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A PILOT EXAMINATION OF QUALITY AND COST OF LONG-TERM CARE  
SETTINGS IN ILLINOIS

BY

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THESIS

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## ABSTRACT

Transitioning residents out of long-term care (LTC) institutions and back into the community has been shown to reduce Medicaid expenditure and improve quality of life for recipients of care. This research was conducted to build upon the findings of previous studies by contrasting components of cost and quality of life between nursing homes and home and community-based care settings (HCBC). Through the PACE Center for Independent Living in Urbana, Illinois, three consumers from the Money Follows the Person (MFP) program were recruited for this study. Each participant completed the 2006 AARP New York Long-Term Care Survey, the Assessment of Quality of Life (AQoL) - 8D Questionnaire, and a phone interview. Thematic analysis was utilized to identify theme saturation in the participants' responses from both sets of questionnaires and the interviews.

The results of this study were consistent with previous research. The participants' responses on questionnaires and in the interview showed that the benefits of transitioning nursing home residents into HCBC include lower costs and an overall higher quality of life for those receiving care. All the participants stated that they would not at all feel confident in their ability to afford the costs of a nursing home in the Chicago area nor did they purchase private LTC insurance because it is too expensive.

Transitioning residents into HCBC improved many subcomponents of quality of life. The participants displayed a higher degree of integration in their families and communities, satisfaction with living arrangements, improved mood status, increased autonomy, decreasing one's feeling of social isolation, increased privacy, and an elevated sense of self-worth. When asked which care setting the subjects preferred, they

unanimously answered HCBC. There was also strong consensus that recipients of care should be given the choice to hire and manage their own personal care assistants.

With regard to the future direction of LTC policy-making in Illinois, the participants felt that the state should create a central place where people can learn about the different types of LTC. Furthermore, in addition to transitioning a greater number of nursing home residents back into the community, there is a need for Illinois provide a broad range of LTC services that prevent unnecessary nursing home admissions and allow people to remain in their homes.

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## CHAPTER 1 - INTRODUCTION

Illinois spends \$3.5 billion of its annual budget supporting people with disabilities living in nursing homes or Long Term Care (LTC) institutions (Johnson and Ucello, 2005; Illinois Department of Healthcare and Family Services, 2011; MEDSTAT, 2005; O'Brien, 2005). According to Johnson and Ucello (2005), this level of spending does not always guarantee that patients will experience high quality of life. Rather, evidence seems to demonstrate that individuals living in Home and Community-Based Care (HCBC) settings experience a relatively higher overall quality of life and witness lower costs for their care services (Reinhard, 2010; White, Simpson, Gonda, Ravesloot, & Coble, 2010). Transitioning individuals from nursing homes into HCBC would not only improve the quality of life for recipients of care, but it would also decrease the amount of the budget spent on LTC.

There is a need for empirical studies of LTC recipients' perception of cost and the impact the care has on their quality of life. These studies can seek to answer important questions pertaining to the delivery of LTC. Specifically, what's the association between the types of LTC setting, whether it is a nursing home or HCBC, and quality of life experienced by a recipient of care? What's the relationship between the type of LTC setting and the cost of delivering care? This study sought to measure what factors have significantly impacted on cost and quality of life by comparing first-hand experiences of individuals who have lived in both nursing home settings and HCBC. The research is significant because it will lead to a better comparison of HCBC and nursing home care by providing preliminary empirical evidence to evaluate how different care settings impact recipients of care.

Previous studies have indicated that nursing homes cost an individual and the state more money than HCBC. Furthermore, the research concluded that quality of care given in nursing homes is inconsistent across institutions and can be improved in many instances. Two hypotheses are assumed and will be examined in this study: 1) HCBC improves quality of life for the recipients of care to a greater degree than nursing home settings and 2) residents in community care settings and HCBC experience lower costs than residents in nursing home settings.

This is a qualitative study that builds upon previous studies and advances our understanding of different LTC settings. Most of the research previously reported did not compare the qualitative differences of first-hand experiences between nursing homes and HCBC nor indicate what main factors influence any differences in quality of life for an individual. I expect that the results of this study will provide useful data contrasting nursing home care and HCBC and their effects on cost and quality of life for recipients of care. Provided that participants for this study were recruited from a multicounty area in Illinois to compare their experiences living nursing homes and HCBC, the implications of the results will help state legislators understand which setting is better-suited to the needs of care recipients.

The purpose of this qualitative study is to further compare and contrast care in nursing homes and HCBC for the state of Illinois by examining and evaluating quality of life and cost. There are 3 specific aims of this study: 1) analyzing the cost of each setting, 2) determining the impact of HCBC and institutionalized LTC on quality of life 2) and 3) identifying areas where the settings can be improved. This will be accomplished through two primary methods: 1) having individuals who have lived in institutionalized LTC and

HCBC evaluate the components of quality of life in each setting and 2) having the recipients of care compare and contrast the costs of LTC in both settings. The study also explores the areas in which current care settings can be improved.

## CHAPTER 2 - LITERATURE REVIEW

### **Cost of LTC**

The United States currently faces the issues of financing and providing LTC supports for individuals with disabilities and the elderly population. LTC services refer to assisting people with disabilities over an extended period of time with instrumental activities of daily living. The main goal of LTC services is to empower individuals with disabilities and chronic conditions to achieve greater independence in their lives (Kaye, Harrington, & LaPlante, 2010).

Presently, 10.9 million Americans need LTC, half of whom are under the age of 65. This figure is expected to double in the coming decades due to the aging baby boomers. The likelihood that a person will require LTC increases with age. Roughly 70% of elderly individuals will need LTC for a portion of their lives (Feder, Komisar, & Friedland, 2007). According to Caldwell and Alston (2012), even though disability is a natural part of a person's life, society provides very little economic security to account for the high costs associated with LTC, despite the fact that services are meant to facilitate health, independence, community participation, and entry into the workforce.

For the past several decades, funding for institutionalized LTC has placed a major burden on Medicaid. Between 1980 and 2003, almost half of the federal funding spent on nursing home care came from Medicaid, and between 1997 and 2003, around 80% of Medicaid's LTC budget was spent on nursing homes (O'Brien, 2005; MEDSTAT, 2005). In the first half of 2010 alone, LTC funding from Medicaid was estimated at over \$1.6 billion. That year, Illinois Medicaid supported approximately 55,000 individuals in 738 licensed nursing facilities (Illinois Department of Healthcare and Family Services, 2011).

Until the past few years, nursing home placement has been the default course of action for disabled persons (Reinhard, 2010).

According to data from the Kaiser Family Foundation (2009), although LTC only accounts for 26.5% of Medicaid expenditure, LTC still costs Illinois roughly \$3.5 billion. LTC expenses for elderly care in nursing homes equate to roughly \$1.7 billion (Johnson and Ucello, 2005). Presently, HCBC and personal care services account for approximately \$1 billion. The remaining \$700 million is spent on Intermediate Care Facilities for the intellectually disabled and mental health facilities. LTC expenditures for the elderly and individuals with disabilities respectively make up 20% and 34% of Medicaid expenditure (Johnson and Ucello, 2005). Low-income elderly and low-income individuals with disabilities must rely on Medicaid to pay for their LTC needs. According to Johnson and Ucello (2005), this is solely due to private insurance benefit as there is limited coverage for services and private insurance is not affordable for people that make an income of less than \$25,000 per year.

