Understanding Adult Foster Care Provider Experiences

Kelly Munly

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Karen A. Roberto, Chair

Katherine R. Allen, Co-Chair

Jyoti Savla

Gresilda Tilley-Lubbs

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ABSTRACT

In this study, I explored Adult Foster Care (AFC) provider experiences. AFC is a small-setting option for community-based long-term care. This option varies considerably in accessibility and structure across states; due to the nature of the state's approach to AFC, this initial research effort focused on AFC provider experiences in North Carolina. As of 2013, there were 632 AFC facilities in North Carolina (NC DHHS, 2013). AFC homes in North Carolina are licensed by the state and allow service for 2-6 residents per home (Mollica et al., 2009). The approach to research was informed by literature on AFC, the disabilities context of AFC, and Child Foster Care (CFC). The theoretical framework guiding the study included theories of care and relational reciprocity; power, difference, and hierarchy; and intersectionality. I conducted semi-structured, guided interviews with 26 providers. As a context for grounded theory data analysis, I also relied on reflexive material stemming from my positionality as a care worker. Emergent codes related to issues of the providers' motivation for beginning work as an AFC provider; providers' personal and professional roles; perspectives on giving residents a choice; balancing "family" with business; reciprocity and how residents express their affection and care to providers; providers' values; and dialectics of power and care. Findings shed light on implications for state and organizational responsibility to the AFC system, and practice context for provider-resident relationships.

DEDICATION

I dedicate this dissertation to "Henry," "Tom," Mabel, and all others who have taken me in and cared for me in my attempts to care for them.

ACKNOWLEDGEMENTS

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CHAPTER 1: INTRODUCTION

Statement of Problem

With the aging of the population, both in the United States and globally, community leaders are facing an increasingly urgent challenge to ensure sufficient care services and providers for the nation's elders (Bloom & McKinnon, 2010; Uhlenberg & Cheuk, 2008). In the United States, the population of adults age 65 and older is expected to increase from 13% in 2010 to nearly 20% by 2030 (Federal Interagency Forum on Aging Related Statistics, 2012). The growth in the older population is a result of the transition of baby boomers (born between 1946 and 1964) into older adulthood and increases in life expectancy due to advancing health practices (Federal Interagency Forum on Aging Related Statistics, 2012; Olshanksy, Goldman, Zheng, & Rowe, 2009). The steepest population increase will be among the oldest-old, individuals 85 years and older. As a group, the oldest-old are likely to have high morbidity and care needs (Bloom & McKinnon, 2010; Federal Interagency Forum on Aging Related Statistics, 2012). This marked increase in numbers of older adults needing more intensive care suggests the need for a range of long-term care housing and service options and sufficient numbers of trained long-term care workers dedicated to the well-being of these elders (Davey & Szinovacz, 2008; Uhlenberg & Cheuk, 2008).

Individuals with disabilities are another group that has a marked need for long-term care housing and services, especially as these individuals age. Over 54 million individuals in the general population—not including those in care facilities—have a disability, whether intellectual, physical, or age-related (National Council on Disability, 2005, 2010). This number does not include the 2.17 million individuals living in care facilities, such as nursing homes or group homes; these individuals are usually not included in census and other federal reports that provide information on housing need (National Council on Disability, 2010). A disproportionate number of individuals with disabilities are racial/ethnic minorities and poor, and they are underserved in numerous ways, including with regard to housing and health services (National

Council on Disability, 2005). Among individuals between the ages of 25 to 64 in the civilian

population, 27% of those with severe disabilities experience poverty, in contrast to only 12% of

those with nonsevere disabilities, and 9% with no disability (National Council on Disability,

2010). Whether living in the community or already living in a care setting, there is an urgent

need to plan for the housing needs for American citizens who struggle with disabilities,

especially those without the financial resources to pay for their housing and care needs.

        The spectrum of long-term care housing options ranges from large to small settings

(FamilyCare America, 2012). Large settings include assisted living facilities and publicly-funded

institutional care, such as nursing homes. However, there is a nation-wide policy-driven move

away from large publicly-funded institutional care, including nursing home care, toward more

integrated community-based care (National Council on Disability, 2003). This movement is

supported by the 2003 Money Follows the Person (MFP) state grant initiatives that have allowed

funding originally paid to nursing homes to "follow" a nursing home resident to a community-

based option that also has the potential to offer the resident greater control over their

experience (Reinhard, 2012). Assisted living facilities may remain prevalent and available to

those who have the financial resources to pay for the amenities that such facilities provide.

However, assisted living facilities are also debated by MFP policy enforcers as being settings

that are too controlling of residents, and in this way resembling the institutional characteristics of

nursing homes (Reinhard, 2012).

        Medicaid funding was originally tied to institutional care, and was especially prevalent in

nursing home care (Reinhard, 2012). Staff attitudes historically dominating nursing home care

were that new residents would need to adjust to the nursing home environment, rather than

anticipating an opportunity to leave it for a more independent environment; these attitudes were

reinforced by ageist views of elders (Reinhard, 2012). Quality of life in nursing homes has

varied according to levels of Medicaid reimbursement within each nursing home context;

increased Medicaid reimbursement is associated with higher quality of care, as measured by

activity of daily living (ADL) decline, restraint use, worsening of pressure ulcers, and persistent

pain (Mor et al., 2011). Smaller, community-based settings, though also often Medicaid-funded,

allow opportunity for more personalized care. The smaller settings are usually designed to be

more home-like (often in a family or family-like home) and are positioned within neighborhoods

and communities that allow greater opportunity for resident choice and integration with the

community. It may be that small settings also vary in quality of care depending on the levels of

Medicaid reimbursement in each state and setting facility.

National Long-Term Care Policy

Precedence for quality long-term care was established with the Omnibus Budget

Reconciliation Act of 1987, stipulating standards and improvements in nursing home care (Kelly,

1989). This momentum toward improved quality of care created a platform for additional

systemic improvements captured by the 1999 Olmstead decision under the Americans for

Disabilities Act (ADA), which mandated quality community-based care options for all individuals

with disabilities—age related or not.

> In 1999, by a clear majority, the United States Supreme Court held in Olmstead v. L.C., 527
>
> U.S. 581 that, under the Americans with Disabilities Act (ADA), undue institutionalization
>
> qualifies as discrimination by reason of disability and that a person with a mental disability
>
> is 'qualified' for community living when the state's treatment professionals have determined
>
> that community placement is appropriate, the transfer from institutional care to a less
>
> restrictive setting is not opposed by the individual, and the placement can be reasonably
>
> accommodated, taking into account the resources available to the state and the needs of
>
> others with mental disabilities. (National Council on Disability, 2003, p. 2)

States have responded in diverse ways to the Olmstead decision to move away from

institutional care, and on varied timelines (National Council on Disability, 2003). This variability

may contribute to the great inconsistency in how states have implemented community-based

forms of long-term care. For example, in Colorado, four separate state agencies created unique

Olmstead plans, theoretically to be eventually combined (National Council on Disability, 2003).

Illinois, with a very high level of institutionalization of individuals with disabilities, established a

steering committee of stakeholders to begin Olmstead planning, with the state acknowledging

that it was simply a first step in their planning stages (National Council on Disability, 2003).

California proceeded as if they were initiating an Olmstead plan through their formerly existing

Long Term Care Council, but did not actually begin initiating their plan until receiving pressure

from disability coalition members (National Council on Disability, 2003). Virginia was also slow

to act in response to the Olmstead decision, with the state legislature finally mandating a related

task force in 2002 (National Council on Disability, 2003; Virginia Department of Social Services,

Division of Family Services, Adult Services Programs, 2010). Virginia is currently in the process

of closing all but one of its largest institutions that care for adults that are dependent due to

intellectual disability, including developmental disability, dementia, and mental illness, often

comorbid with physical disability (Kumar, 2012).

The range of state priorities in implementing the Olmstead decision impacts individuals

needing long-term care. For example, although North Carolina began to develop its Olmstead

plan in 2000, its process for doing so has not yielded significant empowerment or quality of life

changes for residents living in care facilities that may not be aware of their options and potential

for better life experience.

Unfortunately, the process for identifying institutional residents for community placement in

the North Carolina plan is inconsistent with Olmstead and with North Carolina's own

extensive experience with implementation of a pre-Olmstead class action suit, Thomas S. v.

Flaherty. Specifically, the plan provides that assessment for transition will occur only after

the person has expressed a preference for community placement. (National Council on

Disability, 2003, p. 141)

Supportive Housing Options

Community-based supportive housing options include small facilities such as group homes, congregate care, board-and-care homes, and adult foster care (FamilyCare America, 2012). Definitions of these living environments often differ across and within states. For example, group homes may be categorized as assisted living facilities with intensive health services offered, or they may resemble independent but congregate living environments for retired individuals (Janicki, 2011). Group home care is sometimes specialized for individuals with intellectual disabilities who may also experience mental illness or dementia. These divergent models of group homes have different funding mechanisms (private and public) and regulatory agencies, with regulations driving staff and resident ratios, as well as care services offered to residents (Janicki, 2011). The current research literature on group homes primarily reflects adult residential care services outside of the United States and group care options within the United States for youth (Mabry, 2010; Smit, te Boekhorst, de Lange, Depla, Eefsting, & Pot, 2011). With regard to international care setting terminology, the use of the term *group home* in Europe, for example, includes applications to homelike settings that can include more intensive medical care, such as dementia care. In Holland, *group living homes* are homelike settings offering intensive medical care, serving 6-8 individuals, and prioritizing visits and decision making with the biological family of the residents (Smit et al., 2011). Health officials in Holland have recognized the value of the qualities of group living homes to such an extent that some of the characteristics are being incorporated in larger nursing homes (Smit et al., 2011). It is thus suggested that future research examine characteristics of group living home care in all settings, small and large, rather than conducting simple comparative research between settings of different sizes (Smit et al., 2011). The lack of current research on group home settings for adults in the United States may reflect inconsistent terminology for residential care or that group home care in the United States is understudied.

Board-and-care facilities are privately- or publicly-funded and generally have less than 12 adults not related to the home manager. Services provided in board-and-care facilities often

include a room, meals, housekeeping, and general protective oversight. This type of care has also historically provided end-of-life care to individuals, including persons of low income (Carder, Morgan, & Eckert, 2006). Driven by different regulatory policy across states, board-and-care facilities are defined and licensed as adult foster care (AFC) in some states, but as assisted living in others (Carder et al., 2006; Morgan, Eckert, & Lyon, 1993). A strength of board-and-care homes is the capacity for interpersonal relationships with other residents and staff, but this is largely anecdotal and difficult to measure with existing instruments (Carder et al., 2006). More "family-like" care was reported in interviews with 36 operators of board-and-care facilities when the care contexts were more integrated with the facility operator's own family life; more "business-like" care was evident in a small number of individuals whose domestic life was markedly separate from the board-and-care services they provided (Eckert, Cox, & Morgan, 1999). The unregulated nature of board-and-care has allowed it to be more personal and specialized, but there is inconsistency in quality due to this lack of regulation (Morgan et al., 1993).

One approach to categorizing supportive community-based care options is to bring all small care settings under the umbrella of adult foster care (AFC) (McCoin, 1983, 1985). Historically, AFC had included diverse care structures such as adult board facilities, adult family care homes, board-and-care homes, boarding homes, community care homes, personal care homes, residential care homes, and shelter care facilities (McCoin, 1983). The absence of a strict definition of AFC has contributed to the challenge of studying this care option. After finding great diversity in AFC definitions and characteristics across states, AARP developed a consensus definition of AFC -- care settings that provide residents with physical and intellectual disabilities with a home- and family-like environment with opportunity for 24-hour care and community integration (AARP Public Policy Institute, 2009). According to the Americans with Disabilities Act (ADA), a person with a disability is an individual who either has or is seen as having a mental or physical impairment that significantly limits life activities (U.S. Equal

Employment Opportunity Commission, 2008). Depending on funding mechanisms available at

an AFC site (e.g., auxiliary grants for frail elders or Medicaid ID funding for adults with

intellectual disability), AFC can be an appealing alternative to nursing home or other public

institutional care for adults of any age who are dependent due to age-related frailty or an

intellectual or physical disability (AARP Public Policy Institute, 2009; Mollica et al., 2009).

Much of what is known about the current state of AFC across the nation is informed by

data gathered by AARP in 1996 and updated in 2009, based on interviews with state officials,

community informants, and AFC providers (AARP Public Policy Institute, 2009; Mollica et al.,

2009). In December 2008, 18,901 AFC facilities were serving 64,189 residents across 30 states

(AARP Public Policy Institute, 2009; Mollica et al., 2009). AFC varies significantly across states,

in terms of regulations, name of the service (e.g., adult family care homes, board-and-care

homes), financing, and numbers of residents served within an AFC facility. Some states provide

AFC certification to providers, and other states provide licenses. Some state regulations also

include standards for Medicaid participation, and other states regulate AFC through existing

assisted living conventions. AFC providers manage and sometimes own the facility in which

care is provided; the facility can be the provider's own home but is sometimes corporately

owned. Most states have limits of no more than five residents served per AFC home, though

there are exceptions (e.g., North Carolina allows six). Providers typically have backgrounds as

family caregivers, nursing assistants, or nurses, with some degree of medical knowledge

informing their interest and ability to provide or at least oversee care for individuals who may be

experiencing age-related or other disabilities. However, this background is not required if other

certifications for required skills (e.g., first aid, cardiopulmonary resuscitation, medication and

diabetes management, and therapeutic options for behavior management) are available through

the state or a private agency. Furthermore, though providers are usually responsible for the

well-being of their residents 24 hours a day, they often rely on respite services in the form of

adult day care or from visiting back-up workers.

According to data from the interviews conducted by AARP with providers across the nation, AFC providers demonstrate "willingness and ability" to provide service to individuals "with high levels of need" (AARP Public Policy Institute, 2009, p. 2). In contrast, Medicaid-dependent adults who struggle with physical or intellectual disabilities are often not appealing as residents to owners of assisted living facilities who are concerned about making a profit and presenting an attractive façade to other possible clients (AARP Public Policy Institute, 2009). It is more difficult for assisted living facilities to make a profit when caring for Medicaid-dependent adults, due to low Medicaid rates and high staffing ratios needed for individuals with greater need for care due to disabilities. Some assisted living facility owners fear that Medicaid-dependent adults with obvious physical disabilities or speech and behavior unique to their intellectual disabilities may make prospective clients uncomfortable (AARP Public Policy Institute, 2009).

As well as providing a service to an underserved group (i.e., adults with disabilities), AFC saves states money (AARP Public Policy Institute, 2009; Mollica et al., 2009). AFC does not have the overhead and extensive operating costs of large institutions. Medicaid-funded residents usually pay for their room and board expenses with their Supplemental Security Income benefit, and Medicaid pays for some health and additional care services needed. However, the financial burden may be taken from the state and transferred to the AFC provider, as the provider must carefully balance a budget inclusive of home repair, cleaning services, additional respite service, and recreational activities for the residents. Therefore, depending on the funding mechanisms utilized by AFC agencies in each state, providers may only break even financially. Thus, the lack of adequate compensation may threaten the sustainability of the care context, as has already happened in Connecticut and Utah, with two and zero providers, respectively (Mollica et al., 2009).

State financing for AFC comes from the Department of Health and Human Services or the Department of Social Services to one of three options: an AFC corporation that provides

care in family-like but corporately owned residences; an AFC agency serving as an umbrella

over multiple care providers (each providing direct care in a home setting); or directly to

independent providers (Mollica et al., 2009). In Virginia, AFC is funded by auxiliary grants (a

supplement to income for recipients of Social Security Income), private pay by the resident, and

Medicaid ID waivers (funding based on eligibility for long-term care, but not limited to

institutional settings). Conversely, Massachusetts' program includes 36 program sponsors (e.g.,

Franklin County Home Care Corporation), each one that operates the state's AFC program and

oversees caregiver recruitment, training, auditing, and reimbursement.

      As gatekeepers to services and community engagement for the AFC resident, the care

providers are fundamental to AFC resident experience; this central role is true whether

providers work independently, under the umbrella of AFC agencies, or for an AFC corporation.

All providers across these AFC structures are the primary managers of their residences and the

responsible party for their residents' well-being, whether or not there is respite care available

(Mollica et al., 2009). Care providers are uniquely situated between regulations stemming from

policy and the outcomes experienced by the care recipient. Understanding providers'

perspective on and experience of AFC as community-based care will shed light on issues of

state policy implementation and subsequent impacts on care contexts and care receivers.

      I began my efforts to understand AFC through care provider experience in North

Carolina. Many states resisted acting on the Olmstead decision through delay or inadequate

implementation in various forms; North Carolina uniquely resisted it by offering community-

based alternatives to institutional care only if requested by the resident. This reluctance

demonstrated by North Carolina to adamantly share options for community-based care inspired

a question about state dedication to the AFC system, and consequently a question about care

provider attitudes within the system, ultimately affecting the quality of the system and the

experience of the AFC resident. Interviewing AFC providers in North Carolina was a first step to

understanding these issues. Although the understanding provided by these interviews was

through the lens of the provider, this lens has most importantly provided a glimpse of AFC

resident experience within the framework of provider experience, care context and overall

organizational dynamics. With an interest in understanding these contexts and consequences

of community-based care offered to dependent adults in North Carolina, I implemented an

interview protocol for AFC providers in North Carolina driven by the following research

questions.

1. How do Adult Foster Care (AFC) providers perceive the AFC system and their
   relationship to the AFC system?
2. How do AFC providers perceive their residents?
3. What strategies do AFC providers implement in their efforts to integrate residents into
   the AFC homes and communities?
4. How do AFC providers recognize, adhere to, or resist existing power relations and
   constraints in the AFC system as they impact their ability to provide care for residents?

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

This chapter includes a discussion of the history and empirical literature that provides

the background for understanding AFC. Because current research on AFC is limited, I also

introduce literature from the field of child foster care (CFC) that presents similar and sometimes

contrasting issues. I then introduce a theoretical model that includes both theories of care and

power. The theoretical model is inspired by the nature of the care context structure and the

relationship between the AFC resident and care provider, as well as by attributes and struggles

of the population served in AFC.

History of Adult Foster Care

AFC is not a new form of long-term care, with records of family placement of individuals

with mental illness going back to 1250 in Gheel, Belgium (Aptekar, 1965; McCoin, 1983). In the

colonial period of the United States, impoverished individuals with mental illness, as well as

other impoverished children and adults, were sometimes placed with families in private homes,

but funded with public money. This practice stopped near the end of the 1600s with the

inception of almshouses, or charitable housing for impoverished individuals (McCoin, 1983;

Morrissey, 1967). By the mid-1800s, Scotland became famous globally for its practice of

placing individuals with psychiatric illness in adult foster homes (Pollock, 1945). In the mid-

1800s, United States leaders visited the programs in Belgium and Scotland and began to

encourage the idea in the United States as a form of care for individuals with mental illness

(McCoin, 1983). The first states to adopt AFC were Massachusetts, Rhode Island, Maryland,

New York, and Utah (de Alvarado, 1955; McCoin, 1983; Morrissey, 1967; Pollock, 1945). Some

states delayed implementing AFC as an official policy-supported form of care for individuals with

mental illness, while others documented AFC as care supported by policy but lagged in actually

implementing the program (de Alvarado, 1955; McCoin, 1983; Morrissey, 1967; Pollock, 1945).

In the 1950s many psychiatrists began to applaud AFC as a solution for care for individuals with

mental illness (McCoin, 1983). Research and general information on AFC dwindled, however,

until the 1970s, when greater emphasis on community placement of individuals with mental

illness emerged (McCoin, 1983). AFC also began to be considered in the 1970s as a housing

and care solution for frail elders and for individuals with intellectual disabilities who were

beginning to reenter the community from prior institutionalization (Birenbaum & Re, 1979;

McCoin, 1983; Sherman & Newman, 1977). McCoin's (1983) and Sherman and Newman's

(1977) works are the most recent accounts of the history of AFC in the U.S.

Literature Review

There is limited literature on AFC. A search of the Ebscohost Psychology and

Behavioral Sciences Collection yielded only 10 academic papers related to AFC, spanning from

1977-2011. These studies included one dissertation, four program reviews, three studies

employing descriptive statistics, and two studies using more advanced statistics (e.g.,

regression, hierarchical modeling). There are also books by McCoin (1983) and Sherman and

Newman (1988) that reviewed prior history of and very early studies about AFC. Documents

produced at the federal- and state-level provide insights into the current status and nature of

AFC across the country (AARP Public Policy Institute, 2009; Mollica et al., 2009; Virginia

Department of Social Services, 2010).

The literature spanning several decades has presented mixed perspectives on and

nuances about AFC as a care option. For example, Miller (1977) described an AFC program in

Danville, Illinois, that included 52 foster homes. Foster home records indicated that

implementing AFC for persons with mental illness resulted in low institutional recidivism and

participation in community recreation that Miller suggested would not be possible in larger

institutions. Sherman and Newman (1979) conducted field research over the course of seven

years with several groups of AFC residents (e.g., individuals with mental illness, individuals with

intellectual disabilities, and frail elders). These researchers reached the conclusion of the

importance of considering multiple aspects of AFC environments and processes to ensure best

outcomes for residents. Such aspects included the personal or humanistic nature of recruitment

approaches, appropriately matching residents with homes, allowing for residents to visit homes before placement, providing adequate training for care providers, and scheduling comprehensive follow-up visits.

