

The Impact of Moving toward a Culture of Empowerment
in the Lives of Residents of Assisted Living Centers

by

Jay Hedgpeth

A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved November 2011 by the
Graduate Supervisory Committee:

Maria Napoli, Chair
Robin Bonifas
Karen Gerdes

ARIZONA STATE UNIVERSITY

May 2012

ABSTRACT

The massive number of baby boomers approaching retirement age has been termed the ‘gray tsunami.’ As America's gray tsunami approaches, healthcare workers and social workers will become overwhelmed with requests for services and supports (St. Luke's Health Initiative, 2001; Bekemeier, 2009). This impact can be ameliorated by assisting aging individuals in maintaining or in some cases regaining independence. Individuals who live in assisted living facilities (ALFs) come from diverse backgrounds. Many of these individuals have lived in paternalistic environments such as prisons and mental health institutions. As a consequence of these disempowering conditions, residents of ALFs may experience increased depression, decreased self-esteem, and decreased locus of control (R. Hess, personal communication, September 30, 2010). These disabling conditions can severely limit residents’ choice-making opportunities and control over their own lives. If programs can be created to provide empowering experiences and to teach self-advocacy skills, I hypothesize that residents will report an improved quality of life and display fewer depressive symptoms, increased self-esteem, and increased locus of control. Helping these individuals to maintain or regain independence will not only reduce the workload for care workers, it will enhance the lives of residents. The only hypothesis that was supported by the study was an improvement in residents’ quality of life, and that hypothesis was only partially supported. Two of the five domains in the Residents’ Quality of life questionnaire indicated an increase in quality of life.

The Activities subscale of the Ferrans & Powers Quality also indicated that there was an increase in quality of life.

DEDICATION

I would like to dedicate this dissertation to Eldon, Jason, Dick, and Gilbert, who motivated me to complete this dissertation.

ACKNOWLEDGMENTS

The author wishes to acknowledge the following individuals who contributed to the completion of the manuscript.

My doctoral supervisory committee, who spent numerous hours advising and supporting me:

Maria Napoli, chair
Karen Gerdes mentor
Robin Bonifas mentor

My community committee members:

Robert Hess
Jay Klein

Other members of faculty at Arizona State University who supported my work:

Fei Sun
Judy Krysik

The Residents' Councils whose participation made this study possible

And my mother

Grace Hedgpeth

TABLE OF CONTENTS

	Page
LIST OF TABLES.....	vii
CHAPTER	
1 STATEMENT OF PURPOSE	1
Hypothesis.....	3
Importance of the Study	4
Importance to Social Work	5
Addressing the Gap.....	7
2 LITERATURE REVIEW.....	9
Theoretical Foundation.....	10
Brief History of Mental-Health Care.....	19
Self-determination.....	22
Rationale for Using Consumer-directed Services.....	23
Consumer Directed Models	28
Culture Change.....	33
Summary.....	35
3 METHODS.....	37
Sample.....	37
Facilities.....	38
Culture Change Intervention.....	41
Study Design.....	42
Data Collection.....	42

CHAPTER	Page
Data Analysis.....	43
Measures	43
4 RESULTS.....	48
Hypothesis 1.....	48
Hypothesis 2.....	48
Hypothesis 3.....	49
Hypothesis 4.....	49
Measures.....	50
Limitations.....	50
5 DISCUSSION.....	52
Stigma.....	52
Rights	54
Dosage-Intensity.....	55
Residents' Quality of Life.....	58
Future Directions.....	62
Implications.....	63
Implications for Social Work.....	64
Conclusion.....	65
REFERENCES	67
APPENDIX A	
Survey... ..	81
APPENDIX B	
Instituional Review Board Approval.....	88

LIST OF TABLES

Table	Page
1. Facility Demographics	39
2. Council Demographics	40
3. Pretest Posttest Comparisons.....	49
4. Paired Samples Pretest Posttest Statistics	50

STATEMENT OF PURPOSE

The Importance of the Problem

Individuals residing in assisted living facilities (ALFs) have a high level of disability, dementia, and depression. These conditions can severely limit choice-making opportunities and self-determination. The median income of residents in assisted living is \$15,688, and residents on average need assistance with two activities of daily living (Kaiser Commission on Medicaid Facts, 2010). Many individuals relocate to ALFs from their own homes (R. Hess, personal communication, November 10, 2010) following medical or physical decline.

ALF residents' needs can range from simply housing to help with several activities of daily living (ADLs), which "are the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring [i.e. moving from bed to a wheelchair, wheelchair to a vehicle]" (Wiener, Hanley, Clark, & Van Nostrand, 1990, p.4). A national sample of residents in ALFs found that 24% needed help with three or more ADLs and 34% had moderate to severe cognitive loss (Hawes, Phillips, Rose, Holan, & Sherman, 2003). In a stratified random sample of 55 residents from 17 ALFs in the Atlanta area, one study found that 54% of the residents were depressed (Ball et al, 2000). Another study of 196 residents from 22 ALFs in Maryland indicated that 24% were depressed and more than half had some form of dementia (Watson et al., 2006). Not surprisingly, the medical and physical decline that often triggers an ALF move can be associated with depression (Watson et al., 2006).

Before describing the study in detail, the characteristics of ALFs and ALF residents is provided as background information for the reader. Watson et al., (2006) state that the growth in assisted living is outpacing all other forms of long term care and the Assisted Living Federation of America predicts an annual growth rate 4.5% (alfa.org, 2011). In 2007, there were 974,585 units (beds) in 38,373 licensed ALFs in the United States (Long-term care, 2008). Although Medicaid is the primary payer for long-term care (Kaiser Commission, 2010), individuals who live in ALFs are typically private-pay customers (Kane & Brown Wilson, 2007).

Both researchers and professionals in the field argue that the abilities of individuals with disabilities are grossly underestimated (Nerney, 2008; Wehmeyer, 2004). This study examines the impact of a "Culture Change" intervention. The intervention includes self-advocacy and life skills training along with a residence council, providing opportunities for individuals in assisted living settings to express self-determination and to maximize their opportunities for independence can lead to several beneficial outcomes.

Research by Chen, Zimmerman, Sloane, and Barrick (2007) indicates that ALF residents' control over their lives is associated with reduced depression. A study by Park et al., 2009, indicates that opportunities for meaningful relationships and activities increase quality of life for individuals in ALFs. Several studies indicate that self-determination decreases depressive symptoms in individuals with disabilities in independent living (Bekemeier, 2009) and individuals with Parkinson's disease (Schrag, Jahanshahi, & Quinn, 2000). Self-

determination is also associated with increases in total locus of control in individuals with disabilities in independent living (Bekemeier, 2009) and nursing home residents (Anderson-Hanley, Meshberg, & Marsh, 2003). Furthermore, among college students a 2007 controlled study of 120 college students indicated that individuals who experienced a power role (control) in the experiment demonstrated a higher level of self-esteem than those who experienced a subordinate role (Wojciszke & Struzynska-Kujalowicz, 2007).

Hypotheses

Residents enter ALFs due to impairments that limit their activities of daily living. Anecdotal evidence based on the investigator's conversation with assisted living residents suggests they can experience social isolation, depression, and a loss of autonomy. If programs can be created to provide empowering experiences and self-advocacy skills, it is hypothesized that residents will display fewer depressive symptoms, increased self-esteem, increased locus of control and will report an improved quality of life.

Hypothesis 1: Residents will display fewer symptoms of depression at posttest.

Hypothesis 2: Residents will report a higher internal locus of control at posttest.

Hypothesis 3: Residents will report increased self-esteem at posttest.

Hypothesis 4: Residents will report an improved quality of life at posttest.

The purpose of the study is to evaluate the individuals' self-determination and overall quality of life before and after a culture change in their facilities.

Importance of the Study

Nursing homes, homecare, and ALFs are clustered collectively into long-term care (LTC). This dissertation uses the State of Alabama's definition of assisted living--"individuals, corporations, partnerships, or any other entity that provides or offers to provide residents and personal care to individuals who need assistance with activities of daily living" (Alabama State Department of Public Health, 2002, p.1)--because it is broad enough to encompass most other operationalizations of the term.

"There is no federal regulation of AL and no mandatory definition of what constitutes AL" (Hawes & Phillips, 2007, p. 41). Each state establishes its own definition of assisted living. The Arizona State Department of Health Services defines an assisted living facility as "a residential care institution that provides or contracts to provide supervisory care, personal care, or directed care on a continuing basis" (p.1) in comparison to Connecticut's definition of assisted living as

a special combination of housing, supportive services, personalized assistance and health care designed to respond to the individual needs of those who need help with activities of daily living and instrumental activities of daily living. Supportive services are available 24 hours a day to meet scheduled needs in a way that promotes maximum dignity and independence for each resident and involves the resident's family, neighbors, and friends. (State of Connecticut Social Services, 2011)

Other states such as New York and California link assisted living with elders and retirement (Empire State Association of Assisted Living, 2011; Aging Services of California, 2011). The State of Alabama defines assisted living as “individuals, corporations, partnerships, or any other entity that provides or offers to provide personal care to individuals who need assistance with activities of daily living” (Alabama State Department of Public Health, 2002, p.1).

Assisted living can be seen on a continuum between independent living and skilled nursing care (Carpenter, Sheridan, Haenlein & Dean, 2006). In contrast to ALFs, nursing facilities “provide care for the medically chronically ill and for those recuperating from medical illness and who need 24-hour nursing care but not hospitalization” (Arizona State Department of Health Services, 2010, p.1). There is an inconsistent use of the terms ‘assisted living facility’ and ‘nursing home’ that confounds the results of some of the research (Kemper et al., 2008). In an effort to understand more about who uses ALFs, the Center for Disease Control and Prevention is conducting the first National Survey of Residential Care Facilities (NSRFC) (Assisted Living Federation of America, 2010).

Importance to Social Work

When ALF consumer councils are studied, researchers tend to focus on the participation of community members rather than on facility residents’ participation (Kane et al., 2003). The need for research evaluating residents' well-being in ALFs is well-documented. According to Kane and Wilson, 2007, previous research has used unrealistic targets for residents' health and function

goals such as extreme levels of quality of life and autonomy. Studies of facility interventions that can impact quality of life on an individual level are needed as well (Rapaport, Clary, Fayyad, & Endicott, 2005). Few studies include asking residents directly about their quality of life: Researchers are more likely to ask caregivers and family members to provide proxy reports of residents' quality of life (Carpenter, Sheridan, Haenlein, & Dean, 2006). There is also a need to evaluate quality of life as an inclusion criterion as well as an outcome "one research strategy might target subjects with both moderate-to-severe symptoms and substantial impairment in quality of life to a more intensive treatment option (Rapaport, Clary, Fayyad, & Endicott, 2005, p.1176)."

Numerous gaps exist in the literature and in the research examining self-determination of residents in ALFs. Due to recent decreases in government funding and the massive wave of aging baby boomers, more effective interventions are needed in terms of those that can enhance positive outcomes while minimizing expense (Carpenter, Sheridan, Haenlein, & Dean, 2006). The majority of current research focuses on nursing home settings or combines all LTC settings together such that research exclusively emphasizing assisted living is necessary. There is a need for more effective interventions in terms of outcomes and expense (Agency for Healthcare and Research and Quality, 2010). The majority of the research being done today focuses on nursing home settings or they combine all LTC settings together. There is an inconsistent use with the terms 'assisted living facility' and 'nursing home' that confounds the results of some of the research (Kemper, Heier, Teta, Brannon, Angelli, Vasey & Anderson-

Knot, 2008). When consumer councils are studied they tend to focus on the community members participation (Kane, Kling, Bershadsky, Kane, Giles, Degenholtz, Liu, & Cutler, 2003).

In quality of life research, a significant portion of the variance between personal and facility quality of life is not explained by adjusting for ‘case mix’ or ‘symptom severity’. There is a need for facility intervention that can impact quality of life on an individual level (Rapaport, Clary, Fayyad, & Endicott, 2005). Few studies ask residents directly about their quality of life: they are more likely to ask caregivers and family members (Agency for Healthcare and Research and Quality, 2010). There is need to evaluate quality of life as an inclusion criteria as well as an outcome (Rapaport, Clary, Fayyad, & Endicott, 2005).

Addressing the Gap

This study examines two ALFs and focuses on residents’ response to a ‘Culture Change’ intervention--a change from the traditional assisted-living model of care to a person-centered model of care that provides self-advocacy and life skills training. The residents’ council offers opportunities for residents to use self-advocacy and life skills to direct their own lives and increasingly control the operation of their individual facility. The council also addresses quality of life on an institutional level as well as on a personal level. The study focuses on residents in self-reported quality of life, self-esteem, and locus of control.

Self advocacy and life skills training program is designed to provide opportunities and training for individuals to achieve self-determined goals, including some intrinsically motivated goals. Many studies conducted in LTC

settings do not include skills training, though skills are integral to achieving personal goals. In some cases, individuals with disempowered self and public images, such as residents in LTC, are not given tools because it is assumed that they cannot use them (Hedgpeth, Nagoshi, & Nagoshi, 2011). The Culture Change movement seeks a change in attitude in the facilities that affords the residents opportunities to gain more control over their lives and their residences.

Chapter 2

Literature Review

As America's large number of baby boomers nears retirement, a graying tsunami threatens to overwhelm healthcare workers and social workers with requests for services and supports (St. Luke's Health Initiative, 2001; Bekemeier, 2009). The impact of the aging population can be reduced by assisting aging individuals and individuals with disabilities (individual needing help with activities of daily living) in maintaining or, in some cases, regaining independence. Assisting residents in ALFs in maintaining/regaining independence will reduce the workload for care workers while enhancing residents' lives.

Statement of the Problem

As noted above, individuals with functional, cognitive, or mood-related challenges, such as those experienced by residents in assisted living, can lack significant choice-making opportunities and skills (Wehmeyer, & Bolding, 1999; Stancliffe, 2001; Bambara & Kroger, 2005; Petry, Maes, & Vlaskamp, 2007; Nerney, 2008; Deci & Ryan, 2008). In addition, given their disempowered situation, they can require "support beyond that typically needed by others at a similar age and stage of life" (Schalock, et al., 2002, p. 457). Such support may take the form of special social and environmental arrangements or structured opportunities and specialized training (Schalock et al., 2002).

Several studies have illustrated that individuals with challenges related to disabilities can become more independent and lead more meaningful lives through

home ownership (Klein, 1999), education (Wehmeyer, 2003), and employment (Wehmeyer & Bolding, 1999). Other studies by researchers such as Deci and Ryan (2008) and Wong, Nath, and Solomon (2007) indicate that when these individuals learn to make choices for themselves, they can take more control over their lives and participate in their communities more completely, which can lead to more valued roles in their lives and in their communities (O'Brian, 2006). One way for individuals in assisted living to take control over their lives, pursue autonomous choices, and acquire valued roles in society is to take leadership or self-advocacy training (Hess, Clapper, Hoestra & Gibison, 2001; Rogers & Rogers, 2003).