LTC accounts for a large portion of federal and state Medicaid expenditure. It is important to note that the expenditure for LTC does not reflect the population size. In fact, the Kaiser Family Foundation's commission on Medicaid expenditure (2011) found that LTC services make up almost half of the expenditure at 48% even though LTC users only make up 6% of the number of Medicaid enrollees. However, Medicaid has its structural limitations. Eligibility to the program is limited to strict income and asset requirements. Some individuals impoverish themselves to receive support from it. As a federal-state collaboration, there are large disparities in access throughout the states.

Lastly, Medicaid is biased toward denying individuals the choice of receiving the community-based supports that are desired and cost-effective.

The responsibility for financing LTC has traditionally fallen on the recipient of care and their family. More than 90% of persons with disabilities rely on the informal care of their unpaid family and friends (Feder, Komisar, & Friedland, 2007). The cost of this informal care roughly equates to \$450 billion each year. This is more than four times the total amount of money that Medicaid spends on LTC (AARPa, 2011). In order to qualify for Medicaid, individuals and their families are forced to give up personal savings and assets. According to Caldwell and Alston (2011), many engage in strategies like reverse mortgages to convert their home equity into cash so that they may purchase services and supports that allow them to continue living in the home. Due to a combination of variables, private LTC insurance within the United States has not become commonplace. Only 3% of the general population and 10% of elderly individuals have purchased private LTC insurance (Feder, Komisar, & Friedland, 2007).

Uninsured beneficiaries that do not utilize LTC typically spend roughly \$3,700 while those who need LTC account for \$43,000 per individual each year (Kaiser Family Foundation Commission on Medicaid and the uninsured, 2011). This figure increases by almost \$20,000 when HCBC services are added to the equation. According to the Kaiser Family Foundation's Commission on Medicaid and the Uninsured (2011), over 50% of elderly LTC Medicaid beneficiaries use institutional services, amounting to greater than \$53,000 per year for each enrollee. This figure increases by \$40,000 per enrollee for individuals with disabilities.

As part of HCBC, family caregivers provide care for disabled and elderly family members. There are roughly 1.5 million family caregivers providing over 1.6 billion hours of care, roughly equating to an expenditure of \$16.2 billion per year (Feinberg et al., 2004). This compares to the federal profile where there are 34 million families providing 36.7 billion hours of care services, which results in approximately \$350 billion spent on the delivery of care (Feinberg et al., 2004). These numbers illustrate that HCBC could provide significant savings to both state and federal Medicaid programs.

Services provided for LTC beneficiaries vary among acute care services, HCBC services, and institutionalized care. It is the latter that accounts for the greatest expenditure. The annual report on the Illinois Medical Assistance Program (2010) stated that there were roughly 55,000 people living in 738 nursing facilities in the state. The average cost to provide LTC services for each individual in these Illinois facilities is approximately \$48,500 per year whereas HCBC costs approximately \$12,000 (Illinois Department of Healthcare and Family Services Annual Report, 2011; Medical Assistance Program 2008, 2009 and 2010). It is important to consider the trends of increasing residents' independence, community integration and LTC patient preference towards HCBC services that are driving the cost of Medicaid.

Over the last several decades, the disability rights movement, the U.S. Supreme Court's Olmstead decision, and other legislative improvements have improved access to HCBC services. The percentage of total LTC spending on HCBC services increased from 24% to 45% between the years 1997 and 2009 (Eiken, Sredl, Burwell, & Gold, 2010). However, there is a great variation in spending between states. For instance, Oregon has a high of 73.3% while Mississippi has a low of 15.1%. Only about a third of the total LTC

funding goes towards HCBC services, so there is a need to balance the systems. Waiting lists for HCBC services are growing across the states, leaving many needs unmet. The number of individuals placed on waiting lists for the HCBC waiver programs has more than doubled to 428,571 (Kaiser Family Foundation).

### **Quality of LTC**

For decades, nursing homes and skilled care facilities were the primary sources of care for persons with disabilities (Feder, Komisar, & Friedland, 2007). These LTC settings have traditionally viewed persons with disabilities as passive, incapable of self-direction, and needing professional supervision while treatments such as medications, catheters, and suppositories are administered (Batavia, Dejong, & McKnew, 1991). In this perspective, providers view persons with disabilities as patients. As a result, the recipients of care give up responsibilities pertaining to self-maintenance and are promoted to defer decisions around their health care to the medical professional (Zaretsky, Richter, & Eisenbery, 2005). The medical model of rehabilitation, which promotes passivity, submission, and subordination, is counterintuitive to self-advocacy, autonomy, and self-direction (Rubin & Roessler, 2008).

In 2005, Equip for Equality published a report entitled, “Clyde Choate Development Center: A Second Call for Closure,” which detailed numerous violations of negligence and under-supervision in LTC institutions. Unfortunately, these issues remain prevalent in Illinois’s large institutions. The Long-Term Care Annual Report to the Illinois General Assembly (2010) reported that there were over 1,200 accounts of abuse by nurse’s aides from the years 2006-2009. The acts ranged from physical, mental,

verbal, and sexual abuse. The Illinois Department of Healthcare and Family Services Annual Report (2011) and the Medical Assistance Program (2008, 2009, and 2010) point out that only 51 of Illinois's 1163 institutions actually have certification. After numerous offenses were found in these large facilities that house persons with developmental disabilities, the state made the decision to start closing them. The closings increased the number of smaller facilities that house fewer than 16 residents (Lambert, 2005).

According to the 2006 Illinois Disabilities Services Plan (DSP) (2006), it is expected that number of people who will need LTC will increase over the next three decades (Illinois Department of Human Services, 2011). The DSP urges the state to move away from large institutions (Illinois Department of Human Services, 2011). To emphasize the transition towards HCBC, the update outlined several principles, emphasizing the need for choice and access to HCBC and increasing quality of care services (Illinois Department of Human Services, 2011).

**Table 1 - The Illinois Disabilities Service Plan's 7 Principles**

#	Explanation
Principle 1	To emphasize the ability for individuals to choose from a range of appropriate and accessible community services.
Principle 2	To support effective, informed choice
Principle 3	To increase the system capacity to accessible high quality care
Principle 4	To strengthen quality management
Principle 5	To support the network of persons with disabilities, the elderly, their families, friends, neighbors and communities
Principle 6	To develop a strategy to create a stable and high quality direct care staff
Principle 7	To re-engineer the infrastructure to support individual choice

The Illinois Disability Service Plan prioritizes resident choice, improving the quality of the delivery of care services, and increasing access to HCBC care settings (Blagojevich, R. (2006), 2006).

HCBC settings are founded on the 7 the principles of rehabilitation counseling. In terms of ensuring high quality of life for recipients of care, LTC is provided the most effectively in HCBC settings rather than in institutional settings where persons with disabilities may be viewed as incompetent of carrying out instrumental activities of daily living according to Laplante, Kaye, and Harrington (2007). There are consequences if the physical needs of persons with disabilities are not provided through HCBC: the number of opportunities for employment will decrease and quality of life will diminish, the goals of the family members will become secondary to the care needs of the person with the disability, and there will be an increase in the risk of secondary health problems, hospital readmissions, emergency room visits, or death (Batavia, Dejong, & McKnew, 1991). Lack of access to consumer-centered LTC prevents an individual with a disability from participating as fully as possible in society (Caldwell & Alston, 2012).