Some authors have quantitatively compared resident experience in nursing home care and AFC. For example, in interviews with 400 nursing home and 400 AFC residents, Kane et al. (1991) found that AFC residents reported more social activity than nursing home residents, even when controlling for disabilities experienced by the resident. Taking such comparison a step further, resident experience of AFC programs may depend on resident needs and how the opportunity to live in an AFC setting is framed for the resident. Magaziner, Zimmerman, Fox, and Burns (1998) suggested that AFC may serve as a sufficient alternative to nursing home care for individuals with and without dementia if medical needs are not too severe. Reinardy and Kane (1999) interviewed 260 AFC residents and 179 nursing home residents in Oregon and found an interaction between the residence type and the decision to relocate to the residence. Adults who had the opportunity to choose AFC spoke positively of the opportunity for a home-like environment; however, if the relocation transition to AFC resulted in the adult feeling disempowered, they were not satisfied with the new setting. The contrast between having control and not having control was not as marked among nursing home residents.

There have also been comparison studies more thoroughly exploring resident outcomes in nursing home care alongside AFC. For example, a study conducted in Kentucky by Gaugler, Leach and Anderson (2004) included 16 family care homes, 5 assisted living facilities, and 5 nursing homes in an analysis of long-term care outcomes across indicators of psychosocial status. Interviews with 79 resident-family-staff triads revealed that residents in family care homes had lower self-esteem and indicators of belongingness than nursing home residents. In explaining their results, the authors acknowledged the complexity of care contexts, especially with care receivers experiencing diverse chronic conditions, and that their study may not have captured the multidimensionality of each facility experience sufficiently.

The AFC program reviews are anecdotal, emphatically presenting AFC as a positive influence for residents. For example, Edes (2010) presented a program review on veterans in AFC settings that praised the opportunity for injured veterans, suffering from physical, cognitive and psychiatric disabilities, to receive adequate medical care in a family-like setting. The veteran AFC care was further supplemented by the VA Medical Foster Home (MFH) program, which provided support such as technical training specific to veteran medical care needs (Edes, 2010). The dissertation by Johnson and Hoff (2011) took another approach to AFC research with an analysis of corporate capability for expansion of AFC services into a metropolitan area with greater demand for care. The authors concluded that expansion would be favorable because the AFC corporation was family-run with a sense of internal trust and accountability and had promising financial conditions and technology infrastructure for corporate communication and control between sites.

AFC Residents with Disabilities

When considering potential strengths of AFC, including appropriate matching of residents with homes and providing adequate training for staff, it is important to think about who the residents are. Many AFC residents result in their care settings due to the Olmstead Decision and the national impetus for community-based forms of care, and many are funded by Medicaid Waivers for individuals with intellectual disabilities and auxiliary grants for frail elders with disabilities. Therefore, the residents will almost all have some frailty or one or more disabilities. Redfoot and Houser (2010) indicated that increasingly there are fewer older adults with disabilities in institutions, such as nursing homes, and more in assisted living and other types of community-based care. These authors also imply that population shifts in type of care institution can distort the meaning of statistics and ensuing implications for population care needs. For example, they reported that the

decline in the number of older persons with disabilities in institutions was more than offset

by the growth in the number of persons [assumed by the authors to need assistance] in

community residential care facilities such as assisted living between 1999 and 2004.

(Redfoot & Houser, 2010, p. 5)

Furthermore, with increased disabilities among adults ages 18-60, due to obesity and other

physical health conditions, there is potential for young adults to age with functional disabilities

and require community-based care (Freedman et al., 2004; Freedman & Martin, 1999; Heisel,

2012; Redfoot & Houser, 2010; Reynolds, Saito, & Crimmins, 2005; Spillman, 2004; Strum,

Ringel, & Andreyeva, 2004; Uhlenberg & Cheuk, 2008).

AFC residents with disabilities are also likely to be of lower socioeconomic status.

Redfoot and Houser (2010) highlighted data from the 1984-2004 National Long-Term Care

Survey that corroborated that lower income is associated with greater ADL disabilities:

Three out of five older persons living in the community with two or more ADL disabilities

(i.e., inability to perform basic self-care activities, such as bathing and feeding ourselves)

reported annual incomes of less than $20,000, roughly the individual income eligibility

standard for Medicaid assistance in most states in 2004. (p. 5)

Denavas-Walt, Proctor, and Smith (2011) presented an analysis of 2009-2010 U.S. Census

data indicating that there was an increase in both the number and rate of uninsured among

adults with disabilities (increasing from 16 to 17.3%, and 2.3 million to 2.6 million) compared to

adults without disabilities. If AFC residents are more likely to have disabilities (cognitive or

physical) and are poor, it is compelling to examine the community-based long-term care

opportunity offered to this underserved group with multidimensional needs, as well as the

experiences and perspectives of their care provider. Such an examination can serve as a check

to see whether or not community-based care is sufficiently remediating the disparities

experienced by this group, and if more attention is needed from states.

Child Foster Care: A Comparison with Adult Foster Care

Examining relevant literature in the CFC field can inform an understanding of the nature

and experience of AFC, from both a care provider and resident perspective. Furthermore,

contexts in CFC that are unique to the experience of developing children can also shed light on the contexts unique to AFC, serving adults that are many times likely to be dependent for the rest of their lives.

The United States child welfare system oversees the foster care of more than 400,000 children, with most children entering this system as infants and vulnerable to influences from new caregivers and caregiving contexts (Bruskas, 2010). CFC providers working within the child welfare system tend to be less educated and poorer than caregivers of children at large; this is true even if the CFC provider is kin (Barth, Green, Webb, Wall, Gibbons, & Craig, 2008; Scannapieco & Hegar, 2002). If children and youth in CFC have not had family or other caregivers who can adequately care for them, youth aging out of the CFC system are at risk for lacking sufficient housing, educational opportunity, and other types of resources and support (Blakeslee, 2011; Yen, Hammond, & Kushel, 2009). Fortunately, there have been positive developments and collaborations between social service providers, child welfare, and housing in efforts to alleviate the transition into education, employment, and stability for CFC youth (Choca et al., 2004). However, there are CFC youth with disabilities who need supplemental support as they transition, and there are insufficient services tasked to provide such resources and information (Hill, Lightfoot, & Kimball, 2010). Research indicates that care providers are critical facilitators of well-being among CFC youth with greater needs. In therapeutic CFC settings, better relationship quality between the treatment parents (i.e., care providers) and CFC residents with serious emotional and behavioral disorders has been significantly associated with better emotional and behavioral functioning (Southerland, Mustillo, Farmer, Stambaugh, & Murray, 2009).

CFC providers are expected to not only care for their residents, but also maintain working relationships with partner agencies and the residents' biological families, if available (Pasztor, Hollinger, Inkelas, & Halfon, 2006; Warde, 2008). The providers are ultimately tasked with a significant challenge in caring for a foster child that may have special needs; relationships

with partner agencies are therefore crucial for the well-being of the child and to alleviate care

burden for the provider. Understanding and managing the role of the biological family members

is also important for foster children's development and sense of relational place, that is, where

they fit within the foster family and how they are supported by the diverse range of individuals

and agencies in their lives. A collaborative role between providers, partner agencies, and

biological family members may or may not be fulfilled, depending on provider perspectives and

regulations about and auditing of this expectation (Pasztor, Hollinger, Inkelas, & Halfon, 2006;

Warde, 2008). Providers often feel that their first priority is the care of the child and that

fostering other partnerships are of secondary importance (Warde, 2008). In CFC, case workers

are the gateway to making sure the care provider maintains these key relationships, as well as

to all services and programs benefitting the residents (Dorsey, Kerns, Trupin, Conover, &

Berliner, 2012). Furthermore, CFC services and resident overall experience may vary

according to CFC system structure, including staffing policies, services available, and funding

mechanisms. For example, Humphrey, Turnbull, and Turnbull III (2006) found that privatization

of CFC services negatively impacted the services. The authors attributed this negative impact

to factors including that mental-health services were not as accessible, there were inappropriate

placements in homes, caseload levels were too high, agency financial priorities may have held

sway over the best interest of a child, and there were more communication problems among

staff (Humphrey, Turnbull, & Turnbull III, 2006).

      There are both similarities and differences between AFC and CFC providers, residents,

and systems. Both AFC and CFC providers experience financial struggle. However, for AFC

providers, personal poverty is not documented, and the financial struggle may rest within the

context of balancing a caregiving budget; CFC providers on the other hand are definitively

documented as poorer than the general population of child caregivers (Barth, Green, Webb,

Wall, Gibbons, & Craig, 2008; Scannapieco & Hegar, 2002). Both CFC and AFC providers care

for vulnerable residents who are poor and without family who can care for them. AFC residents

are more likely to have disabilities, but some CFC children have disabilities as well. AFC is

modeled to serve adults with disabilities, while there are not always services available to meet

the needs of CFC children with disabilities. Case workers play an important role for both AFC

and CFC residents and providers in linking them to services, including initially linking the

residents to AFC and CFC care contexts. The CFC literature is more replete than the AFC

literature with different veins of research, including how provider and resident relationship

quality and CFC care context structure impact resident well-being. These details are yet to be

fully explored in the AFC context but have great relevance for understanding AFC's value as a

community-based care option.

<div align="center">**Theoretical Framework**</div>

The following theoretical model includes theories of care and concepts of power,

difference, and hierarchy. I integrated these theoretical concepts to develop a model that shows

the complexity of the context in which AFC providers and residents work and live, as well as

their relationships with each other and outside agencies that impact them. Agencies influence

providers and residents through system regulations and offering availability or dearth of services

and resources. I employed this model to guide the development of my research questions

(Chapter 1) and to select the methods that I used to interview AFC providers and analyze their

responses to understand the AFC context through their lens (Chapter 3).

Care and Relational Reciprocity

Care theory and related research spans contexts of caregiving for elders and other

adults dependent on care from others, as well as education and parenting (Fisher & Tronto,

1990; Howard, 2001; Jenkins & Sheehey, 2009; Noddings, 2010; Roberts, 2010; Tronto, 1998).

Care theory also has applications in any organization or area of living that requires interactions

with and dependency on other humans (Fisher & Tronto, 1990; Tronto, 1998). Definitions of

"care" depend on one's ethical vantage point. Not satisfied with the expression of existing care

as mere sets of principles or ethics, feminist care theorists Fisher and Tronto (1990) described

"care" as both a mental state of concern and care practices that are inspired by these concerns. Care has both microscopic and macroscopic value. In light of such a range of conceptual relevance and meaning, Fisher and Tronto (1990) further describe care as:

> everything we do to maintain, continue, and repair our 'world' so that we can live in it as
> well as possible. That world includes our bodies, our selves, and our environment, all of
> which we seek to interweave in a complex, life-sustaining web. (p. 40)

With such a broad concept of care, one can also specify that care theory "credits the cared-for with a special contribution" (Noddings, 2010, p. 2). Care receivers (e.g., patients, students, children) are valued in care theory, because they are part of a relationship and have relational capacity to engage (Fisher & Tronto, 1990; Noddings, 2010; Tronto, 1998). In the AFC context, AFC residents may be similarly valued because of their relational capacity. Benner (1994) captured the care theory value of meaningful relational and reciprocal aspects of caregiving that AFC providers may be able to support through relational and empowering caregiving practices: "Effective caregiving requires more than intent or sentiment. It requires skills and knowledge and being in relation with others in ways that foster mutuality, empowerment, and growth" (p. 45).

Prior literature using care theory illustrates such relational and empowering practices. For example, in studies that examined care theory in educational settings, when students felt respected as individuals and community members, they were consequently more likely to respond with reciprocal caring, self-motivated learning, and success (Howard, 2001; Roberts, 2010). With regard to the AFC care context, it is possible that AFC agency and provider respect for residents may be important for residents to react with reciprocal caring and a sense of developing self-sufficiency. Furthermore, agency respect for providers may be important for providers to reciprocate as professionals enthusiastically engaged in the practice of caring.

Literature on support services and approaches for working with individuals with intellectual and aging-related disabilities provides good examples of caregiving with strong

relational and empowering elements reminiscent of care theory concepts. For example,

Berggren and Gunnarsson (2010) described a kind of personal ombudsman service in Sweden

that supported individuals with mental illness to exercise their rights as they sought health

services. This organizational function included characteristics of friendship, trust, and social

reciprocity that might provide a model for how one can overcome a traditional hierarchical

relationship between a service provider and receiver to achieve a reciprocal caring dynamic.

Furthermore, McVilly, Stancliffe, Parmenter, and Burton-Smith (2006) advocated for practices

supporting self-advocacy among individuals with intellectual disabilities; such a practice could

be intentionally implemented in AFC contexts to the extent possible to support residents to

value themselves as important relational participants. In research by Walker and Allen (1991),

adult daughter caregivers tried to find agentic ways to support their aging mothers to maintain

independence.

Agency or other institutional facilitation of care culture has the capacity to impact not

only care providers but also vulnerable individuals receiving care. O'Brien, Shevlin, O'Keefe,

Fitzgerald, Curtis, and Kenny (2009) presented findings from their qualitative study with

individuals with intellectual disabilities who gained student status and access to a university

setting. The participants included in the university context felt more similar to their peers, rather

than different, and they also felt more accepted and competent. The National Council on

Disability (2004) suggested that in the context of *Olmstead* paradigm-inspired consumer-

directed or –oriented care, individuals receiving care should be involved in all stages of program

design, implementation, and evaluation.

Respect for and appreciation of AFC residents, as suggested by care theory concepts,

may be the inspiration for AFC providers for empowering the residents for their own sake,

supporting them to overcome hardships related to their experiences of aging and disabilities.

The potential for top-down hierarchy experienced in care contexts provides an opportunity and

impetus for making ongoing efforts to examine the caregiving relationship, as well as the

relationship of care-related institutions with providers and residents. As established by the feminist theory of care, one must also acknowledge that care relationships are not simplistic but that all relationship participants are multidimensional beings and bring complex needs and characteristics to the relational dynamic. Relational reciprocity, defined in this study as the acknowledgement or conscious experience of equal benefit in the relationship, is something aimed for but not necessarily ever fully achieved or stabilized (Dressel & Clark, 1990; Ferree, 2010; Ruddick, 1980).

Power, Difference and Hierarchy

The power dynamics that sometimes exist between care providers and residents have the potential to be deconstructed and reconstructed to transform the provider-resident relationship into equal- or near-equal status, with relational reciprocity (Foucault, 1977; Powell & Wahidin, 2006; Turner, 1997). The AFC provider may lose some lifestyle freedom because of his or her intensive professional role, but may gain a sense of family due to the resident's presence (Sherman & Newman, 1988). Efforts may also be made to diminish the sense of hierarchy in the care provider-resident relationship. For example, even if residents experience intellectual delay, they can still be included in care plan meetings and actively participate in decisions about their own care. If residents have difficulty understanding care plan topics and decisions that will impact them, care providers can make efforts to include professionals (such as a case worker) that will be able to help explain content to residents and consequently support the resident's inclusion in decisions about their own future (Sherman & Newman, 1988). This type of inclusion and consideration of individual needs of both providers and residents can help to create a care culture that is respectful and consequently sustaining of all involved.

When contemplating and seeking to understand dynamics in care relationships, whether between an AFC provider and resident or between an institution and provider, it is conceptually useful to think of the relationship as a "binary," or entity comprised of two people. Often, one person will have more power than the other person; frequently, individuals with more knowledge

have more power (Foucault, 1977). Foucauldian theory provides a framework for examining the

potential to empower (i.e., bestow power on) the "the other," or the entity or individual with less

power (Foucault, 1977). Understanding this capacity to support empowerment of more

vulnerable individuals also provides a platform to discuss how values of care and a care culture

may be created, through conscious empowerment of AFC residents who are the most

vulnerable individuals within AFC contexts. These concepts of power may also be applied to

the dynamic between the AFC provider and agencies (funding and regulatory), yielding a vision

of how a reciprocal relationship of care may also be fostered between both entities to benefit the

provider but also to sustain and nourish the agencies.

Prior studies have examined the capacity for empowerment of individuals with

disabilities. Such empowerment has involved resisting norms associated with disabilities, as

well as reconstruction of their identities and relationships with authorities (Allan, 2011; Biggs &

Powell, 2001). Furthermore, as a historical context for understanding power issues in AFC

contexts, Burrell and Trip (2011) note that the most degrading manifestations of categorizing

individuals according to the norms of institutionalization and accompanying philosophy of

eugenics were "the labeling of people as abnormal, mad, simple, lunatic, ill, immoral, and

deviant," resulting in incarceration, being physically restrained, removed and isolated from

families, and sterilized (p. 178). However, the authors make the case that with de-

institutionalization there are simply new pathways for neglect and oppression of vulnerable

individuals, via health and social service professionals and surrounding systems. "Community

facilities risk re-institutionalizing clients where individuality is ignored, and care and interventions

fail to be personalized or individually tailored" (Burrell & Trip, 2011, p. 179).

Recognition and acknowledgement of the individual needs of AFC residents may require

examining and questioning institutional and provider expectations for resident experience and

development. Such expectations may be informed by preconceived notions of successful

aging, which may or may not be reachable, relevant, or meaningful for AFC residents (O'Rourke

& Ceci, 2013; Österlind, Hansebo, Andersson, Ternestedt, & Hellström, 2011; Phelan, 2010).

Communications with vulnerable individuals such as older hospital or home care patients can

acknowledge them as empowered individuals with a range of experiences, rather than as

objects of a health care system (Phelan, 2010; Wreder, 2008). This attitude toward

empowerment of vulnerable individuals can also be applied to the AFC setting and residents.

Effective communication with and empowerment of AFC residents support greater possibility for

their awareness of opportunities and integration in the community. As integrated community

members, AFC residents can be in a better position to also give back to the community as

active participants, engaging with neighbors, friends, and activities that they enjoy (Sherman &

Newman, 1988).

Intersectionality Theory

The concept of *intersectionality* is based in an understanding that individuals exist in a

structure of systems that both oppress and privilege (Allen, Lloyd, & Few, 2009; Collins, 1990;

McCall, 2005). Composite characteristics and experiences may intersect so that one is

positioned to experience oppression or privilege in a way that is specific to the unique

intersections experienced, such as intersections of gender and race. Because AFC providers

serve individuals experiencing both disabilities and aging, I am primarily interested in

intersections defined by disability and age and how these intersections among residents may

impact the providers' experience. Theorists suggest that due to the evolution of the role and

treatment of disability across history for different parts of the population (e.g., women and

African-Americans), disability is inseparable from other intersections, such as gender and race

(Carey, 2009).

Prior research has examined age in relation to other intersections, such as gender and

ethnicity, and how these intersections impact individual experience. For example, researchers

have found that Hispanic older women have less opportunity to accumulate social security

income across the course of their life and are thus cumulatively disadvantaged in older

adulthood in terms of economic status and subsequently, health (Zajicek, Calasanti, Ginther, & Summers, 2006). Stoller and Gibson (2000a, 2000b) have indicated that disability often accompanies but does not necessarily intersect with lower social class (less opportunity for education, often coupled with lower income) and minority race. However, researchers also treat disability itself as a point of intersection, for example intersecting with age, gender and sexual orientation, and creating a complex "mesh" of individual experience (Coston & Kimmel, 2012; Cronin & King, 2010; Krekula, 2007; Shaw, Chan, & McMahon, 2012; Warner & Brown, 2011; Wilinska, 2010; Wilkinson, 2003). Acknowledging and dialoguing about the interdependence between individuals of lower and higher hierarchy and the potential for reciprocal relational exchange and benefit establishes the inherent value of the person with disabilities. A foundational value of individuals with disabilities because of their position in relational reciprocity helps to overcome the injustices experienced by individuals experiencing disability as an intersection (Knoll, 2009). Such suggestions for practices of acknowledging and dialoguing among professionals caring and advocating for individuals with disabilities may inform possible characteristics of AFC care contexts that can help to overcome hierarchical injustice experienced by residents with disabilities and support care culture that recognizes and nourishes individual needs.

Theoretical Synthesis

Overcoming a hierarchical conceptual model of relationships among AFC institutions (regulatory and supportive), providers, and residents can support all parties to gain from moving beyond simple top-down expectations (see Figure 1). If inspired by a care ethic, AFC providers may value residents for their reciprocal and relational role in the resident-provider relationship, in which not only do both parties care about each other, but there is also a reciprocal caregiving relationship in that residents are ready to receive care and the caregiver is able to perceive the resident's appreciation (Noddings, 2010; Tronto, 1998). Valuing residents in this way has the potential to further inspire the provider to understand the potential of the provider role as a

gateway to opportunity for residents, potentially continuing to transform the hierarchical nature

of the provider-resident relationship and overcoming limitations defined by intersections of aging

and disability. Reciprocity between AFC institutions and providers also has the potential to

overcome limitations of hierarchy and to allow for resource sharing (e.g., practice-related

revelations, resident-related insights, miscellaneous community resources).

Figure 1. Theoretical hierarchical model of AFC relationships: Institutions, care providers

and residents
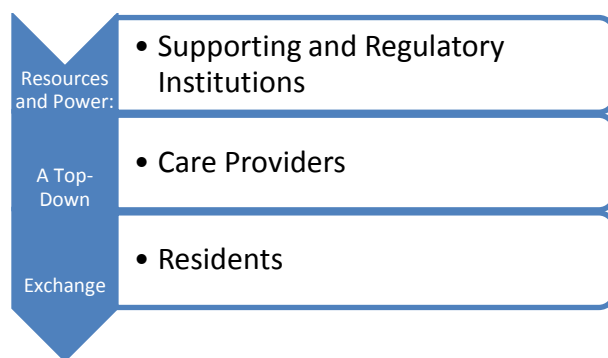
Figure 1. Schematic of the hierarchical relationships between supportive and regulatory
institutions and care providers, institutions and residents, and care providers and residents.

Figure 1 represents an integration of the literature reviewed in this dissertation,

interpreted in light of theory. The central component of the study is the care providers, who

occupy a pivotal position between institutional influence and resident experience. The literature

on AFC, institutional and community-based care, and care residents experiencing disabilities

contributes understanding of the hierarchical relationships between institutions and care

providers, institutions and residents, and care providers and residents. Care theory,

intersectionality theory, and theories related to power provide additional perspective on themes

of hierarchy emergent from the literature. Resources and power flow from the top-down, from

institutions to providers to residents. Thus, the direction of this flow has implications for the

professional experience of the provider, the quality of life of the resident, and ultimately the

quality of institutional support (i.e., without a reciprocal loop of feedback from providers and

residents to contribute to improved systems and resources).

