving, formal paid caregiving is also commonly accompanied by challenges (Cherlin 2010, Nakano Glenn 2010, Duffy 2011, Stacey 2011). Besides mental strain, providing paid care often occurred in depressing and potentially risky atmospheres



(Diamond 1992). Stacey's (2011) research on home care workers illustrated the experience as follows: "home care aids often work without health benefits...are subjected to unpredictable work hours, and can suffer injury providing hands-on care" (46). Furthermore, workers said that they were not adequately prepared to take on some job responsibilities. Research on day care workers also highlights the complex relationships that occur within caregiving. The workers expressed that pressure was placed on them from the mothers of the cared-for children (Loseke 1989). The ideal day care worker, according to the caregivers, was expected to not only be skilled in practical tasks but also in terms of emotional skills. The child care workers felt that mothers expected them to not solely care *for* the children, but also care *about* them.

Current literature confirms the challenges encountered by paid caregivers, but positive benefits were also experienced. Some paid caregivers express that they form close bonds with the individuals they assist (Rodriquez 2011, Stacey 2011). Other caregivers experienced rewarding intrinsic rewards by feeling useful and needed by their clients (Nakano Glenn 2010). Piercy (2001), provides a literature review on the value of close relationships between the elderly and their nonfamily caregivers and similarly points to studies (including her own), indicating that personal relationships in the form of friendship and fictive kin relations commonly form between older adults and their caregivers. Piercy also describes situations where the cared-for individuals' *family* started treating caregivers as friends and integrated them further into their lives (2001). While Piercy's work primarily focuses on relationships between older adults and their family's relationships with caregivers, the women who are the focus of this study also regularly have contact with their clients' family members. Therefore, Piercy's (2001) work is beneficial for the current research, since caregivers may also form relationships with their clients' family caregivers and other kin members. The body of existing literature on informal and formal caregiving illustrates the complex social relations among caregivers and the individuals with whom they have contact. Such complexity is important to acknowledge since the current study seeks to address how paid caregivers characterize their clients, and their clients' family and guardians.

Paid caregiving may become even *more* complex when caring for individuals with cognitive and/or physical impairments (Shakespeare 2006). “Proper care” of individuals with impairments is debated by three opposing narratives: the medical model of disability, the social model of disability, and the feminist ethic of care. A fourth narrative of care endorsing a complex approach to caregiving relationships will also be further discussed. Caregivers’ *self-narratives* provide both a multifaceted representation of caregiving regarding individuals with disabilities and unique insight into how the women employed by Medicaid Waiver-funded agencies make sense of their experiences and caregiving relationships.

### ***Narratives of Care***

According to Spector-Mersel (2010), a “narrative turn” has been transpiring in human sciences. Narrative is beneficial for research due to its ability to “represent a fundamental process of human understanding” (Kirkman 2002: 31). Narratives have been used by scholars to study “how individuals, institutions, and societies create meanings” (Skinner et al. 1999: 482). This present study is looking at caregivers’ personal narratives. In simplest terms, narratives involve a person telling a story (Skinner et al. 1999). Thus, a narrative

“...is an account of a sequence of events in the order in which they occurred to make a point...represents cause and effect relations through its sequencing of events rather than by appeal to standards of logic and proof...are the forms of discourse, vehicles of ideology, and elements of collective action frames, but unlike all three, they can be identified in a chunk of text or speech...” (Polletta et al. 2011: 111-112).

Personal narratives are not constructed in isolation from the social world. Although individuals have an extensive amount of freedom in writing their stories, “this freedom is limited by the contexts in which we tell them, by the ‘honorable’ stories prevailing in our society at a given time and by components of social structure such as age, gender, ethnicity, class, health, marital status, and economic situation” (Spector-Mersel 2010: 212). Therefore, within personal stories, there typically is interplay between the social, public happenings and individuals’ personal sentiments and thoughts regarding the event. The power of narration not only moves private thoughts and internal sensations “into language, but

also turns public events into personal reflections on one's experience in time and place" (Mattingly, Lawlor, and Jacobs-Huey 2002: 745). Narratives also allow for complexity among stories that share similar themes.

Furthermore, "narratives of identity...are produced at cultural, institutional, organizational, and individual levels of social life" (Loseke 2007: 662). Though this research is primarily concerned with personal narratives, caregivers' personal narratives may also be influenced by and reflect the institutional and organizational forces that exist. Loseke (2007) argues that "much could be learned by bringing an examination of these reflexive relationships into the forefront of analysis," an "integration that would lead to a better understanding of how narratives work and of the work narratives do" (662). In the sections that follow, I examine cultural, institutional and organizational narratives of disability and caregiving that may help shape personal narratives of the paid caregivers included in my study.

#### *Cultural Narratives of Disability and Caregiving*

Cultural narratives "describe types of people, and they prescribe particular social relationships among types of people" (Loseke 2007: 666-667). Cultural narratives are broadly circulating stories that are continually constructed, modified and challenged. Narratives that produce cultural identities have been termed "formula stories" (Berger 1997, Loseke 2007), master narratives (Mishler 1995) or schematas (D'Andrade 1995). Formula stories contain plots, characters and morals that are recognizable and predictable, which they obtain by "deploying symbolic and emotion codes in ways that reflect how audience members understand the world" (Loseke 2011: 253). Symbolic codes are systems of ideas about how the world does and should work, whereas emotion codes are systems of ideas regarding how, when, where, and toward whom which emotions should be inwardly or outwardly experienced or displayed (Loseke 2011). Culturally circulating stories of disability have changed over time as dominant narratives (or formula stories) encountered challenges from different perspectives.

The medical model approach dominated as the chief academic/political narrative (formula story) before the social model attained prominence (Priestley 2003, Shakespeare 2006). Also termed the “personal tragedy theory” or the “individual model,” this formula story regarded disability as existing in the individual and originating from individuals’ physical or cognitive impairment (Oliver 1990). This approach centered on the biological or psychological explanations of disability; emphasizing the consequences of individuals’ health-related situation, and largely ignoring the relationship between individuals and their social environment (Oliver 1990, Shakespeare 2006). Concerning care, this medical narrative asserted that the *physician* was the competent expert and individuals with impairments were expected to assume the “sick role,” which meant that individuals were expected to cooperate with medical practitioners and affirmed that illness could only be diagnosed and treated by experts (DeJong 2001). This narrative asserted that individuals with impairments must do everything possible to facilitate their recovery and to cooperate with physicians in that process. Consequently, this approach to care emphasized that individuals must seek out medical assistance from experts and to forgo their own wishes in favor of cooperating with medical staff-including relatively uneducated aides and personal care assistants.

This formula story was vehemently rejected by individuals involved in the disability movement, who argued that it infantilized people with disabilities and did not account for people with long-term impairments. This approach also failed to recognize that those with impairments did not always require diagnosis or treatment, and did not distinguish between acute and chronic illness. Chronic illness, by definition, excludes recovery (Varul 2010). The sick role did not account for long-term illness or disability and assumed that cooperation with medical staff would lead to full recovery. Primarily, however, the model did not account for the degree to which people with impairments are oppressed by existing social structure.

Rejections of the medical approach to disability led to an incipient disability movement that promoted a social model of disability. In the 1970s, the social model of disability emerged in Britain and

replaced the medical model (Shakespeare 2006). Academics and pioneering activists led the disability movement, which sought to replace segregation by establishing opportunities that enabled individuals with impairments to participate fully in society, live autonomously and have control over their lives. This narrative asserted that *society* disabled individuals with impairments by excluding them from significant areas of social life, including education, employment and political participation (Priestley 2003). This model also accounted for attitudinal barriers and stigma-“abominations of the body”-that were often imposed on those with impairments (Goffman 1963, Beckett 2006).

Through the efforts of disability activists and disability studies scholars, the social model of disability has joined the medical model of disability as a powerful cultural narrative of what disability is and how care should be provided to people with disabilities. Significant tensions between the two models should be noted: “good” caregiving, from the point of view of a medical model narrative, expects caregivers to act as “experts” of care. Caregivers come to view care recipients through the “medical lens” and aim to maintain the health and safety of the individuals. The control over how care is administered rests in the hands of the caregiver, and care recipients are perceived as *dependent* on care. Oftentimes, this approach to care has led users of care services to feel taken over, spoken for, undermined, and disempowered (Shakespeare 2006). Advocates of the social model narrative perceive such care as paternalistic. “Good” caregiving, based on the social model narrative, diverges from the medical model by promoting the notion that care recipients should have control over their care and lead self-directed lives- even if their choices involve risk-taking. Based on this narrative, caregivers act as *supports* for independent action and are directed by their care recipients in terms of *how* care is received. This narrative of care and its influence on institutions will be examined further in the following section.

### *Institutional Narratives of Disability and Caregiving*

The “new” formula story of the social model of disability has fed into new institutional narratives of disability and caregiving, which have powerful social functions. Institutional narratives work in the

policymaking process and are able to construct some types of people as “morally good and deserving of sympathy and help while other types of people are constructed as morally deficient” (Loseke 2007: 669). The social model of disability gave rise to a liberation movement termed Independent Living (IL), which further challenged dominant notions of disability and redefined adult independence in terms of *choice* and *control* rather than self-directed physical functioning (Priestley 2003). IL aimed for autonomy: the goal was to increase independence by being able to control how tasks were performed (De Jong 2001, Shakespeare 2006).

The IL movement, stemming from the social model formula story, became instituted in social service agencies by shifting the focus from individuals’ limitations to the service environment and how it could be a source of empowerment. This institutionalization and adoption of the social model-based formula story had very “real” consequences in terms of how caregiving social services became organized. Rather than relying on informal care, experts that “infantilized” individuals, or caregivers provided by organizations, people with impairments demanded direct payments (an IL service in the UK) that enabled them to employ their own care (personal assistants). Individuals were able to dictate who provided help and how that help was provided. For individuals with impairments, having the ability to choose how to live their lives and control over decision-making represented independence (Guess, Benson and Siegel-Causey 2008). This narrative of care also advocated for a depersonalized model of assistance, which stressed that care should be divided into practical tasks and emotional content to be rejected (Shakespeare 2006). Thus, individuals advocated for a depersonalized model of assistance and rejected “care,” stressing that they deserved personal assistance as of *right*, not care (which they perceived as dependent on kindness).

This shift of formula stories—from a medical approach to a social model “way of thinking”—has similarly become institutionalized into the Florida Medicaid Waiver, a program that funds the agencies that employ caregivers who are the focus of this research. Though the women are called Direct Service Providers by the Waiver Program, they have disparate caregiving “titles” (e.g. supported living coach,

companion, etc.). Thus, this study will refer to the respondents as “caregivers.” Recipients are defined as individuals who are eligible for Medicaid and this study will refer to the individuals as “clients,” based on the interviews conducted.

The Medicaid Waiver strives to offer services that enable individuals to live as autonomously as possible and upholds the principles of self-determination that enable recipients the freedom to exercise citizen rights, the control over authorized funds and self-advocacy. Section 1-14 of the *Developmental Disabilities Waiver Services Coverage and Limitations Handbook* states that “the waiver is designed around recipient choice,” who is “free to change....providers as desired” and can select the “most cost beneficial residential environment and combination of services...to accomplish the recipient’s goals.”