This study hypothesizes that the residents who experience the Culture Change program can improve their quality of life. Increasing the ability of residents in ALFs to take control of their lives and providing structured opportunities to exercise that control should result in increased independence for residents.

Theoretical Foundation

"To the extent that man loses his ability to make choices and is subject to the choices of others, to the extent that his decisions are no longer his own because they result from external prescriptions, he is no longer integrated. (Freire Education for Critical Consciousness, 1974 p.4)"

The principles of choice, freedom, and equality are vital parts of self-advocacy seen in the United States Constitution and in the philosophy of critical theorists, such as Paulo Freire. Self-directed programs address power differential

issues similar to those that Freire addresses in the education system. Like the students in Freire's writing, individuals who need assisted living are in positions of diminished authority and power in their lives. As Lovett (1996) states, "Choice is a critical expression of power" (p. 225).

Several theories inform the knowledge base associated with quality of life, choice-making, and autonomy of ALF residents. These theories include Self-determination Theory, Consumer-Directed Theory of Empowerment, and Person-Centered Planning. The following section describes each of these concepts in detail.

Self-Determination Theory.

Self-determination theory emphasizes that the greater the association between an individual's goals and his or her sense of self, the more effective the performance associated with that goal. Furthermore, 'more effective performance' is associated with greater well-being (Hedgpeth, Nagoshi, & Nagoshi, 2010).

Wehmeyer and Bolding (1999) assert the following:

If individuals are supported to make choices, participate in decisions, set goals, experience control in their lives and so forth, they will become more self-determined. As they become more self-determined, they become more likely to assume greater control; make more choices; hone their skills in goal setting, decision making and problem solving; and [gain a] greater belief in their capacity to influence their lives. (pp. 360-361)

Self-determination increases retention to goals and performance and leads to greater control over an individual's life.

One major obstacle for residents of assisted living as well as other disempowered individuals is the public perception of their abilities, or stigma. Dobbs et al., 2008, list three components of stigma. First are societal beliefs that attach 'undesirable characteristics' to the person. The second component of stigma is 'othering,' or creating an '*us versus them*' paradigm. The last component is the experience of being devalued that is, being treated as less valuable than members of the dominant group. Dobbs et al. cite previous research that points to negative outcomes resulting from this stigmatization, including decreased social interaction, lower self-esteem, poor self-confidence, and increased depression (Dobbs et al., 2008).

Disempowered individuals, such as those in ALFs, have public image issues that play a role in limiting their opportunities for self-determination (Nota, Ferrari, Soresi, & Wehmeyer, 2007). Often the public image of individuals in these facilities is that they cannot make important decisions for themselves. If an individual is not expected to make decisions, he or she may no longer try to do so, furthering the spiral of disempowerment. If the individual does not try to make decisions, he or she does not gain experience in making choices. This scenario leads to poorer choices, which in turn lead to lower self-expectations (Madon, Jussim, & Eccles, 1997). Another public image factor that limits opportunities for growth and self-determination is acquiescence. According to Kerr and Shakespeare (2002), "[Individuals] do not make their choices in a vacuum, but they are influenced by the values and the attitudes of society. Medical

professionals, families and friends, and the wider public will contribute to the views that patients hold and the decisions they make” (p. 121).

Vulnerable individuals tend to be easily persuaded by a person they see as an authority figure or from whom they want to gain approval, tainting free choice (Cialdini, 2005). Choice can be as subtle as selecting what to eat, but dissuasion from exercising free choice not only limits opportunities to experience a preferred activity, it limits growth as well. “The opportunity to assert preference and choice is typically viewed as critical to the process of one’s personal growth and fulfillment” (Wehmeyer, Agran, & Hughes, 1998, p.100).

Wehmeyer (2002) stated that “self-determined people are causal agents; they make things happen in their lives. They are goal-oriented and apply problem-solving and decision-making skills to guide their actions. They know what they do well and where they need assistance. For example, Franken-Spaar (2010) surveyed male youths from a residential treatment facility, their family members, and the facility’s staff. Participants reported that although self-determination was important to them, they had little to no training on self-determination skills. Not surprisingly, individuals with disabilities can “exhibit less self-determination” simply because they have learned to employ self-determination skills (Rioch, 2009, p. 2).

Empowerment Perspective.

Principles of choice and power over one’s life are reflected in social work's empowerment perspective, which directs social workers to help individuals to "achieve their own goals, realize their dreams, and shed the irons of their own

inhibitions and misgivings and society's domination" (Saleebey, 2006, p. 1). The empowerment perspective focuses on resilience, recovery, and strengths to maximize individuals' control over their lives. Saleebey (2002) operationalized empowerment within the strengths perspective as "assisting individuals, groups, families and communities to discover and expand the resources and tools within and around them" (p. 9).

The contemporary mental health empowerment movements (e.g., Nothing about Us without Us, peer-to-peer programs, and resident councils) have grown out of the concepts of power theorists such as Freire, Foucault, and Garland-Thomson. For Foucault, power is an intrinsic part of social relations that has two forms: *power-to* and *power-over*. *Power-to* involves locus of control, self-esteem, and self-determination while *power-over* involves domination and exploitation (Clark & Krupa, 2002). The *power-to* perspective can be seen in Wehmeyer's concept of self-determined individuals as "primary causal agent in their own lives" (Wehmeyer, 1996, p. 24) as well as Deci and Ryan's self-determination theory's intrinsic motivation, free of external control.

Consumer-Directed Theory of Empowerment

The consumer-directed theory of empowerment (CDTE) is based on three assumptions. First, consumers are experts on their own needs and should be considered competent regardless of disability (Kosciulek, 1999). Nerney (2008) addresses assumed competence in greater detail. He asserts that incompetence should be replaced with 'assisted competence,' which includes a range of supports

that will enable individuals with cognitive disabilities to receive assistance in decision making that will preserve their rights” (Nerney, 2008, para. 2).

CDTE’s second assumption is that all service delivery systems can include control and choice for consumers. According to this theory, rehabilitation systems should offer a wide selection of options to meet the needs of a diverse group of consumers in a variety of environments. The third assumption is that these services will be available to all consumers regardless of payee, whether public, private, or insurance (Bekemeier, 2009).

Recent research indicates that LTC consumers’ ability to control their interactions and services (including how services are delivered) increases satisfaction in personal relationships (Park, 2009). Kosciulek and Merz (2001) indicate that increased levels of consumer direction lead to increased sense of control, empowerment, quality of life, and community integration. Powers, Sowers, and Singer (2006) state that there is a positive association between perceived sense of control and quality of life. For instance, participants in Robert Wood Johnson self-directed care programs achieved better health outcomes than a control group who did not use self-directed care (U.S. Department of Health and Human Services, 2006, p. 6). When individuals are involved in their personal health plans, they tend show healthier outcomes (Adams & Drake, 2006; Cook, Russell, Grey, & Jonikas, 2008; Cook, Terrill, & Jonikas, 2004).

Self-directed programs have several limitations and barriers. One barrier to self-directed care is the public image of individuals with disabilities. This stigma can lead the public to view consumers with disabilities as incapable and

incompetent. Another barrier involves concerns over consumers' ability to take responsibility for their choices (Dobbs et al., 2007). So far, self-directed care programs demonstrate that individuals with disabilities can be responsible (Department Health and Human Services, 2005; Scala & Nerney, 2008; Hendry 2000). Self-directed care is more than just consumer-operated services or peer support, although these should be included as options (Department Health and Human Services, 2005). According to the Department of Health and Human Services (DHHS), self-directed care is a process that helps people uncover their needs and who they are and build their futures. Self-directed care typically involves the patient/client controlling her own finances and medical care rather than an agency or government agent doing so (Department Health and Human Services, 2005).

Person-Centered Planning.

Person-Centered Planning (PCP) is a treatment plan or an outline used to help individuals achieve their self-determined goals, such as educational achievement, employment, or housing. Individuals in disempowered situations, such those in assisted living, frequently require "support beyond that typically needed by others" (Schalock et al., 2002, p. 457). Such support may take the form of special social and environmental arrangements as well as structured opportunities and specialized training (Schalock et al., 2002). In the past, treatment plans for persons with disabilities were based on the medical model. The *Social Work Dictionary* states that the medical model "includes looking at the client as an individual with an illness to be treated, giving relatively less attention

to factors in the client's environment" (Barker, p. 266). As long ago as 1978, the World Health Organization Alma-Ata 1978 "formally alerted nations worldwide that physician-centred care and hospital based programmes were inadequate" (Zakus & Lysack, 1998, p. 1). Recently, interventions and service delivery have changed from a medical model to a client-directed model (Garcia, 2003). The client-directed or person-centered model emphasizes the individual's personal goals and objectives (Duncan & Miller, 2000; Maes, Geeraert, & Van den Bruel, 2000).

Person-centered planning is a process-oriented approach to empowering people with disabilities. PCP focuses on people and their needs by putting them in charge of defining the direction for their lives. This approach ultimately leads to individuals' greater inclusion as valued members of both community and society. In Arizona, the change from medical model to person-centered model was mandated by the court cases *Jason K.* and *Arnold vs. Sarn*. In the first case, the Maricopa County Superior Court found that the State was not providing appropriate services to children with mental illnesses. In the second case, adults with mental illnesses brought charges against the State for its failure to provide adequate care. They won the case, and the court subsequently appointed arbitrators who continue to work with the State to improve service delivery.

These court challenges forced the State of Arizona to mandate individual service plan (ISP) teams consisting of the individuals themselves, concerned professionals, friends, and family members who help the individual develop a

service plan to aid in their personalized recovery. Following are the Arizona State guidelines for ISP teams:

Five Principles of Person-Centered Planning

1. Behavioral health assessments and service plans are developed with the understanding that the system has an unconditional commitment to its consumers.
2. Services begin with empathic relationships that foster ongoing partnerships; expect equality and respect throughout the service delivery.
3. Services are developed collaboratively to engage and empower individuals, include other individuals involved in the individual's life, include meaningful choice, and are accepted by the individual.
4. Services are individualized, strengths-based, and are clinically sound.
5. Services are developed with the expectation that the individual is capable of positive change, growth, and leading a life of value.

(Arizona Department of Health, Title 9. Health Services: Chapter 21.

Article 3: R9-21- 301.)

ISPs can provide a limited form of self-directed care for vulnerable individuals.

The team helps the individual develop an ISP, a document that includes a list of and short term objectives, along with specific time frames to accomplish each objective. A Wayne State University study demonstrated that this ISP team model, using friends, family, and concerned professionals, has been shown an

effective method of service delivery (LeRoy, Wolf-Branigin, Wolf-Branigin, Israel, & Kulik, 2007).

CDTE and PCPs are tools to help individuals establish and pursue self-determined goals and live self-determined lives. CDTE is a theory that establishes a framework for individuals to be ‘causal agents’ or self-determined directors of the services they want and need. In the PSP, the individual works with a committee of concerned friends, family members, and professionals to achieve these goals.

Brief History of Mental Health Care

In 1909, an individual with an intellectual disability, Clifford Beers, founded the National Committee for Mental Hygiene (NCMH). The organization's mission was the prevention and treatment of mental illness (nervous and mental disorders). The NCMH later became the National Association for Mental Health. During the 1950s, psychotropic medication became the dominant treatment for individuals with nervous and mental disorders, along with a long-established policy of confinement to hospitals, a treatment that had begun in the early 1800s. In 1961, the National Institute of Mental Health released a report that recommended that mental hospitals be updated and be limited to 1000 patients per facility (Stubbs, 1998).

In 1962, President Kennedy altered the direction of U.S. policy, thus legitimizing the deinstitutionalization movement. He stated that under the new policy of deinstitutionalization, “a reliance on the cold mercy of custodial isolation would be supplanted by the open warmth of community concern and

capability” (Isaac & Armat, 1990, in Stubbs, 1998, p. 1). Kennedy’s Community Mental Health Centers Act was to change the way individuals with intellectual disabilities were to be treated: They were to be integrated into the community. Although integration was the policy change, the reality was that there were no accommodations for these individuals in the communities.

In 1965, three years after the Community Mental Health Centers Act, U.S. Attorney General Robert Kennedy visited New York State’s hospital at Willowbrook and publicly denounced living conditions there. Willowbrook housed over 5000 patients who were believed to be insane (Rivera, 1988). The staff-to-client ratio at Willowbrook was over 30 to 1, though the recommended ratio was 4 to 1. Instead of taking showers, residents had to hose themselves off, and they were given less than two minutes to eat their meals. When television cameras were secretly brought into the facility to document these conditions, the State of New York was embarrassed into addressing the inappropriate conditions at this facility. A few months later, the State brought in a camera crew to document improvements in the facility. Less than month after that, another camera crew sneaked in and documented still-deplorable conditions at Willowbrook. The outrage produced by this second expose precipitated the closing of the Willowbrook facility. The State of New York was forced to transfer 5000 individuals into ‘community settings’ (Rivera, 1988). In 2009 the State of New York was still being brought to court for their failure to provide appropriate care for individuals who had been housed at Willowbrook. By not providing appropriate services, institutions not only prevent growth and learning

opportunities for individuals but can contribute to individuals' loss of self-esteem. Lovett states that institutions can magnify disabilities rather than encouraging resilience (Lovett, 1996).

20th Century.

In the late 1800s and into the 1940s, Long-term facilities diversified. Geriatric nursing homes or convalescent homes that primarily provided custodial care began to appear. By the end of the 1940s, in part due to the 1935 Social Security Act, services at these facilities began to improve. By 1952, there were at least 14,000 long-term care facilities providing personal and some medical care. At this time, the institutions were called *boarding houses, rest homes, nursing homes, convalescent homes, sanatoriums*, and *guest houses* as well as *geriatric and chronic-care hospital units* (Zinn, 1999). Several legislative actions during the 1960s changed the face of long-term care. Federal matching funds for the medically indigent were made available through the Kerr-Mills Act of 1960 and Medicare and Medicaid also provided some extended care help. In 1968, amendments to Social Security were added that required nursing homes that accepted Medicaid to meet certain standards (Bell, 2003).

The Omnibus Budget Reconciliation Act of 1987 added further standards, giving the federal government oversight of residents' quality of life (Zinn, 1999). The White House Conference on Aging in 2005 promoted residents' right to self-directed care and to the tools that enable residents to make informed decisions (Carpenter, Sheridan, Haenlein, & Dean, 2006). Today, there are several

consumer- and advocate-backed movements to enhance the quality of life of individuals in assisted living and long-term care settings.