Illinois is currently looking for ways to restructure its LTC system. Due to issues with quality of care that residents were receiving, the state has begun reducing the number of large institutions (Illinois Department of Human Services, 2011). Most states are lagging behind the trend to deinstitutionalize residents who are eligible and willing to be transitioned to HCBC settings, and Illinois falls behind most states in this regard. Other states' research models have demonstrated that deinstitutionalization not only saves money for the states, but it is also a boon for people with disabilities who prefer independent living communities (Illinois Department of Human Services, 2011).

### **Money Follows the Person**

Alternative LTC methods supported by Medicaid are gaining momentum among beneficiaries and politicians. Money Follows the Person (MFP) is a voluntary program that facilitates the transition process from nursing home back into the community (Illinois Department of Human Services, 2012). According to Justice (2010), the program provides states with an enhanced federal match known as the Federal Medicaid Assistance Percentage for community-based services during the first twelve months for each person transitioned back into their home. In addition to transitioning individuals back into the community, MFP seeks to balance systems toward community-based services. The Centers for Medicare and Medicaid Services are undertaking various systems reforms, including the identification of barriers in the availability of affordable, accessible housing and direct support of the workforce (Kaiser Family Foundation, 2011b).

States have widely adopted MFP. Up until now, the government has awarded grants for the program to 43 states and the District of Columbia. States with existing awards are permitted to modify and expand their original goals. By the end of 2012, nearly 12,000 people had transitioned back into the community through the program (Denny-Brown, Stone, Lipson, & Ross, 2011). Out of those 12,000, 35.9% were individuals with physical disabilities, 34.3% were elderly, 25.8% were individuals with developmental disabilities, and 2.2% were individuals with mental illness. Each state varies in the number of transitions they have conducted due to a variety of factors including state population, the extent of previous rebalancing, and the state's infrastructure to support the program. For instance, Texas alone accounts for 30% of the

total number of people transitioned back into the community, having transitioned 3,579 individuals to date (Denny-Brown, Stone, Lipson, & Ross, 2011). Washington, Ohio, Maryland, Michigan, and Pennsylvania have also transitioned a significant number of people back into the community, accounting for roughly 32% of the total.

Positive quality-of-life outcomes have resulted from transitioning recipients of care back into the community. A study conducted by Simon and Hodges (2011) followed 803 MFP participants during the 12 months following their transition from the nursing home to HCBC between January 2008 and 2009. The researchers observed significant improvements in satisfaction with life, needs for personal care being met, being treated with dignity and respect, community integration, mood status, and satisfaction with living arrangement (Simon & Hodges, 2011). Findings were consistent across all subpopulations. Additionally, further analyses showed low rates of reinstitutionalization and death (Schurrer & Wenzlow, 2011).

Even though 12,000 individuals have transitioned back into the community through MFP, the original goal was to transition 36,000 people, which only accounts for 1% of the eligible individuals who currently reside in institutions (Wenzlow & Lipson, 2009). States have faced many unanticipated challenges, not limited to finding affordable and accessible housing (Denny-Brown, Stone, Lipson, & Ross, 2011). To address this issue, the Department of Health and Human Services has built a partnership with the Department of Housing and Urban Development to create additional housing vouchers for MFP participants. The downturn of the economy has also created setbacks to the program, but the rate of transitions has recently begun to increase. With the extension of

the MFP program, states can transition tens of thousands of additional seniors and individuals with disabilities back home (Caldwell & Alston, 2012).

Through last decade's shift by lawmakers toward HCBC, some upstream initiatives have been developed while others are downstream. According to Reinhard (2010), the upstream approach prevents unwanted long-term admissions to nursing homes. The downstream approach ends long-term nursing home stays by helping people transition into HCBC settings. Texas advocated a community-based service with a downstream approach utilizing the MFP program (Reinhard, 2010). Their message to state legislators was simple: people in the nursing homes want to be moved out. Since taxpayers fund nursing home care, the state sought to transition people out of the homes out and have the money follow the people to save costs. Since 2001, the Texas program has helped more than 13,000 people transition from nursing homes into community care settings (Reinhard, 2010).

Advocates across the country took influence from MFP's implementation in Texas. In 2005, supporters propelled the government to pass the Deficit Reduction Act. The legislation approved a MFP Rebalancing Demonstration program on a national scale (Reinhard, 2010). The act allocated \$1.75 billion over five years to the Centers for Medicare and Medicaid Services to fund the national MFP program. In 2007, thirty states were given \$1.4 billion in grants to pay for a year's amount of services for people who have spent more than 6 months in a LTC setting (Reinhard, 2010). States receiving these grants are eligible to receive a greater percentage of federal matching dollars, which help states afford the costs of transitioning people from an institution into a qualified community setting. In addition, the grant program mandated that states indefinitely

provide community services exceeding the 12-month period as long as the beneficiaries remained eligible under Medicaid (Reinhard, 2010).

States have made different degrees of progress in their MFP programs. States like Texas, Washington, and Michigan began their own nursing home transition programs prior to the national initiative. Therefore, these states already possessed an infrastructure and experience before the federal government approved the program on a national level (Reinhard, 2010). Later, the states that adopted the program needed more time to build an infrastructure and the capacity to transfer larger numbers of people from nursing homes into community-based care settings. They also needed to create staffs with trained transition coordinators to work with enrollees and the providers of housing and services. Those states needed to set up extensive reporting systems in order to monitor the progress of the transitions (Reinhard, 2010).

To date, states have been requesting new Medicaid waivers and using matching funds to improve their ability to provide LTC for those people in transition. According to Reinhard (2010), the types of LTC include “intense transitional case management, such as coordinated assistance to move nursing home residents to community settings; providing caregiver education; paying for assistive technology and home modifications; and focusing on ways to coordinate housing with services.” In addition, the states are rebalancing funds by investing federal match money and other saved dollars through reaching out and serving people in less expensive settings. Those rebalancing funds will be used to increase the availability of community-based services within each state (Reinhard, 2010).

For the 22 states that do not participate in MFP, a large population of people with disabilities strongly needs LTC services and support initiatives. According to Reinhard (2010), nursing home placement should not be the only option for those states to fall back on. Rather, legislators and advocates in the states need to emphasize a switch from institutional care to community-based care. Further policy actions at the federal and state levels will lead to the development and the sustainability of the infrastructure that will yield downstream solutions that transition people out of nursing homes and into community-based settings. Finally, legislators and advocates need to refocus their solutions by using the upstream approach to prevent new nursing home admissions (Reinhard, 2010).

Moving forward, policy makers need to recognize that entry into the LTC system should not require nursing home residence (Reinhard, 2010). LTC institutions should not be viewed as the end-point of LTC. Advocates must help remove federal barriers that still limit MFP and other similar initiatives. They also need to add more support structures to ensure successful transitioning for former nursing home residents. Reinhard (2010) said people can accomplish these tasks by “eliminating or otherwise modifying statutory barriers to transitioning out of nursing homes into community care settings, including the four-person limit on qualified residences; offering technical assistance and incentives to states to spur the development of new models of housing and services that would meet the goal of greater consumer control; extending and amplifying existing funding streams, so that all interested states can develop and implement both nursing home diversion and transition programs.” Funds should support diversion approaches to influence a shift to the upstream approach. Policymakers should “ensure that sufficient

resources are available to train required staff” (Reinhard, 2010). Furthermore, these staff members must be able to interact well with people who need LTC and with family caregivers, and, lastly, the program should offer training and other needed support to the family members.