The Waiver employs a *person-centered approach* to caregiving, which Appendix A defines as “an approach, developed from the recipient’s perspective...used to provide the services and supports necessary to meet the recipient’s needs” (A-1). The purpose of the Medicaid Waiver is to “...foster the principles of self-determination as a foundation of services and supports...” (1-8). Thus, caregivers are currently providing their services at a time when individuals with impairments are backed by the social narratives of care, which have become institutionalized into organizations.

### *Organizational Narratives of Disability and Caregiving*

Organizational narratives are constructed by “organizers and workers in ongoing organizations, programs, and groups designed for people who evaluate themselves, or who have been evaluated by others, as having troubled identities in need of repair” (Loseke 2007). The Waiver emphasizes the need to foster independence and self-determination for individuals with disabilities via the delivery of long term support services. To qualify for the program, however, individuals must prove that these long term support services are medically necessary in order to protect health and safety.

The Medicaid Waiver’s purpose statement simultaneously asserts that the program strives to “maintain and restore the health of eligible recipients with developmental disabilities...” and “... to

minimize the effects of illness and disabilities through provision of needed supports and services in order to delay institutionalization” (1-8). This reflects the medical model approach, which focuses on the physical/cognitive impairments and emphasizes the need to preserve and reinstate individuals’ health. Though the Medicaid waiver upholds the care recipients’ freedom of choice and is aligned with the social narrative of care, there are *still* elements of the medical model that exist. Tensions between these distinct narratives may emerge as caregivers navigate these contrasting expectations of care. While they must value and uphold their clients’ autonomy and freedom of choice, caregivers must also provide attentive care to maintain the safety and health of individuals who have significant impairments.

Agencies providing long term support services that are funded by the Medicaid Waiver program must, therefore, develop policies, procedures and organizational narratives of proper care that stand at the crossroads of the medical and social model of disability- with very divergent views of what constitutes proper care.

From the medical model perspective, users of care are dependent on their caregivers-experts of care who must ensure the safety of their clients. From the social model perspective, however, control over care should rest in the hands of the clients. Here, caregivers act to liberate clients from paternalistic styles of care: as clients lead their caregivers through specific tasks, caregivers foster recipients’ independence and decision-making. These disparate narratives may also represent two extremes on the spectrum of care. On one end, caregivers represent powerful implementers of the medical system that encourages care recipients to act within the confines of the sick role. Individuals with impairments have resisted this medical approach to care in favor of more empowering forms of support. At the other extreme, caregivers may come to represent a servant class (Shakespeare 2006). IL, which is based on the social narrative of care, promotes the following: the separation of practical from emotional tasks, and caregiving that is controlled by recipients of care. From the social model extreme, caregiving relations may become distant and devoid of attachment, resulting in caregivers being dehumanized and treated as servants by their clients.



In addition to the medical and social model views of disability and caregiving, women who work for agencies that provide services funded by the Medicaid Waiver program may also be influenced by *cultural expectations* that are placed on women caregivers. Cultural notions concerning care work emphasize that *women* are expected to provide caregiving (whether it is paid or unpaid) since caring for the elderly, the ill, and children has commonly been associated with the nurturing characteristics of women (Martin 2000, England 2005). These dominant notions assert that women do care work “naturally,” and accomplish caregiving tasks selflessly and effortlessly (Malacrida 2009). These endemic gendered care expectations assume that women will take on caretaking responsibilities for minimal pay, and that they will care “about” the individuals they provide for, simply *because* they are women (Parks 2010). As mentioned in the caregiving literature, child care workers were expected to care *about* the children they looked after (Loseke 1989). Furthermore, caregivers providing for the elderly expressed that they formed close bonds with the folks they care for. Thus, based on cultural expectations of women’s care work, the paid caregivers who are the focus of this study may assume that they *should* care about their care recipients and reflect such sentiments, even though they are working in low paid positions.

Such cultural expectations present challenges to the social narrative of care, which resists depicting caregiving as dependent on care or kindness. Disability activists assert that caregiving is a fundamental human *right* and should not be predicated on goodwill or charity. Furthermore, as previously mentioned, supporters of the social narrative of care advocate for self-determination for individuals with impairments; caregivers should be assisting care recipients in maximizing their independence, *not* engaging in emotion-based, relationships. Therefore, according to the social narrative of care, caregiving relationships should not be confounded with emotional bonds.

Moreover, these cultural expectations may also leave both care workers and clients of care vulnerable to exploitation. Workers may feel pressure to work for low pay because they perceive caregiving to be what “good women” do. Clients may also feel pressured to be grateful for the care they

receive and express that gratitude in ways that could leave them vulnerable to exploitation by workers, which is a concern for the social model of care.

Shakespeare (2006) critiques the disparate models of care, and endorses a pluralistic approach. He emphasizes the importance of *combining* disparate notions of care in order to preserve a multifaceted perspective on caregiving. The current project seeks to contribute to this pluralistic approach by examining self-narratives of paid caregivers who work within a program that specifically contains elements of the medical and social model. Based on extant literature, caregivers' narratives may also reflect cultural expectations that are placed on paid caregivers – notions that caregivers must “care about” care recipients. Though these specific women are most likely unaware of these broader narratives of care, the institutional narratives that exist in the Medicaid Waiver are being enacted in real lives. The current research examines how caregivers' self-narratives construct a range of narrative characters including the clients they provide care services for, clients' parents and legal guardians, and caregivers. By looking at these self-narratives, we can observe how caregivers' descriptions of various characters reflect the cultural, institutional and organizational narratives. It is possible caregivers' personal narratives reflect the institutional and organizational narratives, since “socially circulating narratives offer a model for making sense of the self” (Loseke 2007).

## **Chapter 2**

### **Methods**

I used my contacts in the disability community, and a recruitment flyer to recruit caregivers paid through the Medicaid Developmental Disabilities Home and Community Based Services Waiver program. I found my recipients through natural contacts in the disability community and the Agency for People with Disabilities. Interested participants were asked to contact me. I was directed to other interviewees via snowball sampling. Interviewees were asked to give my contact information to other caregivers who might be interested in participating. After replying to the initial email from a potential respondent, I e-mailed my IRB-approved recruitment flyer, verbal script and interview guide a week prior to our interview. The site of the interviews was chosen by each individual respondent. Six interviews were conducted at the respondents' place of work. One interview was conducted at the person's home and one was completed over the phone. In total, eight in-depth interviews were conducted.

Because the topics examined in this research could be uncomfortable and might even pose a risk to the caregivers' employment status, I read a verbal script prior to the start of the interview that fully informed the respondents' of their rights, potential risks of participation, and my contact information. Verbal consent was obtained because signed consent forms would be the only document linking them to the study. At any time throughout the interview, the interviewees had the right to deny further progress. If a respondent chose to stop the interview, all previously recorded material would have been deleted. In order to preserve confidentiality, each respondent was assigned a pseudonym on the transcription. All individuals who were named during the interview (including care recipients and employment supervisors) were also be given pseudonyms.

### ***Overview of Respondents:***

My first respondent, Sharon, is a “Polish and German” 48 year old woman, who has been a caregiver for 12 years. She has been in a long-term heterosexual relationship. Sharon does not have kids. Teresa, who is a mix of “Greek, French, Irish, Welsh and a little bit of Indian,” is an engaged 23 year old woman with a three-year old son, who has been caregiving for three years. Her fiancé is also a caregiver. Gwen, an “average White girl,” is a 47 year old woman who worked at a dental specialty office for 15 years and owned her own orthodontic laboratory business for 12 years. Gwen has been involved in the disability community most of her life. She is married and has two kids. Laura, whose background is “Italian and French,” is a 65 year old semi-retired nurse and private duty caregiver, had three clients when she worked through the Medicaid Waivers Program. Laura is not married and has three adult children. Rose is a White, 26 year old woman who provides care to a woman she’s been best friends with since middle school. Rose does not have children. She has a boyfriend. Nina is a 63 year old White woman, who has been in the field for almost four decades. Nina is now a Chief Operating Officer at an agency funded through Medicaid Waiver. Emiliya, who works for Nina’s company, is a 36 year old Haitian woman who has been living in United States since she was 16. Emiliya has been working as a caregiver for a period of years, is married and “trying” to get pregnant. Allison, a White woman who has been in the field “most of [her] life,” is a 41 year old caregiver. Allison has three adult children. Like Nina, Allison supervises other caregivers who provide services through the Medicaid Waiver program. With her husband, Allison owns and manages a private company that is funded by the Medicaid Waiver. Allison supervises Sharon, Teresa, Gwen and Laura. It is important to mention the caregivers who are supervised by Nina and Allison because both women are in charge of maintaining the organizational narrative that is consistent with the institution narrative of the Medicaid Waiver program. Thus, the caregivers working under Nina and Allison may be taught to endorse a philosophy of caregiving that reflects the narrative of the program.

### *Interview Guide and Data Analysis*

Open-ended interviews allowed caregivers to wholly describe their experiences regarding caregiving in their own terms and at their own pace. I began each interview by asking the participant to tell me about themselves, their families and their demographic background. Then we talked about how the participant got started in caregiving, the aspects of caregiving they found most rewarding and unrewarding, and what they most liked and disliked about working for the Medicaid program. I also asked respondents about the caregiving relationships they participated in with their clients and clients' guardians. Finally, we talked about participants' "typical" work day. The interview guide is included in Appendix A. The interviews were audio-recorded and saved on a password protected computer stored in a locked office at the University of South Florida until they were transcribed. The shortest interview was 41 minutes and the longest interview spanned two hours and 20 minutes. The average interview lasted approximately 60 minutes. After transcriptions were completed, recordings were deleted so that participants' real names and voices will not lead to identification. In total, I have 150 pages of transcriptions.

My analysis was conducted during the fall semester while I was taking a graduate seminar course in narrative with Dr. Loseke. A narrative analysis was the best method for this type of study because I am most concerned with how caregivers make sense of their caregiving relationships and their roles and enabled me to retain relatively large texts of data, providing a more thorough depiction of caregivers' representations of characters.

I looked at cultural, institutional, organizational and personal narratives (Loseke 2007) to ground my work and begin my analysis. Guided by Loseke's (USF, unpublished) "Notes on Empirically Examining Narratives," I first established the social context of the data. This study concerns personal stories authored by women who provide paid care for individuals with physical and cognitive impairments. These women are employed by agencies that endorse a specific narrative of care; one that is

based on the institutional narrative of the Medicaid Waiver. These stories are told by workers who are trained by an agency that has adopted a narrative of care that is in line with the social model. Loseke (2007) emphasizes the reflexivity of these levels of narratives. Thus, caregivers' self-narratives may be influenced by their employing agency's philosophy and could reflect the larger institutional and organizational narratives.

It is also important to consider the researcher's positionality (Lofland et al. 2006). These stories were authored as a response to my open-ended questions. The respondents knew I was conducting this research for my Thesis project. I disclosed information about myself so the women were aware that I had some experience with disability. My mother has provided long-term care to my oldest sister, who has a significant cognitive impairment and I often also had to provide for my sibling. My personal experience in caregiving and disability may have aided my understanding of the type of work my participants do, and it is probable that this personal experience influenced my interaction with the respondents, the stories they narrated, and the data analysis that followed.