CHAPTER 3: METHODS

The methodology for this dissertation was guided by the extant literature and the development of my theoretical framework. In this chapter, I provide details about the study sample and recruitment, including a description of AFC in the region of North Carolina where participants were recruited. I also describe my approach to data collection, the project's interview guide, and data coding and analysis. The chapter ends with my statement of reflexivity.

Study Site and Participants

North Carolina served as the study site. I selected North Carolina because of the state's resistance to the Olmstead mandate to move away from institutional care by offering community-based alternatives to institutional care only if requested by the resident. This resistance raised my curiosity about the state's dedication to AFC as a care model, as well as about care provider attitudes within the AFC system, which ultimately affect the residents' experience and quality of care.

I identified a study population in North Carolina through a sequence of steps. First, I perused North Carolina state government Web sites until I located names of individuals working in the Department of Social Services that held professional titles indicating that they oversaw AFC or other community-based care in North Carolina. On February 22, 2012, I e-mailed individuals that I identified working for Departments of Social Services in Durham, Guilford, and Wake Counties, North Carolina; I targeted these counties because all three include metropolitan areas as well as lesser populated outskirts. The only contact who responded to me during this initial attempt was from Guilford County.

Guilford County is part of the Piedmont-Triad metropolitan area. It has a population density of 756.4 individuals per square mile, which is in contrast to North Carolina's overall population density statistic of 196.1 (U.S. Department of Commerce, 2013). It is located in the north-central part of the state. The county consists of 18 separate townships, with a population

of 500,879. Regarding poverty, 16.2% of individuals live below the poverty level. Sixty percent

of county residents are White, 33.1% are Black or African-American, 7.3% are Asian, and 4.1%

are Hispanic or Latino. The county seat of Greensboro is historically known as the location of

the first Civil Rights sit-in by African-American students in 1960 (John Locke Foundation, 2013).

As of 2013, there were 632 AFC facilities in North Carolina (North Carolina Department

of Health and Human Services, 2013). To be qualified as an AFC in North Carolina, providers

are required to demonstrate financial stability outside of resident income, and be trained and

supervised by local Departments of Social Services (Mollica et al., 2009). In North Carolina,

there are two different models of AFC. First, the *family care home* AFC model is licensed by the

state and allows service for two to six residents per home (Mollica et al., 2009). Second,

facilities in North Carolina called *adult care homes* are defined as assisted living facilities and

offer 24-hour scheduled care services by an overarching management. When *adult care homes*

include no more than 2-6 people, they are simultaneously categorized as *family care homes.*

According to the 2013 data, Guilford County has 22 *family care homes* and 28 *adult care*

homes, but currently no *adult care homes* that are small enough to be categorized as *family*

care homes.

Recruiting from these lists, I initially proposed to conduct semi-structured, guided

interviews with 20 AFC providers in Guilford County, North Carolina (Charmaz, 2006; Patton,

2001; Seidman, 2006). My proposed sample size was an estimate of what it would require to

achieve theoretical saturation (Charmaz, 2006; Patton, 2001; Seidman, 2006). My co-chairs

and I agreed that if I did not reach data saturation with the 20th participant, I would continue to

recruit participants until reaching saturation. To be included in the study, providers needed to

be caring for 2-6 residents in their AFC homes. Individuals were to be excluded from the study

if they were not identified as the sole provider who was responsible for oversight of the AFC

home and back-up care staff (i.e., those that provided respite support to the primary provider).

In addition, providers were to be excluded from the study if they had a hearing impairment that would have impeded their participation in a telephone interview.

As planned, since I was not able to recruit 20 providers from Guilford County, I sought additional provider contacts in comparably urban, diverse and centrally located regions in North Carolina, including Orange, Wake and Durham Counties. AFC contact lists for all counties are now available online (http://www.ncdhhs.gov/dhsr/reports.htm); thus, additional providers by county were easily identified.

Approach

Because AFC providers are responsible for the care of their residents 24 hours a day, their free time is often unpredictable. I conducted interviews with the providers over the telephone to allow for more flexibility of scheduling and greater ease of rescheduling in the face of resident needs and unexpected events (Dillman, Smyth, & Christian, 2009).

Contacting Providers

When contacting providers, I followed an adaptation of a participant contact protocol suggested by Dillman and colleagues (2009). I had AFC site addresses, phone numbers, and points of contact (possibly the providers, though not confirmed until my first call). I first sent a letter to the potential providers a few days before my first call that invited them to participate in the study (see Appendix A). The letter provided some detail about the study, including study purpose, why their interview would be of value, time commitment, and incentive. I offered a $20 gift certificate as a post-interview incentive, primarily as a token of appreciation in respect for the providers' time. This first letter also included an attached consent document printed on yellow paper so that it would stand out apart from the letter (see Appendix B). The consent document included main points about the study, their participation, and contact information for myself and the Virginia Tech IRB. The Virginia Tech IRB provided permission to obtain verbal consent over the phone, after confirming that the providers read and understood the consent document.

Within a week of when they should have received the letter, I contacted the providers by telephone to answer any questions they had about the study and assess their willingness to participate. If a provider was willing to be interviewed, I scheduled a time for a telephone interview, also offering to interview them during the same call if it was convenient. If the interview was scheduled more than a week after the initial call, I sent the provider a card expressing my appreciation for their participation and providing a reminder for the interview date and time (Dillman et al., 2009). I sent a thank you card upon completion of the interview, along with the $20 gift card redeemable at a local store (e.g., Wal-Mart).

Before proceeding with the interview, I reviewed the consent document with the providers, asking if they had any questions and confirmed consent over the phone. Consent included permission to audio record the interview. I documented verbal consent on a form approved by the IRB with my signature and date. If the provider was not available for a scheduled telephone interview, I attempted to reschedule or leave a message. If not speaking directly with the provider about rescheduling, or if I did not receive a call back replying to my message in a week, I made two additional attempts to reschedule the interview (three total). Sometimes I was provided an additional phone number or a better time to call by providers themselves or one of their staff, and I then followed these directions to reach the provider. After sending letters to 84 potential participants across the four counties (20 in Guilford, 4 in Orange, 28 in Durham, and 32 in Wake) and following up with the phone contact protocol with each, I successfully reached and interviewed 3 providers from Guilford, one from Orange, 8 from Durham, and 14 from Wake. I sometimes found out in the process of my contact protocol that multiple sites had the same owner.

Interview Process

After obtaining consent from the participants, I recorded the interviews on a digital recorder, which I then saved as MP3 files (see interview guide in section below). I used a cell phone recording adapter (http://www.telephonecallrecorder.com/universal-cell-phone-

adapter.html) that was compatible with any digital recorder to make the recording fully audible. This simply involved plugging in the adaptor to the recorder, with the attached ear bud and small microphone allowing both my and the providers' voices to be recorded. Once recorded, I saved the MP3 file on a flash drive that was stored in a double locked cabinet in my home office, separate from the consent document, as well as on my password protected computer and on a password protected google drive folder which I used for sharing files with IRB approved transcriptionists. All recordings were transcribed, with transcription efforts shared by myself and three additional transcriptionists, with one transcriptionist serving as the primary, transcribing 15 of the 26 transcripts. Once I completed transcriptions and received transcripts from the transcriptionists, I reviewed each transcript and compared them with audio to confirm accuracy of their content.

Grounded Theory Interviewing and Data Analysis

Charmaz (2006) emphasized that the interview guide in grounded theory must include questions that are both controlled by the researcher, but also flexible to adapt to the narrative spoken by the interviewee. The purpose of the interview questions is not interrogation, but guided exploration (Charmaz, 2006). Thus, I designed the questions presented in the interview guide below accordingly. Through the questions, I tried to understand AFC contexts that related to my research questions, but also left room for the providers' unexpected and potentially important responses. This approach was compatible with my exploration of power dynamics and hierarchy, empowering the providers to contribute to the investigation of the study topic (Abma & Widdershoven, 2011; Krumer-Nevo, 2012).

As a first step in the interview process, I reviewed with the participants the purpose of the study and provided an overall introduction to the study procedures, including verbal consent (see script in Appendix C). I began the interview by asking them several demographic questions about themselves and their residents and recorded their answers on the demographic questionnaire form (see Appendix D). Demographic data gathered included AFC provider

gender, year of birth, ethnicity, race, years providing care, number of residents, and descriptive

demographics for their residents. Providers' answers to the demographic questions helped to

contextualize their responses to the open-ended questions about their AFC experience. After

the first interview, during which the demographic questionnaire comprised an extensive

proportion of the allotted interview time, I decided to ask only the first few demographic

questions before continuing with the interview guide. I then returned to the rest of the

demographic questions for the conclusion of the interview. My co-chairs and I agreed that

participants seemed to engage enthusiastically with the interviews once beginning to answer

questions from the interview guide, as they provided an opportunity for participants to tell their

stories. Asking the lengthy demographic questions yielded a more obligatory response from

providers, and it was easier to move through these if the providers were already enthusiastic

about sharing their experience framed by the interview guide.

The study interview guide is composed of 13 semi-structured, open-ended questions

(with prompts) related to AFC experience. Questions were piloted with seven individuals of

different ages, races, and care work experience including an AFC provider, several AFC respite

care workers, a Certified Nursing Assistant and parent of an AFC resident, a therapist, and a

family caregiver. The primary interview questions and related prompts are shown below.

Appendix E provides a chart showing how the interview questions map to my research

questions.

Questions *(Prompts in italic)*

1. **To begin, tell me about your experience of becoming an AFC provider.**

   How did you get into it? What is it like now? What was your reason for becoming an AFC

   provider? What keeps you going in this role?

2. **What do you call your resident?**

   resident, client, patient

3. **What do you call yourself in your professional role?**

   provider, owner, manager, operator

4. **Tell me about the general process of being matched with residents in your home.**

   Think about a recent match. How did the match happen? How did you feel in this process? How do you decide who is next?

5. **In a word or two, describe each of your current residents.**

   How does each compare with residents you have had in the past (if applicable)?

6. **What is your experience of family in your AFC home?**

   Do you live in the AFC home, or do you go home to a different location? Feel free to answer this question with regard to your biological family or including your Adult Foster Care residents, a "created" or "constructed" family. How has your experience of family changed or stayed the same since becoming a provider? How do you differentiate between being a family member and being a professional caregiver? Since becoming a provider, what are your experiences like with family and friends outside of the AFC context?

7. **Give me an example of a resident(s)' experience of family, in your opinion.**

   How do you feel their experience of family has changed or stayed the same since entering AFC?

8. **Tell me about professional supports that you find most helpful. Least helpful?**

   trainings, resources, staff supervision

9. **How would you describe the way(s) in which you show "care" in your AFC environment? How do your residents show "care" to each other (if applicable, if more than one resident)? How do they show "care" toward you?**

   Tell me about how you help residents feel that they belong. How do they help each other feel a sense of belonging in the AFC home? Tell me about what they have done that has created a sense of positive connection for you.

10. Tell me about how the way you think about "caring" for your residents has stayed the same or changed over time.

If one or more residents? If residents have turned over? Or if the same resident?

11. In what way(s) does your AFC agency promote a sense of "caring" between staff, and between staff and residents?

What do they communicate or do to do this? What do you suggest be different/same?

12. Give me an example of how a resident exercised choice.

How did you support your resident to make a choice in some situation? What are safe options for empowering your residents? If there are times when your resident(s) exercise choice that creates a difficult situation, how do you manage that?

13. Is there anything else that you would like to tell me about working with your residents and your AFC agency?

Coding and Analysis

In addition to being guided by my proposed theoretical framework and research questions, I followed the guidelines for grounded theory construction presented by Charmaz (2006). Charmaz calls attention to maintaining the integrity of the narrative data, through "initial coding," including a modified approach to "line-by-line" (e.g., sometimes section by section), "incident-by-incident" as well as attention to "in vivo codes," or "participants' special terms" (pp. 54-55). "Line-by-line" coding literally assigns codes that attribute meaning to each line (or, in this case, sometimes larger sections) of the transcript. An example of "line-by-line" coding noted from provider transcripts reflecting provider and resident experience related to the facilitation of choice read "acknowledges individual personality, needs, desires," followed by "provider control/need for resident compliance." "Incident-by-incident" coding corresponding to the same lines simply hone in on the actual incidents, with codes such as "use of conversation to provide mix of control and facilitation of free choice." Corresponding "in vivo codes" or

special terms used by the providers being interviewed were important to identify as they were loaded with additional context and meaning. For example, phrases such as "no different than family" and "up to them mostly" are in vivo codes signifying providers' meaningful perspectives on their residents as individuals deserving respect and belonging, as well as providers' carefully navigated value of *safely* facilitating choice for their residents. Analyzing the narrative through these several approaches allowed a comparison among approaches that ultimately helped to preserve and capture the narrative meaning.

As part of this process, initial coding was followed by focused coding, an analytic effort to synthesize earlier codes (Charmaz, 2006). An example of focused coding was pinpointing the theme of providers' perspectives on choice and assigning the code "perspectives on giving residents a choice" to earlier codes capturing providers' feelings about and examples of giving choice to their residents.

Axial coding can then be applied to more deeply understand the focused codes by applying subcategories to them (Charmaz, 2006). A traditional method of determining axial codes for a focused code is delineating a framework for the code including elements such as contextual conditions, related actions/interactions, and consequences or outcomes (Charmaz, 2006). For example, with regard to "perspectives on giving residents a choice" as a focused code, the framework of axial codes included "it's their choice," "it's their choice, but sometimes we negotiate," "it's their choice, we negotiate, but ultimately I decide," and "we might negotiate, but ultimately I decide." Axial coding thus provides an opportunity to relate larger categories to subcategories that bring greater context and meaning to light. I captured initial codes in an open coding chart, subsequently making efforts to reduce these initial codes to focused codes, and then when relevant to the codes, further explicated by axial codes. Compiling these codes in the coding chart allowed for the practice of constant comparison of data with emerging codes.

As an additional step, I completed theoretical coding, which relates or integrates the substantive, focused codes to each other, yielding a theoretical narrative or story (Charmaz,

2006). For example, with focused codes including both "perspectives on giving residents a

choice" and "providers' personal and professional roles," it was possible to begin to create a

theoretical understanding of possible relationships between these two codes. Additional

focused codes created a fuller picture of how the codes related to each other and ultimately

determined new hypotheses and theoretical development (Charmaz, 2006).

Transcript coding iterations were completed both by hand and electronically, eventually

transferring hand-written codes to electronic and saved with dates and initials. Code numbers

(see numbered focused and axial codes in Appendix F) were used to label transcripts. My co-

chairs reviewed coding on transcripts, correcting and supplementing when needed, and closely

evaluated and critiqued the evolution of the codes and related findings across multiple

iterations. To illustrate this study's process of data analysis, in Appendix G, I present examples

of how the axial, focused and theoretical codes have corresponded with the research questions.

Reflexivity

As the researcher, it was important for me to actively reflect on every aspect of the

study, from design to analysis, documenting when needed and maintaining an awareness of

how much my own perspectives and experience influenced the data (Charmaz, 2006). This is

not only standard for grounded theory practice, but also critical because I brought prior

experience to the study from when I worked as an AFC back-up worker (i.e., respite care

provider) for Wall Residences, Inc., a private AFC agency with corporate headquarters located

in southwestern Virginia. I recognized that I was influenced by Wall Residence's orientation to

resident care and agency culture through what was communicated in their trainings, as well as

by the AFC home in which I served (Wall Residences, 2010a, 2010b). Writing participant

vignettes for all 26 participants (see Appendix H) supported my subjective value or orientation

toward presenting each provider in the wholeness of who they are, undivided by categorical

analysis of their attributes and responses.   In their chapter delineating the purpose of portraiture in inquiry, Lawrence-Lightfoot and Davis (1997) wrote:

> I wanted the subjects to feel *seen* as I had felt seen—fully attended to, recognized, appreciated, respected, scrutinized. I wanted them to feel both the discovery and the generosity of the process, as well as the penetrating and careful investigation. (p. 5)

These portraits are also autoethnographic (i.e., writing and method that connects personal experience "to the cultural, social, and political"), because they reflect my experience as the interviewer with the participants on the phone, listening to and conversing with them, observing their concerns, values, distractions, and broader contexts (Ellis, 2004, p. xix). Furthermore, I would like to continue to analyze and present this provider data in the future using methodologies of Creative Alternative Processes (CAP) (Richardson & St. Pierre, 2005). CAP methods are creative in nature, incorporating alternative narrative text formatting and other visual presentation that can be useful for the author's own reflection on the issue at hand (Richardson, & St. Pierre, 2005). Portraiture, Autoethnography, and CAP are implemented with an understanding that reflection and subsequent writing are together an introspective research method, another way of knowing (Ellis, 2004, p. xix; Goodall, 2008; Lawrence-Lightfoot & Davis, 1997; Richardson & St. Pierre, 2005).

I have used autoethnography and CAP methods to capture my experiences working with AFC residents during my Gerontology Center practicum, my prior experiences working in a nursing home setting, and formative experiences with my own grandparents. Reflecting and documenting my positionality, or how I see myself in relation to contexts and people in these settings, helps me to understand the lens through which I may see the data in the proposed study (Fine, 1994). My prior interactions with elders and individuals with disabilities have included complex experiences of affection and ambivalence, with a questioning of the meaning of my role and adequacy in providing care. I have experienced personal frustration at inadequate care provided to my grandparents. I have experienced a combination of frustration

about and distance from the inadequate care provided in the nursing home setting. I have ultimately been reminded in the professional settings—nursing home and AFC—that I receive at least as much relational meaning from residents as I give. For example, in the AFC setting in which I worked, the elder resident always conveyed caring and support, asking me about the status of my car and if I wore enough clothing when the temperature dropped. He repeatedly made sure that I knew when he was joking and not actually "giving me a hard time." I have realized that he was as devoted a friend to me as his situation allowed, regardless of the fact that he is the one documented as the care receiver. Capturing all of these experiences in narrative form with creative diagramming of perceptions has helped me to reflect on myself as a carer and how I may or may not have contributed to AFC and nursing home resident quality of life. Therefore, I also reflected on my own experience when I asked AFC providers questions about their relationship with supportive and regulatory institutions and AFC residents. I discuss this reflexivity as part of the results, with efforts to maintain a fresh perspective to understand how each AFC provider may be having an experience unique from mine and unique from each other's. I believe this clearer vision has yielded a better understanding of the power dynamics at play within the care contexts.

CHAPTER 4: FINDINGS

The purpose of this study was to understand the experiences of Adult Foster Care (AFC) providers. The aim was to examine the motivations and circumstances leading to a career in AFC, the AFC providers' perspectives on their current professional experience and its impact on their personal lives, and the AFC providers' views of their residents and the larger system of agencies and institutions in which they worked. I conducted interviews with 23 female and 3 male AFC providers in North Carolina (see select demographics in Appendix I). In this chapter, I present findings about the experiences of these 26 providers in terms of emergent themes developed from initial, focused, and axial codes. Themes are also discussed in relationship to each other, with two succinct theoretical codes resulting from the analysis. The chapter begins with an overview of the emergent narrative about these providers, and then proceeds to detail each unique theme and subtheme, as well as how they relate to each other and inform the theoretical codes.

Overview

Each provider was motivated toward the career opportunity to serve as an AFC provider for unique reasons. A few providers maintained a family-run business that was already in place or in order to have the financial and practical capacity to care for elder family members. Other providers reported that they had always been drawn toward social services and caregiving, and had extensive business experience. In some cases, providers had a unique combination of both types of backgrounds that supported their efforts in the AFC business context. Regardless of initial motivation and background expertise, providers demonstrated a remarkable ethic of care and aptitude to meet their ongoing responsibilities. This aptitude included implementation of a resident selection process and extensive staff training to achieve a home culture that suited their own and their staffs' care capacity and preference and that was harmonious with residents in place. Providers juggled resources available in the community in unique ways, depending on their own funding sources (e.g., Medicaid or private pay) and the staffing and programming that

they were able to afford. Providers often spoke of paying for resident needs out of their own

pockets, in light of limited Medicaid funding for items such as eyeglasses, and little or no

resident family support.

Depending on the AFC home's financial framework (i.e., Medicaid or private pay; staffing

plan), providers either lived in the home with the residents or returned to their own home as a

"refuge" at night. Even for the majority of providers who were able to go home, there was a

sense of the AFC home being primary in their life. Providers often struggled to make separate

time for their own biological family, but they spoke positively about their own family experience

when they told stories about how their family and residents spent time together. Multiple

providers talked about how they were not able to maintain outside friendships. In light of these

social hardships (i.e., struggling to make separate time for their own family; difficulty maintaining

friendships), the providers emphasized that they were not doing the job for the money. The

work did not pay enough to warrant financial motivation, but provided relational and professional

satisfaction.

Providers demonstrated a strong *ethic of caring* for the residents in their homes, typified

by a strong sense of *empathy, respect for humanity,* and *making others' lives as good as*

possible. They verbalized a universal respect for humanity, including society's castoffs, such as

those individuals living in poverty, experiencing disabilities, and aging. Providers sought to

make their residents' lives as good as possible, supporting them to live fully, with opportunities

for diverse activities and interpersonal exchange, and even to live independently. They

recognized that the residents "could be me" or someone they loved. The relationships between

providers and residents often appeared very personal and affectionate, reflecting a sense of

extended family that perhaps both was responsible and compensated for the providers' limited

social lives. However, there were providers who maintained more of a business sense within

that familial sensibility, and providers who clearly stated that they were not family. Some

providers communicated more than one sense of family during their interviews (e.g., at times

indicating that they saw their home as a business and clearly stating that they were not family, and at other times describing their residents as extended family), reflecting a complex fluctuation between business and home values. The respect for residents also manifested in a range of practices involving resident choice. Providers applied practices that gave residents complete free choice, incorporated a sense of negotiation of choices, and involved authoritative provider decisions in place of resident choice. Oftentimes there was a combination of "choice" practices implemented in a single home.