Self-Determination

Self-determination has been operationalized in several different ways. For the purpose of this study self-determination is a characteristic of individuals that can be enhanced through training and life experiences. This self-determination characteristic that is “achieved through lifelong learning, opportunities, and experiences” (Wehmeyer, 1996, p.1). Lifelong learning can be maximized by reframing self-determination as a characteristic that is already present in the individual; furthermore, methods to teach skills or competencies can be found to improve their effectiveness in employing inherent self-determination tendencies. This characteristic is seen in their ability to achieve goals at their own individual level dictated by their capacity to achieve and environmental factors that either encourage or discourage goal attainment.

For Deci and Ryan (2008), a person’s degree of self-determination can be visualized on a continuum from other-oriented (external), where others heavily influence choices, to self-oriented (internal), where an individual’s personal values influence choices. Individuals can be taught to develop skills to enhance their performance along this continuum (Morgan, Bixler, & McNamara, 2002).

According to Wehmeyer, 2004, self-determined persons are ‘causal agents’ in their lives and have internal loci of control. The concept of locus of control comes out of Rotter's work in social learning theory (Bandura, 1998). Individuals with more internal locus of control are more likely to take

responsibility for their actions and to behave in ways that they believe will impact a desired result. For example, they tend to attribute success on an exam to studying harder rather than attributing the success to luck. They tend to achieve higher personal and educational goals. Individuals with an external locus of control tend to do worse on tests, have difficulty making appropriate decisions, and show maladaptive behavior (Wehmeyer, 2005). Wehmeyer and Schalock, 2005, state that a sense of control over one's life is imperative to establishing self-determination.

Self-determination and Quality of Life.

It is theorized that increased self-determination enhances quality of life. Ferrans and Powers define quality of life as “a person's sense of well-being that stems from satisfaction or dissatisfaction with areas of life that are important to him/her” (Hagell & Westergren, 2006, p. 686). Well-being can be measured with more than a thousand quality-of-life instruments (Australian Centre on Quality of Life, 2010). New quality-of-life studies and scales can be found regularly in several peer-reviewed journals (e.g., *Applied Research in Quality of Life Studies*, *Social Indicators Research*, and *Journal of Happiness Studies*). The reason for using the FPQOL was that we wanted to view the residents as ‘normal’ and felt that their quality of life would be representative of a general population rather than a population of persons with disabilities.

Rationale for Consumer-Directed Services

As of 2011, Wayne County Michigan is conducting a self-directed care pilot study designed to empower individuals receiving services through their

Behavioral Health Organization. The organization's administration notes that preliminary data indicates more than 90% of individuals have incurred lower costs for care under the self-directed program than they incurred before entering the program (Dehem, J., personal communication, August 12, 2008). According to DHHS programs, other localities have produced similar results (Department Health and Human Services, 2005). For example, the Robert Wood Johnson Foundation, who funded the Cash and Counseling self-directed care programs in Arkansas, Florida and New Jersey. These programs found that they did not increase costs. Furthermore, participants achieved better outcomes than the control group who did not use self-directed care (Department Health and Human Services, 2005).

When individuals with disabilities are involved in their personal health plans they tend show healthier outcomes (Cook, Terrill, & Jonikas, 2004; Cook, Russell, Grey, & Jonikas, 2004; Adams & Drake, 2006). Improved health outcomes are only one of the benefits of self-directed care; participants also enhance their sense of control over their lives, which enhances their quality of life. Indeed, Powers, Sowers, and Singer (2006) note a positive association between perceived sense of control and quality of life. When individuals control their health care, they also tend to have more trust in their medical provider (Adams & Drake, 2006). Moreover "clients are best suited to make the decisions because only they can place unique values on the outcomes and make value trade-offs according to their preferences and needs" (Adams & Drake, 2006, p. 95).

The most important benefit individuals receive from self-directed care may stem from the change in paradigm from provider-controlled health care to client-controlled health care. Often older adults "are viewed as incompetent, passive recipients of service and in need of protection" (Powers, Sowers, & Singer, 2006, p. 67). As directors of their own health care, they will be more likely to be viewed as competent and thus be more likely to develop a more positive self-image.

The DHHS lists three levels of "consumer involvement value": the individual level, the behavioral-health level, and the societal level. The individual level includes personal responsibility, freedom of choice, control over one's life, and access to services and support. In reframing health care from the patriarchal managed care model to the more empowering self-directed care model, the individual assumes personal responsibility (DHHS, 2005).

At the systems (behavioral health) level of consumer involvement, DHHS looks at issues including: service quality, consumer satisfaction, effectiveness, efficiency, and cost effectiveness. Individuals gain control of quality assurance functions of their health care by selecting only quality services. If they are not satisfied with a provider's service, they can change providers. Scala and Nerney (2006) speculate that these services will become more effective and cost-efficient as providers compete for business. Scala and Nerney also suggest that the individuals exercising choice will increase their sense of self-efficacy, which will enhance their quality of life (Scala & Nerney, 2006).

At the societal level, values include civil liberties, fairness, freedom from coercion, and use of the free market. Through the application of self-directed care, individuals in self-directed care programs gain increased freedom from coercion, enhanced civil liberties, and a more equitable position in society. These values help to justify the power shift from the managed care industry to the individuals. Such power comes from control over which services are used.

From a civil liberties perspective, DHHS (2005) states that “the rights and freedoms that citizens enjoy in a democratic society” (p. 5) include freedom from discrimination, the right to due process, and the right to personal autonomy. When individuals control the services they use, individuals not only make decisions that limit their exposure to discrimination but create a more empowered image. As the directors of their health care, individuals can insure due process. In turn, the empowering process of controlling their lives, at least in their health care, enhances their sense of autonomy and efficacy (Department Health and Human Services, 2005).

The American people have consistently valued equality, or a ‘level playing field.’ Individuals who practice self-directed care put themselves on an even par with other U.S. citizens in terms of controlling their health care. This leveling of the playing field reduces the possibility that medical professionals or anyone else will coerce these individuals. One of the paths to leveling the playing field is self-directed care.

Self-directed-care.

Powers, Sowers, and Singer (2006) trace self-directed care back more than forty years to the Veterans Administration's Housebound and Aid and Attendance Allowance programs. Self-directed care means more than just consumer-operated services or peer support. According to the DHHS, (2005), self-directed care is "a process to help you discover who you are, your needs, your dreams, [and] the future of your choosing" (p.3). Self-directed care is a system designed to allow consumers to monitor the services they receive and decide who will deliver those services and how they will be provided (Department Health and Human Services, 2005).

According to the DHHS, two elements contribute to the emergence and growth of self-directed care in America. One element is the increasing cost of health care and insurance; the other element is "the inconsistent quality of health care" (Department Health and Human Services, 2005, p. 1). Studies in the following states have addressed these issues: New Mexico, Michigan, Oregon, Florida, Washington, and Vermont (Kitchener, Willmott, & Harrington, 2004).

One of the goals of self-directed care is community involvement. As directors of their own health care, individuals interact in their communities, not just in their assigned programs and services, and they interact on a more empowered level. The most important benefit is that individuals have the freedom to be causal agents in their own lives; that is, they are free to make choices that impact their lives. Self-directed care is an example of decisions being made at the lowest possible level, which also reduces government

intervention in business (Department of Health and Human Services, 2005). The philosophy behind self-directed care is that citizens in assisted living have the same rights and responsibilities as other citizens. As equal participants in society, citizens in assisted living deserve the same opportunities as other citizens to exercise control over their own lives.

Some individuals may need assistance in accessing information needed to make informed decisions. In cases such as this, Saleebey (2006) says those individuals should receive help accessing such information. At times, individuals without disabilities also need help getting all the information they need before making informed health care decisions.

Self-directed care programs have several limitations and barriers. One of the most imposing barriers to self-directed care is the public image of individuals in assisted living settings; often the public believes these individuals incapable and incompetent. If it can be shown that these individuals can manage their own health care, it will go a long way toward correcting that image. So far, individuals and programs have demonstrated that individuals who require assistance with activities of daily living can be responsible (personal interview with Jim Dehem, 2008; Department Health and Human Services, 2005; Scala & Nerney, 2008).

Consumer-Directed Care Models

Consumer-directed interventions are designed to support individuals in exercising control over what services they receive, who provides those services, and how they are provided. Services should include options and information to help consumers make informed decisions (Powers, Sowers, & Singer, 2006). In

1999, there were 185 person-directed programs in the United States, according to the National Council on Disability. However, most self-directed care programs focus on younger people or individuals with developmental disabilities (National Council on Disability, 2008). Most person-directed models have few options available for consumers and limited funding (Powers, Sowers, & Singer, 2006). I will discuss the most prominent consumer-directed or empowerment models: Therapeutic Communities (TCs), Green House Programs (GH), Eden Alternative (EA), Residents' Councils (RC), and the Village.

Therapeutic Communities.

Primarily, therapeutic communities (TCs) are associated with substance abuse, although they serve other populations, such as criminal offenders, victims of abuse, people in long-term care, and the mentally ill. TCs assist tens of thousands of consumers annually (National Institute on Drug Abuse, 2002). TCs can be traced back to the Pardessia, founded in 1960. Pardessia was “an institution for the long-term rehabilitation of chronic patients” (Maller, 1971, p. 3). This approach uses residents, staff, and community members to assist consumers through levels of social and personal responsibility (National Council on Disability, 2008). Consumers learn (or relearn) social skills to help them through the TCs' hierarchical levels of responsibility. Additionally, the National Council on Disability (NCD) (2008) reports that the benefits of TCs include “lower levels of substance abuse, criminal behavior, unemployment, and indicators of depression” (p. 2).

TCs provide treatment in three stages: induction, primary treatment, and re-entry. In the induction stage, the first 30 days, the consumer in treatment learns to trust the staff and the other people in treatment as well as assimilate to the TC's structure. During the primary treatment stage, TCs have community meetings, including morning meetings, special seminars, daily house meetings, and general meetings to assist consumers in learning social skills. During this stage, TCs offer educational activities that focus on topics such as vocational training, interpersonal skills, and communication. The goal of this stage is to influence consumers' behaviors, attitudes, and perceptions through unstructured and structured interactions. The final stage, re-entry, consist of returning to life outside the program. Consumers are encouraged to join self-help groups, such as 12-step groups (e.g., Alcoholics Anonymous, Narcotics Anonymous.). Other services are offered in the re-entry stage, such as family therapy and vocational guidance.

Green House.

Green House (GH) assisted-living projects offer deinstitutionalizing assisted living. The house (rather than the facility) consists of approximately ten private rooms clustered around a common dining area where residents can share meals. Direct-care workers are certified nursing assistants who have taken approximately 120 hours of specialized training beyond their certified nursing assistant training. These direct-care workers also act as teachers and mentors. GHs also have a clinical staff that works with the residents, but in keeping with the home-like atmosphere, they do not have a nursing station (Lum, Kane, Cutler, & Yu, 2008).

Kane, Lum, Cutler, Degenholtz, and Yum's 2007 study compares GH residents to a similar sample of individuals in a more traditional LTC facility. The study indicates that the GH residents scored higher on their measures of privacy, dignity, autonomy, meaningful activities, individuality, relationships, and food enjoyment. In another study, GH residents' families reported higher satisfaction with the care residents received (Lum, Kane, Cutler, & Yu, 2008).

Eden Alternative.

The Eden Alternative (EA) was found in 1991 to combat hopelessness, boredom, and loneliness in ALFs. EA now has over 300 registered homes (Eden Alternative, 2010). The EA emphasizes displacing "the top-down bureaucratic approach to management and moving decision making closer to the Elders [residents]" (Eden Alternative, 2010 About us). Typically, an EA home will have plants and pets and, often, visiting children (Eden Alternative, 2010).

Bergman-Evans's 2004 quasi-experimental study indicated that the EA intervention group demonstrated less hopelessness and boredom than a control group in a traditional nursing home, while loneliness was about the same in both groups. The EA model decreased the residents' feelings of helplessness. According to Bergman-Evens, 2004, residents in the EA model require less help and show fewer behavior problems because the EA model encourages residents to become active in their facilities. William Thomas, the founder of the EA model, states that nursing homes should be more personalized and less regulated (i.e., have fewer house rules) to encourage residents' independence (Bergman-Evens, 2004).

The Village.

In 1990, California's Mental Health Department commissioned a pilot study through Mental Health America (MHA) to create a model for mental health services to address homelessness and incarceration of individuals with mental illness. The model was to integrate all necessary supports and services into one package. Ultimately, the Village pilot became permanent. The program (model) does not have prerequisites for services or a prescribed order of services; they offer a menu of services from which enrolled members choose (Mental Health America, 2010).

The mission of Village programs is to “assist people with mental illnesses, recognize their strengths and power to recover and achieve full participation in community life, and to encourage system-wide adoption of the practice and promotion of recovery and well-being” (Mental Health America, 2011, Mission). The Mental Health America Village's guiding principles include hope, acceptance, self-determination, opportunity, and responsibility.

Resident Councils.

LTC, as well as other human services, has moved from the paternalistic medical model to more empowering self-directed care models. Although traditional service providers are reluctant to embrace self-directed models, resident councils have been gaining acceptance (Hardiman, Theriot, & Hodges, 2005). The objective of the resident councils is to provide opportunities for residents to “execute meaningful decisions” (McIntyre, 2001, p.2), thus maximizing residents' control over their environments and their lives. Residents

should “define and control all aspects of a resident council” (p. 2). Advocates for residents’ councils state that it is both a legal and a moral obligation to empower these councils. The benefits of participation in a residents’ council include increased self-determination, self-esteem, locus of control, and enhanced quality of life (McIntyre, 2001).

Critique of Consumer-Directed Care.

Although consumer-directed care offers multiple benefits (e.g., consumers’ enhanced quality of life, enhanced health outcomes, and consumer empowerment), there are several limitations to these programs. The most damning of these are negative images or stereotypes held by the general public and the self-fulfilling prophecies associated with stereotypes. Consumers’ opportunities to gain self-control are limited by the perceptions of service vendors and the public’s lack of belief in consumers’ abilities. Even educators can lack faith in consumers’ ability to learn the necessary skills to control their lives (Wehmeyer 1998). These negative images can be internalized by consumers, leading them to believe they cannot take control of their own lives (Madon, Jussim, & Eccles, 1997). Another limitation of consumer-directed services is the restricted service options available to consumers (Kosciulek, 1999). The lack of empirical research establishing the efficacy and cost of consumer-directed services is another factor that limits their use (Kodner, 2003).

Culture Change.