I read my data transcripts numerous times prior to categorizing to get a general impression of the data. As I read, I made notes on the transcripts of my cognitive and emotional impressions regarding the data. Once I began categorizing, I looked for "sentences or idea segments" containing references to how the interviewees' viewed themselves as caregivers and "to the idea segments referring to perceived relationships between the self and others" (Loseke, USF unpublished: 6). Since this project concerns character representations, I looked for commonalities between the types of narrative characters portrayed, characters' moral evaluations and the relationships among the characters. I combined segments of data into categories ("clients," "guardians," and "caregivers") and made note of themes within these categories. Consistent with Schultz's (1999) work on identity narratives, I tried to ensure that I did not "shy" away from the complexity existing in my data and organized categories of themes so that large excerpts of interview data were retained.

## Chapter 3

### Findings

Throughout the interviews, the women shared several common perceptions of their clients, clients' parents and legal guardians, and themselves. The stories depicted clients as diverse, and "in control." The self- narratives also constructed caregivers' relationships with parents and legal guardians as complex: both positive and challenging qualities that exist in these relationships were described. Lastly, the women provided a description of "the caregiver," which simultaneously led into a description of themselves as providers. First, caregivers' perceptions of their clients will be discussed, followed by caregivers' accounts of clients' parents and guardians. Finally, an analysis of caregivers' narratives concerning themselves will be provided.

#### *Clients*

Two themes emerged as caregivers spoke about their clients. According to the stories the women told, though some common client traits were assumed, caregivers did not have a fixed image of their clients. Furthermore, caregivers stressed that clients were in control of the day when caregivers were working with them and a majority expressed that they considered their clients to be in control of *them* and perceived their clients to be "the boss."

#### *Clients- Diversity within Commonality*

When I asked caregivers to tell me about their clients, the stories depicted clients as a diverse group of individuals, despite the common traits the individuals may share. The women countlessly reiterated that their clients were all considerably "different" and emphasized the distinctiveness of clients. For instance, when I asked what *types* of clients she worked with, Allison, who runs her own company

through the Med Waiver and therefore has contact with many more clients than most caregivers, provided the following description:

“I have 64 clients right now. They average, from the age of 18 to 60something. . . . Our clients, some of them are total care, where they live in the family home and need help while mom and dad’s go to work and doing their daily activities. We have clients that live in their own home, that are total care, from changing every hour and a half to feeding to bathing. . . . Clients that live on their own that might just need supported employment to help them attain a job. They might need supported living to go to the doctor’s appointments to understand their care. Help them pay their bills. We have personal care assistants that go in. It depends on the care that the client needs. We actually have some clients that have children. Some of our clients, the children were put up for adoption. We right now, for the last two years, we’ve got an individual that we serve, she in the last two years got all five of her kids back and she’s doing wonderful as a mother. So we do work. . . . with adoptions. We got some clientele that are felons. We can’t find them housing. Sometimes they’re living in shelters. We have clients that have sold cocaine to undercover cops. I’ve got clients that’s armed robbery. . . . We’ve got clients that are dual diagnosis, autistic, autism, cerebral palsy, spinal bifida. . . . Each individual is different”

Allison’s narrative lists the differences among her clients, as she describes the perceived kinds of problems (felony, family issues) that make it challenging to provide for clients’ needs. Allison asserts that providing services will “depend on the care the client needs” and describes clients as individuals who vary in need. In a similar fashion, the following description mirrors Allison’s as Nina, who is Chief Operating Officer of a company funded by Med Waiver, explains the variety of clients in the field. Her comment describes clients who need complete assistance, but emphasizes that they may not require “tending” to after their basic necessities are provided for. Her explanation also highlighted clients’ unique personality traits, clients’ differences in sexual orientation, physical needs and family involvement.

“I’ve worked from, anywhere from [points to pictures around desk area] this little girl over here that knocked the crap out of me, to this young man who was reunified with his grandparents and he’s now out on the streets, um, there’s a bunch of my folks out here. Um, we, we have some folks with, with a lot of needs throughout our organization, we have some folks who. . . . have cerebral palsy, um, need total assistance to get up in the morning to eat, their bathing, all their personal needs taken care of, but once they’re up in their chair, and their cell phone is put on their chair, they don’t want anything to do with you. And one young lady. . . ., um, who goes out. . . . and sails in a sailboat by herself, has head controls, uh, snow-skies, uh, has got a wheelchair van, she had a wheelchair van donated to her so her staff can take her where she needs to be. She needs total care; she needs someone to arrive at where she works at noon, to feed her. Um, but she runs her own life, you know? . . . . I mean, we serve, we run the gamut, we have folks who are married. . . . folks who just live together, um, we have folks who have boyfriend-girlfriend. Um, girlfriend-girlfriend. . . . We have folks who have lots of uh, parent involvement. And then folks who have absolutely none.”



I found it interesting that a majority of the women, when describing their clients, provided an extensive summary of their clients' perceived unique characteristics. Above, both of the women portrayed clients as individuals who come from different backgrounds and possess unique lives. However, despite the emphasis on clients' individualism, common client characteristics were assumed by the women and were not elaborated on: the accounts provided construct a common perception of clients as having *some* type of need. Though they emphasize *diversity* among clients and describe how clients will have different needs to tend to, the women's stories also highlight the assumed shared notion of clients as being in need of services, regardless of those differences. In addition to emphasizing differences, Nina's quote also indicates that some clients were perceived as not wanting "anything to do with you," after their basic needs have been met. Nina's comment supports and reflects the social narrative of proper caregiving—one that views caregivers as supports, not friends.

Differences between clients were also mentioned when describing clients who had the *same* medical diagnosis. When describing the types of caregiving jobs she's done, Teresa, who works under Allison, explained how working for two clients with cerebral palsy was a unique experience because the clients' routines were significantly different despite sharing a similar physical trait:

"I have only taken care of...well, my client has a boyfriend that also has cerebral palsy and they needed back-up. So for about two weeks, his mother and father went on a cruise so I went there and they quick trained me and my fiancé happened to be working with him also. So yeah, I took care of somebody else that had cerebral palsy. [*Teresa's vocal pitch increased and speech pattern sped up as she spoke about clients' differences*] But the interesting thing is, even if they both have cerebral palsy, they're both totally different. So that's very interesting. Different routines, different everything. It was interesting." (Teresa)

Here, Teresa's emphasis on clients' different routines and different "everything" signifies how activities throughout the day will vary depending on each unique client. As she described working for these two clients, Teresa became visibly animated. Despite clients' same medical condition, she stressed how dissimilar the clients were.

The women spoke about their clients' differences across their assumed common trait: clients have impairments and thus, have *needs*. While the women acknowledged that clients shared the characteristic of *need*, their self- narratives did not present a generic image of "the client." Rather, a significant amount of weight was given to clients' differences. Furthermore, even with clients that shared a similar medical condition, the women's stories did not depict the individuals through the diagnostic lens and did not solely focus on clients' physical or cognitive conditions. Rather, caregivers' descriptions highlighted clients' differences regarding personality traits, sexual orientation, marital status, and family involvement.

These personal accounts illustrate the complex relationships between caregivers and their clients, and reflect the interplay of disparate narratives of care that the Medicaid Waiver promotes. The emphasis on uniqueness despite commonalities reflects the institutional narrative of the social model of care. The social model of care rejects viewing clients solely through a medical lens; it is possible that the women emphasized differences across clients' characteristic of need due to the philosophy maintained by Medicaid Waiver, which endorses a person-centered approach to care. Both Allison and Nina, who are essentially the spokespeople for their agencies, emphasized diversity, as did the women who work under them.

Furthermore, as shown in Nina's earlier comment, these personal narratives also mirror aspects of the feminist ethic of care. The Med Waiver, as it was institutionalized into the organizational narrative, promotes the value of individualism, which is reflected in the caregivers' accounts of their clients. Given the Waiver's person-focused approach to caregiving, a system is set up where individual differences are appreciated. Even though Nina's quote highlights that some clients may view caregivers simply as supports for independent action, clients' perceived *uniqueness* may also reflect the cultural expectations of care placed on women. These expectations emphasize that caregivers must be attuned to the individuals they care for.

These women are trained by an agency that promotes person-centered care. While these caregivers recognize that their clients have needs (highlighting the medical model narrative), they perceived their clients as *unique* individuals. By remaining attuned to their clients' distinct needs and characteristics, these personal narratives present clients not as patients but human beings with differences, suggesting that these caregivers may have bonded with the individuals they care for, which reflects the cultural expectations of women's care work.

This is significant: although the Med Waiver is aligned with the social narrative of care that endorses the separation of caregiving tasks from emotion, the program also unintentionally sets the stage for emotional engagement, given the person-focused approach of care. Thus, according to the women, clients were characterized as individuals that were diverse, with unique characteristics, despite their shared features. Finally, Nina's matter-of-fact comment regarding clients disengaging from caregivers after their basic needs have been met also suggests that there may be disconnect between clients' and caregivers' views of caregiving. Whereas caregivers' stories reflect a mix of social narrative, and cultural expectations of care, they also suggest that some clients' views may be in line with the social model of care- one that depicts caregivers as servants or supports, rather than friends.

#### *Clients are in Control*

Caregivers' construction of their clients depicted the individuals as "in control" of setting their own schedules and making choices for the day. The women stressed that they did not make choices for them. Rather, clients were characterized as being in control of deciding what activities to engage in. This was evident when I asked for examples of a "typical" work day and/or how the typical day was negotiated, which commonly consisted of caregivers inquiring about clients' interests. Based on what the women said, there was also an emphasis on the rhetoric of *choice*. The caregivers said that they would provide clients with choices:

"A typical day is, get Holly ready. She picks out what she wants for the day. Outfit, jewelry. ....I give her breakfast, every morning. And then after I give her breakfast or after I give her lunch,

soon after, I put on some shoes on her.... And I go “where do you wanna go Holly?” (Claps hands) Then we just drive around. So, basically, if I work eight hours, about five to six hours out of the eight, if not more (giggles), we’re not in her apartment watching TV or movies or anything. We’re *out*. And then, maybe for about two hours, we’ll find a movie, or pop in a movie, or watch some tv. Do her nails...so it’s kind of a mix. Whatever Holly wants to do! Yeah.” (Teresa)

“Oh, I always gave them a choice: “Do you wanna do this or do you wanna do that?” And they pretty much knew what they wanted to do and didn’t wanna do, you know. So that was, yeah, kinda easy (laughs). And I looked in the paper, to see what’s going on, usually things are on the weekends-I didn’t have a lot of weekend work- but there were still things that were like continuous, like the museums and the art center I could take them to and they could, you know, enjoy. But yeah, always asked them what they wanted to do: “What do you think you wanna do today?” (laughs). So that’s kinda how it went.” (Laura)

Teresa explains how she asks her client, Holly, what she wants to do after getting her ready for the day.

Lisa similarly explains how she makes it a point to ask the client what they want to do, illustrating that the typical day was dependent on what the client wanted to do. Even when clients had routines, caregivers explained that clients still maintained control over what they wanted to do. Their accounts suggest that these caregivers left the decision-making regarding workday activities up to their clients. Caregivers reiterated that they encouraged this control by providing clients with *choices*. The women’s narratives also show that they assumed their clients understood which activities they could physically and mentally participate in as they encouraged clients to maintain control over the typical work day.