Two major challenges to improved LTC outcomes remain: the need for increased coordination of these individuals and the missed opportunity to transition as many candidates to independent or community living as possible. Individuals with disabilities are particularly important to target as candidates, because their condition, as opposed to their age, determines how long they will require Medicaid support. It is important to significantly reduce Medicaid costs over a care recipient’s lifetime and simultaneously increase the care and the quality of life they experience (Illinois Department of Healthcare and Family Services, 2011).

### **The Independent Living Movement**

The Independent Living Movement seeks to unify everyone as one group, regardless of their conditions. Today, there are over 600 centers of Independent Living, many of which have satellite organizations (PACE Inc. Center for Independent Living, 2013). The state of Illinois has 23 centers. Centers serve a cross section of people with various disabilities. The Independent Living movement encourages people with disabilities to share their experiences with others so that they can learn how to overcome the barriers and challenges in their lives (PACE Inc. Center for Independent Living, 2013).

Many organizations want to implement consumer directed services, meaning that the person with a disability as a consumer can feel in control. To develop a sense of true consumer control, an Independent Living organization benefits from having people with disabilities working on the board and in staff and managerial positions. When people with disabilities are influencing policies that are developed, consumer control dictates the direction of the organization (PACE Inc. Center for Independent Living, 2013).

The acronym PACE stands for Persons Assuming Control of Their Environment (PACE Inc. Center for Independent Living, 2013). PACE's counterpart to a case manager is a facilitator, and the consumer with a disability becomes the manager in the care-giving relationship. The role of the Independent Living organization is to provide support through information, skills training, advocacy, and peer counseling (PACE Inc. Center for Independent Living, 2013). Early Illinois disability advocates saw service providers as creating a dependency on the system. To alleviate this dependency, consumers must realize they can and have a responsibility to control their own life. The role of the Illinois service provider is to assist and empower the individual so that they experience the control instead of just hearing they are in control. To assist the consumer, PACE staff provide skills training, referral, advocacy, peer counseling and transition services (PACE Inc. Center for Independent Living, 2013).

The concept of consumer is used to illustrate the act of choice. The consumer selects a product or service. The term Client is not used because it implies that a person is taking advice from experts, and the Independent Living Movement considers the person with a disability an expert in their own right. Illinois providers are distancing themselves from the medical model where the person is a patient and needs to be directed. Disability

is not necessarily a medical need (PACE Inc. Center for Independent Living, 2013).

Independent Living views disability as a natural part of life. Issues arise when the environment does not permit difference. PACE supports people in the community by setting up programs that help them to advance past hurdles. The types of barriers include architectural, attitudinal, programmatic, economic, social, and communication-related obstacles (PACE Inc. Center for Independent Living, 2013). For example, to counter against communication barriers, organizations can install flashing fire alarms or hire an interpreter for the deaf. Additionally, it can magnify programs for people who have low vision or provide book audiotapes for people who are blind. PACE focuses on the environment and figures out how customers can overcome the obstacles they face (PACE Inc. Center for Independent Living, 2013).

Since consumers are given control, PACE understands that they may make decisions that are not the most advantageous way to achieve their goal. In those instances, the staff will discuss their concerns with the consumer and evaluate the possible outcomes of the available options (PACE Inc. Center for Independent Living, 2013). If the person chooses a route that may lead to negative issues, the staff will still respect the decision since the consumer has the control to make his or her own decisions. The staff will also respect that the consumer may succeed in making such choices. Not only is it a matter of consumer control, but it is also a matter of learning through trial and error (PACE Inc. Center for Independent Living, 2013).

**Table 2 - The Independent Living or Disability Paradigm**

	<b>Medical Model &amp; Rehabilitation Paradigm</b>	<b>Independent Living or Disability Paradigm</b>
<b>Definition of problem</b>	Physical or mental impairment; lack of vocational skill (in the VR system); lack of abilities	Dependence upon professionals, family members & others; it is the attitudes & environments that are hostile & need fixing
<b>Locus of problem</b>	In the individual (individuals are sick and need to be “fixed”)	In the environment; in the medical and/or rehabilitation process itself; disability is a common part of the human condition
<b>Solution to the problem</b>	Professional intervention; treatment	<ol style="list-style-type: none"> <li>1. Civil rights &amp; advocacy</li> <li>2. Barrier removal</li> <li>3. Self-help</li> <li>4. Peer role models &amp; peer support</li> <li>5. Consumer control over options &amp; services</li> </ol>
<b>Social role</b>	Individual with a disability is a “patient” or “client”	Individual with a disability is a “consumer,” “customer” or “user” of services and products
<b>Who controls</b>	Professional	“Consumer” or “individual”
<b>Desired outcomes</b>	Maximum self-care (or “ADL” - activities of daily living); gainful employment (in VR system)	Independence through control over ACCEPTABLE options for every day living in an integrated community

By Gerben DeJong in 1978; adapted/expanded by Maggie Shreve and June Isaacson Kailes; this chart compares traditional approaches to medical and vocational rehabilitation services with the consumer-driven Independent living approach (PACE Inc. Center for Independent Living, 2013).

## **Ten Principles of Independent Living**

The Independent Living paradigm differentiates itself from the medical model by outlining the ten principles that it supports. Civil rights ensure equal rights and opportunities for all (PACE Inc. Center for Independent Living, 2013). It looks down upon segregation by disability type or stereotype. Consumerism permits a person or consumer to use or buy a service or product and allows the people to decide what is best for themselves. De-institutionalization speaks out against institutionalizing a person by a building program or family based on disability. De-medicalization stresses that individuals with disabilities are not sick as stated by the assumptions of the medical model. Persons with disabilities do not require help from certified medical professionals for activities of daily living. In relying on self-help, people learn and grow from discussing their needs, concerns and issues with people who share similar experiences; medical professionals are not the source of help.

Through advocacy, systematic, long-term and community-wide change activities are developed with the intention that people with disabilities will benefit from all that the community has to offer. Barrier-removal is crucial in achieving civil rights, consumerism, de-institutionalization, de-medicalization and self-help. Barriers, whether they are physical, communicative, or attitudinal, must be removed (PACE Inc. Center for Independent Living, 2013). Consumer control ensures that the organizations most capable of supporting and assisting individuals with disabilities are governed, managed, staffed, and operated by individuals with disabilities. Peer role models emphasize that individuals with disabilities should lead the movements for independent living and disability rights, not their parents, service providers or other representatives. The actions required to

accomplish the principles of independent living must be done in a cross-disability approach. This means that people with different types of disabilities must accomplish the work so that all persons with disabilities receive the benefits (PACE Inc. Center for Independent Living, 2013).

## CHAPTER 3 – MATERIALS AND METHODOLOGY

### **Research Design**

The researcher worked with the Illinois Division of Rehabilitation Services located in Champaign, Illinois and PACE, Inc. Center for Independent Living in Urbana, Illinois, to recruit MFP participants from a multicounty area. In order to qualify for this study, participants were required to have previously resided in a nursing home for a minimum of one year. Secondly, they were required to currently reside in HCBC. With assistance from community reintegration specialists at PACE, 3 participants who had been transitioned from nursing home care into HCBC were recruited and given research packets. They had been receiving HCBC for a minimum of 6 months at the time of participating in the study. The research packets given to them contained a cover letter explaining the purpose, procedure, and significance of the study, the Assessment of Quality of Life (AQoL) -8D Questionnaire, the 2006 AARP New York Long-Term Care Survey, an informed consent form for the two surveys, and an informed consent form for the interview process. Their community reintegration specialists then provided clarification to the participants if they had any questions regarding the purpose or procedures of the study. Together, the AQoL-8D Questionnaire and the 2006 AARP New York Long-Term Care Survey were estimated to take no longer than 45 minutes for the participants to complete. Once completed, the participants returned the surveys to their PACE community reintegration specialists.