One movement to promote consumer-directed care and individuals’ control over their own lives is the ‘Culture Change’ movement. Culture Change

creates “a setting that provides the resident with choices and supports the unique needs of all users – residents, staff, and visitors” (Doty, Koren, & Sturla, 2007). Culture Change is an attitude adjustment throughout the facility that empowers the residents to lead more self-determined lives. The Culture Change movement also includes altering the physical environment to make the institution look and feel more like a home, such as adding personal touches in rooms, halls, and dining rooms and limiting the use of visible nurses' station and medical treatment equipment.

Skills and Opportunity

“People with mental illnesses deserve the opportunity to take the same risks as we all take, and have access to the same rewards as we all have [in relationships]” (Salzer, 2006, p.1). Healthy relationships with close friends can enhance productivity and a sense of accomplishment (e.g., Nuland 2007; Rowe & Kahn 1998), improve anxiety and mood (Bertera, 2005), and result in fewer symptoms of depression (Krause, 2007). Current living situations for individuals with disabilities can include barriers to forming intimate and informal relationships, such as limited opportunities for social connections, side-effects of medication, and the perceptions of others.

Individuals with disabilities experience few opportunities to choose where they live, how they participate in the community, and what roles they play in their communities. This lack of opportunity to develop competencies (skills) that result from opportunities to exercise choice “limit[s] the roles individuals with disabilities play in their communities” (Wolfensberger, 1983, p. 3). Salzer and

Boren (2006) list client capacities and client knowledge levels as major barriers to community integration. One program, Problem-solving and Decision-making Process in the Transition to Independence, has shown promising results in improving the skills of young (aged 14 to 25) individuals with disabilities to make autonomous choices and improve educational, employment, and independence outcomes as they transition to adulthood (Haber, Karpur, Deschênes, & Clark, 2008). The success of programs that provide skills and opportunities to hone those skills to individuals with intellectual disabilities and youths transitioning to adulthood indicates that similar programs with individuals in ALFs could prove valuable.

Summary

There is solid evidence that choice-making opportunities and skill-building, regardless of outcome, are associated with increased quality of life and improved choice-making skills for individuals with disabilities (Deci & Ryan, 2008; Wehmeyer 2008; Ryan, Rigby, & King, 1993; Zuroff, Koestner, Moskowitz, McBride, Bagby, & Marshal, 2007). In spite of these advantages, however, choice-making opportunities for persons with disabilities are limited in practice by both self-imposed and societal barriers (Dybwad, 1948; Wehmeyer, & Bolding, 1999; Stancliffe, 2001; Petry, Maes, & Vlaskamp, 2007; Nerney, 2007; Deci & Ryan 2008). For example, the negative perceptions and expectations of family members, friends, and service providers can create a powerful restrictive force that generates self-doubt, which in turn reduces self-expectations and further decreases opportunities to gain or use new skills (Antaki, Finlay, Walton, & Pate,

2008). Individuals with little opportunity to choose do not learn the skills necessary to make choices.

Individuals with the right opportunities can be more successful even with other barriers in their way. For example, consistent with the strengths perspective (Werner & Smith, 1992), individuals with challenges can succeed and even exceed expectations with a little help from their environment. One example is Jack, an individual with an intellectual disability whose strengths include his charm and pleasant personality. He has built a business--Jack's Mail--using these strengths as a foundation. If someone wants to congratulate a colleague on her promotion, but wants to do more than send flowers or a card, they hire Jack. He personally delivers the message with a unique style of charm and enthusiasm that will not only brighten that person's day but give her or him a lasting memory.

Through a better understanding of the residents' quality of life, new interventions and services can be developed to match residents' wants and needs (Karr, 2009). To enhance the residents' quality of life, both services and resident outcomes in ALFs should be meaningful to residents (Park, 2009). By learning self-advocacy skills and practicing leadership skills, individuals can enhance their environment and improve mental health services (Hess, Clapper, Hoekstra, & Gibison, 2001).

Chapter 3

METHODS

This is a repeated measures design using a pre-test, post-test, and follow-up strategy. Changes across four constructs associated with self-determination were evaluated before and after facility residents' exposure to a culture change program: 1) quality of life, as measured by the Ferrans and Powers Generic Quality of Life Index; 2) locus of control, as measured by Rotter's Locus of Control Assessment, 3) self-esteem, as measured by Rosenberg's Self Esteem Scale, and 4) level of depression, as measured by Yesavage's Six-Item Geriatric Depression Scale. The study also included a quality of life questionnaire created by the residents of the two facilities. As the latter is a participatory action research instrument, results are determined by a negotiated conclusion.

Sample Description

Individuals in the study were residents of the facilities who volunteered to participate, who understood the purpose of the study, and who signed consent forms ($n = 64$) or 79% of the eligible residents. All participants spoke English as their first language. Sixty-five percent were male, and 61% were veterans. Some residents were excluded from the study due to guardianship determination by the Maricopa County Superior Court. Participants' ages ranged from 43 to 89 years. Although a large range in residents' ages may influence results, all participants shared the disempowering experience of having been placed in an ALF, and they all needed assistance in personal care.

At posttest 32 of the original 64 residents completed the questionnaire. Six individuals declined participation at posttest, eleven had insufficient information (missing data on two or more variables), and fifteen residents could not be reached for the posttest either due to death or moving from the facilities. The individuals who left the facilities could not be contacted because their records were confidential. The participants all needed some assistance in personal care. Their years of education ranged from 6 – 16 with a mean of 12.28 years ($SD = 2.94$). The sample was not ethnically diverse: only five residents identified their race as other than white, with three Hispanic and two African American residents participating in the study. The posttest sample included 20 participants from facility A (63%) and 12 from facility B. The posttest sample also included 15 (53%) resident council members.

Facility Profile

Facility A was in the center of a major southwestern city, two hundred yards from a large hospital and five minutes' drive from a veterans' medical center. There was a restaurant next door and a grocery store just over a mile away. Some of the residents walked to a city park 1/8th mile away. Facility A housed 45 residents and the rent ranged from \$1150 to \$1700 per month. Most of the residents had very limited incomes, and many residents shared a room because they could not afford a private room. A few of them worked for their rent by sweeping floors or cleaning the facility. The facility had two enclosed patios, one for smokers and another for nonsmokers. There was one large dining area with a television in one corner. Typically during the day and early evening there were

three or four residents around the television. Twenty residents from facility A had posttest data for the study.

Facility B was in the suburbs of the same city. There were a small restaurant, a tobacco store, and a hardware store within 1/4 mile. The facility housed 66 residents. The rent ranged from \$1150 to \$2000 per month. As with Facility A, most of the residents had very limited incomes, many of them shared a room because they could not afford a private room, and a few of the residents worked for their rent by sweeping floors and cleaning the facility. There was a park next door and a small lake within 1/4 mile. The large dining area was frequently used for social events. This facility had a recreation room and living room with couches and a television. There was patio out front where several residents gathered for conversation. At posttest, there were 12 study participants from facility B.

Due to mortality in this study, only 32 residents, facility A ($n = 20$) and B ($n = 12$), were left at posttest, resulting in a lack of statistical power to compare changes between the facilities. Using Jeremy Miles's (2011) *t*-test power chart, a sample size of 12 would be expected to have a power coefficient of .35.

Table 1 Demographics by facility

		Council member	Veteran	Education	Age
Facility B ^b	Mean	.67	.83	13.17	59.92
	Std. Error of Mean	.142	.112	.638	2.533
	Median	1.00	1.00	13.00	57.50
	Mode	1	1	12	53 ^a
	Std. Deviation	.492	.389	2.209	8.775
	Range	1	1	7	31

Facility A^c

Mean	.45	.65	11.75	65.40
Std. Error of Mean	.114	.109	.725	2.685
Median	.00	1.00	13.00	68.50
Mode	0	1	14	53 ^a
Std. Deviation	.510	.489	3.242	12.006
Range	1	1	10	46

a. Multiple modes exist. The smallest value is shown b. N = 20 c. N = 12

Council Member Verses Non-council Member

In Facility A, nine of the 20 participants were council members, and in facility B, eight of the 12 residents were council members. Although any resident could join the council, only 10% did. The average age of the council members was 62.29 years, compared to 64.53 years for non-council members. Council members had a slightly higher mean education level at 13.29 years, compared to 11.13 years for non-members. They were mostly male (75%) and were veterans (53%).

Table 2 Council / Non Council Member Demographics

Council member					
Non council		Male	Veteran	Education	Age
<hr/>					
Non					
Council Member	Mean	.87	.80	11.13	64.53
	Std. Error of Mean	.091	.107	.780	2.832
	Median	1.00	1.00	12.00	60.00
	Mode	-	-	8	53 ^a
	Std. Deviation	.352	.414	3.021	10.967
	Range	-	-	10	37
	Sum	13	12	167	968
<hr/>					
Council					
Member	Mean	.65	.65	13.29	62.29
	Std. Error of Mean	.119	.119	.617	2.770

Median	1.00	1.00	14.00	62.00
Mode	-	-	14	53
Std. Deviation	.493	.493	2.544	11.422
Range	-	-	10	39
Sum	11	11	226	1059

a. Multiple modes exist. The smallest value is shown

Culture Change Intervention

Culture change is primarily a change in attitude in facilities where residents assume more control. Culture change recognizes and enhances individuality not only of residents but of staff. The attitude change in culture change impacts staff members and needs management support. Owners of the two facilities bought into and supported the culture change. Training classes were developed to help staff members understand this new respect for individuals' self-determination and to help residents achieve greater personal freedom (Kane, 2003). The culture change program was supported by several one-hour classroom training sessions addressing problem solving, self-advocacy, peer support training, social relationships, nutrition, physical fitness, and weekly mentoring sessions to give the residents skills to become more empowered. The classes helped provide the skills the residents needed to take more control over their lives and their environments as well as set an expectation of independence and control. The other component program was a residents' council to provide opportunities for the residents to exercise those skills

Residents' Council.

The residents' council was open to all residents in the two facilities. They met once a week on Thursdays at 9:00A.M. in Facility A and at 11:30 P.M. in

Facility B. Typically anywhere between eight to twelve residents attended the weekly meetings. In the beginning, staff members were in charge of the meetings, but as the council grew in number and in authority, residents slowly assumed more control and participated more in facility operations. For instance, the council interviewed job applicants and recommended a new activities director for an open position, whom management hired. The council also dismissed a cook because he could not adjust to the change in residents' independence. New candidates for cook were interviewed, and the council recommended their selection to management. He was hired. The council also interviewed potential residents to determine if they fit into the facility community.

Study Design

The study used a pre-test post-test design with two cohorts, one each at Facility A and Facility B ALFs. Semi-structured interviews that incorporated the quality of life, self-esteem, locus of control, and depression instruments were conducted six months apart (April 2010-October 2010 in Facility A and May-November 2010 in Facility B) either in the residents' private rooms or other private rooms at the facilities. Depending on the resident's talkativeness, the interviews lasted from 45 to 75 minutes. A follow-up study was conducted in April 2011 at Facility A and in May 2011 at Facility B. This study uses data from the initial interviews (April 2010 and May 2010) and the follow-up data (April 2011 and May 2011).

Data Collection

Data was collected and stored to protect participant confidentiality using procedures approved by the university's Institutional Review Board. To limit recorder bias, one graduate student conducted the interviews. Research by De Brabander, Hellemans, and Boone, 1999, indicates that when interview subjects feel pressured, their responses produce a stronger internal locus of control that is not reflective of the true value. Data collection efforts minimized this effect by offering participants their choice of time and place for the interviews as well as allowing them to take as much time as they needed to respond.

Data Analysis

This study examines changes in residents' scores on quality of life, locus of control, self-esteem, and depression scales before and after exposure to the culture change. The hypothesis was that they would exhibit fewer depressive symptoms, increased self-esteem, increased locus of control, and would report an improved quality of life following exposure to the culture change interventions.

Measures

The measures used in this study included Ferrans & Powers Generic Quality of Life Index (FPQOL), Rosenberg's Self-esteem Scale, Yesavage's Geriatric Depression Screening Instrument, Rotter's Locus of Control Scale, the FPQOL activities subscale, the FPQOL relations subscale, and the Residents' Quality of Life Measure.

The study used Ferrans and Powers' Generic Quality of Life Index (Ferrans, & Powers, 1992), which distinguishes four separate domains of quality of life:

Health/Functioning, Socio/Economic, Psychological/Spiritual, and Family. This index measures quality of life with a self-report 33-question survey. Possible responses are recorded on a Likert scale ranging from 1 to 6: (1) very dissatisfied, (2) moderately dissatisfied, (3) slightly dissatisfied, (4) slightly satisfied, (5) moderately satisfied, and (6) very satisfied. The Ferrans and Powers Quality of Life Index has been in use for 25 years and has been translated into 16 languages (Ferrans & Powers, 2010; Kimura & Silva, 2009). The reliability and the validity of this index have been established by multiple studies with a wide variety of subjects, such as elderly individuals and individuals with cancer and Parkinson's disorder (Kane, 2003).

Residents' Quality of Life.

The residents' councils measure Residents Quality of Life (RQOL) is a participatory action research measure created by three residents in collaboration with the author. This measure consisted of five simple questions: Are your safety needs being met? Are your activity needs being met? Are your social needs being met? Are your food needs being met? Are your health needs being met? The residents' responses were combined, and the results were negotiated consensuses of the residents in the councils.

Activity and Relations.

The author created two subscales of Ferrans & Powers Quality of Life Index that represented activities and relationships. The Activities subscale related to satisfaction with activities not requiring interpersonal skills. Items included *taking care of yourself without help* and *my energy for everyday activities*. The

other subscale related to satisfaction with relationships that required interpersonal skills. Items on this subscale included *satisfaction with friends*, *emotional support from people other than family*, and *how useful I am to others*. Residents' possible responses were as mentioned above: a Likert scale ranging from 1 to 6: (1) very dissatisfied, (2) moderately dissatisfied, (3) slightly dissatisfied, (4) slightly satisfied, (5) moderately satisfied, and (6) very satisfied. Scores on the individual items were averaged to create a composite score. The SPSS reliability analysis indicated that the FPQOL Activities subscale indicated that there was a strong correlation between the items at pretest $r = .63$, $p < .000$. However at posttest the correlation fell to $r = .271$. This could be due to the lack of power with a larger sample or an increase intervention dosage.

Locus of control.

Locus of control is evaluated on a spectrum that pinpoints the degree of control one feels over significant life outcomes. The scale goes from internal (where the individual exercises influence based on self-determined values) to external (where other forces influence outcomes) (Kane, 2003). This study included the most commonly used measure of locus of control, Rotter's Locus of Control Assessment (Moshki, Ghofranipour, Hajizadeh & Parviz, 2007; Beretvas, Suizzo, & Durham, 2008; Domino & Domino, 2006).