Furthermore, in the stories women told, participants stressed that they were *not* choosing for the clients. Clients were not only in control of the day; clients also lead *caregivers* throughout the day:

“You know, it depends on the individual. Some will come in and they’ll want to do something right away....If they wanna come in and lie down for a little bit or just sit and chill for a little bit, do that. Uh, if it’s a Friday night, there’s probably a dance going on somewhere and so we’ll go to the dance. Um (brief pause) which is always entertaining....So it’s really their call. Now I know that there are a lot of clients that will go “well, what do you want me to do?” “Well....I want you to do what you want to do”. And so, some of that goes back and forth, and some folks, you know, if I work a relief for somebody, um, I’ll usually get the folks to “you know, you gotta show me, what is it, I dunno this job, what is it I need to do? You know, you got to show me.” And you know, it becomes kind of fun.” (Nina)

“.... If I’m living with someone, it depends on if they could get up, how they feel. Some of our clients don’t have transportation. And they can’t ride in a client’s car. So they can’t afford 8 dollars a day to go transport....So, it depends on the weather. It depends on their money and how they feel. Do they wanna go visit a neighbor? Or do they wanna go up to the community center, is there certain movies they wanna do...if they want me to sit here and read a book with them...sometimes *to* them. Again, it depends on that person.” (Allison)

These caregivers explained that they were led by their clients. Nina lists the myriad of activities clients may choose to do and maintains that “it’s really their call.” She says that she both encourages her clients to tell her what they would like to do and what they would like *her* to do. Likewise, Allison’s comment supports this perception of the client as in control given her explanation of her work as a live-in caregiver. Her quote, “if they want me to sit here and read a book with them...” highlights how her actions during work are dependent on the client.

Not only were clients portrayed as in control, they were also constructed as one of the “bosses” for the majority of the women. Remarkably, without my prompting, some of the women freely expressed that they perceived their clients as a boss, irrespective of their employment through the agency. For instance, when I asked Gwen, who works for Allison, what she would do in a disagreement with a client, she stated: “And that’s *difficult*, because they are my boss.” Equally, when I asked Allison, who is the owner of a Med Waiver-funded company that most of my participants work through, if it were up to the clients to decide what to do for the day, she stated without hesitation that “our clients is my boss.” When I asked explicitly, she provided the following explanation:

“Our clients are the ones that hires us. I’ll never hire a staff. Clients hire who they want in their lives and they can fire you at any time. They’re our boss. So that’s who hires us, individuals we serve. “

Allison’s comment is significant, because she is the spokesperson for her company, and author of the organizational narrative for majority of my participants. Allison’s personal narrative reflects the organizational narrative that is designed to fit within the institutional narrative of the Med Waiver program. Allison’s comment illustrates that she perceives her clients as her bosses, a sentiment that is aligned with the social model formula story- one that promotes a client-directed approach of care. She explains how clients do the hiring and the firing; caregivers are there to serve the care recipients. Her statement shows how vulnerable that she and her agency are to this client-directed narrative of care. Sharon, who works for Allison, and Nina, who is Chief Operating Officer at a separate company, similarly explained:

“I would consider, I mean, I would consider, you know, Sammie and her parents. My client to me is my boss. Because, honestly, what a lot of these agencies don’t understand, you know, my boss can hate my guts. But if my client likes me, there’s really not much they’re gonna do.” (Sharon)

“Oh, the individual. The individual.... You know, like on a table of organization, there’s a direct line: supervisor.... So, it’s the individual to *me*, and a dotted line, here, to the guardian. I have to respect that there’s a guardian here and I have to notify them, however this is my boss and this boss can fire me... Uh, this person, it’s a courtesy, and I understand that I have to do what they ask me to, but not devoid of the client. Yeah.”(Nina)

Sharon and Nina, who work in different organizations, *both* assert that their client is their boss. Nina echoes Allison by saying clients can fire caregivers. Furthermore, the women state that even with parental involvement, the client remained *one* of the primary bosses. Sharon also explains how even if her boss through the agency did not approve of her, her relationship with the client was most important. The *same* kind of organizational narrative is reflected in the personal narratives of caregivers who work for different agencies. Based on their accounts, a typical day was client-focused and client-controlled; caregivers emphasized clients’ power over making decisions for the day. This “control” was preserved by caregivers, who stated they made a conscious decision to ask their clients what they wanted to do.

Clients were depicted as characters that are in control over their lives, and were perceived as supervisors. These personal narratives mirror the social narrative of care that has been institutionalized into the Med Waiver. The IL movement, which is based on the social narrative, proposes that care recipients *should* have the ability to choose how to live their lives and control their decisions (Guess, Benson and Siegel-Causey 2008). The social narrative of care further stresses that caregivers must foster their clients’ independence; control over caregiving rests in clients’ hands and they are able to control how care tasks are performed (Shakespeare 2006). Consequently, caregivers’ comments vis-à-vis the characterization of clients as “supervisors” and “in control” may be directly tied to their employing agency, which is client-centered and grounded in the social narrative approach to caregiving. Section 1-8 in the *Developmental Disabilities Waiver Services Coverage and Limitations Handbook*, outlines the following institutional narrative related to clients: “...authority to exercise control over authorized funds...” and to “achieve productive lives as independently as possible.” A majority of my participants’

stories endorsed this value. Perceiving their clients as supervisors, these caregivers said they were led by clients' choices and followed through with their clients' decisions for the day. To reiterate, these women are trained to adopt the philosophy that clients *must* be in control of their lives, and their personal narratives demonstrate how they may have adopted the social model narrative of care that is institutionalized by the Medicaid Waiver.

### ***Parents and Legal Guardians***

While there was considerable agreement that clients were unique, and controlled the work day, there was much less agreement about the characteristics of two other significant characters in these women's work lives: parents and legal guardians of clients. This variation was partly because some of the adult clients had court appointed legal guardians. In some cases, these legal guardians were the client's parents while other clients had non-parental legal guardians. Some of the parents my participants had contact with were *not* legal guardians of the clients, but still maintained a strong presence in the clients' lives. While some of my participants used "parents" and "guardians" interchangeably, they also made some distinctions between the two characters.

Relationships between paid caregivers and parents and legal guardians are complex because having parents or legal guardians in the mix challenges the very foundation of the notion that clients are adults who are in control of their lives. When a legal guardian has been appointed by the court, at least *some* of the clients' legal rights to make choices have been taken away; the guardians are really the bosses and own the choices, despite the values the institutional and organizational narratives endorse. In the case of parents who are *not* legal guardians, tensions emerge because they do not have the right to override clients' choice. *However*, parents may still experience tremendous social pressure to protect their adult child-even if they are not legally bound to do so.

Thus, caregivers' perceptions of "helpful" and "challenging" attitudes and beliefs of parents and legal guardians varied. While my participants described qualities that were beneficial in relationships with

parents and legal guardians, over half also described challenging qualities that may exist. It should be noted that *each* of these relationships is likely to contain qualities that may be perceived as challenging and helpful. While caregivers' personal narratives regarding challenging and helpful qualities especially concerned clients' *parents*, legal guardians were also mentioned. The following section will first address caregivers' perceptions of the qualities they found particularly helpful in the relationships they had with parents and legal guardians.

*Helpful Attitudes and Behaviors: Communication, and Consultation*

When describing attitudes and behaviors of parents and legal guardians that were helpful, my participants said they found communication an important quality. The women also found consultation with parents and legal guardians to be helpful in the relationship. Communication as a helpful behavior will be the first quality expounded.

Communication. My participants expressed that consistent communication with clients' parents and legal guardians was significantly important, and perceived it as a helpful behavior. These personal narratives indicated that steady communication enhanced caregivers' relationships with clients' parents and legal guardians. Their personal narratives depicted parents and legal guardians who possessed communicative qualities as individuals that could be "talked to."

Caregivers' interactions with parents were more likely to be described in positive terms when these relationships contained communication qualities. Half of the caregivers who found communication helpful have been working with their clients for a relatively long period of time. For example, Rose, who has known her client since middle school, stated that her relationship with her client's parents was "pretty good" and that she communicated with the parents a great deal, especially her client's mom, "about the day and what's going on...the plan and all that." When I asked if she had a bond with her client's parents, she stated they were "Friends. I can talk to them."

Teresa, Sharon, and Laura similarly explain:



“Um. My client’s parents known my fiancé’s family for many years. And when I talk to them, we socialize, or whatever, we just talk about my son or.....unless we’re talking about what we’re gonna do for the day, if her mother comes over, she’s like “what are your plans for the day, ladies?” It’s like “*Uh*, up to Holly” (laughs). You know, so when we do talk, it’s just like “what are your plans?” and “these are my plans, hope you have fun”. We have a pretty good relationship.” (Teresa)

“Oh. I think I had a good rapport with them, they were always willing to listen, not, uh, ....but I guess because of my medical background, you know, they felt comfortable with me. You know, the parents would go out of town even for a week and they would feel comfortable that I was there with her....I’ve really been fortunate to have good, patient parent relationships.” (Laura)

“...Sammie’s mom and dad are usually in and out and around. So we have conversation. Some conversations are longer or shorter than others. It just depends on their schedule or whatnot. But if there’s something important, then I definitely make it a point to let them know, you know. “Hey, medication was given at 2:30 today instead of 2 *because....*”So there *is* contact most of the time” (Sharon)

All of these women had worked with their clients for a number of years. While it is possible that familiarity with parents may be a reason these relationships were considered “positive”, the perceived *communicative* quality that existed in these relationships was most significant. Although not all of the parents that the caregivers interacted with had legal custody over the clients, the women said they frequently spoke to their client’s parents about “the plan” for the day, and Sharon’s explanation depicted parents as individuals who were typically present and put caregivers at ease when communicating about clients’ medical issues. According to these women, when parents were perceived as “willing to listen”, engaged in communication with the caregivers, and were open to caregivers’ comments regarding clients, a beneficial relationship emerged. Caregivers expressed that they were able to talk to parents and guardians about clients’ health and other relevant matters, indicating that these individuals could also be a source of help.

A number of the women who expressed that they had *good* relationships with these individuals emphasized the importance of communication. However, regular communication commonly led to friend-like relationships between caregivers and parents. Although these specific excerpts primarily concern

clients' parents, my participants also implied that communicative, friend-like qualities were important in their relationships with legal guardians (who may or may not be parental guardians).

These caregivers' accounts demonstrate that these women may associate communication with friendship, commonly describing clients' parents as "friends." Friendship, which may emerge from the consistent communication these caregivers maintain with clients' parents and legal guardians, presents tensions between the social narrative of care and caregivers' personal narratives.

Caregivers' personal narratives regarding friendships that form between them and clients' parents challenge the social narrative of care, which resists emotional components in caregiving. Furthermore, the Med Waiver primarily endorses a social narrative of care that values client's choice and control, and espouses *client-focused* caregiving. As caregivers develop personal relationships with parents and legal guardians, a relationship that is *independent* of the client emerges. These women explain that they did not solely communicate with clients' parents *about* the client, but also about aspects of their personal lives. Communication that leads to friendships between caregivers and parents and legal guardians that is independent of the client is *not* client-focused anymore. Therefore, there is possibility that clients may be left out of the loop due to another person sharing a relationship with their caregiver- a relationship which the client may not be aware of.