This study's independent variable was the type of LTC setting, specifically nursing home care or HCBC. The dependent variables were quality of life and cost of care. In order to study how nursing home care and HCBC influence cost and quality of

life, the two following instruments were administered to the subjects: 1) AQoL-8D Questionnaire and 2) 2006 AARP New York Long-Term Care Survey.

The AQoL-8D Questionnaire evaluated how LTC settings impacted each participant's quality of life by scoring them on 8 separately scored dimensions, totaling 35 items to create a simple global utility score (AQoL-8D Questionnaire, 2009). The dimension of independent living measured to what degree the participants were able to complete in household tasks, go mobile outside the home, and engage in self-care. In measuring relationships, the participant's friendships, family role, community role were analyzed along with degree of relationship satisfaction, social isolation, and social exclusion. The mental health dimension asked the participants if they experienced feelings of despair, worry, sadness, tranquility, agitation, anger, and whether they had trouble sleeping. The coping dimension was interested in observing whether a participant has enough energy, feels in control, and is able to cope with his or her problems (AQoL-8D Questionnaire, 2009). In assessing pain, subjects were asked to report the frequency of pain they experience, its severity, and how often it interferes with usual activities. The senses measure analyzed the quality of the subjects' vision, hearing, and verbal communication. While contentment, enthusiasm, and degree of feeling happiness and pleasure were the focus of the happiness dimension, feelings of self-worth, confidence, and thoughts of being a burden were analyzed by the self-worth dimension (AQoL-8D Questionnaire, 2009). The AQoL-8D Questionnaire took the participants 20 minutes to complete.

The purpose of the 2006 AARP New York Long-Term Care Survey was to examine where the participants preferred to receive their LTC services (Burton and

Bridges, 2007). The survey measured 11 different dimensions pertaining to LTC services: use of services such as delivered meals, nursing home, home health care, or chore services, employment status, number of sick days a family members take to care for the recipient of care, likeliness of a family member needing LTC services in the next five years, preferential location for LTC, importance of a centralized place for LTC information, ensuring legislation and a broad range of LTC services, hiring personal assistants, degree of worry about affording LTC services, support of legislation to make LTC more affordable, and reasons for pursuing LTC (Burton and Bridges, 2007). The 2006 AARP New York Long-Term Care Survey took the participants 20 minutes to complete.

Phone interviews with the participants comprised the next component of this study. When the participants received the packets from their community reintegration specialists, they were provided with a consent form to interview. Consent was obtained from the participants at the time they completed the AQoL-8D Questionnaire and the 2006 AARP New York Long-Term Care Survey. The interviews more deeply compared and contrasted the care the subjects received in nursing homes and HCBC. They were asked their reasons for wanting to transition out of nursing home care and how long they have been in HCBC. Next, they were asked to assign a rating to their nursing home care and HCBC experiences, providing an explanation for each rating. Subsequently, the subjects were asked to discuss how strongly they felt integrated into the community following their transition. To conclude the interview, the subjects generally compared their experiences living in the nursing home and in HCBC. They were also asked to state whether any aspects of HCBC can be improved upon. Each phone interview took 15

minutes to complete. At the conclusion of the interviews, the participants were debriefed by the investigator about the purpose of this study.

### **Data Analysis**

Using thematic analysis, trends among the responses on the AQL-8D Questionnaire and the 2006 AARP New York Long-Term Care Survey and the interviews were identified. To identify common themes, the participants' responses on the questionnaire and the verbatim interview transcripts were checked. The researcher then became immersed in the data and took notes, identifying the dimensions on the AQL-8D Questionnaire and 2006 AARP New York Long-Term Care Survey for which there was strong consensus among the participants' responses. After the dimensions of the surveys and the interview transcripts were reflected upon, they were read again and themes in the data and thematic definitions were developed. Finally, another round of reflection and reading the questionnaire responses and the interview transcripts was completed. Thematic definitions and thematic coding were refined until data saturation occurred, which was the point at which no new data emerged (Parahoo, 1997).

## CHAPTER 4 – RESULTS AND DISCUSSION

### **AQoL-8D Questionnaire**

The AQoL-8D Questionnaire asked the participants to answer questions pertaining to quality of life that they were experiencing in HCBC. Due to their chronic conditions, the participants indicated that they possess limited mobility. Their disabilities limit them from traveling long distances. When they go shopping or visit family and friends, they said they experience moderate difficulty getting around outside on their own without assistance. Some of the respondents stated that they have the ability to carry out instrumental activities of daily living such as washing themselves, toileting, dressing, eating, or looking after their appearance; others indicated they require help from their caregivers to carry out those basic tasks. When asked how much assistance they require to perform tasks around the house, including preparing food, cleaning the house, or gardening, some of the participants said that they can carry out these tasks independently, but very slowly. Sometimes, pain interferes with their daily activities. When the respondents were asked how often they feel pain, they stated that they usually feel moderate pain and discomfort. Other respondents said they are unable to complete the tasks without assistance.

Next, the AQoL-8D Questionnaire had the participants describe how integrated into their families and communities they felt following the transition. Thinking about their health and their relationship with their family members, the participants feel that there are some aspects of their familial roles that they cannot carry out, causing them to sometimes feel left out from social activities. The participants feel that they are a moderate burden to their caregivers and family members. Despite feeling excluded at

times, the participants indicated that the close relationships they share with family members and friends are satisfying and thoroughly enjoyable.

### **2006 AARP New York Long-Term Care Survey**

From the results of the 2006 AARP New York Long-Term Care Survey, it was evident that the expenses of institutionalized LTC are unaffordable for many of those who need the services. In 2010, nursing homes cost an average of \$5,518 per month in Chicago, which amounts to \$66,216 per year. Over the course of three years, a nursing home would cost a consumer \$198,648 (Burton & Bridges, 2007). The participants said that they have no confidence that they would be able to afford the cost of nursing home care in Chicago. As a follow-up question, they were asked if they would be able to afford the cost of assisted living. In 2010, it cost an average of \$3,615 per month in Chicago. This figure equates to \$43,380 per year and \$130,140 for three years (Burton & Bridges, 2007). As with nursing home care, the subjects felt no confidence that they would be able to afford the cost of assisted living in Chicago. The cost of private health insurance is another issue. Only 3% of the general population possesses private long-term care insurance (Feder, Komisar, & Friedland, 2007). Consistent with the national trend, none of this study's participants purchased a private insurance policy that pays for LTC services because they can't afford the high costs. These results indicate that the cost of institutionalized LTC services and private insurance act as barriers for potential consumers who need care.