I also analyzed respect of providers for residents in terms of reciprocity, or how providers verbalized mutual relational benefit with residents. Many providers saw their residents as contributing to the home (e.g., helping other residents; helping to do chores) and participating in mutually rewarding, relationally equitable exchanges. Providers' overall attitudes toward the meaning of their work, how they managed the resources available to them, and their high degree of personal commitment influenced their perceptions of whether they would be likely to stay in their role as a provider. In two cases, providers described limitations of the context in which they worked, including financial strain and not being able to control other influences in the larger care system (e.g., prescribing physicians). These two providers indicated that such limitations resulted in questionable sustainability of their business and their ability to control their care decisions and how they as providers were impacting their residents. There was consequently a sense of ambiguity with regard to whether these two providers would stay in the business. However, despite hardships, most of the providers were extremely dedicated to their residents and supported people that, in the case of Medicaid-funded homes, might otherwise have no place to go.

Pathways to Becoming an AFC Provider

Providers revealed five different motivations to begin their work as AFC providers. Motivations were not mutually exclusive, but overlapped in some cases, such as having both a business background and being drawn toward helping others, greatly enriching their abilities as

care providers and business owners and administrators. Several of their motivations related to

family circumstances, including caring for family members. Other events outside of family

circumstances, including chance meetings and conversations, also inspired providers to begin

looking toward the possibility of starting a home.

Family Ownership

Family ownership took two forms. Providers either took on a business that their family

had already started (n = 3), or they started a business with family as a new career opportunity

(n=3). For example, Alex's father had previously started the business, including two homes,

and Alex worked to maintain the effort beyond his father's passing.

My father started the business…and then I became involved in it probably about four years

after he started it. And then he passed away after I had been working in the business

maybe a year… and so I've been working in the business since he passed away in '94. So

I've been working on a day-to-day basis since '93 I guess.

There were three providers who went into the AFC business with family as a new career

opportunity. For example, Irene started an AFC business with her husband after working as a

mental health provider for seven years. Being very familiar with the challenges of meeting

individual mental health needs, Irene and her husband seemed to derive satisfaction from

providing residential care that was supporting people in a comprehensive manner and

preventing people from being on the street. She said "we're making a difference in people's

lives and I see the change on a daily basis." Nicole and her husband started their facility two

years before she left her job in hospital administration, in which she had been referring

individuals to long-term care options. She was inspired "to do it better than what [she] was

referring people to…a hospital-based model."

Caring for Older Family Members

Providers also started AFC businesses with the purpose of caring for their own elder

family members (n = 2), or decided to do professional care work after caring for their own family

member (n = 1). As an example of providers who started the business to care for family, Helen

talked about quitting her job in preparation for caring for her parents. She was fully licensed for

a year before her mother had another stroke, and then her father agreed to move in with her.

At that time my Dad, I think, was 90-something years old and she [Mother] was in her 80s.

And, when she left the hospital they came to stay with me. They stayed with me a year,

and like I said, I was in business a year…and she stayed with me a year before she passed

away. She was 89, and my dad is still with me. He will be 103 … So that's how I started in

the business. I knew absolutely nothing about the business when I started…I didn't know

that a family care home existed. I knew about the rest homes, and I knew I would never let

my parents go there. I knew I would take care of them…And once she passed, you know, it

was just a good business to be in.

Veronica cared for her own mother just prior to starting her own AFC business. She

described how her care for her mother led to opening the business:

I took care of my own mother…until she died. And during that process she told me I

needed to do this, and I didn't understand what it was she wanted me to do and so she kept

insisting. And then…I started, you know, getting the information from the county on how to

open up a family care home. . . .during the process she had dementia and congestive heart

failure and she said, "You need to keep people like me."

One provider, Bernice, had experienced a lifetime of limited career opportunities due to

extended care of multiple family members. Although not a paid caregiver in her earlier

adulthood, Bernice talked about how her lifetime of care work for her own family was

foundational for her professional family caregiving:

When I first got married, my husband's aunt had a stroke…I took care of her until she died,

and then my mother-in-law got sick and I took care of her. And my mother, and my sister.

Basically, I've been a health-care provider all my life. I didn't get paid for it…you just got to

love [the work].

Circumstantial Reasons

Providers also "fell into" opportunities to become AFC providers, either through chance conversations and subsequent discoveries of career opportunities (n = 4), or as a result of searching for a new opportunity for income in the event of career change, unemployment, or job loss (n = 3). Qadira was working as a nurse when she discovered the opportunity through a chance conversation with the adult child of a caregiving client. Qadira's situation was unusual in that the son of a woman she worked for provided her with several houses to transform into AFC homes. Her older adult client was on life support, and the client's son wanted an alternative to nursing home care for his mother. Qadira had just completed the test to be certified as an administrator when the adult child offered her the opportunity:

He said to me, "did you ever go take that test?" I said "yeah." He literally took the keys off of his key ring for his mom's house. He said "go open that house next door." That's what I did. I started slowly learning, I wrote my rules, regulations, and I opened it up, kind of just like that, and it went from there, and once we got that one up, it turned a profit . . . .He was like wow . . . and then he actually has a small cul-de-sac full of houses that he built. He pulled the key chain off another house and said 'hey open that one too.' And that's how I got two houses. And then, they have a third house that they just built, and he gave me the keys to that third house.

Wilma started an AFC business with her husband, who had lost his job. They benefited from her prior experience in care work that could be applied to the AFC setting. Wilma said, "I've been in the mental health field for maybe 20 years. My husband was about to lose his job; we needed to open a business and that was something I was familiar with."

Drawn toward Helping Others

Most providers had prior experience in paid social service and caregiving. Their passion for these human services both led them to the AFC business and sustained their satisfaction in

the provider career role (n = 20). For example, Tanya had prior social service experience, was

unsatisfied with the level of services that she saw provided, and wanted to make a difference.

> I was a case manager . . . I had people, I would care for them in other people's homes and
>
> the home positions they was living in was pathetic and upsetting. I just wanted to provide
>
> them with something better.

Similarly, Olivia described always being drawn toward social service and caregiving, but

without the financial resources to go to school, she found opportunities in AFC.

> I worked in a nursing home for years. And I've just always been compassionate. I've
>
> always dealt with the elderly, even at church or any social . . . .Actually, I wanted to go to
>
> school to be a nurse, but always…something came up, maybe finances or something like
>
> that, so I couldn't do it. And, one day I just decided "Hey, I'm going to do this. You know,
>
> I'm going to. This is what I want to do."

Business Background

Eleven of the providers spoke about their strong business backgrounds. A few providers

had prior organizational experience (e.g., union leadership or corporate work), and eight had

educational backgrounds across diverse business areas, such as accounting and

administration. Zada described her experience getting into AFC through her real estate work.

She had six AFC homes and combined her strong business sense with the compassion for her

residents.

> I used to do real estate, what is called fix and flip. I made them look like they were very,
>
> very expensive homes because I wanted to give them the experience of having that feel of
>
> a home that was beyond their usual experience of having a rental property. So this man
>
> saw that and he asked me if I had ever thought about family care, and I said, "No; what is
>
> that?" He said, "Well let me take you to a house." He took me to a house, a family care
>
> home, and the home was very nice and there were elderly people there and with the home
>
> being very nice, there were two men sitting at the counter eating frank and beans. And the

frank and beans appeared to have been cold and they were just kind of piled up on the

plate. My heart just dropped and I said…I can't save everybody, but those that who will

come into my home, I can care for them and give them a good life.

Leah brought a foundation of business education to her work, with undergraduate

degrees in Accounting and Business Administration, supplemented by a Master's degree in

Social Work. Similarly, Nicole complemented her Master's degree in Community Health

Nursing with two additional Master's degrees in Business Administration and Health

Administration. Nicole described a confidence in reaching a successful conclusion through her

academic and professional accomplishments, and a subsequent readiness for a new

experience as an AFC provider. "I had gone through the glass ceiling, of course, and did very

well in my job. And you know…position, money, and all that that everybody wants…but then

you know what, I had another dream."

Providers' Personal and Professional Roles

The great majority of providers conveyed a personal relationship with their residents,

and this closeness persisted for most providers even while they continued to attend to broad job

responsibilities. Many providers struggled to have a personal life and maintain time for friends

and family. Sometimes this struggle to have a personal life was coupled with inadequate

support from regulatory agencies. Other providers were able to harness their own biological

family as a social resource for their AFC home, as well as take full advantage of resources

available to them in the community. Almost all indicated an enthusiasm for their work that would

make it seem likely that they would stay in their AFC practice. Comments by only two providers

conveyed a sense of ambiguity about their likelihood to stay.

Relational Dynamic with Residents: "Oh They're My Peeps!"

Almost all providers (n=24) indicated relational closeness, or a personal and caring

connection with their residents. This relational closeness took a unique form for each provider.

Veronica presented an example of relational closeness with residents as well as with their

biological family members, with this closeness fostering an AFC culture that supported spiritual

intimacy among residents:

> During that time [a resident's] daughter started sort of a prayer group and we'd get into
>
> what was called a circle of prayer and all the ladies would pray and they could pray for
>
> different things—we weren't converting anybody to any religion, just praying together.

Patrice characterized one of her residents that she was initially afraid of as "wonderful,"

describing him with a thoughtful understanding, including his hobbies and personality:

> I have one that's been in my house for, like, I think about 12 years. And he came from the
>
> hospital . . .for the very mentally ill people. But I have to be honest, the very first time I met
>
> him, I was a little bit scared about taking him into my home. They showed me that he's
>
> been on these medications and he's stable and when he comes out he'll be okay. And, he
>
> is one of the few people that has a very supportive sister that was coming, so I decide to
>
> give him a chance and took him in…he's been a really, really wonderful client to have.

Uniyah described her personal and caring way of being with and comforting her

residents with memory loss:

> Memory loss is a big thing, and a lot of times you go through the same experiences over
>
> and over again. For example, losing your mom, going back and thinking that you're a
>
> certain age and Dad is supposed to be coming to pick me up. I take whatever I am doing…
>
> I sit with that client, I'll hold that client, I'll hug that client and I will comfort that client. You
>
> know? A lot of people be like, "Oh, you just gotta remember whatever." I'm not seeing that
>
> in our houses. You know, like, in a nursing home and it's like they're ignoring, they're like,
>
> "they always do that."

Breadth of Job Responsibilities: "All of That Is My Responsibility."

Concurrent with their ongoing relationships with residents, most providers reported that

they were responsible for a great range of tasks—administrative, clinical, and logistical—and

also often expressed a responsibility (n=21) to care for and protect the residents in their homes.

Patrice, who worked with her husband in her home, described both the breadth of their

responsibilities as well as the indigence and vulnerability of their residents:

> It's the passion for some of the people we deal with…because most of these people don't
>
> have family members. Most of them are really mentally ill. And, some of them don't have
>
> anybody to take care of them. . .so on Mondays [my husband] took time off so he can do
>
> doctor appointments for the clients, do grocery shopping, do all the things the clients need.
>
> It's just a passion for doing the work and seeing what needs to be done.

Olivia also emphasized her breadth of responsibilities across numerous roles, depending

on the need of the moment:

> I call myself…it depends on, you know, what aspect of the…if I'm here with the state, I'm
>
> the administrator, and I'm the care provider, I'm the cook, I'm the transportation person. So
>
> with the doctor's office I'm the care provider/administrator, so I know their records. I know
>
> everything concerning them.

Presence of Personal Life: "So Yeah, We Come Home, That's Our Refuge."

Most of the providers (n=21) were able to go to their own home as a refuge from their

work at the AFC facility, although a few of these providers lived very nearby the AFC home.

Providers expressed the value of having their own home separate from their AFC business for

their own well-being, the quality of life of their family, and at times for the residents as well. For

example, Nicole expressed care for the residents in her home and the quality of life she and her

husband facilitated for them through their business, but she emphasized that she saw it as a

business, with her own home as a refuge: "Oh, good heavens, yeah! I don't live there. It's a

total business for us. We live probably about 20 minutes away. So yeah, we come home, that's

our refuge."

Although Elon and her young daughter lived with her residents much of the time, she

described taking weekends away to their actual home to support their family life, also noting,

however, that her home was "right around the corner" from the AFC home.

I am a very family-oriented person and…so I do take maybe like every-other weekend off to

make sure that we – in my immediate family – we are spending quality time together and

doing family things. . . .We go back to our home which is right around the corner and kind of

bring some normalcy back into our lives. . .balance out the two.

Dan explained positive aspects of the boundary between staff and the residents of AFC

home. He described how an intentional separation between staff and residents helped

residents to feel that the facility was their home, not the staff's home. He clearly stated that the

AFC facility was "not my house" and that staff were also trained and supported to honor this

separation.

Well I'm definitely not a family member…And I don't live there, I don't work there. I spend

time there, but I am definitely the administrator. I'm not told to be a family member so-to-

speak. And I think, you know, the household team…when they're there working on their

shift, they're there working on their shift. They're a member of the household, but…they

don't feel like…their boundaries are when they clock in and when they clock out.

Community and Agency Supports: "We Have All Kinds of Supports."

Over half of providers (n=14), such as Shelli, spoke positively about the community

supports available to them. However, these positive narratives also revealed difficulties and

how providers worked hard to support their residents (e.g., finding free clothes and eyeglasses)

in a system that is not always supportive or equitable.

I will say that everything that I have experienced has been helpful, as far as the Department

of Health and Human Services. The organization is real helpful from telling you where to go

to, to get clothing free for your residents. You know a clothes closet. That kind of thing.

They tell you how you may take your resident, you know somewhere that's to get glasses

because Medicaid doesn't pay for glasses, unless you have an existing problem with your

eyes. So, most of the information that I have encountered has been good.

Gayle expressed satisfaction with the regular monitoring from the Department of Social Services, serving as a check on all of her efforts, and providing her with some peace of mind that she is doing things right. Gayle's experience is a good example of providers being central to AFC efforts, with outside agencies simply providing some resources, information, and confirmation.

> We have a monitor that comes in our home every month. She works for DSS and she monitors everything that go on…such as medication management, making sure our staff has the qualifications they need. I think it's really good because at the end of the year when it's time for the state – not the county government agency, but the state government agency – comes in to see if we are up to par and if we're eligible to reapply for license, it's easier because we stay on top of everything, you know…because of the monthly checks that we have.

Struggles

Fourteen providers communicated some kind of struggles in their AFC business. Sometimes they were challenged to maintain a personal life, with time for family and friends. Providers also expressed that they experienced challenges financially, as well as with supportive and regulatory agencies that were not understanding or effective. Yolanda also spoke to declining friendships in the consuming context having her own business:

> I don't have so many friends, my family and my kids are basically my friends. It's hard. It's sad to say when you go into your own business, you know when I first started out, nobody wanted to help me, you know, with what I was trying to do. So it kind of like taught me, it made me strong in learning to be hands-on, with just my kids, and you know that I know I try to help anybody that needs the help.

Yolanda furthermore provided a clear example of how unsupportive or inadequate regulatory agencies also heightened the financial struggle to make AFC businesses work:

We used to be able to bill [Medicaid] personal care for the residents and what happened

was they changed the 35 descriptions . . . basically, they cut the things as far as billing for

the person and if they don't have a certain level of care then we can't bill for them period. If

we're not hands-on all the time we're not able to [provide] personal care services for them,

like bathing, dressing, hygiene, feeding them, you know, things like that, that's personal

care. A lot of the family care home and group homes depend on that money to pay staff.

Qadira also described hardships related to making the financials of the business work,

with full staff while she works another job. She indicated that it is the residents that keep her

going:

I'm going to be honest, right now it's staffing and financially that is killing me…I'm very

frustrated…I wasn't making any money, and I think because I used my full time job as my

money, and every dime that I made, I put back into it. And, I don't work in the houses

unless there's a shortage, or I just want to see what's going on. I have a full staff. But, that

is truly taking all the money.

Rhonda talked about her unhappiness with the type of oversight that was provided by

local government, not as aware of client realities as it should be, and expecting a lot for little pay

for the providers:

We have so much paperwork to do, which is not really necessary, but because they are law

makers and they make the rules, so we have to go along with it. Or else we don't get

anything! They want us to be considered as a business, but it's not a business that makes a

lot of money. More or less, it's a stipend. Yep, we dedicated, or else we wouldn't be in this

business.

Leah also described that although there are supports, it is problematic when outside

agencies do not understand the internal workings of the business: "I mean the support's been

wonderful, but …the agencies out there haven't understood what *we're* doing and how we're

doing things for them to be able to work with us that well." Leah's statement suggests that

providers have created their own internal systems for making things work, sometime assisted by outside authority agencies, but largely successful due to their own initiative.

Likely to Stay

Almost all of the providers (n=24) said that they would be likely to stay in their role as an AFC provider, due to professional and relational satisfaction, as well as being able to harness their resources in the community, in their own families, and in residents' families. Ability to activate these resources gave a sense of sustainability to the AFC practice. For example, Veronica encouraged residents' family involvement as an integral part of her family care home, supporting her own experience with the residents and capacity to provide a supportive, family-like environment for the residents as well. One of the family events she described was a barbeque organized by one of the resident's daughters. This skillful involvement of family is an example of a practice that can support Veronica to stay in the AFC business. She conveys herself as part of the group that is enjoying the home environment that she is facilitating. This evident satisfaction results from a culture that she has created.

> So they end up having the whole nine yards: the hushpuppies…and the coleslaw and barbeque. And they just have a good time. We spread the table out and they are happy. So we have another one [that] go to the Food Lion grocery store and buy all their PBJ's— all their peanut butter and jelly sandwiches. Wiped out the whole counter. The ladies would have sandwiches. They love that. We warm them up and get them nice and good and soggy. And she would bring watermelon too, a whole watermelon, and they would cut it up and eat. And it was good because the family sort of stays with us and they start treating the ladies as if they were one family.

Ambiguous Commitment to Stay

Although none of the providers gave clear indications that they would be likely to leave the AFC business, responses of two providers suggested they were uncertain or had mixed thoughts about their future. This ambiguity appeared to be associated with insufficient

community supports, which, in the providers' perspective, impeded their ability to provide care to their residents that met their own expectations for what the quality of care should be. For example, Alex expressed some disillusionment with this capacity to achieve his professional ideal due to systemic constraints:

> Sometimes, you begin to question your purpose when a lot of times there are situations that you have no control over…by outside individuals, outside agencies, outside families…and so a lot of times, you know, you begin to question… "If I have to go through all of this, then what's the purpose of me doing this?"

Qadira also described systemic constraints that have impacted her financially, possibly making her role in the business unsustainable if circumstances do not change:

> I'm doing this, my husband and I. We're not turning a profit…And, you know, I recently quit my job to make sure that this was successful. I'm just hoping my husband's taking care of me [laughter], thank you husband. Eventually I know it will get better. Like I said, it's a lot of issues with payroll and, you know, females. It's different… Family care is just a choice, it's not a paid job.

Resident Choice

Providers had different ways of navigating resident rights in a caregiving context that fell within four distinct categories. First, two providers were adamant about residents having choice, ultimately having the right to inform the provider about what they would like to do in every aspect of their lives, and these providers did not make mention of any need for negotiation or intervention. Second, 14 providers who cared about resident choice also conveyed situations in which they would negotiate with their residents about decisions, especially choices that posed challenges for the other residents, the living environment, and the inquiring resident's own safety and well-being. Third, there were seven providers who identified three elements of choice: they valued resident choice, negotiation was needed, but ultimately the provider intervened and decided on the best choice for the resident. Finally, three providers did not

express any enthusiasm about resident choice, distinguishing them from the first three categories described above, but described that while they may negotiate choice with their residents, they ultimately decided on and clearly intervened regarding the best option in a given situation.

The diverse values of choice, especially when a single provider expressed two or all three values reflects the various moments and the more long term challenges in which providers find themselves. Such moments and challenges naturally elicited different responses from providers, depending on what was needed at the time for resident well-being and safety, as well as the resources available to the provider (e.g., staff availability which impacts resident freedom to choose different activities). Below I present examples of the three core elements of the four categories of choice: prioritizing resident choice, needing to negotiate, and needing to intervene. A provider that fits the third category might have described all three elements at once or throughout the course of their interview.

It's Their Choice: "You Should Tell *Me* What You Want to Do."

Dan described a skillful presentation of choices in a dementia care setting, so that residents were truly making choices within a safe context, with providers staying attuned to resident needs.

So, whether people want to linger at the table or whether they want to sit in the recliners or they want to go out on the deck –those choices are given to them continuously throughout the day. It's supported, you know. They may be encouraged to…say…"You know, today would be a great day to take a shower. Why don't we work that in today?" It isn't like they're just given a choice to be told, you know…"Well you just tell me when you want to take a shower," but it's worked into clothing choices, you know…helping them clean rooms and do their laundry and all those kinds of things.

Let's Negotiate: "We'll Sit Down and Talk."

Most providers were not able to facilitate a constant opportunity for choice because of limited funds to pay for additional staff supervision necessary to support residents' various activity preferences. Like Rhonda, when these providers were not actually able to provide such staff supervision of diverse options for residents, they instead exercised skill in talking with their residents to negotiate the choices that were possible.

If we all were trying to go out, and this resident decided they don't want to go out, they wanted to stay here...and see, this is a 24 hour/7 job. You don't leave them alone by themselves, someone has to be with them. We don't make enough money to have someone, a staff member here, to take care of one resident. So, what I usually do is just kind of coach them and talk to them, and find out why they're not interested in going out, and where would they like to go, is there another place they would want to go? And I say well, let's maybe what we can do is make compromise. We go your place, and then you go their place. And so, most of the times, they'll go.