It is also important to highlight that these caregivers considered being friends with clients' parents *beneficial*. During the interviews, my participants expressed pleasure at maintaining "positive", friendly relationships with parents and guardians. Not only did having these types of relationships make their work easier, but as they talked, my participants' conveyed happiness at maintaining congeniality with clients' parent and guardians. The friend-like relationships that formed between my participants and clients' parents supports Piercy's (2001) work, which asserts that friendships commonly form between clients' families and their non-kin paid caregivers. However, these friendships may also present challenges to the cultural expectations of care, which asserts that bonds will form between caregivers and

the individual that is *cared* for. However, in the case of my participants, “caring” relationships may occur not only between the care-recipient and caregiver, but also between caregivers and their client’s parents. Though Piercy’s (2001) work looked at relationships between client’s family and their paid caregivers, friendship could also form between caregivers and guardians who are not parents of the client. These personal narratives suggest that mutually satisfying relationships may emerge between caregivers and individuals who are significant to clients and are often present in their lives.

Consultation. My participants also emphasized that *consultative*-based communication was perceived as helpful. Caregivers found it helpful to consult with parents about what was considered best for the client. The women described relationships that were consultative as beneficial; the caregivers consulted with the clients’ parents and legal guardians about the clients’ well-being, emphasizing the importance of clients’ safety and health. As Sharon’s account demonstrates above, communication with parents often concerned her client’s medication. Laura further highlights the value of consultation-based communication, expressing that the parents were “always willing to listen” and stating that caregiver-parent communication consisted of:

“Anything that was out of the ordinary or something that I saw as a problem. Like when the medication really wasn’t working as well, and I thought she needed an antispasmodic, and to stay away from caffeine because caffeine is a stimulant and you know, you’re taking all this expensive medicine to keep you relaxed, why take something that’s gonna fight the medication? You know, so yeah, that’s...and I’ve been happy with the rapport (laughs)”

Laura’s narrative demonstrates that she considered consultation with clients’ parents as valuable for the clients’ well-being. Her account depicts parents as individuals who could be talked to when caregivers had concerns about their clients’ health. Emiliya’s account of the relations she has with her clients’ parent and legal guardians also promotes the notion that consistent communication and consultative-based relationships were perceived as “positive:”

“Some parents, I have built a relationship with them, like you know, some of them, like you know, some of them, if they call, like if they’re not the guardian and ask me question, I have to get permission from the individual to talk to them...Like you know, some of family, if they call me or I call them to check, or like, you know to touch base. For example, like, you know, some of the family are in control of the money. If they need more money, I call them. If they have a

medical issue or concern, like you know, I call them to give them update after a doctor's appointment. Yeah. Then every week, like, you know, when I'm with them, I'll probably call them to touch base, so they don't have to call me then when I am with them, then I will call them to touch base about the individual. Like you know, like, to touch base a lot. Some of them I have a good relationship with but some of them...(laughs)"

Similar to the previous narrative excerpts, Emiliya describes that she has "built" a relationship with her clients' family and asserts that she will often "touch base" and update the clients' parents. Here, Emiliya highlights that family members may not always be legal guardians. Thus, she has to get "permission" from clients to communicate with them. This sentiment was echoed by a number of my participants: the caregiver can, and *should*, give priority to the clients' wishes when parents are not legal guardians. Emiliya explains that after she has her clients' permission, she will update the parents on her clients' progress. However, when parents *did* have custody, these caregivers acknowledge that parent and guardian relationships become much more complicated. In such situations, the women have to figure out what decisions the client is entitled to make and which ones the legal guardians are legally responsible for.

As Emiliya's story demonstrates, some parents have control over finances; she explains that in the case where her clients needed more financial support, she would call the parents and communicate with them on her client's behalf. Describing how she will update parents if they have "a medical issue or concern" concerning her clients, Emiliya further emphasizes the beneficial qualities of maintaining a communicative and advisory-based relationship. Her parting comments indicate that she perceives herself as "touching base" with clients' parents and legal guardians "a lot." However, Emiliya also hints that her relationships with some parents and legal guardians are *not* always as good as they ones she described up until that point.

My participants' narratives indicate that parents and legal guardians could be considered a source of help. They perceived parents and guardians who would listen to their concerns regarding clients' physical well-being as valuable. They said that they could consult with these individuals about clients' health and would "update" them on their clients' progress. These sentiments reflect the medical model of

care, because all three individuals-caregivers, parents, and legal guardians-could work together to support clients' health and safety. Consultative relationships operated through a medical model lens, as these various significant others took clients' safety and health into account.

While consulting with parents and guardians was done for the benefit of the client, it is also important to note that clients may not always be present during these interactions and may not have control over the consultation. As mentioned, when clients were legally independent, they could grant their caregivers permission to consult with parents. In situations where parents were not full legal guardians but controlled *some* aspects of the client's life (for instance, finances), caregivers would still ask for permission to consult. Regardless, consultation with parents and guardians about clients challenges the notion of client choice, because these individuals have the potential to exert some control over clients' lives. Consultation about the client may unintentionally challenge client control, because the individual is not leading these consultative-based interactions. Thus, consultation supports the medical model of care, which depicts care providers as the "experts," and challenges the social model of care.

In the case of helpful qualities, my participants' personal narratives reflected alignments with and tensions among the disparate narratives of care. Both the social and medical narratives of care have fed into the Med Waiver, which has been institutionalized into the organizational narrative of Waiver-funded employing agencies. Regarding helpful qualities, communication and consultation with parents and legal guardians was perceived as valuable. Communication with clients' significant others presents challenges to the social narrative of care, since these friendships are formed independent of clients. Furthermore, these friendships demonstrate tensions between cultural expectations of care and my participants' personal narratives. While cultural expectations emphasize that caregivers will care about their care *receivers*, my participants' narratives challenge that notion by indicating that friendships and emotional bonds may also form between caregivers and clients' parents and guardians.

The social narrative of care is *both* challenged and reflected in my participants' personal narratives. A few of the women explained that, in the case where clients were legally independent, they would check with the individuals prior to communicating with their parents. Emiliya's account reflects this situation. This perspective aligns with the social narrative of care, which emphasizes that clients should have control over their lives (Shakespeare 2006). These caregivers maintained that control by requesting consent from clients. Such comments also indicate that tensions may arise when clients had legal guardians, who may or may not be their parents. Here, caregivers are placed in a sticky situation as they carefully navigate clients' wishes, while simultaneously honoring the authority of legal guardianship.

These tensions will be further addressed in the following section. Here, caregivers describe qualities they consider challenging as they engage in relationships with clients' parents and legal guardians.

*“Challenging” Attitudes and Behaviors: Vision of Client and Disapproval of Clients' Choices*

While communication and consultation with parents and legal guardians were considered beneficial qualities for maintaining positive relations, my participants also talked about qualities that they perceived as challenging. Qualities in these relationships that were considered challenging include parents' limiting vision of the client. Difficulties in caregiver's relationships with these significant others - particularly with *parents*- emerged when their views of clients contrasted with the vision of clients the caregivers endorse. These caregivers said that *parents* primarily had a particular image of their child; an individual perceived as “broken” and infantile. According to the caregivers, this attitude concerning the client ultimately led parents- and in some cases, also the legal guardians- to “control” clients lives. Caregivers expressed their disapproval of this, arguing that this challenging belief was detrimental, and kept their clients undeveloped and *dependent*. These sentiments are evident in the following excerpts:

“Some of the parents, they don't understand that the client is in supported living, they're trying to be independent. You cannot control them but some of the families still control them. But if they don't live with you, they want to be independent! But you cannot control them like they're a little child, like they live with you... You have to give them like, freedom to do, like, you know, learn

from their mistake, ... it take a while for them to learn you cannot baby them. Like I understand, that's your baby, but you have to give them a chance to grow up too." (Emiliya)

"Parents sometimes come... with a different set of ideals or... prejudices that hold back the progress of the individual. That goes back to sometimes parents saying "Johnny doesn't need food stamps cuz' I'm here for him". So here comes me, the supported living coach saying "Well, you know, mom, you're not gonna be around forever and if you choose to not take advantage of what's being offered now, not only does Johnny not understand how to budget, something that is gonna be necessary for *life*, but he doesn't-he doesn't develop self-reliability" (Gwen)

"Sometimes the guardians don't think out the box. They see their loved one as this helpless individual or even a child, who they tell them "oh, Monday, Wednesday, Friday, you're gonna have chicken! ..." they're just so controlling over... Especially, coming to dating, they're very close-minded... Everybody wants a boyfriend but some of the guardians will absolutely say no and at the end of the day, if they have guardians, you want to see the guardian paper or are they full guardian or just over money. And guardians can put a halt to a lot of stuff" (Allison)

Though Emiliya does not work with Allison and Gwen, all three women reflect the same view. According to these narratives, both parents *and* legal guardians were often perceived as holding a view of the client that contrasted with the philosophy that caregivers uphold. The women complained that parents *especially* viewed the client as "helpless" or child-like, and had difficulty understanding that clients were attempting to live independent, self-directed lives. Allison highlights that some legal guardians put a "halt" to a lot of clients' choices. Here, she differentiates between *types* of legal guardianship and asserts that *if* clients have legal guardians, caregivers needed proof of that status prior to following through with their requests. Nina, who supervises Emiliya, shared a similar sentiment and explained that *parents* may have difficulty seeing the client as anything else than their child, and distinguished between *parents* and *guardians*. We had the following exchange when she described the contact she has with parents and legal guardians:

"...most of the time with guardians, it's not too difficult. Now, what's difficult is with parents. Because parents think they're guardians but they're not unless they've legally gone to court but they think "that's my child, it's always my child, you can't do that." Well, sometimes that's kind of a fine line, and some things (pause) if a client doesn't want their parent to know something and they're not a guardian, then we don't tell them. We have to keep that promise. Um, and sometimes that's very difficult, very difficult. Um, but when people go "well, what do you mean, you don't tell them?!" And I go "did you want your parents to know everything that you ever did? And they answer that "No" (laughs). So, it's the same thing. But if they are not guardians, um, we have some parents, that's very difficult. That's very difficult; it's a very difficult concept."

When I asked her if the difficult aspect of such situations was due to parental *control*, Nina said:

“It’s control, and wants to ‘my child is not right, my child is broken, so I need to make sure that they’re safe and in order to do that they really don’t need to be going and doing that or going to do that’, or, you know, whatever, whatever. They’re hovering and they’re keeping their child a child.”

Similar to the previous accounts, Nina asserts that parents maintained a limiting vision of the client and by attempting to control the clients’ choice, kept the client “a child.” She makes an important distinction between parents who are solely *parents* versus parents who are *legal guardians*. Nina echoes Allison and the sentiments that were addressed in the previous section: if parents aren’t legal guardians, her loyalties lie with her *client*.

Here, caregivers’ stories reflect the organizational narrative that is promoted by their employing agency, which upholds a vision of clients that is aligned with the IL approach to caregiving. This model rejects the medical model approach to care, which tends to uphold an infantilizing view of individuals with impairments as (DeJong 2001). According to these women, legal guardians and specifically parents had the tendency to view clients as “helpless.” Thus, challenges arose when guardians were perceived to uphold visions of clients - one that aligns with the medical narrative of care - which caregivers argued barred clients from experiencing life on their own terms and denied them independence. Such a conflicting vision led to difficulties in caregivers’ relationships with parents and guardians.