Self-esteem.

Self-esteem, important for self-determination, consists of "affective judgments emerging from individuals' comparisons of what they are like to what they aspire to be" (George & Bearon, 1980, p. 30). Self-esteem is a factor in

developing the necessary skills for self-determination (Morgan, Bixler, & McNamara, 2002) and is associated with empowerment. Pranic (2009) asserts that self-esteem is an important part of measuring empowerment; Wojciszke and Struzynska-Kujalowicz (2007) contend that self-esteem increases with personal power. Maslow considered self-esteem to be a vital factor in personal development and personal growth (Cutler, 2006).

Self-esteem comes from environmental competence. Cutler (2006) states that being able to competently interact in your personal environment is key to being attached to your surroundings and to self-esteem. Self-esteem is not only tied to self-determination but is associated with quality of life. While self-esteem is a crucial component of quality of life (Ferrans & Powers, 1992; Yelsma, 1995), low self-esteem is associated with self-defeating behavior and alexithymia (Yelsma, 1995). A person with alexithymia has difficulty expressing and experiencing emotions.

Depression.

The Geriatric Depression Scale (GDS) is a screening tool to help identify individuals who should be assessed using more elaborate tools (Sheikh et al., 1991). The study used a shortened version of the GDS, the Yesavage Six-Item Geriatric Depression Scale (GDS-6), in which each item is scored 0-2 for frequency of occurrence over the last 30 days (never = 0, sometimes = 1, always = 2), with a higher score indicating more depressive symptoms (i.e. evident sadness, poor communication with the environment, poor initiative in physical performance, poor implication in routine activities, evident signs of sadness, and

alexithymia (Yesavage et al., 1983). The depression scores are reverse coded.

Higher scores indicate fewer depressive symptoms.

Chapter 4

DATA ANALYSIS AND RESULTS

Using the Statistical Package for the Social Sciences 19 (SPSS, 2011) Test, paired-samples *t*-tests, and independent *t*-tests, descriptive and bivariate correlation analyses were conducted to evaluate the change in the quality of life, self-esteem, locus of control, and depression measures for residents at two assisted living facilities in a major southwestern metropolitan center, who were interviewed prior to a culture change intervention, six months, and again one year later. This study evaluates the data from the first and third wave of interviews. The sample consists of residents of the two facilities who volunteered to participate, who understood the purpose of the study, and who signed consent forms ($n = 64$). Some residents were excluded from the study due to an incompetence determination by the County, and others chose not to participate.

Hypothesis 1: Depression

A paired samples *t*-test conducted to assess differences in depression scores from the pretest mean of 10.50 ($SD = 1.59$) to the posttest depression mean of 10.28 ($SD 1.30$) was not statistically significant: $t(31) = 1.65, p = .11$. The hypothesis that depression would decrease was not supported.

Hypothesis 2: Self-esteem

A paired samples *t*-test comparing the pretest self-esteem mean of 19.38 ($SD = .77$) to the posttest self-esteem 18.41 ($SD 4.73$) was not statistically significant: $t(28) = .98, p = .34$. The mean of the negative ranks (16) was 13.66, and the

mean of the positive ranks (10) was 13.66. The hypothesis that residents' self-esteem would increase at posttest was not supported.

Hypothesis 3: Locus of Control

A paired samples t-test comparing the mean pretest locus of control 6.75 ($SD = 1.90$) and the mean posttest locus of control 6.09 ($SD = 2.31$) was not statistically significant: $t(31) = .17, p = .11$. Hypothesis 3, that the residents would report greater locus of control at posttest, was not supported.

Hypothesis 4: Quality of Life

A paired samples t-test comparing the pretest mean on quality of life of 4.26 ($SD = 1.06$) and the posttest quality of life mean of 4.27 ($SD = .77$) was not statistically significant: $t(31) = -.08, p = .94$. Hypothesis 4, that residents would report a greater quality of life, was not supported by comparing Ferrans and Powers Quality of Life Index pretest and posttest reports. However, the residents' own quality of life measure did indicate a significant increase in several domains of quality of life (see table 3).

Table 3 Pretest Posttest t-test: t-value (SD)

	Posttest Quality of Life	Posttest Self-esteem	Posttest Locus of Control	Posttest Depression
Pretest ^a Depression	.099 (.589)	.330 (.065)	.013 (.943)	.883 ^{**} (.000)
Pretest ^a Quality of Life	.800 ^{**} (.000)	.379 [*] (.033)	.252 (.164)	.162 (.377)
Pretest ^b Self-esteem	.608 ^{**} (.000)	.495 ^{**} (.006)	.242 (.206)	.343 (.069)
Pretest ^a Locus of Control	.325 (.070)	.117 (.523)	.447 [*] (.010)	-.153 (.402)

^a. N = 32 ^b. N = 29 * p < .05 ** p < .01

Table 4 Pretest – Posttest Depression, Quality of Life, Self-esteem, and Locus of Control

Measure	Pretest Mean (SD)	Posttest Mean (SD)	t-value (df)	Sig. 2- tailed
Depression ^a	10.50 (1.586) ^a	10.28 (1.301) ^a	1.648 (31)	.109
Quality Of Life ^a	4.60 (1.057) ^a	4.269 (.774) ^a	-.078 (31)	.938
Self-esteem ^a	19.38 (5.722) ^a	18.41 (4.725) ^b	.977 (28)	.337
Locus of Control ^a	6.75 (1.901) ^a	6.09 (2.305) ^a	1.659 (31)	.107

Measures

As reported above, these results support both the mixed results of the Residents' Quality of Life measure and previous studies, which indicated that early results (less than 18 months) tend to show qualitative but not quantitative differences. The results indicate that domains that require more interpersonal skill were not sufficiently impacted by the culture change program and that they may require more intense treatment. This finding supports the assertion in chapter 2 that skills, choice, and opportunities are an important part of resilience, recovery, and enhanced quality of life. The residents' councils measure, Residents Quality of Life (RQOL), was a participatory action research measure that indicated an increase in the residents' quality of life in several domains. The RQOL reported increased satisfaction in the domains of Food, Activities [facilitated by staff], and Safety. The residents' responses in the other domains, Health and Relationships, were inconclusive. The participant researchers determined that the level of health was too variable to produce a reliable response "level of health can change from

hour to hour; we cannot say with any certainty that there was change from pretest to posttest (resident council, 2011)". More than half (90 of 175) of the residents responses were neutral (i.e. so-so, not applicable, or not much).

The results for these subscales reaffirmed the results from the RQOL that activities that did not require interpersonal skills were enhanced comparing pretest scores to posttest scores. This result also supports the assertion in Chapter 2 that skill, choice, and opportunities are important parts of successful recovery or enhanced quality of life. The culture change program overall did not appear to impact much more than the residents' safety, personal activities, and satisfaction with food.

Limitations

A major limitation of this exploratory study was that we could only evaluate a voluntary and accessible population, and the sampling frame was limited even more by the exclusion of individuals who had been determined by the Superior Court of Maricopa County to require a guardian. Another major limitation of the study related to the sample was the limited small n methodologies. Another weakness in the sample is the mortality between wave 1 ($n = 68$) and wave three ($n = 34$). Only the residents at the two facilities were available for this research resulting in a control or a comparison group.

Chapter 5

DISCUSSION

As America's baby boomers age, current service systems and the assisted living industry may not be able to meet the demand for services and supports (St. Luke's Health Initiative, 2001). Providing skills and opportunities for individuals of any age in assisted living settings to become more independent will not only reduce the load on these systems but can enhance the residents' quality of life, self-esteem, and locus of control while reducing symptoms of depression.

Stigma

Given negative perceptions regarding the capacity of individuals in assisted living to participate in choice-making activities, scholars in the disability field need to use care in terms of how research findings are translated in the field. Indeed, work that is intended to promote individuals' growth can actually become a limiting factor. If we do not think that an individual is capable of making what we consider the best choice, is that individual "allowed" to then make a seemingly poor choice? The answer needs to be *yes*. Individuals' rights to self-determination are limited when others protect them unnecessarily, limit their choice opportunities, disseminate and accept disempowering images of them, and assert undue influence on them. Kerr and Shakespeare (2002) question the validity of shared control as purported by federal legislation's vision of the individual and his or her family as primary decision makers: "The notion of 'informed choice' raises questions about information as well as choice" (p.121). Knowledge held by persons with disabilities needs to be respected. "People are

experts in their own lives, and their knowledge has to be valued alongside the evidence of genetics and the clinical opinion of doctors” (Kerr & Shakespeare, p.121).

Individuals in assisted living settings can have public image issues that play a role in limiting their opportunity for autonomous choice. As noted above, a common stereotype of individuals in assisted living settings is that they cannot make choices for themselves. This negative perception creates a spiraling decline in decision-making capacity: if one is not expected to make decisions, he or she no longer tries to do so; if he or she does not try to make decisions, he or she does not gain experience in making choices. This scenario leads to poorer choices, which in turn lead to lower self-expectations.

Individuals in assisted living settings in particular have to overcome many obstacles, including stigma, but state and federal policies should not be among the impediments. “One way to increase the chance that members of stigmatized groups will benefit from positive self-fulfilling prophecies is by instituting policy changes that encourage perceivers (e.g., employers, teachers) to hold realistic, but high, expectations for targets” (Madon et al., 1997, p.807). Although we may not have much of an impact on changing these stereotypes in the larger community, we can limit the impact of these stereotypes in ALFs through culture change. In the broader forum, Karr, 2009, identifies stereotypes as a barrier to acceptance by the community. A more empowered long-term care resident can positively impact negative stereotypes of older individuals in adjacent communities (i.e. staff, shop keepers, and neighbors) by demonstrating efficient self-advocacy

skills. For example, the self-advocacy training provides a role-play scenario where the resident speaks to a case worker or doctor. Such an exercise should help the resident learn to self-advocate more effectively. In addition, as case workers and doctors experience more appropriate/effective interactions with residents, these professionals may see the residents in a more empowered role.

Residents' Rights

Residents, as citizens, have the same rights and responsibilities and deserve the same opportunities as other citizens to exercise control over their lives. Indeed, some residents may require help to access the information necessary for making intelligent, informed decisions. In such cases, family members, friends, and advocates can play a role in helping them obtain that information. However, it is important to remember that many of us living independently may also need help getting all the information we need before making intelligent, informed decisions and that needing such help is not an indicator of incapacity.

Choice and the broader concept of self-determination are keys to freedom for thousands, but there are many barriers to individuals in assisted living settings claiming the freedom that others accept as a basic human right. These major barriers include a lack of opportunity for choices, insufficient skills to make those choices meaningful, and the negative images or stigma associated with people in assisted living settings. Wehmeyer and Bolding (1999) assert:

If individuals are supported to make choices, participate in decisions, set goals, experience control in their lives and so forth, they will become more self-determined. As they become more self-determined, they become

more likely to assume greater control; making more choices, hone their skills in goal setting, decision making and problem solving, and greater belief in their capacity to influence their lives. (pp. 360-361)

The way choice and autonomy are framed will determine what opportunities are available to individuals in assisted living settings. This framing can also affect other factors that limit these individuals, such as stigma, undue influence, and self-image.

Dosage-Intensity

Few studies examining change in quality of life associated with cultural change interventions had been conducted before this research. Earlier studies found mixed results, with positive results being revealed by qualitative measures more so than quantitative measures (Bishop, 2005). For example, following a cultural change effort, a study of 132 clients with diagnoses of severe mental illness and co-occurring substance disorder indicated improved quality of life among individuals with dual diagnoses in intensive treatment settings. Quality of life was represented by using a revised version of the Social Adjustment Scale DII, Wieduwilt and Jerrell's self-report structured interview, and Schooler, Weissman, and Hogarty's Role Functioning Scale. The amount of variance accounted for in the qualitative measure and quantitative measure were "almost identical (p. 329)" (Jerrell & Ridgely, 1999). Rahman and Schnelle, 2008, report that there has been little quantitative support for the impact of culture change efforts, and only anecdotal evidence was available to attest to the influence of such interventions on quality of life prior to 2005. However, they state that the

culture change movement is ready for quantitative analysis. In 2010, the Center for Excellence in Assisted Living reported that "to date, there has been no comprehensive research examining what specific elements are needed to support PCC outcomes in any of the aging service sectors" (p.6).

In this study, residents' responses to cultural change were tracked over 12 months. Meta-analysis research by Drake, Mercer-McFadden, Mueser, Hugo, and Bond (1998) indicates that such interventions require a longer duration for results to be evident, specifically more than 18 months. The ten most promising studies "differed from most earlier studies by following patients for longer than 1 year" (Drake et al., 1998, p. 596). These authors found that individuals with co-occurring disorders drop out of programs when "the program does not provide extensive efforts at engagement and motivation" (p. 593). The culture change project described in the current study used the residents' council as a tool to engage the residents in their self-determined goals and objectives, which may have contributed to increased motivation to participate, as suggested by Drake et al. (1998). Drake et al. evaluated 36 studies that compared the effectiveness of integrative treatment (integrated treatment models) with dual-diagnosed "patients."

Integrative therapies are used in the Therapeutic Community model for individuals with substance abuse issues and those with mental illness (NIDA, 2002). A Therapeutic Community "is a self-help program whose primary goals are the cessation of substance abuse behaviors and fostering personal growth" (Day top, 2011, What Is a Therapeutic Community?). Over the last 50 years,

these programs have reported several positive outcomes, e.g., reduced substance use and decreased depression (NIDA, 2002). As described previously therapeutic communities typically involve daily therapeutic interaction on a daily basis (O'Maller, 1971). Individuals' outcomes are measured more than a year after they begin treatment. This study's culture change program was less intense.

Resident councils met once a week for forty minutes, and training classes were less than once a month for forty minutes which may explain why this study failed to statistical significance in some areas. Residents comments that the such as council meetings are just complaint sessions and that the there is no follow through on council actions point the need for more help removing barriers to their self-determined goals.

Compared to successful treatments like the Therapeutic Community programs, the length of this culture change experiment was relatively short. While the research by Drake, et al, 1998, indicates that intensive treatment enhances participant retention and that studies using intensive treatment had superior outcomes, the residents in this experiment met for residents' council meetings only once a week and training classes were held less often than once a month. In addition, the culture change experiment had only been in place for one year. It is possible that with continued treatment a significant change may become apparent.

Residents' Quality of Life

This research indicates that it is not just self-determination and choice that enhance quality of life. Choices and opportunities in the areas of Activities,

Safety, and so on should be achievable, but residents also need other skills, such as interpersonal skills, to make meaningful changes in their quality of life. For example, in the residents' domain Food, their life quality improved in part due to their advocacy skills and knowledge of nutrition. They had the opportunity to impact their Food domain by the residents' council's input into the hiring and firing of kitchen staff. However, in the Satisfaction with Neighborhood domain, there was not a significant change, as residents did not have the ability to change their neighborhoods.