It was also clear from the surveys that the participants strongly favored HCBC care over institutionalized LTC. After they were transitioned out of nursing homes

through PACE, they moved back into home or the home of a family member. Some of them indicated that they use services such as home-delivered meals, nursing care, home health care, or chore services to help them remain in the home. When asked where they would like a family member to receive LTC services if they needed it, they said they would like that person to receive care in HCBC, displaying a strong preference for their family member to receive care in the home from family, friends, and home health care professionals instead of enrolling them in a nursing home. When asked if they supported Illinois delegating more funding to promote HCBC, all of the participants supported the notion that the state should allocate more funding to HCBC services such as in-home health care. They would support it even if it meant that Illinois must increase state taxes. Given that the participants felt their family members should receive care in HCBC and that they think Illinois should fund HCBC services to a greater extent, it was evident that they value a change in focus from institutionalized LTC to HCBC. They want people to be allowed to remain in their homes as they age instead of entering a nursing home.

The participants felt the state of Illinois should prioritize improving the availability of a broad range of LTC services that will allow people to remain in their homes. The participants said they support the downstream approach, where community reintegration programs transition LTC recipients out of the nursing homes and back into the community (Reinhard, 2010). There was a strong consensus that Illinois should support the development of programs that have their foundations in the upstream approach. The upstream approach prevents unneeded nursing home admissions, permitting consumers to remain integrated in their communities (Reinhard, 2010).

There is also a strong need for Illinois to develop educational programs to inform consumers about the LTC services that are available. When asked if the state should make it a high priority to create a central place where people can obtain information about the different types of LTC, the participants indicating that educating people about the services available to them is extremely important. This finding was in line with the first two principles of the Illinois Disability Service Plan: that individuals should be given the choice to choose from a range of appropriate and accessible community services and that the state should support effective, informed choice (Blagojevich, 2006). In order for people to make informed decisions about the type of LTC to pursue, people should possess the knowledge to confidently assess the benefits and drawbacks of each type of care setting.

Having the autonomy to make their own decisions was of particular importance to the participants. When asked if recipients of care should be given the choice of hiring and managing their own personal care assistants, the subjects said it is extremely important to give recipients of care control of those decisions. Changing the infrastructure of how care is delivered and supporting individual choice is principle 7 of the Illinois Disability Service Plan (Blagojevich, 2006). Progressing a shift to HCBC would give more consumers the ability to choose who delivers their care and how it is delivered. To accomplish an infrastructure of care that puts the consumer in charge of selecting their services, Illinois providers need to continue to distance themselves from the medical model that views the person with a disability as a patient needing direction (PACE Inc. Center for Independent Living, 2013).

## Interviews

The aims of the phone interviews were to gain a more in-depth insight into the participants' experiences in nursing homes and HCBC and to explore the benefits pertaining to quality of life that they witnessed after their transition. First, the participants were asked to compare their experiences living in the nursing home with HCBC by assigning ratings to each setting. They ranked HCBC very highly, stating they preferred HCBC for a variety of reasons, while their ratings for the nursing home were significantly lower.

Living back at home, the participants were able to enjoy the comfort of their home again. Elaborating on this benefit, they indicated that they did not need to worry about what they are going to eat for the day's meals, what television show would be selected for them to watch, or adjusting to the schedules of the nursing home staff. The activities planned for the residents in a nursing home lacked variety. According to participant A, "all they did in the nursing home was have *Wheel of Fortune* and play Bingo every day". Additionally, the nursing home staff rarely took the residents outdoors. The participants desired more autonomy in the nursing home to make decisions about what they want to do and more options for activities to engage in. In HCBC, recipients of care possess more independence to decide how they are going to spend their time. There is more lenience with their caregivers in the home. Participant B stated that living at home is "more comfortable" because he has "more choices available to him". They have the control to choose what activities they want to engage in, whether they want to read a book, watch a specific TV show, or leave their home to attend a community event.

Strengthening one's integration into the community is one of the greatest benefits of HCBC. While they said that some of the nursing home caregivers excelled at their jobs, the participants felt the institutional LTC system wasn't conducive toward sustaining and improving one's self-worth. Becoming reintegrated into the community improved the participants' sense of self-worth to a great extent. Living at home, the participants are able to engage in daily living activities such as cleaning and getting themselves ready for their day. They stated that performing these instrumental tasks increases their sense of self-worth. Community integration also decreases one's social isolation. After completing the transition, the participants were able to see their families and friends more frequently. Participant A stated, he can see his relatives and grand kids and do other stuff like going to the mall or to the show", and that, "it feels wonderful". Furthermore, they were able to engage in activities that they previously enjoyed in their communities before they entered the nursing home, including going to restaurants, libraries, and stores. Living in HCBC, the participants were able to interact with more people than they could in the nursing home.

The quality of life results from the interview were consistent with previous literature. As stated by Simon and Hodges in their report on quality of life of MFP participants during the 12 months following their transition back into the community (2011), recipients of care in HCBC experienced significant improvements in satisfaction with life and their needs for personal care being met by their family members or home health aids. Also consistent were the increases in the degree of community integration, mood status, and satisfaction with living arrangement (Simon & Hodges, 2011). In comparison to institutional settings, LTC is provided with a greater degree of quality,

partly because HCBC has its foundations in Independent Living Paradigm (Laplante, Kaye, & Harrington, 2007).

### **Other Considerations and Implications**

Interviewer bias may have been present in the study. While the participants indicated in the questionnaires and interviews that they favored HCBC over the nursing home, they may have denied negative thoughts they had while they were receiving care in the nursing homes or during the transition process in association with the PACE Center for Independent Living. According to the PACE reintegration specialists, the participants may have portrayed the nursing homes and PACE more positively in hopes of transitioning into HCBC sooner. The participants could have withheld negative information out of fear that the reintegration program will view them negatively. With regard to this study's instruments, their responses on the AQoL-8D Questionnaires' quality of life dimensions may have been biased in the sense that they wanted to be viewed positively.

This study's sample size ( $N = 3$ ) was justified because it utilized a qualitative design. The research used the following instruments: the 2006 AARP New York Long-Term Care Survey, the AQoL-8D Questionnaire, and the interviews. Thematic analysis was conducted to identify theme saturation. The sample is significant because it represents the experiences of many residents currently living in nursing homes in the nursing home systems. This research demonstrates how recipients of care can experience a greater quality of life if they were transitioned back into the community.

The results support the hypotheses that recipients of care living in HCBC experience a higher quality of life and fewer costs than those who live in nursing homes. Furthermore, the findings were consistent with previous research and suggest that Illinois should restructure its LTC services by supporting a systematic shift to HCBC. As witnessed in the Texas MFP program, people in nursing homes want to be moved out (Reinhard, 2010). Given that tax dollars fund institutional-based LTC, putting more resources into the downstream approach of transitioning people out of nursing homes and setting up an upstream initiative to prevent additional unnecessary nursing home admissions would drastically reduce Illinois's LTC expenditure.

## CHAPTER 5 – SUMMARY AND CONCLUSIONS

The results of this study were consistent with previous literature. The participant's responses on questionnaires, the interview, and the literature showed the benefits of transitioning nursing home residents into home and community-based care. Utilizing the downstream approach and transitioning people back into the community improves overall higher quality of life and reduces costs for those receiving care.

Due to the physical abuse, mental abuse, verbal abuse, and sexual abuse that still occur in Illinois's large institutions and their numerous violations of negligence and under-supervision, Lambert (2005) says it should be a high priority for the state to continue closing LTC institutions in favor of smaller HCBC centers. The data from this study demonstrates that transitioning residents into HCBC improves quality of life. Once transitioned back into their homes, recipients of care feel integrated into their families and communities. Furthermore, they experience more satisfaction with their living arrangements, elevated moods, a higher level of autonomy, a decrease in feeling socially isolated, more privacy, and an elevated sense of self-worth than they do in nursing home settings, making HCBC the preferred care setting. There was also strong consensus that recipients of care should be given the choice to hire and manage their own personal care assistants.