A significant point of tension in these relationships for caregivers was that *legal guardians* could be considered as one of their supervisors. In the section about clients, these caregivers maintained that clients were perceived as “bosses” and had freedom of choice. A number of caregivers said they agreed with putting a halt on a client’s choice if they had a *legal guardian* who disapproved of that decision:

“Well, I say, ‘mom doesn’t think that’s a good idea and you know why’ and I explain to her, you know, *reinforce* it, so that you’re not caught in the middle of being, you know... and it’s like a child with the parents; they manipulate one parent against the other so you’re kinda like a third parent there! (laughs).” (Laura)



[When explaining what she would do if a guardian disagreed with a clients' choice]"That, I'd have to put my foot down. 'Mom and dad do not want this'; I'm not gonna push an issue like that because if they're saying no, there's usually a very good reason and I'm also not gonna override mom and dad to make the client happy and then I'm in trouble. No, no. There's good reason why they're saying no. I have to respect that." (Sharon)

"Um, technically, the way I see it is, if a parent says no, and um, their kid, or their child or whatever, is still living in the house [was interrupted briefly] so the way I see it is...my fiance's been in this situation more than anything, um (brief pause) but if they go "no, they can't do that", I probably won't. Because there must be a very good reason." (Teresa)

Here, the women discuss *parents* who are legal guardians to their clients. My participants state that they will act in agreement with legal guardians if they disagreed with a client's choice. To some extent, compliance with parents who are legal guardians was a method of *self-preservation* for caregivers, because they wanted to avoid being "put in the middle." These sentiments accentuate the vulnerable situations that caregivers may be put in. Interestingly, despite caregivers' displeasure with parents' limiting views of clients, and their beliefs that this view prevented clients from leading autonomous lives, the women also shared the opinion that *if* parents were legal guardians, there "must be a good reason" for their disapproval of client choice.

These narratives indicate that the women were put in a difficult circumstance. Though the caregivers and agency's beliefs of clients promoted clients' autonomy, this ideology also put these women in the middle of difficult situations when dealing with clients' parents and legal guardians. These personal narratives also mirrored a medical approach of caregiving: a number of women expressed their disapproval with abiding by guardians' decisions, *unless* there was a health or safety issue. To reiterate, caregivers said that relationships were considered *especially* difficult when guardians disapproved of a client's choice. In these situations, caregivers were placed in a vulnerable position; they had to both honor their clients' independence and uphold their freedom of choice, while also following authorized guidelines in situations where clients had legal guardians. Here, the social narrative of care that promotes clients' independence conflicted with caregivers' personal narratives because they agreed with putting a stop to clients' choice in case of risk. The social narrative of care also conflicted with both parents and

guardians' perceived perspectives and commonsense notions of safety. Though the social and medical narratives of care are both present in the Med Waiver, dealing with parents and legal guardians especially brought out the tensions between the disparate approaches of care.

However, it is important to note that *despite* caregivers giving higher rank to safety and guardians' wishes, my participants were wistful about denying clients' choices. Asking if the client was still in charge if a legal guardian disapproved of their choice, Allison said:

"I wish I could say that. To an extent, but the guardian overrules. The guardian overrules. And we educate the guardian, you know. We've been in this field for 20 years, we'll do different scenarios, different things, "so how are you gonna know if you don't let them try?" "How did you know you were gonna be successful at cooking and cleaning and having a boyfriend until your mother let you? You need to see their abilities and not their disabilities. You need to stop it." So we educate the guardians a lot."

Allison's story further illustrates caregivers' tenuous position. Though the client has control "to an extent", Allison says that the guardian will have the final say. She said she navigates this situation by educating guardians and encouraging them to see clients' "abilities," suggesting that she *still* tried to maintain client's choices. When I interviewed her, Gwen described a situation where parents, who were also legal guardians, did not agree with the adult client's dating life. Gwen, who works under Allison, similarly asserted that it was important to "educate the parents!" and to "document everything as much as possible." She echoed a common solution of getting outside help if legal guardians simply did not budge:

"Usually what we try to do is rally the support team to see if my vision is singular or if the other supports are seeing what I'm seeing. And in this particular situation, the rest of the support system was seeing it, we're all eye to eye. We had a meeting with the parents and attempted to negotiate on the behalf of the individual-eight of us, together- because she individually threatened to fire us all. So we all got together, had a nice meeting (laughs), not nice, and the mom, um, was pretty distraught that we were all of a similar mind..."

Nina, who works for a separate company, and maintained that clients were *still* her primary boss despite guardian presence, similarly said:

"I document it very carefully, for the regulators (laughs). But we try to work through it with the guardian or and reach some sort of compromise or try to put the guardian's mind at ease or make sure that we can put the safeguards that the guardian would feel comfortable with. Uh. We try to work through it. Um, because *if* you have a guardian, you don't necessarily have choices; the choices belong to the guardian, not to you, *legally*. So..."

These narratives highlight that the caregivers' personal narratives aligned with the social narrative of care that endorsed clients' autonomy and living life based on their own terms. These women, while working for separate agencies, share the organizational narrative that values client choice and control. Caregivers considered over-protective parental attitudes to be challenging, which supports the social model notion that clients should be in control. However, the women also acknowledged legal constraints if parents acted as legal guardians. The caregivers' narratives point out that parents as individuals maintain a vision of clients that conflicts with the view the social model endorses. As Nina's account illustrates, when clients have legal guardians, clients no longer have choices: "the choices belong to the guardian...*legally*."

In situations where guardians (particularly, *parental* guardians) were intransigent in their opinions- ones that caregivers perceived as detrimental to clients' quality of life- the women communicated with and worked to *educate* these individuals about clients' choices, and encouraged them to see clients' *abilities*. The women also looked for outside support and leaned on other caregivers to validate their outlook on the situation. These caregivers' actions support the social narrative of care because they navigated their vulnerable positions with guardians in order to preserve clients' independence.

To summarize, qualities in these relationships that were perceived as challenging consisted of parents and legal guardians' visions of clients as "helpless," which encouraged these individuals to control client's choices. While these caregivers primarily adopted the social narrative of caregiving, parents and legal guardians tended to align with the medical model approach, which views care recipients as *unskilled* in making decisions over their care. These narratives suggest that clients' parents may have assumed the medical model approach that insists on individuals with impairments to forgo their own wishes and remain cooperative (De Jong 2001). However, when clients wanted to do something their legal guardians perceived as unhealthy, caregivers *also* aligned with the medical approach, citing "good reasons" for guardians' disapproval and refusing to be "put in the middle" by clients. This sentiment also

echoes the previous section depicting helpful qualities that exist in these relationships. These caregivers appreciated the consultative-based communication they maintained with clients' parents and guardians because they saw it as beneficial to effective caregiving and maintaining clients' well-being. Still, the caregivers insisted that these over-protective beliefs and controlling behaviors were challenging qualities because they were detrimental to clients' development.

Hence, these caregivers' personal narratives demonstrate the tensions between the medical model and social model of care. While they are appreciative of the medical model approach to an extent, and are required by the Med Waiver to look after their client's health and safety, they also saw the medical narrative of care as challenging because it limited client choice. When the medical model approach of caregiving surpassed maintenance of the client's physical well-being to *dominance* over clients' choice-making and personal lives, my participants found this vision challenging. Tensions between the social narrative and medical narrative of care became more prominent as caregivers carefully negotiated with parents and legal guardians so that all parties could reach a comfortable consensus. *Both* of these narratives are present in the Med Waiver and have been instituted into the organizational narrative. Here, caregivers' personal narratives indicate that these women are placed in a vulnerable situation as they negotiate between the disparate narratives of care at the ground level.

### ***Caregivers***

In addition to caregivers' construction of clients and guardians, caregivers discussed characteristics of "good" caregiving. Here, the women described *themselves* as caregivers, while simultaneously describing the *type* of person caregivers should embody. Based on their narratives, the women presented "good" caregivers as individuals who preserved clients' choices by *educating* them about their choices and providing *alternative* choices. The caregivers also emphasized "knowing" clients. The women's narratives concerning preservation of client choices will be discussed in the next section.

*Caregivers Preserve Clients' Choices through Education and Provision of Alternative Choices*

The women emphasized that clients should be able to experience life on their own terms. Caregivers said that they worked to ensure that their clients were making choices for themselves throughout the day and said that they always provided clients with a variety of choices. One of the ways caregivers maintained clients' freedom of choice was through education; the women highlighted the importance of educating clients about their choices prior to letting them follow through with a certain choice. This value is demonstrated in Nina's explanation:

“...Educate them about what's out there. And *then* let them make a choice. Um, they can't choose if they don't *know*, you know. Um (pause), for some of our first time cruisers, they thought “Oh, cruise, that'll be great!” Hated it! Hated every-seasick, don't wanna go on one again; that's fine, they've experienced it, you know?”

Gwen shared a similar sentiment and explained that clients may not be aware of the *consequences* associated with their choices. When describing the qualities of a good caregiver, Gwen insisted that allowing clients to make their own choices rather than deciding for them was imperative. She said that this was difficult because “it's faster choosing for the individual rather than having, sort of, the individual choose and then educating them on *why* their choice is good or bad and supporting them through it.” She further explained:

“... Well, one of the most important things [caregivers do] would be education. And just as in a life lesson, of choosing to eat the right foods to feel good; always educating but *supporting* is one of the most important things, to me. ....When people understand that their choices will have consequence because we've educated them, then they will be protected and choose the best path for themselves. Because most of the individuals that I work with do not have a full-time babysitter educating them to make the right choices on their own; it is the best pathway to their overall success.”

These narratives illustrate that respondents understood themselves as valuing and preserving clients' choices by educating clients on their choices. While Nina and Gwen work for different companies, they share the same perspective: educating clients on their rights and choices enabled the individuals to *know* about “what's out there,” but also made them mindful of the ramifications of their decisions. As Gwen's comment implied, education worked as preventative measure if clients wanted to do something the

caregivers perceived as unsafe or unhealthy. This was also suggested by Allison and Emiliya, when describing what they would do in such situations:

“Um, sometimes the clients don’t want to maybe, drink enough water or something. And you have to reason like, well, you’ve got that UTI, so you know, why don’t you drink 2 cups of water and then I’ll give you a drink of soda? (laughs). It’s really compromising. We’re not gonna take their rights away, we’re *not* gonna take their choices away, but we *do*, for their health and safety, we do have doctor’s orders sometimes that we have to follow. And they don’t have to follow them if they don’t want to but we want to encourage it. And if they choose not to do it, we’re gonna say “well, we educated them on it, but they chose not to and they understand the consequences.” (Allison)

“...I will talk to them about it, I will explain to them, that’s not safe or it’s not healthy for you, then like you know, we will talk about it, like, you know, about it, then we will discuss about it and I will explain to them, like you know, we discuss it together, then I will give them opinion, that why it’s not safe or not healthy, then I will ask them ‘what you think about my opinion and give me an opinion about what you think. ‘ Yeah.” (Emiliya)

Again, these two women work for different companies but echo one another. Allison, who manages her own company, and Emiliya, who works under Nina, both say that they will talk to clients about choices and consequences of their decisions. These stories highlight the perceived importance of exposing clients to different experience. The women stated that caregivers must first educate clients about their choices so they are aware of what the choice entails. The respondents said that they would explain consequences for clients’ choices so clients could then make the perceived “right” choice. Furthermore, education served as a tool for *empowerment*.