Study Instruments.

Although depression can be associated with efficacy of treatment (Zadeik et al., 1991), the impact of depression in this study was mediated by residents' ongoing treatment for depression. Another factor affecting the failure to achieve statistical significance could be the self-selection process, limiting participation in the survey because of residents' loss of interest and energy associated with depression (Kosciulek & Merz, 2001). There was little to no variance in the depression measure across waves.

Locus of control was not significantly related statistically to quality of life and did not show statistical significance between waves. One factor influencing this lack of statistical significance is that significant life outcomes were not impacted during this study. According to Kane (2003) locus of control is the degree of control one has over significant life events. In this study we looked at some control over diet and activities, but not residential status (residents living in their own home or in the facility), increases in income, or educational goals.

During the study, the residents did not establish much control over what they did on a daily basis or their activities. For example, when the councils were given control over their activities budget, an administrator insisted on taking the money to bring an entertainer into the facility without consulting with them. After some negotiations, the money was returned to the residents. This example illustrates that the administration was not ready to empower the council to self-govern, thus undermining their locus of control.

The residents did not have the responsibility and causality that Wehmeyer (2005) states is necessary for the development of self-determination. This lack of self-determination may help to explain the failure to find increased quality of life in the FPQOL. For example, after several residents went to a night club to listen to a jazz singer, some guardians threatened to remove their wards from the facilities, believing that providing such entertainment was an inappropriate practice. Legally, unless the activity created a 'threat to self or others,' the guardians should not have intervened. The facility nevertheless stopped the night club outings, creating a serious blow to the residents' ability to claim another piece of control over their lives. As a result of these outings, several guardians put pressure on the facility, forcing management to fire the activities director.

According to Morgan, Bixlers, and McNamara (2002), self-esteem is a factor in developing skills for self-determination. Self-esteem is therefore a crucial component of quality of life (Yelsma, 1995) and an important element in measuring empowerment (Pranic 2009; Wojciszke & Struzynska- Kujalowicz, 2007). In this study, quality of life across waves remained fairly consistent, with

a slight but statistically insignificant decrease. It is not surprising that FPQOL was not associated with depression in this study. Individuals in the facilities with extreme levels of depression were already receiving treatment for their depression, eliminating those cases. Residents in this study were volunteers, and individuals with depressive symptoms could self-select out of the study.

Conceptually, locus of control should have been impacted by the culture change program, but this was not the case. It was hypothesized that residents would demonstrate an increase in locus of control. As mentioned above, the dosage (intensity and length of exposure) was considerably less than that in more successful models. Another factor may be a lack of follow-up on council actions. For example, the residents planned trips to the bowling alley, and for two weeks in a row, suddenly the facility van was not available. In the first week, fourteen residents had gathered and were waiting to go to the bowling alley, and in the second week, only eight residents showed up.

It is not clear if the residents were able to address goals that were important to them, a key quality of life stressed by Hagel and Westergren (2006), due to insufficient duration and dosage (i.e. one year between pretest and posttest, only monthly training and weekly meetings). The FPQOL domains (Health/Functioning, Socio/Economic, Psychological/Spiritual, and Family) may not have been germane to the residents. Many disciplines have a unique perspective on quality of life: disability studies, economics, education, law, medicine, sociology, philosophy, psychology, and public health. Each discipline has several quality of life instruments, and most of the instruments have several

versions, e.g., versions for adults, children, and persons with disabilities. New quality of life studies and scales can be found on a regular basis in several peer reviewed journals, such as *Applied Research in Quality of Life Studies*, *Social Indicators Research*, and *Journal of Happiness Studies*. Quality of life instruments use many diverse domains such as Being, Becoming, and Belonging (Quality of Life Research Unit) or Physical Health, Psychological State, Personal Beliefs, Social Relationships and their Relationship to their Environment (WHOQOL). The large number of diverse quality of life instruments for specific populations would support developing a quality of life tool specific to the residents in assisted living.

The International Wellbeing Index, a 10-year national survey in Australia (n =2000) that uses a random sample of the country's general population, also supports the results of this study. The International Wellbeing Index found that for individuals living with unrelated adults generally scores low on most domains with the exception of Health, Safety and Future Security (Australian Unity Wellbeing Index Report 12.0, 2005).

The Ferrans & Powers Quality of Life Index's domains may not be germane to residents in our facilities, but the quality of life measure they created for themselves should be relevant. For example the domains Families and Economic Situation were not part of the residents' own measure; in fact, families in most residents' lives were nonexistent, and residents' economic situations were not likely to be impacted by this study. The fact that there are so many quality of life instruments would support the use of the residents' own tool.

Future Directions

Future studies should include larger samples in multiple sites, enabling control and contrast groups. Larger samples will allow for more elaborate data analysis as well as enhance generalizability of the results. Approval of the appointed guardians of the vulnerable individuals in ALFs should be sought. Future studies should seek larger samples as well as contrast and control groups. The best methods of providing effective and empowering intervention need to be examined (Powers, Sowers, & Singer, 2006). Other studies that examine diverse symptomologies (i.e. dementias, Parkinson's disease, and depression) and psychopharmacological treatments associated with quality of life and self-determination of individuals in ALFs would be valuable (Rapaport, Clary, Fayyad, & Endicott, 2005; Schrag, Jahanshahi, & Quinn, 2000). Future research into self-determination and quality of life should include ethnographic and single-case studies (Karr, 2009). Other research methodologies and analysis systems should be evaluated for use with this population, including small n studies.

Future programs should include a resilience coach and more intensive interactions between training staff and residents. A resilience coach "provides insight, resources, and experience that helps you remove obstacles, clear barriers, and experience higher levels of personal success" (Resiliencecoach, 2011, p.1)

The purpose of this study was to examine whether a culture change intervention would impact residents' self-determination and quality of life by evaluating level of depression, self-esteem, locus of control, and quality of life. It is hypothesized that after the intervention residents would display fewer

depressive symptoms, increased self-esteem, increased locus of control and would report an improved quality of life. The data did not demonstrate a statistically significant change in any of these quantitative measures, however, the residents in their council meetings reported increased satisfaction in several domains on the participatory action research questionnaire, including *food, staff-facilitated activities, physical activities, and safety*.

Implications

Some of the residents explained that a lack of follow-up was why their lives did not improve. Other residents explained that the residents' council meetings became complaint sessions because there was little or no follow-through on their actions. This result would indicate that not only do the choices/options need to be meaningful, respected by others in their lives, and acted upon but that residents need to have self-advocacy skills to help make meaningful opportunities real possibilities.

Residents and residents' councils need to have meaningful achievable choices as well as support from significant individuals and groups to make those choices respected. Staff, management, families, and case managers need buy into the concept of culture change. Most importantly, residents need to buy into culture change. The culture change should start with increasing "resident choice over daily activities" (Rahman & Schnelle, 2008, pp. 145). Residents need a structure that works for them and goals that are meaningful to them (Nota, Ferrari, Soresi, & Wehmeyer, 2007). There is a real danger that staff members can

control residents' councils (McIntyre, 2001), so the organization needs to take steps to empower the residents.

Implications for Social Work

This study would support social workers starting with service plans focusing on daily activities that can be achieved more readily than social interaction goals. The goals still must be meaningful to avoid residents feeling that their goals are just given lip-service and not supported to completion. When social worker consider an individuals' competency level the should careful not limit that individuals opportunities for growth or expose the individual to unsafe circumstances. Residents are capable different levels of recovery/ resilience take care not to limit that individual's growth. It maybe that they need a different structure in their environment to help them succeed.

Literature from other culture change models point out that it often takes more 12 months to see impact from treatments. The change in quality of life associated with the Activities subscale would indicate that actives (i.e. residents having energy for everyday activities and the ability to take care of themselves) could have an impact on the residents in a shorter term social- or relationship-oriented activities. This research would support the social worker including physical activities with the residents as well as traditional social work interventions. Social workers need to be a aware that culture change or any other intervention need be delivered at an appropriate dosage and frequency.

Conclusion

In today's economic climate, given cuts in medical and therapy services, it is more important than ever that residents learn self-advocacy and other self-help skills. Programs and services that enable residents to take more control and responsibility for their lives and living situations can reduce the burden on professionals and agencies that lack resources and that often rely on outdated service models and can create more desirable outcomes. These empowerment programs can assist residents in expressing self-determination and can enhance their self-esteem. Future studies will help social workers in the field uncover and develop the strengths and skills of their clients. As these clients are empowered to pursue self-directed objectives and goals, they should demonstrate increased retention toward goals and improved outcomes.

Empowering programs that create choice-making skills and opportunities can be created to provide empowering experiences. Through a better understanding of the residents' quality of life, new interventions and services can be developed to match residents' wants and needs, reducing the work load of staff, reducing staff turnover, and increasing staff and resident satisfaction (Moos & Lemke, 1996).

This research reaffirms previous research that indicates that intervention programs need to be of a significant dosage (frequency, strength, and duration). Future studies should provide 18 months or more between pretest and posttest and should incorporate intense training for residents and staff, more representative sampling plans, and control groups. Future studies should use measures that are

not only sensitive enough to detect changes in quality of life but that are relevant to the residents. Progress in programs such as this culture change study and therapeutic communities are not linear.

The study found that the domains that were germane to the RQOL and were significant were Physical Activity, Food, Social Activities [facilitated by staff], and Safety). Domains of Personal Relationships, Interpersonal Relationships, and Community Connectedness were not impacted by the culture change program in either FPQOL or the RQOL.

Of the quantitative variables related to self-determination in the literature, only self-esteem and FPQOL were associated. Locus of control and depression did not predict FPQOL; however, the subscale Activity (*things I do for fun and my energy for everyday activities*) was significantly increased. Just as importantly, interpersonal relationships (*satisfaction with friends, emotional support from people other than family, and how useful I am to others*) did not improve.

REFERENCES

- Adams, J. & Drake, R. (2006). Shared decision-making and evidence-based practice. *Community Mental Health Journal*. 42(1), 87-104.
- Aging Services of California (2011). *Assisted living and continuing career retirement communities*. Retrieved from: <http://www.aging.org/i4a/pages/index.cfm?pageid=631>.
- Alabama State Department of Public Health, (2002). In Park, N. (2009). The relationship of social engagement to psychological well-being of older adults in assisted living facilities. *Journal of Applied Gerontology* 28(4): 461-480. doi: 10.1177/0733464808328606.d
- Anderson-Hanley, C., Meshberg, S., & Marsh, M. (2003). The effects of a control-enhancing intervention for nursing home residents: Cognition and locus of control as moderators. *Palliative and Supportive Care*, 1, 111-120.
- Antaki, C., Finlay, W., Walton, C., & Pate, L. (2008). Offering choices to people with intellectual disabilities: An interactional study. *Journal of Intellectual Disability Research*, 52(12), 1165-1175.
- Arizona Department of Health Services (2008). *Five principles of person centered planning* Retrieved from: [http://www.azdhs.gov/bhs/pdf/Five%20Principles%20for%20Person %20Centered%20Planning.pdf](http://www.azdhs.gov/bhs/pdf/Five%20Principles%20for%20Person%20Centered%20Planning.pdf).
- Arizona Department of Health Services (2008). Arizona Administrative Code Title 9, Ch. 21, A 21. Retrieved from <http://azdhs.gov/bhs/ppsmi.pdf>.
- Assisted Living Federation of America (2010). About. Retrieved from http://www.alfa.org/alfa/Assisted_Living_Information.asp?SnID=349974359.
- Assisted Living Federation of America (2010). Information. Retrieved from http://www.alfa.org/alfa/Assisted_Living_Information.asp?SnID=596749702.
- Australian Centre on Quality of Life (2010). *Instruments*. Retrieved [http://www.isqols.org /Australian_Centre/ instruments](http://www.isqols.org/Australian_Centre/instruments) from May 1, 2010.
- Australian Unity Wellbeing Index Report 12.0 (2005). Normative data for the personal wellbeing index: Australia. Retrieved from [ttp://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/](http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/).
- Ball, M., Whittington, F., Perkins, M., Patterson, V., Hollingsworth, C., King, S., & Combs, B. (2000). Quality of life in assisted living facilities:

- Viewpoints of residents. *Journal of Applied Gerontology*, 19(3): 304-325. doi: 10.1177/073346480001900304.
- Bambara, L. & Kroger, F. (2005). Opportunities for daily choice-making. *Mental Retardation and Intellectual Disabilities*, M.L. Wehmeyer (Ed.). Boston: Merrill Prentice Hall.
- Bandura, A. (1998). Social learning theory. Retrieved from <http://tip.psychology.org/bandura.html>.
- Barker, R., (2003). *The Social Work Dictionary (5th Ed.)*. Washington, DC: National Association of Social Workers.
- Bergman-Evans, B. (2004). Beyond the basics: Effects of the Eden Alternative model on quality of life Issues. *Journal of Gerontological Nursing*, 30(6), 27-34.
- Bekemeier, K. (2009). The relationship between self-determination and quality of life among individuals with disabilities involved with a center for independent living. Doctoral dissertation. Retrieved from Michigan State University. (AAT 3381090).
- Bell, P. (2003). *The history of Medicare and Medicaid*. Retrieved from: www.oucom.ohiou.edu/currents/archives/2003.
- Beretvas, S. N., Suizzo, M. & Durham, J. A. (2008). A reliability generalization study of scores on Rotter's and Nowicki-Strickland's locus of control scales. *Educational and Psychological Measurement*. 68(1), 97-119.
- Bertera, E. M. (2005). Mental health in U.S. adults: The role of positive social supports and social negativity in personal relationships. *Journal of Social and Personal Relationships* 22(1), 33-48.
- Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and Acquired Disability: A Conceptual and Theoretical Synthesis. *Journal Of Rehabilitation*, 71(2), 5-13.
- Black, A. & Deci, E. (2000). The effects of student self-regulation and instructor autonomy support on learning in a college-level natural science course: A self-determination theory perspective. *Science Education*, 84, 740-756.
- Blair, T. & Minkler, M. (2009). Participatory action research with older adults: Key principles in practice. *The Gerontologist*, 49 (5); 651-662.
- Carpenter, D., Sheridan, S., Haenlein, K. & Dean, D. (2006). *Environmental scan*

of instruments to inform consumer choice in assisted living facilities.
Prepared for: Agency for Healthcare Research and Quality U.S.
Department of Health and Human Services. Retrieved from: <http://www.ahrq.gov/> Contract No. 290-01-0003.