I'm in Charge: "I Have to Intervene at that Point."

There were providers who felt that they might overstep rules and regulations (e.g., medication compliance or a physician's order) if they did not intervene in resident decisions. As an example, Ken described feeling compelled to intervene for the sake of his residents' well-being, while trying to allow as much choice as possible with that as a priority.

Everyone loves certain things, and most times you tend to love the things that aren't good for you as far as your dietary needs. But we try to let them make appropriate choices as far as what they would buy – say when we're out to eat or whatever – what they would order. I try to give them as much liberty as possible with doing that. But then, if it's something that I know that is not appropriate for their health, then I have to remind them, "You know that you're not supposed to be having this because of your high blood pressure or because of your cholesterol" or whatever.

Balancing "Family" with Business

Depending on the structure of their AFC home(s), providers demonstrated varying capacities to balance their responsibilities to the AFC home and "family" with their own personal life, including time with family and friends. There were four succinct categories of providers related to the focused code "Balancing 'Family' with Business." Six providers saw their residents as "one big family" without this vision being accompanied by a business sense, while 12 providers maintained a vision of their residents as family but seemed more cognizant of the AFC home as a business. Only two providers firmly maintained that they were not family. Finally, six providers expressed values of being both family and not family during their interviews.

Family Identity: "It's Just Like One Big Family."

There were providers who described their AFC home as a family context, without a simultaneous business sense related to this extended family experience. In addition to contributing to the quality of family experience of her residents, Elon's biological family experience seemed enriched and engaged (i.e., being able to attend her daughter's basketball games) because of involving her residents:

> We like our residents to feel like they are part of the family. A few of our residents. . . don't
> have a lot of family that come and visits, so we are *it*. We encourage and make them feel
> like they are part of the family and so we do activities together and we take them to our little
> girls' basketball games. So they're happy. And they're just really thankful that they actually
> *are* with us, because we put a little more love in it, it's just not a job, it's just not a place that
> they live – this is actually their home.

Family-Like with a Business Awareness: We Are Their Family, but this is Still a Business

Twelve providers conveyed more of a business sense about their AFC home, even while simultaneously acknowledging a sense of extended family. Olivia described that the family care home is truly a home for her residents, but she has had to remain aware of the rules and regulations involved in making it run as it does:

So it has all the rules and regs that we have to follow by doctor's orders and things of that

nature. It's not, you know…to me when I think of a foster care home, I'm thinking you

know…they get x amount of dollars per month from the state or something like that, and it's

like a *foster care* home. That's what *I* had envisioned, but the family care home…the

setting is just like they're at home, but I'm the one that has to follow all the rules and

regulations. [Laughter]

Shelli also retained a business sense about her AFC home, but clearly described how

she created a sense of extended family over the holidays, making a tradition of bringing her own

family together with her residents:

What I do is that I cook for every holiday occasion, just like we had a cook-out for Labor

Day. We had for 4th of July, we had one for Memorial Day . . .We had Easter dinner. And

we're getting ready to have Thanksgiving and Christmas. What I do is that for the residents

that don't go home, I make Thanksgiving dinner here. And, my family comes here as well,

so we all eat together, so they know my family, and my family knows them. Not just my

children, but my siblings as well and their family. They know the whole family.

Does Not Identify as Family: "Well I'm Definitely Not a Family Member."

Only two providers firmly maintained throughout their transcripts that they were not

family to their residents. However, not identifying with family did not imply lower quality care,

but simply a different care strategy. For example, Wilma created a clear boundary between

herself and her residents, as she is not a provider in residence, wants to maintain her business

role, and supports the residents' attachment to the staff providing care in her AFC facility. "I do

limit how much I do with them because they need to be more attached to the person that lives

there. I'm guarded."

Patrice talked about her and her husband's work caring for their residents to the point of

compensating for lack of family and agency support. However, she never defined herself and

her husband as the residents' family.

I have a resident that Medicare pays for their medication, and they give them $66 dollars.

That's their allowance they give each one of these clients. Well, $66 is not enough.

Because I think medication and its copay is up to 100 and something dollars. Who's going

to pay for that? They don't have any family members, so we have to step in and pay the

difference.

It is Both Family-Like and Not Family-Like

Six providers spoke of their AFC business as both family-like and not family-like. For

example, at one point, Xaveree made clear that she was not a family member, although later in

her interview she said that "It is like family" and made reference to the "homelike" nature of her

home. She also maintained an empathetic value although stressing the importance of her

professionalism.

The bottom line is you have to be a professional provider because when you get into

healthcare management and from my years of experience you will never be the family, you

will always be the healthcare provider. You cannot be the family. You will have to

understand when you decide to be a healthcare provider that you are going to provide the

same services that you will want somebody to provide to you if you were to be in their

shoes. And that is what the quality of a nurse or healthcare provider whether doctor or

CNA nursing assistant should be. . . .And that should be what will motivate you to do what

you need to do for them but then that does not mean you are a family member.

Reciprocity: How Residents Express Their Affection and Care to Providers

Nearly all providers acknowledged an equitable and mutual relational dynamic with their

residents (n=23). Providers expressed this reciprocity in two different, sometimes overlapping

ways: residents making life easier (n=23) for providers by helping with chores or with the care of

each other, and as expressions of affection (e.g., hugs or leaving small gifts) (n=14).

Make my Life Easier: "They'll Volunteer to Help Me do This or That."

All 23 providers who mentioned reciprocity described experiences in which residents volunteered to help with tasks or looked out for each other and the providers, which helped take some of the burden off of the provider. Shelli described both types of reciprocity from her residents. The passage below illustrated how her residents looked out for each other.

They look out for the ones that are not able to look out for themselves, such as for the gentleman that...he sees a little...he's partially blind. But for him, everybody makes sure for him that when they sit down to dinner, that there's all of his silverware and everything is in front of him. They'll take him to the bathroom. They'll make sure that he's in the vehicle, you know. Whatever it is that they're doing, if they're watching TV in the living room, they'll tell him to come on too, to be a part of the group. And they all sit and laugh and talk and joke together.

The residents also respected Shelli's need for quiet and rest later in the evening.

I've had them let me have quiet time to myself. After I've got everybody settled in, and ready for bed and night, and giving them their medicine, they're like "you know don't bother her."

Further, Bernice described how her residents have tended to look out for each other's needs:

Yeah, they share with each other whatever…if they see one don't have it, [they will] give to the other one. Like if one don't have deodorant and they've got two or three, they give the other one. Whatever they have, they'll pretty much share it with each other.

Expressions of Affection

Fourteen of the 23 providers who described some type of reciprocity indicated that their residents demonstrated care for the provider through expressions of affection, such as hugs or giving small gifts. For example, Cadi shared that "Sometimes when I come in, I'm greeted with a hug. Sometimes before I leave I make sure I hug them, tell them I love them." Miriam described a similar kind of ongoing affectionate exchange, clearly fostering a sense for her of

being cared for by her resident. Miriam's words describing how her resident gifted her a meal at McDonald's indicated she was aware of the value of reciprocity present in this experience.

> Sometimes she treats me to something to eat if we go to McDonalds. [She says] "I'll pay for it," you know, that kind of thing. I let her do it. It's part of being in the community and caring about other people.

Providers' Values

Providers demonstrated a profound commitment to residents, striving to make their residents' lives "as good as possible." They communicated an empathy for residents, acknowledging that it could just as well be themselves in their residents' shoes. With such a commitment to reciprocity, expressed as values to make life as good as possible, and driven by empathy, providers were exceedingly careful in creating a home out of their AFC facility, including taking care to match residents with each other, and in hiring staff.

Commitment to Residents

Almost all providers (n = 21) indicated a humanitarian motivation for the commitment to residents with 6 providers describing a religious or spiritual motivation in addition to humanitarian values, and one provider describing a motivation in solely religious and spiritual terms. When describing what kept her motivated, Tanya emphasized that her dedication was about serving people in need, and not financial: "It definitely ain't the money. Yeah, really knowing that you're helping somebody, you know you're giving somebody a stable home and environment for them." Olivia spoke of an ethic for taking care of older adults:

> It's not about the money, it's about the people, and providing the care that they need at that age. Because they have earned and worked in life and deserve to be treated fairly with dignity, respect…at a later age in life.

Nicole expressed a commitment to the families that place their loved ones in her care:

> I think what keeps me going is responsibility and the trust and the confidence that these families placed on us. They're actually placing their loved ones in our trust. And so I feel

that – as a nurse, as a woman, as a mother, as a daughter, I have to live up to that

standard…So I go the extra mile to make sure they're comfortable clinically, socially,

personally…all of that is my responsibility and…I take that very serious.

Zada demonstrated a dedication that seemed to be driven by both her religious values

as well as sense of being a dedicated community citizen:

Getting started, I made the commitment to someone greater than Wake County; I promised

the Lord that I would take care of the people and that I would never hurt them. And that's

what I've done. And He has sustained me and He has been the main one that I've wanted

to please and my objective was to do unto others' family members as I would have them do

unto mine… And now it's going on 13 years and I've been faithful to my word.

Making Resident "Life as Good as Possible"

Providers sought to make their residents' lives as good as possible, supporting them to

improve their health conditions and to live dynamically, with regular opportunities and

encouragement to engage in activities both in the home and in the larger community. Providers

even worked to support residents to live independently, with prospects to eventually leave the

AFC home. Miriam, the oldest and most experienced provider interviewed, spoke to her

successful history of fostering independence across the decades:

I give them a lot of help and the things that have changed is that when they leave, several

have gone to their own places, so that makes me feel really good. They're working part-

time or they have their own apartment, or sharing it with someone else.

Shelli described the range of residents with both lifelong and late life impairments that

she has worked with and the satisfaction she has found in helping individuals.

I have a variety of people, and a lot of them have been really, really sick, when they first

came to me, but after a while, getting them the medical treatment that they needed, their

condition got better. That was refreshing, to be able to help someone other than yourself

sometimes.

Empathy

Sixteen providers overtly expressed empathy for their residents, relating to their condition, and understanding that it could be them or someone they love in the same situation. For example, Rhonda paraphrased the golden rule, implying that the "human beings" that need help could easily be anyone: "Yeah, I treat them like I want to be treated. And I treat them as you know, as a human being that needs help." Cadi clearly related her relationships with the residents to that of extended family, and the consequent imperative that she felt to care for them like family.

> We've always made sure that…we provide the type of care we would want for our family members, because they are our family. If it's an older person, I want to provide the same type of care that I would want someone to provide for my grandparent. Or if I had an aunt or an uncle that was in placement, I want to make sure that they're getting proper care and they're happy and being loved.

Creating "the Home"

Every provider interviewed indicated vigilance—a careful, consistent alertness—about reviewing the backgrounds (e.g., health conditions, behavioral records) of residents before determining admission, to ensure that they and their staff would be capable and comfortable providing care for these residents. They also emphasized that the assessment of a compatible fit was also for the sake of the potential residents, to make sure that their needs would be met. Furthermore, providers spoke about careful staff training and management, indicating a marked protectiveness of their residents. Three providers, including Helen (described above in "Caring for Older Family Members"), purposely admitted family and friends without necessarily stating other criteria for those individuals (e.g., health and behavioral conditions, age bracket, gender), though still communicated that they followed a procedure for screening new residents in general.

Making a careful match. Providers revealed their care with regard to creating their AFC home in terms of cautiously making matches with both residents and with staff. For example, Patrice talked about how there are residents that do not fit into the family care home paradigm:

And sometimes you want to meet with the clients also, just to get a feel, because you have to find a good fit, because some people are really very mentally ill and should not even be in a family care home or should be like maybe in a hospital.

Gayle made reference to the standard North Carolina FL2 form that providers used as part of their screening process, as well as to her perception of the "core group" that subsequent residents needed to fit. The FL2 form is North Carolina's long-term care services prior approval form and solicits resident information categories including identification, admitting diagnoses, resident health information, and medication details (http://info.dhhs.state.nc.us/olm/forms/dma/dma-372-124-ach-ia.pdf). "We receive the FL2 and see if they're a good fit for our core group, which are um…three males. They get along pretty well and we don't want to disturb them."

Zada framed her matching process as one that considered both the potential residents, but also the realistic capacity of her staff.

I visit all of those people who will potentially come into my home and in my mind I see them as "Would they fit to the home? In which home would they be most comfortable? And how could I serve them?" So that is the reason that I visit with them before they come into the home, to be sure that the home is compatible to them, as best I can. Not only that, but I think about my staff and myself: "Could I comfortably take care of this person? Would I want to be awake all night long while this person is walking the floor or tearing up furniture or running?" So I select people who I think would be compatible to the other people as well as to my staff.

Similarly, Rhonda's sense that her residents' plight could be anyone's translated into her staff training and protectiveness of her residents: "I've had people that will just not treat my clients right, and then they have to go, I can't not...I will not tolerate that."

Taking in family and friends. Driven by a different purpose in creating an AFC home culture, Alex was one of the providers whose AFC home was started to provide care for his family.

> [T]he main purpose the business was opened was to provide care for immediate family members…because we had a situation in our family where we had family members that were…they were beginning to get up in age…and, consequently as a result of that…my father felt like it would be… a great idea that if we opened a family care that we could provide healthcare for our aging parents and grandparents. So it was not opened as a means of income, a profiting income. It was open more in a sense to provide a service for family members.

However, as Alex's home now includes individuals other than family members, like other providers, he puts effort into making careful resident matches. For example, he requires physical and psychological history forms be completed to help him understand potential residents' conditions prior to their placement.

Toward a Theory of Dialectics of Power and Care

The analysis of the previous six focused codes led to the final level of constructivist grounded theory, that of selective or theoretical codes. This analysis included constant comparison of the focused and axial codes in concert with reexamination of the coded transcripts, eventually reducing cumulative assessments of data to the theoretical codes. Two theoretical codes characterize the final story line represented in the data: (a) multiple dimensions of investment, and (b) dialectics of gain and loss.

Multiple Dimensions of Investment

Providers demonstrated one or more styles of investment in their AFC settings including exhaustive business commitment, fostering a safe and family-like setting, verbal or other behavior toward residents, or facilitating choice and other opportunity for residents. Sometimes investment was communicated in humanitarian or religious terms. Cadi captured the intersecting investments as she described how residents are closely integrated in her family life and how her employees support this value as well. She conveyed not only her investment in fostering a family-like setting, but also her investment in warm behavior toward her residents and maintaining a group of good employees for her business:

> We have an extended family, and so do they. One of my residents – I call him Uncle Mike. And I mean… they're just like family members. And we treat them that way because when you come into our home, you're not just a number. You are a part of the family. We make you feel like extended family, and…we want to appreciate the love that is within the house. And we're truly blessed to have a good group of people and employees. I mean our staff has been great with our residents. I have two small children and the residents love…you know, always ask about my children. I got married 10 years ago and at least five of them [residents] came to my wedding.

Dialectics of Gain and Loss

Providers indicated a dialectics of gain and loss (i.e., simultaneous and sometimes contradictory experiences) surrounding their investment in their AFC settings (Teddlie & Tashakkori, 2011). Such juxtaposition of gain and loss experiences was demonstrated through the providers' interviews, and analyzing them in concert allowed for a greater understanding of the providers' experiences. Providers' experiences were not only defined by relational or professional gain, or only by relational and fiscal loss. Providers communicated complex experiences that included both gain and loss, and this complexity calls for both support of what is working and intervention in areas of challenge from regulatory agencies in the state and nation.

When providers discussed or alluded to losses, they ultimately described ways in which gains helped them to compensate for, overcome, and proceed in the face of loss, yielding a synthetic resolution of gain and loss. Experiences of loss included loss of personal time with family and friends and for some providers, a loss of friendships altogether, loss of life experience separate from their AFC business, loss of financial stability or flexibility, and perceived loss of a control over their business due to outside agencies. Gain experiences included expansion of support networks to include helpful community organizations (e.g., daytime recreation programs for residents), additional support through local health and human services supervision, support from their own or residents' biological families, and support from residents who tried and did make life easier for them.

Joelle's experience captures this dialectic of gain and loss in ways that resonated with the other providers. Joelle was a Supervisor in Charge at the AFC. She and her two sisters and brother maintained the business, while her parents, still the owners, were struggling with their own health problems. Joelle's family experienced dialectics of family harmony (gain) and health struggle (loss), as well as simultaneous and contradictory work fulfillment (gain) and lack of personal life (loss).

> We've all been supportive towards each other since the business been open. My mom is
> not well, my mom or dad. My dad had three strokes. My mom…she's a diabetic…and [is]
> having knee problems. . . . . I just like being around [the residents]. So I don't have no
> problem not having a day off.

Providers used their power positions as authority figures to bring maximum opportunity and benefit to their residents. They leveraged their abilities and resources as they invested their expertise, time, and relationships to support the experience of their residents. Hand in hand with this investment, providers experienced personal fulfillment or gain from their professional accomplishments and the relationships with their residents, staff, and supportive family members. Providers also experienced loss along with the gain, with minimal personal time,

infringement on their own opportunities for friendship, and expending their personal resources when state funds were insufficient. An emerging theory of the dialectics of power and care is that providers revealed a commitment toward their residents and their AFC business that was integrative across multiple dimensions of investment, and that providers experienced dialectics of gain and loss as a result of their AFC role.

Chapter Summary

During the interviews, the providers revealed their motivations for starting their businesses, the nature of their personal and professional roles, their perspectives on giving residents a choice, and how they balance a sense of "family" with business. They shared their perspectives on how residents express affection and care to providers. Providers also described their values, including commitment, making residents' lives as good as possible, empathy, and dedication to creating "the home." The analysis of these key themes captured as initial, focused, axial, and theoretical codes led to an overarching understanding of provider experience, which may be captured as a theory of the dialectics of power and care. Crucial tenets of this theory are that (a) providers revealed a commitment toward their residents and their AFC business, integrative across multiple dimensions of investment, and (b) providers experienced dialectics of gain and loss as a result of their AFC role.

CHAPTER 5: DISCUSSION AND CONCLUSIONS

Adult Foster Care (AFC) provides housing and 24-hour care for adults with physical and intellectual disabilities. AFC is unique in the home-like environment it provides, as well as in the opportunity for community integration. My research evolved out of a review of state responses to the Olmstead Decision with regard to long-term housing for older adults and adults with disabilities. National momentum for better quality long-term care has spanned more than two decades and continues to play out in state-level implementation of the Olmstead Decision supporting community-based care options. There is a range of compliance with the decision among states, and North Carolina is one state that has uniquely resisted the decision by only informing individuals of opportunities for community-based care if they proactively inquire. The purpose of this study was to understand the experiences of North Carolina AFC providers as a first step to understanding AFC as an option for long-term care, including understanding the state context of AFC (e.g., supportive and regulatory institutions) and resident experiences.

Semi-structured, guided interviews were conducted with 26 providers. Interviewees were candid, revealing both the gains and losses experienced across their multiple dimensions of investment in their work. Their responses revealed much about contributions to thriving AFC settings, which include provider vision and recognition of reciprocity in their care relationships; provider personal, family and business investment; ongoing practice supporting strong relational ties and empowering efforts with residents; and the interactive presence of the residents themselves. I conducted grounded theory data analysis, along with reflexive documentation of my own positionality and consequent lens on the data. As I analyzed the data presented in Chapter 4, I uncovered detailed characteristics of the relationships and dynamics between providers and regulatory institutions and their residents. In this concluding chapter, I discuss the study findings in relationship to my research questions and how the schematic representing the relationships and dynamics between providers, institutions, and residents has shifted as I developed a grounded theory of the dialectics of power and care.

Discussion of Research Questions in Light of Findings

The research questions guiding this study were informed by the literature on AFC and Child Foster Care (CFC) and the theories of care and relational reciprocity; power, difference and hierarchy; and intersectionality. In the following sections, I provide a discussion of my findings in response to each of my research questions: (a) provider perceptions of and relationship to the AFC system; (b) provider perceptions of residents; (c) strategies to integrate residents into AFC homes and communities; and (d) recognition, adherence to, or resistance of existing power relations and constraints.

Provider Perceptions of and Relationship to the AFC System

Providers overwhelmingly found the AFC system—including its personal, interpersonal, and institutional aspects--to be an opportunity for relational and professional satisfaction. Personal and professional satisfaction undergirded provider commitment; only two providers expressed ambiguity about their likelihood to stay in their professional role. In these two cases, as well as for other providers that expressed unwavering commitment to their professional position, there was tension between their professional ideals and systemic constraints and limitations (e.g., insufficient funding, overwhelming and seemingly irrelevant paperwork, physicians who were out of touch with provider and resident experience). Some providers voiced appreciation of supportive and regulatory institutions that provided monthly audits (and consequently support to keep up with AFC home paperwork and programmatic requirements), advice and support in working with residents with specific needs (e.g., mental health needs), and community programs (e.g., work and recreational programs for individuals with disabilities). However, other providers described problems in the system, including administrative tasks that detracted from time spent with residents, insufficient compensation for and recognition of the extent of provider work, and inadequate funding of residents that were dependent on Medicaid.

Researchers have documented that inadequate compensation of providers has threatened the sustainability of AFC care in other states, such as Connecticut and Utah (Mollica

et al., 2009). Despite problems in the system and ultimately threats to AFC home sustainability, the providers I interviewed in the current study were in large part completely committed to their work, which often included widely diversified responsibilities such as hands on care work, resident and staff recruitment, resident intake, staff training, financial and resident paperwork, and physical maintenance of the facility. Thus, AFC providers, either alone or with assistance from additional staff were responsible for all aspects of the residents' well-being of residents (Mollica et al., 2009).