With a projected 20 million Americans needing LTC in the next decades due to the aging of the baby boomers, it is imperative that the states make high quality and cost efficient services available for them (Feder, Komisar, & Friedland, 2007). Many people who demonstrate the need for LTC services do not feel confident about their ability to

afford the high costs associated with nursing home care nor private long-term care insurance. On average, it costs the state \$48,500 per year to provide services in nursing homes for each individual while HCBC costs only \$12,000 a year per person (Illinois Department of Healthcare and Family Services Annual Report, 2011; Medical Assistance Program 2008, 2009 and 2010). Given the fact that LTC costs Illinois roughly \$3.5 billion per year, there is much room for the state to restructure how LTC is delivered to reduce costs.

Shifting from institutional-based LTC to HCBC is the logical solution to cut LTC expenditures for the state. Illinois will need to endure short-term costs to achieve long-term savings in its restructuring of LTC services toward HCBC, but it is also important to consider how the shift will improve quality of life. For instance, creating a central location where people can obtain information about LTC services will help people to make more educated decisions in their search for LTC services. Furthermore, the state can increase residents' independence, control, and degree of community integration by transitioning a greater number of eligible care recipients back into their communities and preventing unnecessary nursing home admissions to ensure they receive care in the HCBC settings.

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## APPENDIX: RESEARCH INSTRUMENTS

### Contents:

1. Cost of Long Term Care Questionnaire
2. AQoL-8D Quality of Life Questionnaire
3. LTC Interview Questions

### **2006 AARP New York Long-Term Care Survey**

- i. Are you currently cared for in your own home or in a family member's home?
  1. Yes
  2. No
  3. Not sure
  4. Refused
- ii. Do you use any services to help you remain at home, such as home-delivered meals, nursing care, home health care, or chore services?
  1. Yes
  2. No
  3. Not sure
  4. Refused
- iii. Are you or someone else in your family, such as a spouse, parent, or in-law currently receiving these types of services?
  1. Yes
  2. No
  3. Not sure
  4. Refused
- iv. How likely is it that a family member will need long-term care services in the next five years? Would you say a family member is...
  1. Extremely likely
  2. Very likely
  3. Somewhat likely
  4. Not very likely
  5. Not at all likely to need long-term care services in the next five years
  6. Not sure
  7. Refused

- v. If a family member needed long-term care services (i.e. a nursing home, personal assistant, home health aid, etc.), where would you want to have this care provided...
  - 1. At home, with help from family and friends
  - 2. At home, with help from home care professionals
  - 3. At home, with help from family, friend, AND home care professionals
  - 4. In a residential care facility, such as assisted living
  - 5. In a nursing home
  - 6. Not sure
  - 7. Refused
  
- vi. If a family member needed long-term care services (i.e. a nursing home, personal assistant, home health aid, etc.), how important would it be for you to have a central place where you could get information about all types of long-term care services as well as apply for the services and benefits you or your family members are eligible for?
  - 1. Extremely important
  - 2. Very important
  - 3. Somewhat important
  - 4. Not very important
  - 5. Not at all important
  - 6. Not sure
  - 7. Refused
  
- vii. How much of a priority should it be for Illinois to work on ensuring the availability of a broad range of long-term care services throughout the state that will allow people to remain in their own homes?
  - 1. Top priority
  - 2. High priority
  - 3. Medium priority
  - 4. Low priority
  - 5. Not a priority
  - 6. Not sure
  - 7. Refused
  
- viii. How strongly would you support or oppose Illinois increasing funding for home and community-based care services, such as in-home health care, to allow people to remain in their own home as they age instead of going to a nursing home?
  - 1. Strongly support
  - 2. Somewhat support
  - 3. Neither support nor oppose
  - 4. Somewhat oppose

5. Strongly oppose
  6. Not sure
  7. Refused
- ix. Would you support increasing funding for home and community-based services even if it meant an increase in state taxes?
1. Yes
  2. No
  3. Not sure
  4. Refused
- x. How strongly would you support or oppose giving individuals the choice of hiring and managing their own personal care assistants?
1. Strongly support
  2. Somewhat support
  3. Neither support nor oppose
  4. Somewhat oppose
  5. Strongly oppose
  6. Not sure
  7. Refused
- xi. In 2010, nursing homes cost an average of \$5,518 per month in Chicago or \$66,216 per year. Knowing this, how confident are you that you could afford the cost of nursing home care for yourself for three years? This would be about \$198,648 for three years.
1. Extremely confident
  2. Very confident
  3. Somewhat confident
  4. Not very confident
  5. Not at all confident
  6. Not sure
  7. Refused
- xii. In 2010, assisted living cost an average of \$3,615 per month in Chicago or \$43,380 per year. Knowing this, how confident are you that you could afford the cost of nursing home care for yourself for three years? This would be about \$130,140 for three years.
1. Extremely confident
  2. Very confident
  3. Somewhat confident
  4. Not very confident
  5. Not at all confident
  6. Not sure
  7. Refused

- xiii. How strongly do you support or oppose the New York State Legislature making assisted living more affordable for low and middle-income people?
1. Strongly support
  2. Somewhat support
  3. Neither support nor oppose
  4. Somewhat oppose
  5. Strongly oppose
  6. Not sure
  7. Refused
- xiv. Would you support making assisted living more affordable for low and middle-income people, even if it means an increase in state taxes?
1. Yes
  2. No
  3. Not Sure
  4. Refused
- xv. Currently, Medicare only covers very limited amounts of nursing home care and home health care. Do you currently have a private insurance policy that pays for long-term care, such as care provided over an extended period of time in a nursing home, at home, or in an assisted living facility?
1. Yes
  2. No
  3. Not sure
  4. Refused
- xvi. If you did not purchase long term care insurance, what are the primary reasons for not doing so?
1. It is too expensive
  2. I have other resources to pay for long-term care
  3. The insurance policy doesn't cover what I need
  4. I don't understand what the insurance policy covers
  5. I don't trust insurance companies
  6. I don't think I'll need long-term care
  7. I am too young
  8. I have never considered it
  9. I would be turned down because of an existing medical condition
  10. I rely on Medicaid or the state to pay for my care
  11. Looking into it, considering it
  12. Just don't want it
  13. Other

14. Not sure
  15. Refused
- xvii. How strongly would you support or oppose a policy that would let people make tax-free payroll deductions to save for future long-term care needs like they currently do for retirement or college savings?
1. Strongly support
  2. Somewhat support
  3. Neither support nor oppose
  4. Somewhat oppose
  5. Strongly oppose
  6. Not sure
  7. Refused
- xviii. What is the highest level of education that you completed?
1. 0-12<sup>th</sup> grade
  2. High school graduate or equivalent
  3. Post-high school education (no degree)
  4. 2-year college degree
  5. 4-year college degree
  6. Post-graduate study (no degree)
  7. Graduate or professional degree
  8. Refused
- xix. Which of the following best describes your employment status?  
Are you...
1. Employed full-time
  2. Employed part-time
  3. Retired, not working at all
  4. Unemployed but looking for work
  5. Not in labor force for other reasons
  6. Refused
- xx. What was your income before taxes last year?
1. Less than \$10,000
  2. \$10,000 to less than \$20,000
  3. \$20,000 to less than \$35,000
  4. \$35,000 to less than \$50,000
  5. \$50,000 to less than \$60,000
  6. \$60,000 to less than \$75,000
  7. \$75,000 or more
  8. Not sure
  9. Refused