Center for Excellence in Assisted Living (2010). Person centered care in assisted living: An information guild. Retrieved from [ttp://www.theceal.org/assets/PDF/Person-Centered%20Care%20in%20Assisted%20Living.pdf](http://www.theceal.org/assets/PDF/Person-Centered%20Care%20in%20Assisted%20Living.pdf).

Chen, C., Zimmerman, S., Sloane, P. & Barrick, A. (2007). Assisted living policies promoting autonomy and their relationship to resident depressive symptoms. *American Journal of Gerontological Psychology*, 15, 122-129.

Cialdini, R. (2005). Basic social influence is underestimated. *Psychological Inquiry*, 16(4), 158. doi: 10.1207/s15327965pli1604_03.

CMS (2001). Center for Medicare and Medicaid services: Presentation for the inpatient rehabilitation facility patient assessment instrument. Retrieved from http://www.cms.gov/InpatientRehabFacPPS/downloads/day1_IRFPAI.pdf.

Cook J., Russell, C., Grey, D., & Jonikas, A. (2008). Economic grand rounds: A self-directed care model for mental health recovery. *Psychiatric Services*, 59(6), 600-602.

Cook J., Terrell, S. & Jonikas, J. (2004). *Promoting self-determination for individuals with psychiatric disabilities through self-directed services: A look at federal, state and public systems as sources of cash-out and other fiscal expansion opportunities*. Chicago, IL: National Research and Training Center.

Cutler, J. (1922). Studies of training for social work: The point of view of the training schools. *Journal of Social Forces*, 1(1), 44-47.

Cutler, L. (2006). Physical environments of assisted living: Research needs and challenges. *The Gerontologist*, 47(1), 68-82.

Day Top (2011). About us. Retrieved from: <http://www.daytop.org/about.html>

Department of Health and Human Services (DHHS) (2005). *Transforming behavioral health care to self-direction*. DHHS Publication No. SMA-05-3982. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

De Brabander, B., Hellemans, J., & Boone, C. (1999). Selection-pressure induces a shift towards more internal scores on Rotter's 1-E locus of control scale.

Current Research in Social Psychology. 4(1), 15-22.

- Deci, E. & Ryan, R. (2008). Facilitating optimal motivation and psychological well-being across life's domains. *Canadian Psychology*, 49(1), 14-23.
- Dobbs, D., Eckert, J., Rubinstein, B., Keimig, L., Clark, L., Frankowski, A., & Zimmerman, S. (2007). An Ethnographic Study of Stigma and Ageism in Residential Care or Assisted Living. *The Gerontologist* (2008) 48 (4): 517-526. doi: 10.1093/geront/48.4.517
- Domino, G. & Domino, M. (2006). *Psychological testing: An introduction* (2nd ed.). Cambridge, MA: Cambridge UP.
- Doty, M., Koren, M., & Sturla, L. (2007). Culture change in nursing homes: How far have we come? Findings From The Commonwealth Fund 2007 National Survey of Nursing Homes.
- Drake, Mercer-McFadden, Mueser, Hugo, & Bond, (1998). Review of integrated mental health and substance abuse treatment for patients with dual disorders. *Schizophrenia Bull* (1998) 24 (4): 589-608.
- Duncan, B. & Miller, S. (2000). *The heroic client: Doing client-directed, outcome informed therapy*. San Francisco: Josse-Bass.
- Dybwad, G. in Jenkins R., 1999, *Question of competence: Culture classification and intellectual disability* (1st ed.). Cambridge, MA: Cambridge UP.
- Eden Alternative (2010). *About us*. Retrieved from: <http://www.edenalt.org/about-the-eden-alternative>.
- Egley, L. (1994). *New federal PC Option PAS funding rules: Summary*. Berkeley, CA: World Institute on Disability.
- Elderweb (n.d.). *Long-term care timeline*. Retrieved from: <http://elderweb.com/book/export/html/2807>.
- Empire State Association of Assisted Living (2011). *About*. Retrieved from: <http://www.ny-assisted-living.org/>
- Fernet, C., Guay, F. & Senécal, C. (2004). Adjusting to job demands: The role of work self-determination and job control in predicting burnout. *Journal of Vocational Behavior*. 65(1), 39-56.
- Feinberg, L., & Whitlatch, C. (1997). Family caregiver and consumer choice: Options for in-home respite care. In L.F. Feinberg, *State of the art:*

Research on consumer directed care. Annual meeting of the American Society on Aging, Nashville, TN.

Franken-Spaar, C. (2010). *Knowledge, perceptions, and experiences of students, parents, and educational staff of self-determination skills.* ProQuest, UMI Dissertations Publishing. ProQuest Dissertations and Theses, n/d. Retrieved from <http://login.ezproxy1.lib.asu.edu/login?url=http://search.proquest.com/docview/733921198?accountid=4485>.

Freire, P. *Education for Critical Consciousness*, London: Sheed and Ward Ltd, 1974.

Freire, P. (2006). *Pedagogy of the oppressed*. Translated by Myra Bergman Ramos. Anniversary Edition, New York: Continuum.

Ferrans, C. & Powers, M. (1992). Psychometric assessment of the Quality of Life Index. *Research in Nursing and Health*, 15, 29-38.

Ferrans, C. E. & Powers, M. (2010). *Quality of Life Index*. Retrieved from: <http://www.uic.edu/orgs/qli/>.

Geiser, R. (1973). *The illusion of caring*. New York: Beacon Press.

George, L. & Bearon, L. (1980). *Quality of life in older persons: Meaning and measurement*. New York: Human Sciences Press.

Grolnick, W. S. & Ryan, R. M. (1987). Autonomy in children's learning: An experimental and individual difference investigation. *Journal of Personality and Social Psychology*. 52(5), 890-898.

Haber, M. G., Karpur, A., Deschênes, N., & Clark, H.B. (2008). Predicting improvement of transitioning young people in the partnerships for youth transition initiative: Findings from a multisite demonstration. *Journal of Behavioral Health Services and Research*. 35(4), 488-510.

Hagell, P. & Westergren A. (2006). Quality of life if individuals with chronic venous ulcers. *Quality of Life Research*, 15(5), 867-876.

Hardiman, E., Theriot, M., & Hodges, J. (2005). Implications and challenges for consumer-run programs. *Evidence-Based Practice in Mental Health*, 1(1), 105-122.

Hawes, C., Phillips, C., Rose, M., Holan, S., & Sherman, M. (2003). A national sample of assisted living facilities. *The Gerontologist*, 43(6): 875-882.

Hawes, C. & Phillips, C., (2007). Defining quality in assisted living: Comparing

- apples, oranges, and broccoli. *The Gerontologist*, 47(3), 40-50.
- Hedgpeth, J., Nagoshi, C., & Nagoshi, J. (2011). Choices and skills leading to success. (Unpublished paper.) Arizona State University, Tempe, Arizona.
- Hess, J., Clapper, C. R., Hoekstra, K. & Gibison, F. (2001). Empowerment effects of teaching leadership skills to adults with a severe mental illness and their families. *Psychiatric Rehabilitation Journal*, 24(3), 257-265.
- Jerrell, J. & Ridgely, S. (1999). The relative impact of treatment program 'robustness' and 'dosage' on client outcomes. *Evaluation and Program Planning*. 22 (3); pp. 323-330. doi: 10.1016/S0149-7189(99)00023-3.
- Kemper, P., Heier, B., Teta, B., Brannon, D., Angelli, J., Vasey, J. & Anderson-Knott, M. (2008). What do direct care workers say would improve their jobs? Differences across settings. *The Gerontologist*, 48(1), 17-25.
- Kaiser Commission on Medicaid Facts, October 2010. Medicaid and the uninsured. Retrieved from <http://www.kff.org/medicaid/upload/2186-07.pdf>
- Kane, R. (2003). Definition, measurement and correlates of quality of life in nursing homes: Toward a reasonable practice, research and policy agenda. *The Gerontological Society of America*. 43(special issue 2), 28-36.
- Kane, R., Lum, T., Cutler, L., Degenholtz, H. & Yu, T. (2007). MHA resident outcomes in small-house nursing homes: A longitudinal evaluation of the initial green house program. *Journal of American Geriatrics Society*, 55(6), 832-839.
- Kane, R. & Wilson, K. (2007). Introduction improving practice through research in and about assisted living: Implications for a research agenda. *The Gerontologist* (47: suppl 1): 4-7. doi: 10.1093/geront/47.Supplement_1.4
- Kane, R., Wilson, K., & Spector, W. (2007). Developing a research agenda for assisted living. *The Gerontologist* (2007) 47 (suppl 1): 141-154. doi: 10.1093/geront/47.Supplement_1.141.
- Karr, V. (2010). *International perspectives of persons with disabilities on human rights, self-determination, and quality of life*. (Doctoral dissertation). New York: Columbia UP. Retrieved from Dissertations & Theses: Full Text. (AAT 3343513).
- Kitchener, M., Willmott, M. and Harrington, C. (2004). *Home and community-based services: Federal funding to states*. UCSF National Center for

- Personal Assistance Services. Retrieved from: http://www.pascenter.org/federal_funding_to_states/Federal_Funding_2004.pdf
- Kerr, A. & Shakespeare, T. (2002). Genetic politics: From eugenics to genome. Cheltenham, Eng.: New Clarion.
- Kemper, P., Heier, B., Barry, T., Brannon, D., Angelelli, J., Vasey, J., & Anderson-Knott, M. (2008). What do direct care workers say would improve their jobs? Differences across settings. *The Gerontologist*, 48(I), 17-25.
- Kimura, M. & Silva, J. (2009). Ferrans and Powers quality of life index. *Revista da Escola de Enfermagem da USP*. 43, 1098-1104.
- Klein, J. (1999). Homeownership for people with disabilities: The state of the states in 1999. *Journal of Vocational Rehabilitation* 15(2), 67-77.
- Kodner, D. (2003). Consumer-directed services: Lessons and implications for integrated systems of care. *International Journal of Integrated Care*, 17(3), 3-4.
- Kosciulek, J. (1999). The consumer-directed theory of empowerment. *Rehabilitation Counseling Bulletin*, 42(3) 198.
- Kosciulek, J. & Merz, M. (2001). Structural analysis of the consumer-directed theory of empowerment. *Rehabilitation Counseling Bulletin*, 44(4), 209-216.
- Krause, J. S., Stanwyck, C. A., & Maides, J. (1998). Locus of control and life adjustment: Relationship among people with spinal cord injury. *Rehabilitation Counseling Bulletin*, 41(3), 1-9.
- Krupa, T. & Clark, C. (2002). Reflections on empowerment in community mental health: Giving shape to an elusive idea. *Psychiatric Rehabilitation Journal*, 25(4), 341.
- Krysik, J. & Finn, J. (2010). *Research for effective social work practice*. (2nd ed.), New York: Routledge.
- LeRoy, B., Wolf-Branigin, M., Wolf-Branigin K., Israel, N., & Kulik, N. (2007). Challenges to the systematic adaptation of person-centered planning. *Best Practices in Mental Health*. 3(1), 6-25.
- Longterm care (2008). *Cost of care*. Retrieved from http://www.longtermcare.gov/LTC/MainSite/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx.

- Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior*. Boston MA: Paul H. Brookes.
- Lowry, R. (n.d.). Subchapter 3b: Rank-order correlation. In R. Lowery, Concepts and Applications of Inferential Statistics. Retrieved from: <http://faculty.vassar.edu/lowry/ch3b.html>.
- Lum, T., Kane, R., Cutler, L., & Yu, T. (2009). Effects of greenhouse nursing homes on residents' families. *Health Care Financing Review*, 20(2), 35-51.
- Madon, S., Jussim, L., & Eccles, J. (1997). In search of the powerful self-fulfilling prophecy. *Journal of Personality and Social Psychology*, 72(4), 791-809.
- Maller, J. O. (1971). *The therapeutic community with chronic mental patients*. New York: S. Krager.
- McDougall, D. & Smith, D. (2006). Recent innovations in small-n designs for research and practice in professional school counseling. *Professional School Counseling*, 9(5), 392-400.
- McIntyre, S. (2001). *Resident council handbook*. Belfair, WA: Residents Council of Washington.
- Mercer, S. L., Green, L. W., Cargo M., Potter, M., Daniel, R. & Olds, S. (2008). Reliability-tested guidelines for assessing participatory research projects. In: Minkler M, Wallerstein N, eds. Community Based Participatory Research for Health: From Process to Outcomes. 2nd ed. San Francisco, CA: Jossey-Bass; 2008:407-418.
- Miltenburg, T., Ramakers, C., Mensink, J. (1996). *A personal budget for clients, summary of an experiment with cash benefits in home care in the Netherlands*. Nijmegen, Netherlands: Institute for Applied Social Sciences.
- Mental Health America (2011). Mission. Retrieved from: <http://www.nmha.org/go/mission-vision>.
- Medical History of Michigan (1930). *Michigan state medical society*. Retrieved from: <http://Onlinebooks.library.upenn.edu/webin/book/lookupid?key=olbp23725>.
- Miles, J. (2011). *Getting the Sample Size Right: A Brief Introduction to Power Analysis*. Retrieved from <http://www.jeremymiles.co.uk/misc/power/>;

- Morgan, S., Bixler, M., & McNamara, J. (2002). *Self-determination for children and young adults who are deaf-blind*. Retrieved from <http://nationaldb.org/documents/products/self-determ.pdf>.
- Moshki, M., Ghofranipour, F., Hajizadeh, E., & Parviz, P. (2007). Validity and reliability of the multidimensional health locus of control scale for college students. *BioMed Central*, 7, 295-301.
- National Council on Disability (NCD) (2008). *Inclusive livable communities for people with psychiatric disabilities*. Retrieved from: <http://www.ncd.gov/newsroom/publications/2008/LivableCommunities.html>.
- National Institute on Drug Abuse (2002). *Research report series: Therapeutic community* (NIDA Publication No. 02-4877). Retrieved from <http://www.nida.nih.gov/researchreports/therapeutic/default.html>.
- National Institute of Mental Health, (2010). Depression. Retrieved from: <http://www.nimh.nih.gov/health/topics/older-adults-and-mental-health/index.shtml>.
- Nerney, T. (2008). *Mental health and self-direction a shift in power*. Retrieved from: <http://www.centerforselfdetermination.com/guard.html>.
- NIST/SEMATECH (2010). *E-handbook of statistical methods*. Retrieved from: <http://www.itl.nist.gov/div898/handbook/>, date. 3b.
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007) Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, 51 (ii), 850-865. doi: 10.1111/j.1365-2788.2006.00939.x
- Nuland, S. B. (2007). *The art of aging: A doctor's prescription for well-being*. New York: Random House.
- O'Brian, J. (2006). *Reflecting on social roles identifying opportunities to support personal freedom & social integration*. Retrieved from: <http://www.inclusion.com/socialroleinventory.pdf>.
- Park, N. (2009). The relationship of social engagement to psychological well-being of older adults in assisted living facilities. *Journal of Applied Gerontology*, 28(4): 461-480. DOI: 10.1177/0733464808328606.
- Petry, K., Maes, B., & Vlaskamp, C. (2007). Operationalizing quality of life for people with profound multiple disabilities: A Delphi study. *Journal of Intellectual Disability Research*, 51(5), 334-349.