Providers also demonstrated an enthusiasm in the opportunity to make their homes thrive, expressing great satisfaction in the activities, progress and well-being of their residents. The enthusiasm of providers in this study offered a detailed picture of the "willingness and ability" to serve that the AARP reported based on their interviews with providers across the nation (AARP Public Policy Institute, 2009, p.2). Mollica et al. (2009) described AFC providers' absolute role in being responsible for the well-being of residents, whether or not the providers receive assistance from additional staff. With a decline in the number of individuals with disabilities living in nursing homes, and an increasing number living in community-based care settings, AFC providers are contributing a needed role in accounting for the needs of these residents with disabilities, who are also often more likely to be of lower socioeconomic status and uninsured (Redfood & Houser, 2010; Denavas-Walt, Proctor, & Smith, 2011). Similarly, the Child Foster Care literature has made clear that care providers are critical mobilizers of well-being for CFC youth with disabilities, and providers demonstrate the child as the priority in their work (Southerland, Mustillo, Farmer, Stambaugh, & Murray, 2009; Warde, 2008).

Providers' Perceptions of Residents

Providers viewed their residents as human beings, deserving of empathy, family, opportunity for choice and a good quality life. Many providers paraphrased the Golden Rule as they described their relationships with their residents. As a segue from the idea of treating others as one would want to be treated, providers also saw their residents as individuals

capable of reciprocity, i.e., human beings able to give back to the provider and other residents.

This capability for relational give and take supported providers' behavior and feelings. It made

their jobs easier, whether it was helping to keep an eye out for other residents' needs, offering

to clear the table, or giving the providers time for themselves or small tokens of affection. These

findings are similar to reciprocity found within the context of family care. For example, older

parent caregivers reported receiving more than they gave in emotional and tangible reciprocity

from their adult children with intellectual disabilities (Perkins, Haley, LaMartin, & Wang, 2014).

Reports of day to day reciprocity that occurred within the environment of the AFC home

suggests that reciprocity existed without much effort to facilitate such behavior.

Strategies to Integrate Residents into AFC Homes and Communities

AFC providers integrated residents into their AFC homes and surrounding communities

by including residents in the family-like environments of the facilities, including their biological

family's activities. Across the 26 providers, there was a range of efforts to balance family and

business, with family and business intersecting uniquely for each provider and AFC home. The

providers' success with running their businesses allowed the family-like quality of their AFC

home to be viable and sustainable. Building upon the foundational work of Sherman and

Newman (1979) on home and practice characteristics that result in best outcomes for the

residents, data from the current study provided new insights about the providers' contributions

that made their AFC homes a success. For example, while Sheman and Newman (1979)

pointed to the importance of appropriately matching of residents with homes and facilitating

resident visits before intake, the current providers extended this approach to include ongoing

active choice opportunities.

Providers' consistent value and negotiation of resident choice was an active way of

regularly affirming and including residents as members of the AFC home and surrounding

community. All but a few providers were adamant about resident choice, and most discussed

their efforts to negotiate opportunities for choice, especially in the face of system constraints

(e.g., insufficient staff funding resulting in fewer choices for residents). Providers' practice of facilitating choice opportunities has been highlighted by other researchers as a critical contributor to residents feeling positive about relocation to an AFC home (Reinardy & Kane, 1999).

Recognition, Adherence to, or Resistance of Existing Power Relations and Constraints

Regardless of their backgrounds (e.g., education level), providers rose to the occasion to meet the ongoing and broad business requirements of running their AFC practice. Their level of investment reflected both tenets of care theory, (a) a mental state of concern as well as (b) care practices (Fisher & Tronto, 1990). This heightened performance of care allowed the AFC providers to meet the nuanced needs of residents resulting from unique intersections of aging, disability, gender, social class, race, and ethnicity. Intersections of race, gender, and ethnicity can bring experiences of privilege or lack thereof (Zajicek, Calasanti, Ginther, & Summers, 2006) and consequent experiences of greater ease or discomfort in disability and aging, especially when considered in light of the additional intersection of social class (Carey, 2009). Providers in the current study worked competently with residents, meeting the needs of individuals with great diversity in their life experiences. They sometimes chose to provide specialized services to individuals with certain common conditions, such as dementia or mental illness. This approach allowed then to provide more efficient care and created an environment that was perceived as comfortable for residents.

Providers typically overcame tension between professional ideals and systemic constraints as they persisted in their multidimensional work to create home-like environments for their residents that met or exceeded regulatory standards. In most cases, their care values superseded system constraints. This persistence, above and beyond agency limitations (e.g., providers funding residents' medications, eye glasses, and personal needs beyond what Medicaid provides), was critical to providing the support needed by residents.

The majority of providers also skillfully navigated their own privilege in the hierarchy of the provider/care recipient relationship (Clark, 1997; Ottman, Allen, & Feldman, 2009), allowing opportunities for the residents' initiative and personalities to add to the strengths of the care context, facilitating a partnership with the residents beyond a top-down care provider-recipient relationship. Such skillful navigation was demonstrated in instances when providers took time to negotiate choice, or when providers allowed themselves to receive small but meaningful supports from residents.

The early work of Sherman and Newman (1988) supported the idea of AFC as a context that can be supportive of resident integration into the communities by engaging with people and life opportunities as independently as possible. The providers in the current study shared numerous examples of how they put this value into action with their AFC residents. Negotiating choice was not always easy for providers in the context of insufficient funding, for example, when a provider had limited or no staff to support residents' differing activity preferences. However, providers took the time to talk through situations with residents, and if a resident's choice was not possible in the moment, providers often worked to make it possible in the future. Providers sometimes overcame their own need to always be in charge when they accepted supportive efforts from residents, such as when residents reminded each other that the provider might need quiet time at night, or when they initiated washing the provider's car or doing the dishes. Providers also used their privilege and supportive, resourceful role to support resident growth, including helping residents prepare to live independently.

A Theory of Dialectics of Power and Care

The original schematic in Figure 1 (Chapter 2) presented a hierarchical representation of AFC relationships, with resources and power flowing from the top-down, from institutions to providers to residents. However, a different schematic is suggested by the theory emergent from the study data. The *Theory of Dialectics of Power and Care* considers the overwhelming investment of the provider not only on behalf of the residents but in partnership with them. This

close relationship is represented in Figure 2 by the shorter connecting line and the equal

dimensions of the representing boxes. The provider is a strong partner with the resident

because of both business and personal investment, offering expertise as well as relational

fortitude. Providers gain relationally and practically from this connection with residents as well,

though their personal lives are impacted and sometimes limited by their level of investment in

their residents.

The *Theory of Dialectics of Power and Care* also acknowledges that providers are the

central nexus of activity sustaining the AFC system, as required by the system in which they

work. They maintain contact with agencies on behalf of the residents. They manage the

breadth of professional requirements to make things work for the residents, even when sufficient

resources for residents are not there. The providers are at times supported by agencies, but it

is often the providers who make things work in spite of agencies, not because of agencies.

However, it is also the close and reciprocal relational experience with residents that contributes

to optimal functioning of the AFC setting. Finally, it is the presence of the residents that

supports the existence of the AFC business. The data informing Figure 2 suggest a greater

consideration of the role of residents in the success of the care setting.

Figure 2. Theory of Dialectics of Power and Care
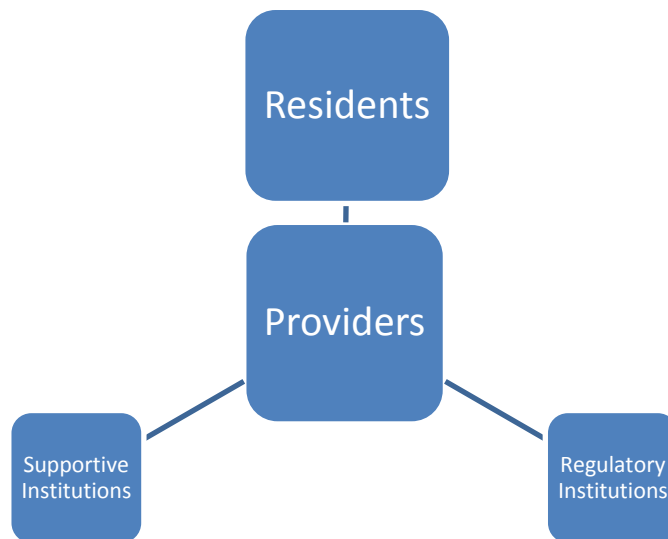
Strengths and Limitations

The purpose of this study was to understand North Carolina Adult Foster Care (AFC) providers' perspective on and experience of AFC as community-based care. Based on semi-structured guided interviews, findings provide a perspective of one state's AFC system through the provider lens and contributes to a content area that has been addressed in only 10 academic papers and two books between 1977 and 2014.

The findings of this study provide new insights into the lives of AFC providers. However, the study is not without its limitations. First, residents' views about their care and relationships came through the eyes of the providers only; it is not certain if the residents would have the same assessment of themselves and their experience in the AFC context as providers described about them. Similarly, insights into the functioning of North Carolina's state regulatory agencies and how the AFC system works across the state was through provider reports; state employee agencies might provider alternative perspectives. Each of the providers offered a unique perspective into their respective AFC home functioning, their residents, and

how their homes were impacted by outside agencies. Collectively, the 26 interviews provided a

broader vision for what is happening in AFC across the state of North Carolina. However, it is

unknown if the 26 providers who engaged in the this research project differed from the other 58

individuals who were not available to participate, did not respond to my recruitment efforts, or

did not wish to participate in the study. It is also important to note that all of the providers

interviewed were business owners and/or administrators, cultivated in their ability to make their

business work, which may include some level of public relations, including speaking with

interviewers. It may be that in light of this business and public relations savviness there are

elements of resident experience that were not conveyed.

Implications for Research

While the current study begins to fill the gap in knowledge about AFC, findings raise

additional questions that need to be addressed. For example, further research is warranted to

understand if the providers' perceptions of disconnect with state agencies results from

inadequacies on the level of state understanding and implementation of AFC as community-

based care (National Council on Disability, 2003). It is also possible that agencies need to be

more in contact with providers who have unique and specific insights from doing the actual day

to day work.

First, future research also needs to consider variability by state context. In the current

study, providers' experiences were presented from the state context of North Carolina. In North

Carolina, providers were in direct contact and negotiation with government agencies, whereas in

other states, like Virginia, there is the possibility of working under a nonprofit or private umbrella

agency. Such an agency can provide an infrastructural buffer for government agency

requirements as well as provide additional training supports and guidance to providers.

However, an umbrella agency could also serve to limit individual providers in their independent

efforts to facilitate optimal care climates. In addition to examining different state contexts, a full

picture of the nature and contribution of AFC practice requires interviews with additional AFC

stakeholders, such as Department of Social Services employees, AFC home support staff, AFC

home residents, and residents' biological families.

Second, I recommend continued exploration of AFC context through the use of more

diverse methodologies. Additional methodologies have the capacity to provider additional

perspectives on the same research context. For example, I would like to continue to analyze

and present this provider data in the future using methodologies of Creative Alternative

Processes (CAP), incorporating visual and performance methods to examine power, hierarchy

and relational interplay within the data, as well as between research participants, their data, and

myself as the reflexive researcher (Richardson & St. Pierre, 2005). CAP approaches have

supported my continuing understanding of my data through reflexivity and also provide an

additional means of communicating data to the community. As Mayan (2009) writes, "Research

is dialogic: It is about being in a relationship. . . .We assume that there are multiple realities and

multiple truths and that we are presenting just one possibility" (p. 25). One area in particular

that CAP has been useful to me to grasp such multiple realities is in the consideration and

understanding of my own experience as a caregiver, in a relational context with a care recipient.

Diagramming my perspective on my reality as a caregiver in relation to my perspective of my

care recipient has helped me to understand the power dynamics between us. Scripting

autoethnographic dialogue based on conversations between us and performing this with an

audience supported both myself and the audience to better understand the experience of

caregivers and care recipients, the power hierarchy between the two, and the power dynamics

in the caregiving context (Munly & Tilley-Lubbs, 2014). This type of visual diagramming,

scripting and performance of the current study's data could also support continued

understanding of the North Carolina AFC context, including provider and resident experience.

Implications for Practice

Across AFC homes, providers demonstrated investment in strong partnership with their

residents, facilitating relational give and take among residents and between residents and the

provider. In the current study, this presence of reciprocity or relational give and take was a

marked quality of AFC setting success. Thus, a first implication of this research is the

importance of states to go beyond training providers on good management practices (Reinardy

& Kane, 1999; Sherman & Newman, 1979) to educating providers on the value of residents

themselves for their contribution to the success of AFC settings. Educating providers on the

value of residents may require practice simulations and reflexive exercises to try to understand

the perspectives and positions of potential residents.

Furthermore, the profession of AFC provider demands that individuals be able to devote

themselves fully to the role. Consequently, a second implication of this research is that

providers, in the current system, should be trained to prepare for this level of professional

immersion and dedication. Some providers were able to manage professional demands by

integrating their own biological family into the experience, benefitting themselves and the

residents. Such practices provide insight to promising practices that could be used to support

sustainability of the AFC provider role.

A third implication of the current study is that regulatory agencies need to formally

recognize and commend the massive administrative and care work that AFC providers are

accomplishing. They must work to find ways to facilitate additional mechanisms of support for

the providers, which may include advocating for increases in Medicaid funding, so that providers

are not funding resident needs out of their own pockets. The quality of AFC as a community

integrated long-term care option, fulfilling the requirements of the Olmstead Decision, will also

remain optimal if quality providers are maintained; there is danger of this not being the case if

their professional demands are not adequately compensated. One possibility may be to support

the roles of AFC providers through more focused efforts of existing supportive and regulatory

agency staff. For example, the role of case workers has been described as essential for Child

Foster Care (CFC) provider connection with agencies, biological families, services and

resources (Dorsey, Kerns, Trupin, Conover, & Berliner, 2012). Similarly, case workers with a

capacity to be more in contact with dedicated AFC providers and the realities of AFC homes could be a key point of state intervention to maximize agency connection with and understanding of AFC provider experiences and resident needs, and consequently improving state care practices at large.

A fourth and final implication is that, it is furthermore important for states and the public (e.g., families of potential and current residents, individuals residing in the same communities as the homes, tax payers potentially contributing to funding of mechanisms of support) to gain insights into how much providers are giving in their various ways of investing. This understanding will help the public and governments at local, state and national levels to support providers in their strengths while also finding ways to support them so that they are not taking on relational and fiscal losses as part of their profession.

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Appendix A

Recruitment Letter

Participant Address

Dear *(Participant Name)*:

I am a graduate student in Virginia Tech's Department of Human Development, and I am interested in learning more about your work in Adult Foster Care (AFC). I saw that your home was listed as an AFC location on North Carolina's Department of Health and Human Services Web site. I worked for some months as an AFC back-up worker, and I developed an interest in understanding the AFC provider experience better. I am inquiring to see if you would have time to participate in a 45 minute, confidential interview with me. I will ask questions about your experience as a provider, and I will audio record the interviews. Your name or agency will not be associated with what you say.

You would be mailed a $20 gift card after the interview to compensate you for your time.

I am also enclosing a consent document that I would ask you to review if you are interested in participating. I will call you later this week to follow-up and am happy to answer any questions at that time. I will be calling from my own cell phone, which is 301-379-2891.

Thank you for considering participation.

Sincerely,

Kelly Munly, M.S.

Doctoral Student

Department of Human Development

Virginia Tech

Kellyam5@vt.edu

301-379-2891

Appendix B

Virginia Tech

Consent Document

Title: Understanding Adult Foster Care Through Provider Experiences

Investigators:

Kelly Munly, M.S., Doctoral Student of Human Development, Virginia Tech

Karen A. Roberto, Ph.D., Professor of Human Development, Virginia Tech

Katherine R. Allen, Ph.D., Professor of Human Development, Virginia Tech

Purpose:

The purpose of this study is to understand the Adult Foster Care (AFC) through greater knowledge of provider experiences.

Procedures:

You will be called by Kelly Munly to see if you are available to schedule a time for a telephone interview, with the possibility of interviewing within the same call if it is convenient for you. Before proceeding with an interview, Munly will review this consent document with you, offering to answer any questions you may have. Consent will include permission to audio record the interview. Each interview will be approximately 45 minutes. After the interview, Munly will send you a $20 gift certificate to thank you for your time.

Adult Foster Care is an area of long-term care that has not been widely studied or understood. Participating in this research will contribute to the country's greater understanding of Adult Foster Care. With a greater understanding of this service, there will be more potential for federal- and state-level support of this type of service, as well as of those who work in and those who are served by it.

Confidentiality:

The interview recordings and transcripts from this study will only be reviewed by the investigators and transcriptionist. All staff involved with this project understand the confidential nature of the interviews. Virginia Tech's Institutional Review Board (IRB) may review interview data for auditing purposes.   The IRB oversees the protection of this project's interview participants.

Freedom to Withdraw:

Interview participation is completely voluntary, and you are free to withdraw from the study at any time.

Research Approval:

As required, the research project has been approved by the Virginia Tech IRB. If you have any questions about this study or its conduct, or your rights as an interview participant, you may contact:

Kelly Munly, M.S.   (301) 379-2891 / kellyam5@vt.edu

Co-Investigator   Telephone / e-mail

David M. Moore   (540) 231-4991 / moored@vt.edu

Chair, IRB   Telephone / e-mail

Office of Research Compliance

Research and Graduate Studies

Appendix C

Script

Thank you so much for taking this time to speak with me on the phone—I imagine you have (*had*) a full day. I worked for some months as a back-up worker in Adult Foster Care, and I developed an interest in understanding the AFC provider experience better. I am interested in understanding your experience better. This interview will take about 45 minutes and is confidential; your name or agency will not be associated with what you say. Any identifiers will be removed from the transcript. You will also be asked basic questions about yourself and your residents. Do you have any questions for me before we begin?   (*pause*)

(*interview*)

Thank you for participating. I will send you a gift card that you should receive within a week. If I have forgotten anything, I may call you back. If there is something that you remember later that you would like to share as part of the interview, feel free to call me.

Appendix D

Demographic Form

Thank you again for taking this time to help me understand your AFC setting. First I would like

to ask you a few questions about yourself and your residents. Remember there is no right or

wrong answers, and all responses will be kept confidential. I will be asking all the providers I

interview the same questions.

Please feel free to ask me to speak more slowly or loudly, or to repeat a question or the answer

choices.

1. How would you describe yourself?

    a. Female

    b. Male

    c. Other

2. What year were you born? _____

3. What race do you identify with? Are you…

    a. White

    b. Black or African American

    c. Asian

    d. American Indian or Alaska Native

    e. Native Hawaiian or Other Pacific Islander

    f. Multiracial

    g. Other (please specify)

4. What is your ethnicity?

    a. Hispanic or Latino

    b. Not Hispanic or Latino

    c. Other

5. How many years have you been a paid care worker? _____

    Where was this work? _____

    What kind of work was it? _____

6. How many years have you been providing care in an AFC setting? _____

7. How many years have you been providing care in your current AFC setting? _____

8. Do you use respite or back-up care?

    a. Yes

    b. No

    If yes, how many workers do you employ? _____

    And for how many hours a week total are your workers employed? _____

    How many of hours of respite care take place outside of the AFC home? _____

9. What trainings have you received in your AFC setting (*if more than six trainings are listed, list on back)*?

    a.

    b.

    c.

    d.

    e.

f.

10. What trainings have you received in prior AFC or other kinds of caregiving settings (*if more than six trainings are listed, list on back)*?

   a.

   b.

   c.

   d.

   e.

   f.

11. What is your educational background?

   a. Less than high school (*record last grade completed*) _____

   b. High School Diploma/GED (*if a technical high school, record special training*)

   _____

   c. Two year college/technical degree (*indicate major/specialized training*)

   _____

   d. Bachelor's degree (*indicate major)_____*

   e. Master's degree (*indicate major area)_____*

   f. Doctoral/Medical degree (*indicate major area or residency)*

   _____

   g. Other (*specify, e.g., a law degree*) _____

12. How many residents do you *currently* have? _____

13. How many residents do you *typically* have? _____

14. Of the *X* number of current residents, how many are female, male, or other*? (Indicate number of residents in each category).*

    a. Female_____

    b. Male_____

    c. Other_____

15. Tell me the age of each of your current residents.

    R1_____

    R2_____

    R3_____

    R4_____

    R5_____

    R6_____

16. With regard to race, how many of your residents are_____? *(Indicate number of residents in each category below).*

    a. White_____

    b. Black or African American_____

    c. Asian_____

    d. American Indian or Alaska Native_____

    e. Native Hawaiian or Other Pacific Islander_____

    f. Multiracial_____

    g. Other (please specify) _____

17. How many of your residents are _____? *(Indicate number of residents in each category below).*

    a. Hispanic or Latino_____

    b. Not Hispanic or Latino_____

    c. Other_____

18. Tell me about how each of your current residents funds their AFC stay and services

    (*prompt for independent income/private pay, types of Medicaid funding/waivers,*

    Medicare, other auxiliary grants).

        R1_____

        R2_____

        R3_____

        R4_____

        R5_____

        R6_____

19. Do you have resident spots allocated in your AFC service for specific kinds of funding

    (*e.g., Medicaid ID Waiver or Developmental Disability Waiver*)? If so, please describe

    these for me.