**Assessment of Quality of Life (AQoL) - 8D Questionnaire**

- xxi. Thinking about how much energy you have to do the things you want to do: I am
1. Always full of energy
  2. Usually full of energy
  3. Occasionally energetic
  4. Usually tired and lacking energy
  5. Always tired and lacking energy
- xxii. How often do you feel social excluded or left out?
1. Never
  2. Rarely
  3. Sometimes
  4. Often
  5. Always
- xxiii. Thinking about how easy or difficult it is for you to get around by yourself outside your house (e.g., shopping, visiting):
1. Getting around is enjoyable and easy
  2. I have no difficulty getting around outside my house
  3. A little difficulty
  4. Moderate difficulty
  5. A lot of difficulty
  6. I cannot get around unless somebody is there to help me
- xxiv. Thinking about your health and your role in your community (that is to say neighborhood, sporting, work, church, or cultural groups)
1. My role in the community is unaffected by my health
  2. There are some parts of my community role I cannot carry out
  3. There are many parts of my community role I cannot carry out
  4. I cannot carry out any part of my community role
- xxv. How often do you feel sad
1. Never
  2. Rarely
  3. Some of the time
  4. Usually
  5. Nearly all the time
- xxvi. Thinking about how often you experience serious pain, I experience
1. Very rarely
  2. Less than once a week

3. Three to four times a week
  4. Most of the time
- xxvii. How much confidence do you have in yourself
1. Complete confidence
  2. A lot
  3. A moderate amount
  4. A little
  5. None at all
- xxviii. When you think about whether you are calm and tranquil or agitated, I am
1. Always calm and tranquil
  2. Usually calm and tranquil
  3. Sometimes calm and tranquil, sometimes agitated
  4. Usually agitated
  5. Always agitated
- xxix. Thinking about your health and your relationship with your family:
1. My role in the family is unaffected by my health
  2. There are some parts of my family role I cannot carry out
  3. There are many parts of my family role I cannot carry out
  4. I cannot carry out any part of my family role
- xxx. Your close relationships (family and friends) are
1. Very satisfying
  2. Satisfying
  3. Neither satisfying nor dissatisfying
  4. Dissatisfying
  5. Unpleasant
  6. Very unpleasant
- xxxi. When you communicate with others, e.g. by talking, listening, writing or signing:
1. I have no trouble speaking to them or understanding what they are saying
  2. I have some trouble being understood by people who do not know me. I have no trouble understanding what others are saying to me
  3. I am understood only by people who know me well. I have great trouble understanding what others are saying to me
  4. I cannot adequately communicate with others
- xxxii. How often do you have trouble speaking?
1. Never
  2. Almost never

3. Sometimes
  4. Often
  5. All the time
- xxxiii. How often do you feel angry?
1. Never
  2. Almost never
  3. Sometimes
  4. Often
  5. All the time
- xxxiv. Thinking about your mobility, including using any aids or equipment such as wheelchairs, frames, sticks:
1. I am very mobile
  2. I have no difficulty with mobility
  3. I have some difficulty with mobility (for example, going uphill)
  4. I have difficulty with mobility. I can go short distances only.
  5. I have a lot of difficulty with mobility. I need someone to help me.
  6. I am bedridden.
- xxxv. How enthusiastic do you feel?
1. Extremely
  2. Very
  3. Somewhat
  4. Not much
  5. Not at all
- xxxvi. And still thinking about the last seven days, how often did you feel worried?
1. Never
  2. Occasionally
  3. Sometimes
  4. Often
  5. All the time
- xxxvii. Thinking about washing yourself, toileting, dressing, eating or looking after your appearance:
1. These tasks are very easy for me
  2. I have no real difficulty in carrying out these tasks
  3. I find some of these tasks difficult, but I manage to do them on my own
  4. Many of these tasks are difficult, and I need help to do them

5. I cannot do these tasks by myself at all
- xxxviii. How often do you feel happy?
1. All the time
  2. Mostly
  3. Sometimes
  4. Almost never
  5. Never
- xxxix. How much pain or discomfort do you experience:
1. None at all
  2. I have moderate pain
  3. I suffer from severe pain
  4. I suffer unbearable pain
- xl. How much do you enjoy your close relationships (family and friends)?
1. Immensely
  2. A lot
  3. A little
  4. Not much
  5. I hate it
- xli. How often does pain interfere with your usual activities?
1. Never
  2. Rarely
  3. Sometimes
  4. Often
  5. Always
- xlii. How often do you feel pleasure?
1. Always
  2. Usually
  3. Sometimes
  4. Almost never
  5. Never
- xliii. How much of a burden do you feel you are to other people
1. Not at all
  2. A little
  3. A moderate amount
  4. A lot
  5. Totally
- xliv. How content are you with your life?
1. Extremely

2. Mainly
  3. Moderately
  4. Slightly
  5. Not at all
- xliv. Thinking about your vision (using our glasses or contact lenses if needed):
1. I have excellent sight
  2. I see normally
  3. I have some difficulty focusing on things, or I do not see them sharply. E.g. small print, a newspaper or seeing objects in the distance.
  4. I have a lot of difficulty seeing things. My vision is blurred. I can see just enough to get by with.
  5. I only see general shapes. I need a guide to move around.
  6. I am completely blind.
- xlvi. How often do you feel in control of your life?
1. Always
  2. Mostly
  3. Sometimes
  4. Only occasionally
  5. Never
- xlvii. How much help do you need with jobs around the house (e.g. preparing food, cleaning the house or gardening):
1. I can do all these tasks very quickly and efficiently without any help
  2. I can do these tasks relatively easily without help
  3. I can do these tasks only very slowly without help
  4. I cannot do most of these tasks unless I have help
  5. I can do none of these tasks by myself
- xlviii. How often do you feel socially isolated?
1. Never
  2. Rarely
  3. Sometimes
  4. Often
  5. Always
- xliv. Thinking about your hearing (using your hearing aid if needed)
1. I have excellent hearing
  2. I hear normally
  3. I have some difficulty hearing or I do not hear clearly. I have trouble hearing softly-spoken people or when there is background noise.

4. I have difficulty hearing things clearly. Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
  5. I hear very little indeed. I cannot fully understand loud voices speaking directly to me.
  6. I am completely deaf.
1. Your close and intimate relationships (including any sexual relationships) make you:
    1. Very happy
    2. Generally happy
    3. Neither happy nor unhappy
    4. Generally unhappy
    5. Very unhappy

### **LTC Interview Questions**

1. How long have you been receiving care in Home and Community-Based Care?
2. What do you like about Home and Community-Based Care?
3. Please compare your experience living in a nursing home with Home and Community-Based Care.
4. Why did you want to transition out of the nursing home?
5. On a scale of 1 to 10 with 10 being the highest quality, please rate your experience living in a nursing home. Please explain your rating.
6. On a scale of 1 to 10 with 10 being the highest quality, please rate your experience living in Home and Community-Based Care. Please explain your rating.
7. How integrated into the community do you feel? Please explain your answer.
8. What aspects of Home and Community-Based Care do you think can be improved?