It is important to note that caregivers saw themselves as individuals who hold knowledge of what was perceived as “healthy” or “unsafe” for clients, which reflects a medical narrative of care. The medical model of care is based on the notion of care providers as competent “experts”; individuals who receive care must forego their own wishes and follow through with caregivers instructions (DeJong 2001). Though the Med Waiver is primarily founded on the social narrative of care-one that encourages client choice- there are also elements of the medical narrative that have been instituted into the program. As mentioned earlier, caregivers working for Med Waiver-funded companies are responsible both for upholding client *choice*, and maintaining their clients’ health and safety. These personal narratives reflect

the interplay between the social and medical narratives of care that have been instituted into the Med Waiver.

In addition to education, a majority of the women said that communication skills and “being able to talk” to clients were important talents to have in this field. In situations where clients wanted to go through with something the caregivers considered risky to their well-being, caregivers had to become skillful negotiators. As Allison stated, caregivers *cannot* simply deny clients’ choices. Thus, when clients wanted to engage in something that the caregivers perceived as unsafe, communication skills were *especially* important as caregivers negotiated with and provided clients with alternate choices that resembled clients’ *initial* choice. When I asked them how they would proceed if a client wanted to do something “unsafe” or “harmful,” caregivers expressed that they had to redirect their clients by negotiating with them and providing them with other choices that are similar to the perceived “risky” choice.

“You need to direct their attention to something else. You know, like when I had that one kid. Mom and dad [said] “No French fries for Dave”. And I said “Okay”. Get to the Burger King, he says “I want French fries”. I say “no French fries”. He says “Yes, I want”. “C’mon, mom and dad said...”. “But I want them!” starts throwing a tantrum. So I say “Okay, small fry please!” (laughs). I will eventually give in if I *have* to. I will *try* to direct them to “mom and dad said no”...Some clients are gonna keep pushing it. “Well, I want it...that’s what I want and that’s what I get”. So you just kinda have to use your judgment. You’re gonna try to convince or suggest a positive alternative, but if that doesn’t work, through the lesser of evils, instead of getting them the jumbo soup or extra large, well you can have the *small* one. Try to make it not as bad. That’s what I do.” (Sharon)

“Well, with the girl in the wheelchair, I would explain to her why it wasn’t a really a good idea, and um, would do, suggest an alternate thing that may be similar but not as drastic, because of her situation or dangerous, you know, because of her situation, you know.” (Laura)

“Um, unhealthy, definitely just a litany of education and just trying to explain to them um, by, by their favorite person, by, you know, so that we’re all kind of saying the same thing. Unsafe, I think it would depend on what, what it was and whose perception of it being unsafe. Um, if they wanted to ride a motorcycle...if they wanted to ride a motorcycle, I probably wouldn’t want them to be driving a motorcycle, but I might find someone who would let them ride on the back. Um (brief pause) My, my look at most things is well, ok, let’s really look at, let’s just not be a mother and go “Oh no, no, no, not my child, no, no, no.” Um, our job is to let them get to the edge of the roof, but don’t let them fall off.” (Nina)

Here, caregivers' personal narratives reflect the social model of care that has been adopted by their employing agencies: the choice of clients must be preserved. The women's accounts' indicate that they maintained that value by providing even *more* choices their clients could choose from. These narratives also indicate that caregivers perhaps exhibited *some* control over their clients' actions if a choice was perceived unhealthy or unsafe, through their negotiations with clients.

This is significant for the following reasons. The cultural narrative of the social model, which has been institutionalized into the organizational narrative, emphasizes that clients should be in control over their lives. Therefore, my participants work for agencies that hold caregivers responsible for upholding client choice. Their personal narratives reflect this value and highlight that these women maintain client choice through education and provision of alternate choices.

Concurrently, caregivers are also responsible for the *consequences* of clients' choices. Due to the combination of medical and social narratives of care that exist in the Med Waiver, caregivers are also held responsible for their clients' well-being. Hence, in situations where caregivers perceive a choice as "risky," the women have to set the stage where clients are still maintaining control over their lives and have freedom of choice. When these women redirected clients and provided substitute choices, negotiation was done in a way where the client still had the perceived control, freedom of choice, and maintained dignity. Consequently, presenting clients with alternative choices could be perceived as an "illusion" of choice, which goes *against* the social model of care, because alternate choices do *not* represent clients' initial choice. Though the substitute choices *resemble* clients' original idea, they still do not imply "real" choice.

This circumstance indicates existing tensions between the caregivers' personal narratives and institutional narratives. Because of the differing expectations that accompany the social model and medical model of care, caregivers are put in difficult situations: they must maintain clients' freedom of choice, but also support clients' safety and health. My participants' narratives regarding clients' control



over choices and dignity support the institutional and organizational levels of narrative they were trained to endorse, and they acknowledge they *must* maintain client choice. However, because they are responsible over their clients' health, they have to create an environment in which the individuals are forced to choose from substitute options. Provision of alternate choices does not accomplish the purpose of the social model of care, because substitute choices do not correspond with "real" choice, or parallel clients' "original" choice. However, negotiation between caregivers and clients is completed under the impression that clients are in control and possess autonomy to make choices for their lives. Thus, there are tensions between the medical and social narrative of care-which have been institutionalized into organizational narratives by the Med Waiver- and my participants' personal accounts.

### *Caregivers Must Know Their Clients*

In addition to preserving clients' choices via education and provision of substitute choices, the women expressed that caregivers should *know* their clients. A number of women stated that "getting to know" clients was an on-going process, illustrating that "good" caregivers take on an active role in communicating with their clients. Knowing clients was vital because caregivers emphasized the importance of *individualizing* work relationships. The women maintained that knowing their clients was achieved via communication: "listening" to the client, and learning who they are in order to effectively assist them.

"...out of anything I teach, several classes up at the state, is you've got to know your client, you gotta know their nonnegotiables, you gotta know their medical, you gotta know their likes, you gotta know their dislikes. You have to be invested....And you gotta know upfront, it's not about the money. It's about who you are and who you want to help....You've gotta listen to the client, you have to listen, you have to show up, you have to follow the laws . And when I say following the laws, if they can't drink, you don't want to take them out drinking. If they can't have sugar, you have to educate the client. You can't tell them no! Because we all make bad choices. But again, it's going back and know, know, know the client....But most of all, always get permission from the client; "hey, can we figure this out?", what works, what doesn't. "Let's start over and find out what does, what's most comfortable? Do you feel safe", you know? "Are you healthy?" It's just knowing everything that you can about your client." (Allison)

Allison, who manages a Medicaid-funded company, explains how *knowing* the client was a priority for effective caregiving. Her personal account reflects the medical and social narratives of care: caregivers

must be skilled in their clients' health (know "if they can't drink...can't have sugar"), but also get permission from clients to inquire further about their well-being. This sentiment was echoed by a number of women. A majority of respondents expressed that *understanding* clients' needs was dependent on the caregiver "learning" about the individuals they worked with. Caregivers explained that some clients were nonverbal or communicated via sign or body language. Therefore, getting to know the client was perceived as beneficial to both caregivers and clients. When I asked Nina how she could comprehend a nonverbal client's needs, she stated:

"Uh, their actions, or they'll, they'll, at some point, we have a gentleman who is pretty independent but he can't talk. So he makes "ah, ah, ah" um, if I am looking at him, I can come close to what he wants. Sometimes I know right away, sometimes he has to say it to me and he'll do something with his hands or leads me to where it is.....Uh, you just learn them and you will, and you will figure it out. You have to, you have to want to know...it's a relationship, every day is a relationship. Uh, every day you have to try to figure out something new about the person that you're working with. Uh, it's like any marriage or whatever, you have to work at the relationship. If you stop working at the relationship, it becomes boring, and you're gonna miss out on something."

Nina reiterates that caregivers *must* be willing to continuously study their clients and "work" to learn the ways they express themselves in order to accurately comprehend what they need. As Allison and Nina indicate, getting to know the client was also done for safety reasons, which also reflects a medical model of care.

This outlook was similarly echoed by my other participants. Given the person-centered approach of care that is endorsed by the Med Waiver, the participants' personal narratives suggest the importance of individualizing work and getting to know their clients' idiosyncrasies, which enable the caregivers to build a relationship with their clients. The women also expressed their preference for having a close bond with clients, since it ensured that caregivers would be able to effectively assess their emotional and physical well-being. Emiliya, who preferred a close bond, further explained the benefits of "getting to know" clients:

"Like, you know, for example, they know you are here for them. Like, you know, they depend on you. Like for example, if anything happened, they know you are there to back them up, like, you know, to help them out, you know? Then you have a relationship with them. Then they say "Ok. If I'm in trouble and I'm trying my best, if I'm in trouble, if I do whatever I'm supposed to do, and I'm in trouble, I know my coach will back me up", you know? Like you know, when they go

to the doctor, for example, if they cannot find their medical history, they cannot explain to the doctor, I explain to the doctor, like you know, you know about them, they know that you're there for them.”

By “knowing” their clients, my participants said they were able to “be there” for them if they were in trouble or could not express themselves to a medical practitioner. Though the women promoted clients’ independence, “knowing” clients let the individuals know they *could* depend on their caregivers. Getting to know their clients means caregivers learn how to effectively assist each individual they care for. This perspective reflects a medical narrative of care, since caregivers emphasize knowing their clients’ medical history and being able to accurately assess their needs. Furthermore, as mentioned earlier, the Med Waiver endorses client-focused caregiving. Though primarily based on the social narrative of care, a person-centered approach of care may lead to bonds between clients and their caregivers- emotional components that are supported by cultural expectations of care, but vehemently resisted by the social model. Thus, the social narrative of care, which the Med Waiver is based on, may encourage relationships as caregivers individualize their work and “get to know” each client. While familiarizing themselves with clients is completed in order to effectively maintain clients’ well-being, caregivers also expressed that they could “be there” for their clients, suggesting that these caregiving relationships went beyond just assisting their clients with tasks.

My participants’ personal narratives also indicate that building relationships with clients was intrinsically rewarding for caregivers. In addition to comprehension of needs and safety reasons, “knowing” a client was completed for the personal, one-on-one factor. As mentioned, majority of the women preferred having a bond with clients, stating that they *wanted* and *liked* having a personal relationship. Some women made parallels to inanimate objects and expressed that clients were not “hamburgers” or a “computer you can shut off”. For instance, Teresa made the following assertion: “you’re not dealing with, you know, groceries! You’re dealing with people.” My participants told me that maintaining a close bond *validated* the caregiver-client relationship as more than just a work-based association. Sharon’s comment regarding knowing her clients highlights the intimate nature of caregiving:

“I’ve even tried nursing homes. I did not like that. *Because* (coughs) it’s not one-on-one. I like one-on-one.... I like to get to know my person, my people that I work with..... This is a very one-on-one, very up close and personal. You *know* the person. Like, I was gonna work, manage one of the group homes. And they told me they weren’t gonna hire me. They loved me. They said “we really like you, but you don’t have a degree”. And I said, “Well, you know what? You go hire a person with that degree that doesn’t know what-we’ll just say, I’ll make up names-Jimmy, Susie, Cathy, Peter-I said, call them in the middle of the night and see what they need. I *know* those clients; you call me up at 4 in the morning and Susie can’t breathe. I can tell you what Susie needs. But you go ahead and hire the person with that degree. So it’s about the caring and the one-on-one aspect. The personal aspect. You get to know the person. And you get the right client, and you get very close.”

Sharon differentiates between working at an institution and as a caregiver through the Medicaid Waiver.