    _____

    _____

20. How many of your residents are in your AFC due to _____? *(Indicate number of*

    residents in each category below; residents may fall into multiple categories).

    a. Intellectual disability_____

    b. Dementia or other memory problems_____

    c. Chronic health problems_____

    d. Mental health problems_____

    e. Mobility challenges_____

    f.   Not having existing family_____

    g. Not having a family member who is willing or able to provide care_____

Appendix E

Correspondence between Interview and Research Questions

	Interview Questions	Research Questions			
		How do Adult Foster Care (AFC) providers perceive the AFC system and their relationship to the AFC system?	How do AFC providers perceive their residents?	What strategies do AFC providers implement in their efforts to integrate residents into the AFC homes and communities?	How do AFC providers recognize, adhere to, or resist existing power relations and constraints in the AFC system as they impact their ability to provide care for residents?
1	Tell me about your experience of becoming an AFC provider.	X			X
2	What do you call your resident?		X	X	X
3	What do you call yourself in your professional role?	X	X		X
4	Tell me about the general process of being matched with residents in your home.	X	X	X	X
5	In a word or two, describe each of your current residents.		X		
6	What is your experience of family in your AFC home?	X	X	X	
7	Give me an example of a resident(s') experience of family, in your opinion.		X	X	X
8	Tell me about professional supports that you find most helpful. Least helpful?	X			X
9	How would you describe the way(s) in which you show		X	X	X

	"care" in your AFC environment? How do your residents show "care" to each other (if applicable, if more than one resident)? How do they show "care" toward you?				
10	Tell me about how the way you think about "caring" for your residents has stayed the same or changed over time.		X	X	X
11	In what way(s) does your AFC agency promote a sense of "caring" between staff, and between staff and residents?	X			X
12	Provide example of how a resident exercised choice.		X	X	X
13	Is there anything else that you would like to tell me about working with your residents and your AFC agency?	X	X	X	X

Appendix F

Focused and Axial Codes

Focused Code 1: Motivation for Beginning Work as an AFC Provider
1.1: Family ownership (existing, or needing to start a new business)
1.2: Care needs of elder family members
1.3: Circumstantial (e.g., just fell into it; chance career opportunity; husband lost job)
1.4: Drawn toward social service and caregiving
1.5: Business background

Focused Code 2: Providers' Personal and Professional Roles
2.1: Relational dynamic with residents: "Oh they're my peeps!"
2.2: Breadth of job responsibilities: "All of that is my responsibility"
2.3: Presence of personal life: "So yeah, we come home, that's our refuge."
2.4: Community and agency supports: "We have all kinds of supports"
2.5: Struggles (e.g. with degree of responsibilities, not enough support, sometimes unspoken)
2.6: Likelihood to stay (e.g., likely or ambiguous)

Focused Code 3: Perspectives on Giving Residents a Choice
3.1: It's their choice
3.2: It's their choice, but sometimes we negotiate
3.3: It's their choice, we negotiate, but ultimately I decide
3.4. We might negotiate, but ultimately I decide

Focused Code 4: Balancing "Family" with Business
4.1: "It's just like one big family"
4.2: "We are their family, but this is still a business"
4.3: "Well I'm definitely not a family member"
4.4: It's both family-like and not family-like

Focused Code 5: Reciprocity: How Residents Express Their Affection and Care to Providers
5.1: Make my life easier: "They'll volunteer to help me do this or that"
5.2: Expressions of affection (e.g., hugs, leaving small gifts)

Focused Code 6: Providers' Values
6.1: Commitment to residents: "We dedicated, or else we wouldn't be in this business"
6.2: Making resident "life as good as possible": "What we do is assist the *living*"
6.3: Empathy: "it could be me" or someone I love
6.4 Creating "the Home" (e.g., Making a careful match, Taking in family and friends)

Focused Code 7: Toward a Theory of Dialectics of Power and Care
7.1: Multiple dimensions of investment
7.2: Dialectics of gain and loss

Appendix G

Correspondence of Research Questions with Axial, Focused and Theoretical Codes

Research Questions	Example Axial Codes	Example Focused Codes	Theoretical Codes
How do Adult Foster Care (AFC) providers perceive the AFC system and their relationship to the AFC system?	2.1: Relational dynamic with residents 2.2: Breadth of job responsibilities 2.3: Presence of personal life 2.4: Community and agency supports 2.5: Struggles 2.6: Likelihood to stay 4.1: "It's just like one big family" 4.2: "We are their family, but this is still a business" 4.3: "Well I'm definitely not a family member" 4.4: It's both family-like and not family-like	2: Providers' Personal and Professional Roles 4: Balancing "Family" with Business	• Multiple dimensions of investment • Dialectics of gain and loss
How do AFC providers perceive their residents?	3.1: It's their choice 3.2: It's their choice, but sometimes we negotiate 3.3: It's their choice, we negotiate, but ultimately I decide 3.4: We might negotiate, but ultimately I decide 5.1: Make my life easier 5.2: Expressions of affection	3: Perspectives on Giving Residents a Choice 5: Reciprocity: How Residents Express Their Affection and Care to Providers	• Multiple dimensions of investment • Dialectics of gain and loss
What strategies do AFC providers implement in their efforts to integrate residents into the AFC homes and communities?	3.1: It's their choice 3.2: It's their choice, but sometimes we negotiate 3.3: It's their choice, we negotiate, but ultimately I decide 3.4: We might negotiate, but ultimately I decide 6.1: Commitment to residents 6.2: Making resident "life as good as possible" 6.3: Empathy 6.4 Creating "the Home"	3: Perspectives on Giving Residents a Choice 6: Providers' values	• Multiple dimensions of investment • Dialectics of gain and loss
How do AFC providers recognize, adhere to, or resist existing power relations and constraints in the AFC system as they impact their ability to provide care for residents?	1.1: Family ownership 1.2: Care needs of elder family members 1.4: Drawn toward social service and caregiving 1.5: Business background 6.1: Commitment to residents 6.2: Making resident "life as good as possible" 6.3: Empathy 6.4 Creating "the Home"	1: Motivation for Beginning Work as an AFC Provider 6: Providers' values	• Multiple dimensions of investment • Dialectics of gain and loss

Appendix H

Provider Vignettes

1. **Alex**

   Alex was a 63-year-old African American male. He described himself as "Afro American." His original home was licensed in 1988 in Greensboro, North Carolina, started by his father with the intention of providing a framework to be able to provide care for elder family members. A second home was added in Jamestown, North Carolina in 1994. When interviewed, Alex was very proactive about discerning the purpose of the interview, what the information would be used for, and sharing his knowledge and perspective on the encompassing health care system of which family care (the name for adult foster care in North Carolina) is a part. His undergraduate studies in political science and sociology were reflected in his rich discussion of his view of the contexts of his care work, and he seemed eager to have a channel to share his views and voice. All 12 of his clients in both homes were male, with an age range from 30s to 60s, and an equal number of African American and White residents. Two of his residents were private pay, and the rest funded their stay through Medicaid and social security. Several of his residents experienced intellectual disability, one experienced a mobility challenge, and all experienced some kind of chronic health problem that required medication. All residents also had mental illness as part of their multiple diagnoses. None had dementia or other memory problems. Alex was the owner-administrator of the homes, but did not feel comfortable with the word "owner." As with all of the interviewees, he referred to the adults receiving care in his homes as "residents," but he also specified that he refers to them individually and speaks to them using their last name (e.g., "Mr. Jones").

2. **Bernice**

Bernice was a 58-year-old African American female. She worked in family care settings

for almost a decade, including the current site and a prior one. She was an

administrator and worked one of three daily shifts. She was educated through the tenth

grade. The home where she worked has six residents, with ages ranging from 42 to 83

and an equal number of African American and White residents, funded by both private

pay and Medicaid. She expressed in her interview that it makes her feel good to take

care of people's needs and make them happy. Bernice found out about the home

because her niece was a good friend of the owner. She had been looking for work for a

year before meeting the owner and beginning work there. She seemed to have high

regard for the owner. Her prior work experience included extensive unpaid family

caregiving for four of her own family members. She called the adults who live in the

home "residents," but also said that "they feel more like brothers and sisters." Three of

the residents experienced intellectual disability, five had mental health problems, and

three had mobility challenges. She indicated that only one had chronic health problems.

No residents experienced dementia or other memory problems.

3. **Cadi**

Cadi was a 41-year-old African American female who identified as "Black." She had

worked in family care since she was 14; her mother was a social worker and opened a

home, which is how Cadi began working in this field so young. She was an owner-

administrator and she and her family (husband and parents) co-owned three different

facilities, with full capacity (6 residents) in each. Resident ages ranged from 30s to 60s.

Her bachelor's degree was in Arts and Sciences Interdisciplinary Studies. In her

interview, she stressed how much she loves this work. She seemed very professional

but also very family-oriented with her residents, citing how five of the residents came to

her wedding. She called the adults who live in her family's homes "residents," but also

stated that "it's just like one big family," calling one of the residents "Uncle Mike." Among

the 18 residents in her family's three family care homes, 4 had an intellectual disability, 2

had dementia or other memory problems, all 18 had some kind of chronic health

problem as well as mental illness, and 6 had mobility challenges.

4. **Dan**

Dan was a 57-year-old White male, an administrator of the only nonprofit family care site

in North Carolina. He had worked for about 20 years in care work, including family care,

intermediate care facilities (serving as Activities Director), hospitals (serving as Director

of Geriatric Services, including community-based programming), and adult day services.

He had been working in family care for three years. Although Dan was similar to other

providers in conveying a sense of caring about his residents, he was also clear to

distinguish himself as staff and not family. He also noted the caring of the staff, which

he described as members of the "household team," a personal and home-like descriptor

used despite the home's intentional professionalism. He clarified that staff do not live

onsite, and that the home is foremost the residents' home. With six private pay

residents, his home may be one of the most lucrative sites; most residents were involved

in an adult day program that preceded the opening of this site. These residents' family

members were all very involved but simply not able to serve as the primary care provider

for the residents anymore.   As with other family care home providers interviewed, Dan

called the adults living in the home "residents." Five of the residents had been

diagnosed with dementia or other memory problems, two had chronic health problems,

and three experienced mobility challenges. Dan also volunteered additional information

that one resident had Multiple Sclerosis, one had macular degeneration, one was in

post-stroke recovery, and one was healing from temporary fractures. No residents had

been diagnosed with intellectual disability or mental health problems.

5. **Elon**

Elon was a 45-year-old African American female who had recently opened her family

care site eight months prior to the interview. However, she had been working in paid

care work for 15 years, as a CNA, in medication management roles, for personal care

agencies, and in other family care sites. She had a high school diploma and one year of

college studies in sociology. She was the owner/administrator of her home. She

currently had three residents at her site, but hoped to fill her site to capacity of six. She

had two female and one male resident, all African American with ages ranging from 56

to 62. One of her residents was private pay and the other two were Medicaid-funded.

She indicated that beyond the two Medicaid-funded residents, financially she needed the

other residents (up to four others) to be able to pay with resources other than Medicaid.

As with other providers, she calls the individuals living in her family care home

"residents;" at times when speaking about them, even affectionately, she used a formal

prefix such as "Mr." She acknowledged that her residents do not have engaged family,

so she was proactive about including her residents in her own family life and she

described that "they just feel like family" and that this facilitates bidirectional ease in the

care relationship. Across Elon's three residents, one had an intellectual disability, one

had dementia or another memory problem, one had a chronic health problem, and one

had a mental health problem. There were no residents in this home that experienced

mobility challenges.

6. **Francis**

Francis was a 43-year-old African American female who had worked in paid care work

for eight years, starting with her own group homes (one in the past, and one more

recently), and then with her own family care home starting three years ago. She was the

owner/administrator of her home but called herself the administrator. Francis had an

MBA. She currently had four residents with a maximum capacity of six. The residents

included three females and one male, with ages ranging from 53 to 62. Two were White

and two were African American. All four of her residents were Medicaid-funded. One

was diagnosed with an intellectual disability, four had chronic health problems, three had

mental health problems, and four had mobility challenges. None of her residents had

dementia or other memory problems. She described herself as living outside of the

home and had a daughter; she expressed that she sometimes needs to make sure she

spends enough time with her daughter in the face of resident needs. She felt that she

has had a maternal instinct in her care of residents, an instinct that developed from

having to care for her younger brothers: "wanting to take care of others and make sure

everybody is okay." As with other providers, Francis called the adults in her home

"residents" but wanted them to feel "we're a huge extended family."

7. **<u>Gayle</u>**

Gayle was a 30-year-old African American female. She had worked two years as a paid

care worker, in an assisted living facility and then for the past 1.5 years as the

administrator/owner of her family care home. She had a Bachelor's degree in

psychology and, at the time of the interview, was working on her Master's degree in

gerontology. She had three residents and can have up to five (versus the state licensing

limit of six), limited by the square footage of the bedrooms in her home. All of her

residents were male and African American, two in their fifties and one in his eighties.

Current residents at the time of the interview were all funded by Medicaid; she indicated

she will take the residents that she can get, but that ideally there would be a couple of

private pay residents in the future. Two of her residents experienced dementia or other

memory problems, two had chronic health problems, one had mental health problems,

and two had mobility challenges. None of Gayle's residents had been diagnosed with an

intellectual disability. As with other providers, Gayle referred to the adults in her house

as "residents," and in the interview described them collectively as "considerate men."

Her father was the guardian of one of the residents, and another resident, a preacher,

had been supported in an authoritative role in the house as he conducted Bible study at the house each week.

8. **Helen**

Helen was a 62-year-old African American woman who had been working as a paid care worker for eight years, with all of this experience in her family care home. She started the home in order to have a place for her parents, as well as to place the family member of a coworker. All of her "residents," which was her primary name for the adults in her home, were people that she had known—either extended family or extended family of her ex-husband. When she found out about the opportunity to start a family care home from Social Services, she quit her job within a week and started the home within 14 months. She completed two years of coursework toward a Bachelor's degree in business, in addition to other courses in business, such as accounting/taxes. She was also a licensed cosmetologist. She currently had five residents, which is the maximum that she is licensed for, due to a private septic tank on her property. Her residents included four females and one male, ranging in ages from 68 to 100. One resident was White and four were African American. One resident was funded by Medicaid, and the rest were private pay. Her residents' happiness seemed to be a priority for her with regard to staff training, versus other household tasks (e.g., cleaning). One of Helen's residents experienced intellectual disability, two chronic health problems, one mental health problems, one mobility challenges, and five were diagnosed with dementia or other memory problems.

9. **Irene**

Irene was a 49-year-old African American female who had been working as a paid care worker for over 20 years, including in her family care homes, mental health facilities, substance abuse and prisoner recidivism programs, and homeless transitional housing. She was an owner/administrator and has had her family care homes for three years.

She also described herself and her husband as "working owners." As with other providers, she referred to the adults in her care as "residents." As a working owner, she worked shifts and then at the completion of shifts went to her own home. However, she found it difficult to separate completely from work. She acknowledged a sense of family with her residents; for example, she stated that when they are on the care home site, her "grandkids are everybody's grandkids." She had a Bachelor's degree in psychology and at the time of the interview was working on a Master's degree in counseling. She had two homes, each with a maximum capacity of six residents, totaling to 12. One house had one female and five males, five White and one African American, with all residents funded by Medicaid; furthermore, in this house four individuals had chronic health problems, five had mental illness, four had mobility challenges, and one had a traumatic brain injury. The other house had two females and four males, four African American and two White residents, and two residents funded by private pay and four by Medicaid. In this latter house, two of the individuals were diagnosed with dementia or other memory problems, four had chronic health problems, four had mental health problems, and four had mobility challenges. There were no residents in either house who had intellectual disability. Both houses included a range of ages from 50s to 70s.

10. **Joelle**

Joelle was a 42-year-old African American female who had worked in her two family care homes for five years, with no prior care work experience. The homes were family-owned businesses. The other owners and staff in the house were her two sisters and one brother. Her two parents started the business and were both too ill at the time of the interview to take in active role in running it. Her father had had three strokes and her mother was diabetic and had knee problems, declining surgery. However, Joelle indicated that her mother was the owner of the business, and Joelle called herself a Supervisor in Charge (SIC), rather than owner. Joelle had a high school diploma. She

was a unique provider in that she does not call the adults living in their homes

"residents," but she calls them "clients." The first house had three residents, though it

usually had six, because two residents became sick shortly before the interview and

were hospitalized and the other went to residential rehabilitation. The other house had

six residents. The residents in house one were all male, one White and two African

American, with ages ranging from 50 to 68. The residents in house two included three

females and three males, three Whites and three African Americans, and with ages

ranging from 60 to 82. Both houses each included three individuals with dementia or

other memory problems, one individual with a chronic health problem, and two

individuals with mental health problems. Joelle indicated that all residents were funded

by both Medicaid and Medicare. She would prefer for financial reasons that two rooms

per house be designated for private pay, but she acknowledged the reality that

participant intake does not always result in that and they have to take what they can get.

Joelle seemed hesitant to provide much detail at times during the interview; one might

conjecture that this is because she is not the official owner and is being cautious about

disclosure. She described her residents as "good," and that they didn't have any "bad"

residents. She acknowledged a familial role of the homes for the residents.

11. **<u>Ken</u>**

Ken was a 53-year-old African American male who had been a paid care worker since

1985, including in a center and as a case worker serving individuals with intellectual

disabilities, a group home serving individuals with mental illness, and the family care

home setting. He had had a family care home since 1997. He called himself an

administrator, but was also the owner of an umbrella business that included oversight of

both the family care home and a separate group home that served individuals with

mental illness and was governed by regulations unique from family care homes. He

discussed the evolution of resident descriptors over time, including "client," "patient," and

"consumer." He stated that "for my individuals that live in my home, I call them my

family." However, at different moments in the process of the interview, he did call them

"resident" and "client." Ken had a Bachelor's degree in criminal justice and was currently

working on a Master's degree in special education. At the time of the interview, he had

six residents in his family care home, which was maximum capacity for the state. All

residents were male, African American, and with ages ranging from the 30s to the 60s.

It seemed important to him to state that in the past he had had more of a diverse mixture

of racial backgrounds, including White and African American. Five were funded primarily

by Medicaid, and one was private pay. Three residents had an intellectual disability, one

had dementia or another memory problem, one had a chronic health problem, two had

mental health problems, and one had a mobility challenge.

12. **Leah**

Leah was a 37-year-old African American woman who had been a paid care worker

since 2005, all in the family care setting that she was in at the time of the interview,

which included four homes (started in 2005, 2007, 2008, and 2013). Leah had a

Bachelor's degree in accounting and business administration, as well as a Master's

degree in social work. She called herself the owner/administrator and called the

individuals in her homes "residents." However, she also affectionately stated "And

sometimes – you know, most of the time – they're like 'Oh they're my peeps!' You

know?" During the interview, she referred to residents as "Mr," followed by the male's

surname, and "Miss," followed by female first names. Three of her homes were at full

capacity with six residents each. Her fourth home established the year of the interview

had only two residents, with an eventual capacity for three. Her first home had six

female residents, with one in her 70s and five in their 60s, three White and three African

American residents, and all six residents funded by Medicaid (this is Leah's allocated

Medicaid-funded house). Two of these residents had chronic health problems, one had

mobility challenges, and all six had mental health problems. Leah's second home had

four female and two male residents, with all six residents in their 80s, White, and funded

by private pay. Six of the residents in this house had dementia or other memory

problems, two had chronic health problems, and four had mobility challenges. The third

home included six females, with three in their 90s, two in their 80s, and 1 in her 70s.

Five in this home were White and 1 is African American. All were funded by private pay.

In this third home, six individuals had dementia or other memory problems, two had

chronic health problems, and four had mobility challenges.   In Leah's fourth home,

there was one female and one male, both White and private pay, and one was in her 80s

and the other in his 70s. Both individuals had dementia or other memory problems, one

had a chronic health problem, and one had a mobility challenge. None of the four

homes had individuals with an intellectual disability.

13. **Miriam**

Miriam was a 67-year-old African American female who had been working as a paid care

worker for 45 years, in hospitals, nursing homes and family care, as both a charge nurse

and care provider/facility owner. Her hospital work was in New Jersey, but the rest was

in North Carolina. She had had her family care home for 18 years and employed one

staff person. In addition, her daughter sometimes helped her. She achieved her LPN

certification. Miriam used to have three residents, but at the time of the interview only

had one due to her own "getting older" and the greater challenge of having a younger

client. Her resident was a 30-year-old, Asian (Korean) female. The resident's degree of

need made her eligible for Medicaid, as well as special assistance from the county and

Medicare. The resident has some memory problems that did not have a conclusive

diagnosis and mental health problems. She had family that is not willing or able to

provide care. Miriam called her one resident "client" and "resident," interchangeably; she

stated this with laughter in the interview and said that the resident helped her with that.

She called herself a family care home provider, though she was an owner. Miriam

stated about her resident that "she's not my biological family or anything like that but

she's an extended family in a sense that she's a part of us and what we do." The

resident's mother passed away and her father remarried but was still in touch with the

family care home regarding important care issues, such as matters of providing choice to

the resident.

14. **Nicole**

Nicole was a 61-year-old African American female whose first care work was three years

ago with the inception of her family care home in 2010. She employed 4-5 workers for

12 hour shifts across four days. Wage employees also supported activities such as

shopping. Nicole had a Bachelor's degree in nursing, as well as three Master's degrees:

in Community Health Nursing, an MBA, and an MHA. She usually had six residents but

at the time of the interview had five, as one recently transferred out. Of those six, five

were female and one male. Of the five there at the time of the interview, ages included

77, 85, two that were 91, and 93. Of the remaining residents, two were White and three

were African American. All residents were private pay; Nicole clarified that she was not

Medicaid-certified. Five residents had dementia or other memory problems, five had

chronic health problems, five had mobility challenges, one did not have any family at all,

and four had family that were not willing or able to provide care. Nicole seemed to be

one of the most comprehensively organized providers that I spoke with, strategically

thinking about each element of her care, including her own title, how she referred to the

residents, and why she was in business. She called the adults in her home "residents."

She stated: "You know, I think that's the most friendly name that I can give them. Um,

they're residents and that's their home, you know? And you know…you're a resident in

your home and so I think that's the most friendly title that I could possibly give them."

Regarding what she called herself, she provided thoughtful detail on the reasoning

behind several titles she employed in an effort to convey a sense of authority and

confidence to potential residents' families. Regarding ownership of the home, she

clarified that "actually, my husband and I are owners, and I let folks know that because

often times you never find the owners of a facility, you know?" She also delineated that

she is the administrator, and assumed the title of "CEO" related to administrative

leadership of the facility, with a practical consideration of how others will view her: "And

so I definitely call myself administrator…I just titled myself probably after three years…I

titled myself the CEO because, you know, um…in a business environment, for some

reason people like titles. You know what I mean? [Laughter]." Nicole also adopted a title

"Director of Nurses" that describes her clinical expertise: "I also tell them that I *am* a

clinician so I will be able [inaudible] in evaluating and taking care and managing your

mom or your dad on a *clinical* basis, not just as an administrator." She was fervent in

describing the proactive purpose of her home as not a place to die, but to live for an

indefinite amount of time: "And so what *we* do is we assist their *living*, you know?"

15. **<u>Olivia</u>**

Olivia was a 50-year-old female. She preferred not to answer many of the

demographics for both herself and her residents. She had had her family care facility for

five years and did not do care work prior to this ownership. She received some support

from a nurse that stopped by to see residents, and she greatly complimented the support

of Easter Seals for mental health emergencies. Olivia had an Associates degree in

business, but she stated that her passion was always in healthcare. At the time of the

interview, she had two residents, but typically had four (with a maximum capacity of

five). Her two residents were White and they were both funded by private pay. She said

that she called her residents by name, but she did use the term "resident" when

speaking about them in general during the interview. Olivia was the owner of her home,

but she provided this nuanced, context-dependent description with regard to how she

called herself: "I call myself…it depends on, you know, what aspect of the…if I'm here with the state, I'm the administrator, and I'm the care provider, I'm the cook, I'm the transportation person. So with the doctor's office I'm the care provider/administrator, so I know their records. I know everything concerning them."

16. **Patrice**

Patrice was a 47-year-old woman who identified as Black and was of African descent. She had been a paid care worker for 16 years, all in her own family care setting. She employed three full time staff and one part time staff person who worked a few hours a week as needed. She had a Bachelor's degree in Business Administration. Patrice's family care home included five residents, with a maximum capacity of six. All five of the residents were male and Black or African American, and included ages 45, two who were 55, 70, and 71. All residents were Medicaid-funded, as well as receiving benefits from special assistance. Her home had two single rooms that would be appropriate for private pay individuals, but she was also open to filling them with Medicaid-funded residents. Two of her residents had intellectual disability, one had dementia or other memory problems, one had mental health problems, one had mobility challenges, and all five had family that were not willing or able to provide care. Patrice called herself the owner/administrator. She indicated that she called the adults in her home "residents," as well as by their names.

17. **Qadira**

Qadira was a 36-year-old African American female. She had worked as a paid care worker for 17 years, including as a nurse and as a family care provider. She emphasized that it was her choice to be a family care provider, as it was not a paid job for her (perhaps due to the number of staff she employs and the fact that all of her houses are not full). Her prior nursing experience was extensive, including settings such as life support, emergency room, trauma, transplants, and geriatrics. She had had her

family care homes for three years and employed 10 workers as independent contractors

(providing a flat rate for 24 hour shifts). She had an Associate's degree in nursing and a

Bachelor's degree in Biology. At the time of the interview, she had eight residents

across three homes. House 1 had four residents, House 2 had three, and House 3 had

one (having one is typical while in the process of getting licensed, which was true in this

case for the third house). The maximum capacities for the houses were four, four, and

three, respectively. House 1 had two females and two males, House 2 had two females

and one male, and House 3 had one female. The ages in House 1 are 74, 86, 89, and

92. In House 2, ages included 74, 82, and 101. And the resident in House 3 was 72.

House 1 included three African American and one White resident. House 2 had one

multiracial resident (African American and White), one African American, and one White.

The resident in House 3 was White. All residents in all houses were private pay, but she

was open to taking Medicaid in House 1 only. House 1 included three individuals with

dementia or other memory problems, four individuals with chronic health problems, three

individuals with mobility challenges, one person who did not have family at all, and three

individuals who had family that were not willing or able to provide care. House 2

included three residents with dementia or other memory problems, three individuals with

chronic health problems, three individuals with mobility challenges, and three individuals

who had family that were not able or willing to provide care. The resident in House 3

had dementia or other memory problems, chronic health problems, mobility challenges,

and had family that was not able or willing to provide care. Qadira called the adults in

her home by different names at different times. Sometimes she called them "clients,"

explaining that she and other staff "are providing them a service." As a nurse, she also

called them "patients" when they were receiving care from a doctor. However, Qadira

also acknowledged them as "residents," the people who called the family care home

their home where they actually live. It was also important to Qadira that they were

recognized by "Mr." and "Mrs." "such and such." She called herself the administrator;

the facility was originally started due to the care needs of the owner's mother.

18. **Rhonda**

Rhonda was a 69-year-old African American woman. She had worked as a paid care

worker for over 40 years, in both hospital and family care settings. She had worked in

Philadelphia, New York, and North Carolina. Roles included nursing and

administrator/owner. She had also worked as a nurse in medication administration with

the Veteran's Administration. She called herself an administrator/owner in her current

family care setting where she has been for the past 31 years. She employed one worker

for three 24 hour days a week. She received her LPN certification. Her family care

home included four residents, which is typical for her. She used to have more than one

home under the same business. Her residents included two female and one male, with

two individuals who were 50 (or in their 50s) and two who were 70 (or in their 70s). All

residents were African American and funded by Medicaid and special assistance from

the state. Four residents had chronic health problems, four had mental health problems,

one had mobility challenges, one did not have any existing family, and three had family

that were not willing or able to provide care.

19. **Shelli**

Shelli was a 55-year-old African American female who has been a paid care worker for

18 years, in both nursing home and family care settings. She had worked as a CNA and

a dietary assistant manager. She had worked as an administrator in family care setting

for 14 years and employed one worker as needed. There was a separate owner. She

received her CNA certification and had completed two years of Biblical Studies toward a

Bachelor's degree. At the time of the interview, she had six residents, including two

female and four male, two White and four African American. The ages of her residents

included 35, 49, 50, 54, 56, and 70. All residents were funded by Medicaid, Special

Assistance and Social Security. Two of her residents had intellectual disability, one had

dementia or other memory problems, one had mental health problems, one had mobility

challenges, and all six had family who were not willing or able to provide care. One of

them had had a stroke and was going through rehabilitation of her ADLs with the owner.

The other five had family members who all worked.

20. **Tanya**

Tanya was an African American female who indicated she was born in the 1960s, but

preferred not to give her exact birth year. She had worked as a paid care worker since

1989, as a CNA, working with both elders and teens, in community-based support

settings, as a case manager (with 30-40 clients), in group homes, and finally in the

family care home setting. She had had her family care home for five years and

employed 3-4 staff who worked part-time or on an as-needed basis. She received CNA

training and had a bachelor's degree in rehabilitation and kinesotherapy. She had six

residents in her home, including two female and four male, ranging in ages from 40-65

and a mix of White and African American individuals (she chose not to detail

demographics for resident privacy concerns). She had residents that were funded by

both Medicaid and private pay, with no space specifically allocated for either. She also

did not want to detail health conditions of her residents, but indicated that "a couple" had

dementia or other memory problems, chronic health problems, mental health problems,

mobility challenges, and all had family that were simply not able or willing to provide

care. Tanya emphasized a sense of responsibility in her role "because you got people's

lives in your hands to take care of." When asked why she wanted to become a provider,

she underlined that she wanted to provide better care than she had witnessed in

previous work settings. "You know why? I was a case manager and I just want people—

I had people, I would care for them in other people's homes and the home conditions

they were living in were pathetic. . . .Was upsetting. I just wanted to provide them with

something better." Her motivation for care stemmed from that sense of providing something better for her residents: "you know, really knowing that you're helping somebody, you know you're giving somebody a stable home and environment for them." She stated emphatically that income was not the motivator: "It definitely ain't the money." Her response to what she called her residents illustrated the combined personal and professional relationships and roles: "I called them clients and my people and by name." She responded affirmatively to my examples that she was an administrator, owner, provider, and a manager "Because you do it all." Tanya was very resident-centered with regard to her own role and her support of their activities. "You got a role. You got the role of provider, the sister, the aunt; it's just whatever they want at the moment, that's the role you play." Her approach seemed to elicit resident care, as they were always offering to support her and expressed their concern: "Don't overwork yourself."

21. **Uniyah**

Uniyah was a 48-year-old African American female who described herself as a "health care provider" at the two family care homes where she worked. Another woman (unable to be interviewed) was the owner and administrator. Uniyah had worked as a paid care worker for 25 years, in special education settings in schools, in a state psychiatric center, in in-home care, and in family care. She had only been working with the two family care homes for three or four months. Two of her sisters worked as healthcare providers for the same homes. They all worked twelve hours shifts for three days in a row. Uniyah had numerous associates degrees, including degrees in Business Administration, Data Processing, Accounting, and Liberal Arts. She also had experience as a systems engineer and accounting clerk. Family care House 1 had four residents, and House 2 had six, and all of the residents were female. In House 1, the resident ages were 50, 60, 69, and 70, and in House 2, they were 50, 55, three others in their 50's for which Uniyah was unable to specify the exact ages, and 79. All residents were

White. There had been an African American resident in House 1 that recently passed. In Uniyah's professional role, she was not sure of the funding of each of the residents. She reported that in House 1, four of the residents had intellectual disability, four had dementia or other memory problems, and all four had family that were not able to provide care. In House 2, two had intellectual disability, two had dementia or other memory problems, two had mobility problems, and six had family that were not able to provide care. Uniyah emphasized that it's never that the families are not willing to provide care, but that they are not able to provide safe care. She also clearly conveyed the reciprocal benefit of working in the family care setting, and how it influenced her thinking and experience, as well as that of her children. "I don't take time for granted, you know what I mean? I feel blessed. I always knew I was blessed but even my children have changed because I bring my children around some of my clients. Their ideals of life have changed somewhat. So appreciation—life appreciation—has changed." She described herself as a very spiritual person, though not religious, and that that influenced her perspective on care. She was also very emotive about the residents: "I love my residents. I love them." She described residents as very supportive of each other: "they're friends. They're, they're associates. You know? So it's like when they want something and can't remember where it is the other will get up and take them. I mean they are very attentive to each other. They're very attentive to each other. It's like being in the same situation and relating so I think they're very attentive because they know that we're all in the same boat." They are also supportive of her and will say things like "You know what, I wish you would sit down for a while. You look tired. You're always doing something. How was your day?"

22. **Veronica**

Veronica was a 65 year old African American female who seemed to feel uncomfortable that race was one of the first questions asked. However, she continued with a very rich

interview. She had been working as a care worker for seven years, starting with her own family care home, and her mom's needs were the inspiration and training ground for this. When her mom had dementia and congestive heart failure, she told Veronica that "You need to keep people like me." Veronica employed up to six staff members that worked varying shifts. Veronica seemed to live in the home, but I did not ask this explicitly. Veronica had a bachelor's degree in special education and a master's degree in teaching reading. She had found the background in special education to be very helpful for her family care work. She had four full time residents, and three respite care that were only there periodically on weekends (and were often individuals who could not afford the monthly private pay fee for full time care). She had had five full time, but one recently passed. All of her residents were women. Among the full time residents, one was 52, one was in their late 70s, one was in their early 80s, and one was 95. The respite care attendees included another in their late 70s, one in their early 80s, and one who was 88. Among her full time residents, two were White, and two were African American. Her respite care attendees included one who was White and two who were African American. All but one resident were private pay; the one was funded by Medicaid. All of the residents and respite care attendees had dementia or other memory problems, mobility challenges, and family that were not able or willing to provide care. However, Veronica put a lot of effort into engaging family, and there were children of residents who visited regularly and attended facility activities such as a weekly prayer group and barbecue dinners. She said she called her residents "residents" or "divas." She felt that her role was a "kind of religious, spiritual promise of being able to do this for people who are at the end of their life." However, Veronica emphasized that she wanted to facilitate the most opportunities and best quality of life for these residents, so that they can say "Did I do the things or see the things that I wanted to do before I die?"

23. **Wilma**

Wilma was a 40-year-old African American female who had been doing care work for 20 years, in both mental health and family care settings in Virginia and North Carolina. She had worked as a program manager, case manager, and a rehabilitation technician. She had had her family care facility for four years and employed one staff person. She had a bachelor's degree in psychology and recreation management. She began her site during a time when her husband was losing his job, and they needed to open a business. She called herself an administrator, but she is also technically the owner. Wilma said that she interchangeably uses the terms "resident" and "client" on paperwork, but otherwise she said that "I just call them my folks." Her site had six residents, including three female and three male. One of her residents was less than 30, three were about 55, and two were in their upper 60s. Two of her residents were White, and four were African American. One was private pay, and five were funded by Medicaid. Three of her residents experienced intellectual disability, one experienced dementia or other memory problems, six experienced chronic health problems, six had mental health problems, and one had a mobility challenge. Two didn't have family at all, and four had family that were not able or willing to provide care to them. Wilma worked at another mental health job during the day, but went on site to do activities and go shopping with residents, as well as administrative work. She worked to not create too much attachment so that residents were more attached to the person living there. It seemed that the facility retained a homelike environment and that there was warmth among residents, and from them toward her when she stopped by. She described residents saying "I'm so glad I'm here." She also said they show care to each other by cooking together and greeting and complementing each other and her. Regarding staff culture, she tries to lead by example with other staff.

24. **Xaveree**

Xaveree was a 53-year-old female who identified as African, and specifically as

Nigerian. Xaveree considered herself the administrator of her family care home, but she

was also the owner of an umbrella agency that was licensed to oversee multiple kinds of

elder care services, including family care, but also home health care. She called the

adults who live in her homes "residents." She emphasized being a professional provider

versus a family member, and this striving toward professionalism was dominant in her

interview, making me feel that this was one of the least home-like venues, though with

great efforts toward quality care. Xaveree started as a nurse in Nigeria in 1983, with

extensive experience in many different kinds of settings, including home care, hospitals

(medical and surgical charge nurse), acute care, nursing homes (director of nursing),

nursing education, and eventually family care. She had had her family care site for two

years and employed five staff. Her home evolved from her home health clients wanting

an eventual care option beyond their own home other than nursing home care. Xaveree

received a diploma to be a registered nurse and a registered midwife in Nigeria (a three-

year program), and then received her Bachelor's and Master's degrees in healthcare

administration. At the time of the interview, she had three residents in her family care

home (with a maximum capacity of six), as three had been recently discharged to the

hospital. Her residents included one female, two male, all three residents in their 70s,

and one White resident and two African American. One of her residents was funded

through Medicaid and special assistance, and two were private pay. She was open to

taking residents with any type of funding mechanism. Three of her residents had chronic

health problems, three had mobility challenges, two had no existing family (but they had

guardians), and one of the residents had family who was not able or willing to provide

care. Xaveree emphasized that her residents were "elderly" and very "cooperative." Her

statements about what she valued reflect her professionalized services, with

declarations such as "you will never be the family" and that one should "provide the

same services that you will want somebody to provide to you if you were in their shoes."
Her staff did not try to replace family but encouraged residents' families to visit.
However, she contradicted herself at one point when she said "I think it's family. It is like
a family. You know because that's what it is. That's why you do not want to go to the
traditional nursing home. They want to stay in a homelike environment so you try to
make environment warm and homelike." She described the value in her home's care for
residents as including consistency in caregivers and respect. However, she did not
vocalize a sense of reciprocity in caring as much as some of the other providers, and
compliance seemed very important for her, what she received in return to make her and
her staff's jobs easier: "No, I say that they're there for me to care for them and so I
would say by you know complying with the rules, every facility has rules, and we do not
like, they don't smoke in the house, no alcohol, so just for the fact that they agree and
understand the rules and comply with it, and we have time that we lock up the house like
at night when they go to bed we have time that you know they even though they may be
up and watching TV those that smoke cannot go outside at a certain time because we
have to shut the door and turn on the alarm. And they respect that so to me that helps
me that caring for me because they are not making it hard for me to care for them."
Resident choice was provided through small freedoms, such as being able to eat
breakfast later than the group. Xaveree did not talk about her own family experience
when prompted and remained professional throughout the interview, and she appeared
more motivated by a knowledge of Christian principles and health care ethics than by
emotional or relational connection to the residents. However, this impression may
simply be due to her efforts to create and present a very professional setting.

25. **Yolanda**

Yolanda was a 44-year-old African American woman. She had done family care home
work since 1996, when she worked with a home serving individuals specifically with

HIV/AIDS. Her first of two homes was licensed in 2008. Yolanda called herself the

administrator/owner, and she called the adults living in her homes "residents." She

employed three staff across her two homes and worked a 9-5 shift herself almost every

day. With recent changes in Medicaid, further confining reimbursement to only select

services, she had found it even more difficult to fund the extra staff needed to take out

residents (so if one person did not go, no one went). However, some of her residents

were able to go out independently and did quite often, as long as they signed out and

returned by their curfew. Her background included CNA certification, as well as

certifications for Medication Administration and Administrative capabilities. At the time of

the interview, she had three residents in one home (with a maximum capacity of four)

and four in the other (with a maximum capacity of six). In House 1, the residents

included one female in her 20s and two males in their 50s, and in House 2, one female

and three male, with one individual in his or her 40s, two that were in their mid-50s, and

one who was almost 70. House 1 included one African American resident and two

White. House 2 included two African American residents and two American Indian

residents. All of the residents received Medicaid benefits, and two in each house also

had Medicare benefits. When Medicaid did not cover costs, there was sometimes

additional coverage from Special Assistance from Social Services. Two individuals in

House 1 experienced chronic health problems, and three mental health problems. In

House 2, four had chronic health problems, and four mental health problems. Two

residents in House 2 did not have any existing family that could be contacted. The other

residents in both houses (three in House 1 and two in House 2) had family who were not

willing or able to provide care. Yolanda emphasized mutual respect in her houses,

among residents, staff, and herself. She was also a proponent of fostering resident

choice: "Well I don't try to make them feel like they are in a prison or in a facility with a

whole lot of rules you know. I try to make it feel as much as home as possible. So you

know they will come and ask my advice about some things but I let them know that they have a choice to say yes or no. I don't push things on them. Not unless it is regulated."

26. **<u>Zada</u>**

Zada was a 65-year-old female who identified as "Afro-American." She was an administrator/owner and had had a family care home since 2000, and at the time of the interview had six family care homes and four group homes (homes for individuals with mental illness). She called the individuals living in her homes "residents." Regarding the family care homes, she employed between 12-15 staff members who each worked 35-40 hours per week. At the time of the interview, Zada worked from an office outside of the homes, and two of her daughters worked with other staff in her office with her. She also had a special services coordinator on staff who served all of the homes. Zada achieved her GED in 1978, and she then she earned her B.S. in psychology. She had also received many certifications, including studies in pharmacology. She was also an ordained minister and had been accepted in a theological Master's program. Within the limited time frame of the interview, it was difficult for her to think through the demographics for all 36 residents across her six homes. It was not apparent that Zada spent time doing direct care, but she did appear to have a regular presence in her homes, getting to know residents, bringing them extra cigarettes when they ran out, and providing staff trainings and meetings. She was able to provide some poignant, personal stories of residents and then also summarized more general experiences and observations. She estimated that her homes had more males than females, with ages ranging from 18-85, but with most residents between the ages of 40-65. She also assessed that approximately 60% of the residents were African American, and 40% were White. Zada expressed a motivation closely tied to religious motivation and responsibility, as well as a responsibility and love inseparable from her role as a biological mother of 10 children, with ages now ranging from 37-49. She stated that

"family care was no different for me." She made a clear statement acknowledging the

reciprocal nature of her care relationships: "So the family care homes—my first and most

learning experience was about me. The family care home has transformed my life and I

say [to staff] 'In the family care home [inaudible] we all come to bring something as well

as to get something.'" However, she also clearly saw those she serves as marginalized

individuals needing uplifting that she was in a position to provide and had pledged to

provide, both to her county and religiously: "caring for the aged, the disabled, and the

mentally challenged." She approximated that 5% of her residents had an intellectual

disability, 2% had dementia or other memory problems, 5% had chronic health

problems, 15% had mental health problems, 2% had mobility challenges, 98% had no

existing family, and 2% had family that were not willing or able to provide care.

Appendix I

Select Provider Demographics

Participants	Gender	Age	Race	Care Work Years	AFC Years	Number Current AFC Homes	Resident Number By House (H)
Alex	M	63	Black	25	25	2	H1=6 H2=6
Bernice	F	58	Black	8	8	1	H1=6
Cadi	F	41	Black	27 (since age 14)	27	3	H1=6 H2=6 H3=6
Dan	M	57	White	20	3	1	H1=6
Elon	F	45	Black	15	8 months		H1=3
Francis	F	43	Black	8	3	1	H1=4
Gayle	F	30	Black	2	1.5	1	H1=3
Helen	F	62	Black	8	8	1	H1=5
Irene	F	49	Black	20+	3	2	H1= 6 H2=6
Joelle	F	42	Black	5	5	2	H1= 6 H2=6
Ken	M	53	Black	28	16	1	H1=6
Leah	F	37	Black	8	8	4	H1=6 H2=6 H3=6 H4=2
Miriam	F	67	Black	45	18	1	H1=1
Nicole	F	61	Black	3	3	1	H1=5
Olivia	F	50	Not available	5	5	1	H1=2
Patrice	F	47	Black	16	16	1	H1=5
Qadira	F	36	Black	17	3	3	H1=4 H2=3 H3=1
Rhonda	F	69	Black	40+	31	1	H1=4
Shelli	F	55	Black	18	14	1	H1=6
Tanya	F	~55	Black	24	5	1	H1=6
Uniyah	F	48	Black	25	3.5 months	2	H1=4 H2=6
Veronica	F	65	Black	7	7	1	H1=4
Wilma	F	40	Black	20	4	1	H1=6
Xaveree	F	53	Black	30	2	1	H1=3
Yolanda	F	44	Black	17	17	2	H1=3 H2=4
Zada	F	65	Black	13	13	6	H1=6 H2=6 H3=6 H4=6 H5=6 H6=6