Since she goes into the home of her clients, Sharon asserts that this is a “personal” and “one-on-one” job and expressed her satisfaction with getting personal with the clients she works with. Her account also aligns with the earlier narratives by stating that because she gets to know her clients, she will know their needs. Again, getting to know a client reflects a client-centered approach to care-one that is in line with the social model of care-and, since my participants stated they could better assess their clients’ needs, also parallels a medical model of care. However, knowing clients and developing closer bonds was also *valued* by these women.

A majority of my participants explained that they often became integrated into the lives of their clients, and their relationships went beyond work interactions. This theme demonstrates that these women perceived “good” caregivers as individuals who must learn about their clients; there is an expectation that caregivers will *know* their clients. “Knowing the client” was accomplished as a way to avoid possibly risky health or emotional situations, and a number of the women expressed that knowing their clients enabled them to see if their client was sick or if “something was not right.” Since these caregivers are responsible for maintaining their clients’ well-being, their personal accounts regarding “knowing” their clients reflect a medical model of care. However, the women did not solely learn of their clients’ *medical* backgrounds, but viewed their clients as unique individuals. Individualizing their work relationships aligns with the person-centered approach of caregiving that the Med Waiver rests on. It is important to note that *despite* the medical approach to care that is mirrored in their personal accounts, the women

countlessly explained the value of fostering their clients' independence, a sentiment that reflects the social narrative of care. Since the Med Waiver is predicated on client control, assisting each client means effectively supporting their autonomy and decision-making. Thus, by *knowing* their clients, my participants expressed being better able to assist each unique client.

Principles of the social and medical narratives of care are both visible in my participants' narratives. However, the combination of these disparate approaches of care may lead to close bonds between caregivers and their clients, which reflects the cultural expectations of care. By knowing their clients and individualizing their work, my participants could effectively assist with medical needs, while maintaining person-focused caregiving. Yet, these women also expressed a preference for having a closer bond with their clients, due to the "one-on-one", personal nature of the job. The women not only cared for their clients, but also grew to care *about* them-values that reflect the cultural expectations of care that are placed on women. As Sharon states, "you get to know the person. And you get the right client, and you get very close." By adhering to the differing expectations of care that exist in the Med Waiver, my participants inadvertently formed close relationships with the individuals they care for, aligning their personal narratives with the cultural notions of care. Thus, my participants' accounts reflect a combination of and interplay between the social, medical and cultural narratives of care.

## Chapter 4

### Discussion

The current study examined caregivers' self-narratives to gain insight into how the women portrayed the various characters they had contact with. A narrative framework was utilized to examine the parallels between caregivers' personal narratives, and institutional and organizational narratives. The findings from the analysis demonstrate that caregivers' narratives closely reflected the institutional and organizational narratives of the Medicaid Waiver Program and also aligned with the cultural notions of care; this was evident based on how the women talked about their clients, legal guardians and themselves. However, tensions between these disparate narratives of care and my participants' personal narratives were also presented.

Regarding their clients, caregivers' narratives emphasized clients' individualism. Though there was a common assumption of clients as in *need* of care and requiring assistance due to their condition, the women did *not* view the individuals through a one-dimensional view or a medical lens. Rather, caregivers maintained that clients were all "different" and each one was evaluated as a unique individual, even when clients shared similar medical conditions. Furthermore, the women's narratives characterized their clients as in control and perceived them as "bosses." These women work through organizations that train caregivers to adopt the philosophy that clients *must* be in control of their lives. Based on these caregivers' stories, it is evident that caregivers' personal narratives mirror the institutional and organizational narratives. *Through* the caregiver, clients were able to control their own actions and the activities of the day.

Caregivers' narratives also suggested that relationships with clients' parents and guardians were complex. According to their stories, qualities in the form of communication and consultation formed beneficial relationships between these individuals. The women expressed that they found it valuable when guardians were perceived as individuals who caregivers could communicate and consult with about the client. The women also said that there were challenging qualities that presented difficulties within these relationships. These challenging qualities are exemplified when parents and guardians' viewed clients as "child-like" and tried to control clients' choices. The Medicaid Waivers Program promotes a vision of clients that is in line with the social model approach to caregiving. Caregivers are trained by their agency to accept and endorse this social model-based narrative. Caregivers' self-narratives regarding their views of clients resonate with the agency's narrative regarding their view of clients. Conversely, guardians may have adopted a view of clients that reflected the medical model approach. Thus, challenges emerged when guardians were perceived to uphold views of clients that aligned with a medical narrative, a view that is oppositional to the social model narrative of care. The women argued that such a vision precluded clients from experiencing life on their own terms and denied them independence.

Given the organizational narrative that emphasizes clients' independence and right to choose, it is not surprising that caregivers constructed themselves as preserving clients' choices. The analysis of these narratives indicates that elements of the social, medical and feminist narratives of care were interrelated in good caregiver-client relationships. The women's narratives reaffirmed the agency's social model-based philosophy. Educating clients about their choices was one way caregivers maintained the agency's values. Furthermore, in case of safety or health concerns, caregivers provided clients with substitute choices that closely resembled clients' perceived "risky" choices. This is particularly important because even though caregivers' sentiments tended to align with the social model of care (they saw their clients as "whole" beings, rather than their medical diagnostic, and maintained clients' control and independence), they simultaneously took on the medical model perspective as they looked out for their clients' health and safety via education and provision of alternate choices. Here, caregivers had to provide an "illusion" of

choice when clients wanted to do something perceived as dangerous to their well-being. Finally, caregivers depicted “good” caregivers as individuals who “know” their clients, allowing the women to comprehend clients’ needs. They also expressed a preference for having a closer bond with their clients, due to the personal nature of the job. These findings show how the different levels of narratives within the realm of caregiving (personal, organizational, institutional) are reflexive. The cultural notions of care emphasizes that caregivers must be attuned to the individuals they care for, and to care *about* them. This finding suggests that caregivers’ narratives paralleled cultural notions of care as they developed an intimate bond with their clients.

Existing literature commonly focuses on paid caregiving as it relates to elderly or child care. Regarding caregiving of individuals with impairments, studies primarily focus on informal caregiving. My research adds to the discourse on disability and caregiving by looking at personal narratives of women who are employed to care for individuals with impairments. I do this by employing a pluralistic approach to care that accounts for multiple disparate narratives of care. This research also provides empirical evidence that indicates how at the ground level, these narratives of care become “muddled” as caregivers interact with clients and other significant individuals. According to their self-narratives, the work my participants do requires careful balancing of often contradictory expectations. My study accounts for aspects of this balancing act and illuminates the amount of skill this work takes. Walking between the medical and social models of care creates a need for complicated skill sets that my participants are *not* paid for. Furthermore, my participants’ narratives implied that tensions emerged related to what was expected of them from the disparate narratives of care, and what they expected of *themselves* based on the prevailing cultural expectations of care.

My research provides insight into experiences of paid caregivers of individuals with impairments, but there are some limitations to consider. Though my findings are not intended to generalize, it is important to consider the limited sample size of my participants. A larger sample size may be able to provide a deeper understanding into the representations of individuals these women work with.



Furthermore, a vast majority of my sample were Caucasian women, which does not make for a diverse population. Though I specifically focused on the experiences of women, given the gendered nature of this work, future research could also consider adding a varied perspective by including men in their study. Other findings from the analysis are also worthy of consideration. A majority of women talked about caregivers being “underpaid,” which is in line with existing literature that depicts caregiving as a low-wage field. The women also discussed the various skills and talents they picked up over the course of their caregiving careers, and benefits associated with this work. One specific benefit was the belief that care recipients encouraged my participants to “come out of their shell,” since they often had to advocate for their clients. These findings are worthy of further examination, given the amount of people-work and communication skills these women must do despite the low pay they get.

I argue that experiences of caregivers who provide services for individuals with impairments should be further addressed. Similar agencies that cater to individuals with impairments should be examined in scholarly work, specifically from the perspective of the workers who are paid to provide direct services. Given the complex caregiving relationships and balancing of contradictory expectations these workers engage in, and the unfolding “care crisis” in United States, gaining further insight into these experiences would be beneficial. By studying narratives of individuals who have typically been overlooked in the field of disability and caregiving, I hope my research is an additional substantive step.

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## Appendix: Interview Guide

Note: This is a general guide. Interviews will be conducted as informal conversations and interviewees will be allowed to talk about issues not included on the guide.

### 1. Could you tell me a bit about yourself and your family?

Age  
Ethnicity  
Education background  
Where they grew up  
How long they've lived in FL/Tampa  
Married/living with someone  
Any children/grandchildren/current family caregiving responsibilities  
Hobbies, etc.

### 2. Could we talk about how you got started in caregiving?

When and why they started  
If they've done other caregiving jobs  
Other kinds of work they've done  
How they think their friends and family feel about their work as caregiver  
When they tell people what they do for work, how they usually respond  
Do they plan to stay in this line of work or move on to something else?  
Is there anything about caregiving that keeps them in this line of work?

### 3. What do you think it takes to make a good caregiver?

What they think the most important things caregivers do and why  
**(If it doesn't come up in the conversation) Do you feel like there are any skills or talents that you've picked up from being a caregiver? If so, what are they?**

How do you think such skills are important or useful for this line of work?  
How long did it take you to pick up on these skills?  
Do you use these skills outside of your work?

### 4. What's it like to work for the Medicaid Waivers program?

How does the program define a "good" caregiver and if they agree  
Anything they especially like and dislike about being a caregiver  
Do they talk to other caregivers and if so, what they talk about  
If they could change anything about the Medicaid Waivers Program, what it would be

**5. (Before asking this question, ask what they prefer to call the people they work with, and if the Medicaid Waivers Program has a specific term they are ‘supposed’ to use). Can you tell me about some of the clients you've worked with?**

How many they work with now and to describe the ones they work with the most  
How they understand the wants/needs of clients if they don't communicate it  
(If the question applies) Can you tell me about how long it took you until you were able to comprehend what specific clients needed or felt?

**6. Can you walk me through a typical day in your job as a Medicaid Waivers caregiver?**

Types of things that may happen they find particularly rewarding/pleasing, and things they may find particularly unrewarding/unpleasing.  
How the client and they decide what to do each time they're with them  
If the client and they've ever disagreed on what to do. If that were to happen, ask what would they do, and what the Medicaid Waivers Program say they should do  
What they would do if a client wanted to do something unsafe/unhealthy  
If they have contact with legal guardian of client, ask to tell me about that  
What they would do if the client wanted to do something the guardian didn't want them to do  
Who they typically consider to be their boss/supervisor

*If they talk about close bond with client/client's family, ask if they ever feel like an extended family member or other mother to the clients they work with:* How long it took until reaching this point and ask to describe that process. Ask if they prefer to have a close bond with clients, and if so, why?

**7. Can you tell me what it's like when you and your \_\_\_\_ go out in the community together?**

*If/when they take client out into the community, what typically happens:*  
What they and their client like/dislike to do,  
Things they typically do for client when out in the community,  
Responses they get when out in the community,  
If reactions are different based on different client, why they think that is and what they do about it  
If they do things with their own family and/or friends and the client  
If they do things with the client when they aren't being paid?

**Concluding inquiries:**

**Is there anything else you think is important to know about this job, and if there is anything else you'd like to tell me about your job as a caregiver?**

**Do you have any questions for me?**

**Thank you so much!**