- Penn Medicine, (2011). History of the Pennsylvania Hospital. Retrieved from: <http://www.uphs.upenn.edu/paharc/>.
- Powers, L., Sowers J., & Singer, G. (2006). A cross-disability analysis of person-directed, long-term services. *Journal of Disability Policy Studies*, 17(2), 66-76.
- Pranic, L. (2008). Service recovery from the customer's perspective: Extending the consumer-directed theory of empowerment (CDTE). ProQuest, UMI Dissertations Publishing). *ProQuest Dissertations and Theses*, n/a. Retrieved from <http://login.ezproxy1.lib.asu.edu/login?url=http://search.proquest.com/docview/287954196?accountid=4485>
- Rahman A, Schnelle J. (2008). The nursing home culture-change movement: Recent past, present, and future directions for research. *The Gerontologist*, 48: 142–148.
- Rapaport, M., Clary, C., Fayyad, R., & Endicott, J. (2005). Quality of life impairment in depressive and anxiety disorders. *American Journal of Psychiatry*, 162(5), 1171-1178.
- Resilience Coaching (2011). Resilience Coaching: For the success in your life. Retrieved from: <http://www.resiliencecoach.com/>
- Rivera, G. (1988). *Willowbrook 25 years after*. Retrieved March 21, 2010 from [willowbrook stateschool.blogspot.com](http://willowbrook.stateschool.blogspot.com).
- Rioch, S. (2009). An examination of self-determination and locus of control in adolescents with and without learning disabilities. ProQuest, UMI Dissertations Publishing. ProQuest Dissertations and Theses, n/a. Retrieved from <http://login.ezproxy1.lib.asu.edu/login?url=http://search.proquest.com/docview/304832680?accountid=4485>.
- Rogers, J. & Rogers, S. (2003). *Self-determination for people with psychiatric disabilities: Personal obstacles and facilitators*. National Self-Determination & Psychiatric Disability Conference Papers.
- Rowe, J. & Kahn R. (1998). *Successful aging*. New York, NY: Pantheon Books.
- Ryan, R., Rigby, S., & King, K. (1993). Two types of religious internalization and their relations to religious orientations and mental health. *Journal of Personality & Social Psychology*. 65(3), 586-596.
- Saleebey, D. (2002). Practice the strengths perspective: Everyday tools and resources. *Families in Society*, 82(3), 221.

- Saleebey, D. (2006). *The strengths perspective in social work practice*. (4th ed.). Boston, MA: Allyn and Bacon.
- Salzer, M. (2006). *Community integration is the opportunity to live in the community and be valued for one's uniqueness and abilities, like everyone else*. Retrieved from: <http://www.upennrrtc.org/>.
- Salzer, M. & Boren, R. C. (2006). Promoting community integration: Increasing the presence and participation of people with psychiatric and developmental disabilities in community life. Philadelphia, PA: University of Pennsylvania, available at www.upennrrtc.org.
- Scala, M. & Nerney, T. (2008). *People first: The consumer in consumer direction*. Retrieved from: [http://self-determination.com/images/stories/Articles/Self% 20DeterminationPublications.pdf](http://self-determination.com/images/stories/Articles/Self%20DeterminationPublications.pdf) Publications Position Papers.
- Schalock R., Brown I., Brown R., Cummins R., Felce D., Matikka L., Keith, K., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel. *Mental Retardation*. 40(6), 457-469.
- Schrag, A., Jahanshahi, M. & Quinn, N. (2000). What contributes to quality of life in patients with Parkinson's disease? *Neurology Neurosurgery Psychiatry*, 69(3), 308-312.
- Sheikh, J. Yesavage, J., Brooks, J., Friedman, L., Gratzinger, P., Hill, R., Zadeik, A., & Crook, T. (1991). Proposed factor structure of the geriatric depression scale. *International Psychogeriatrics*, 3, 23-28. doi: 10.1017/S1041610291000480
- St. Luke's Health Initiative (2001). *Into the light*. Retrieved from <http://www.slhi.org/IntoTheLight/Volume%20I/introduction.html>.
- Stancliffe, R. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities*, 7(1), 91-98.
- State of Connecticut Social Services (2011). Assisted living program: What is assisted living? Retrieved from: <http://www.ct.gov/dss/cwp/view.asp?a=2353&q=391114>.
- Stubbs, P. (1998). *The Story of deinstitutionalization*. Mental Health Net Perspectives, 3(4), Retrieved from: [http://www.mentalhelp.net/poc/ view _doc.php? type= doc&id=368](http://www.mentalhelp.net/poc/view_doc.php?type=doc&id=368).

- Thomas. P. (2010). Is it better to give than to receive? Social support and the well-being of older adults. *The Journal of Gerontology*, 35(3), 351-357.
- Todman, J. & Dugard, P. (2001). *Single-case design and small-n experimental designs: A practical guide to randomization test (2nd ed.)*. Mahwah, NJ: Lawrence Erlbaum Associates, 245.
- Turnbull, H., Turnbull, B., Wehmeyer, M., & Park, J. (2003). A quality of life framework for special educational outcomes. *Remedial and Special Education*, 24(2), 67-74.
- United States Census (2003). Research reports. Retrieved from <http://www.census.gov/srd/www/abstract/ssm2003-09.html>.
- Veenhoven, R. (2008). *The science of subjective well-being: A tribute to Ed Diener* Michael Eid & Randy Larsen (Eds). New York, NY: Guilford Publications.
- Wallerstein, N. & Duran B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*. 100: 40 – 46. doi:10.2105/AJPH.2009.184036).
- Watson, L. Lehmann, S., Samas, Q., Baker, A., Brandt, J., Steele, C., Rabins, P., Rosenblatt, A. & Lyketsos, C. (2006). Depression in assisted living is common and related to physical burden. *American Journal of Geriatric Psychiatry*, 14(10): 876-683.
- Wehmeyer, M. (2002). *Self-Determination and the education of students with disabilities*. Retrieved from: <http://www.athealth.com/Consumer/disorders/selfdetermine.html>.
- Wehmeyer, M. (2004). Self-determination and the empowerment of people with disabilities. *American Rehabilitation*, 28(1), 22-29.
- Wehmeyer, M. (2003). *Promoting self-determination of students with severe disabilities*. Retrieved from: <http://www.ericdigest.org/2003-4/severe-disabilities.html>.
- Wehmeyer, M., Agran, M., & Hughes, C. (1998). Teaching self-determination to students with disabilities: Basic skills for successful transition. Baltimore, MD: P.H. Brookes.
- Wehmeyer, M. & Bolding, N. (1999). Self-determination across living and working environments: A matched-samples study of adults with mental retardation. *Mental Retardation*, 37(5), 353-369.

- Werner, E. & Smith, R. (1992). *Overcoming the odds: high risk children from birth to adulthood*. Ithaca, N.Y: Cornell UP.
- Wiener, J., Hanley, R., Clark, R., & Van Nostrand, J. (1990). Measuring activities of daily living: Comparison across national surveys. U.S. Department of Health Services Retrieved from <http://aspe.hhs.gov/daltcp/reports/meacmpes.htm>.
- Wojciszke, B. & Struzynska-Kujalowicz, A. (2007). Power influences self-esteem. *Psychology and Social Cognition*, 25(4), 472-494.
- Wolfensberger, W. (1975). *The origin and nature of our institutions*. Syracuse, NY: Human Policy Press.
- Wolfensberger, W. (1983). *The basis and logic of the normalisation principle*. Sixth International Congress of IASSMD, Toronto, 1982. Retrieved from Saracusuniversity/articlearchives.com.
- Wong, Y., Nath, S. & Solomon, P. (2007). Group and organizational involvement among persons with psychiatric disabilities in supported housing. *Journal of Behavioral Health Services & Research*, 34(2), 151-167.
- Yelsma, T. (1995). Self-esteem and alexithymia. *Psychological Reports*, 77(1), 735-738.
- Yesavage, J., Brink, T., Rose, T., Lum, O., Huang, V., Adey, M. & Leirer, V. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37-49.
- Zadeik, A., Sheikh, J., Crook, T., Hill, R., Gratzinger, P., Brooks, J., Yesavage, J., & Friedman, L., (1991). Proposed factor structure of the geriatric depression scale. *International Psychogeriatrics*, 3:1, 23 – 28. DOI: 10.1017/S1041610291000480
- Zakus, D. & Lysack, C. (1998). Revisiting community participation. *Health Policy and Planning*, 30(1), 1-12.
- Zinn, L. (1999). A good look back over our shoulders. *Nursing Homes: Long Term Care Management*, 48(12), 19-20.
- Zuroff, D., Koestner, R., Moskowitz, D., McBride, C., Marshall, M., & Bagby, M. (2007). Autonomous motivation for therapy: A new common factor in brief treatments for depression. *Psychotherapy Research*, 17(2).

APPENDIX A
BIG DOG SURVEY

Posttest

Participant _____

Date _____

Age ____

Gender _____

Veteran Status _____

Education level _____

Specialized Training _____

Prior Residence _____

Time at the Facility _____

Why did you come to this facility

Recap

Yesavage Depression _____

Locus of Control _____

Ferrans and Powers QOL _____

Self-esteem _____

UPENN Community Integration _____

DEPRESSIVE SYMPTOMS BY OBSERVATION OF THE PATIENTS

Score _____

The scores of possible answers: never (0) sometimes (1) always (2)

1. Evident sadness _____

2. Poor communication with the environment _____

3. Poor initiative in physical performance _____

4. Poor implication in routine activities _____

5. Evident signs of sadness (crying, tearfulness) _____

6. Alexithymia _____

Locus of Control: Rotter

Score _____

Select one statement that best describes how you feel. (4, 8 deleted)

- 1.____ A. Many of the unhappy things in people's lives are partly due to bad luck.
B. People's misfortunes result from mistakes they make.
- 2.____ A. One of the major reasons why we have wars is because people don't take enough interest in politics.
B. There will always be wars, no matter how hard people try.
- 3.____ A. In the long run, people get the respect they deserve in the world.
B. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.
- 5.____ A. Without the right breaks, one cannot be an effective leader
B. Capable people who fail to become leaders have not taken advantage of their opportunities.
- 6.____ A. No matter how hard you try, some people just don't like you.
B. People who can't get others to like them don't understand how to get along with others.
- 7.____ A. I have often found what is going to happen will happen.
B. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.
- 9.____ A. Becoming a success is a matter of hard work; luck has little or nothing to do with it.
B. Getting a good job depends mainly on being in the right place at the right time.
- 10.____ A. The average citizen can have an influence in government decisions.
B. This world is run by the few people in power and there is not much the little guy can do about it.
- 11.____ A. When I make plans, I am almost certain that I can make them work.
B. It is not always wise to plan to far ahead because many things turn out to be a matter of luck anyway.
12. ____A. In my case, getting what I want has little or nothing to do with luck.
B. Many times we might just as well decide what to do by flipping a coin.
13. ____A. What happens to me is my own doing.
B. Sometimes I feel that I don't have enough control over the direction my life is taking.

Ferrans and Powers QUALITY OF LIFE INDEX© GENERIC VERSION III

Score ____

PART 1. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers. (1) Very Dissatisfied (2) Moderately Dissatisfied (3) Slightly Dissatisfied (4) Slightly Satisfied (5) Moderately Satisfied (6) Very Satisfied

HOW SATISFIED ARE YOU WITH:

- | | | | | | | |
|---|---|---|---|---|---|---|
| 1. Your health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Your health care? | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. The amount of pain that you have? | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. The amount of energy you have for everyday activities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. Your ability to take care of yourself without help? | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. The amount of control you have over your life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. Your chances of living as long as you would like? | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Your family's health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. Your children? | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Your family's happiness? | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. Your friends? | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. The emotional support you get from people other than your family? | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. How useful you are to others? | 1 | 2 | 3 | 4 | 5 | 6 |
| 18. The amount of worries in your life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 19. Your neighborhood? | 1 | 2 | 3 | 4 | 5 | 6 |
| 20. Your home, apartment, or place where you live? | 1 | 2 | 3 | 4 | 5 | 6 |
| 23. Your education? | 1 | 2 | 3 | 4 | 5 | 6 |
| 24. How well you can take care of your financial needs? | 1 | 2 | 3 | 4 | 5 | 6 |
| 25. The things you do for fun? | 1 | 2 | 3 | 4 | 5 | 6 |
| 26. Your chances for a happy future? | 1 | 2 | 3 | 4 | 5 | 6 |
| 27. Your peace of mind? | 1 | 2 | 3 | 4 | 5 | 6 |
| 28. Your faith in God? | 1 | 2 | 3 | 4 | 5 | 6 |
| 29. Your achievement of personal goals? | 1 | 2 | 3 | 4 | 5 | 6 |
| 30. Your happiness in general? | 1 | 2 | 3 | 4 | 5 | 6 |
| 31. Your life in general? | 1 | 2 | 3 | 4 | 5 | 6 |
| 32. Your personal appearance? | 1 | 2 | 3 | 4 | 5 | 6 |
| 33. Yourself in general? | 1 | 2 | 3 | 4 | 5 | 6 |

QOL PART 2 11, 12, 21, 22 NOT APPROPRIATE SCORE _____

PART 2. For each of the following, please choose the answer that best describes how important that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers. (1) Very Unimportant (2) Moderately Unimportant (3) Slightly Unimportant (4) Slightly Important (5) Moderately Important (6) Very Important

HOW IMPORTANT TO YOU IS:

1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Taking care of yourself without help?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6
18. Having no worries?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Being able to take care of your financial needs?	1	2	3	4	5	6
25. Doing things for fun?	1	2	3	4	5	6
26. Having a happy future?	1	2	3	4	5	6
27. Peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Achieving your personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Being satisfied with life?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Are you to yourself?	1	2	3	4	5	6

Facility Residents P.A.R. Qualitative Interview

1. What are your goals and expectations? This year? In life?
2. Are your needs being met? (Activities, Social, Safety, Food, Health)
3. How are treated by other residents, staff, and neighbors?
4. How well do you get along with residents of the Facility? in the community?
(borrowing money/cigarettes, courtesy, respect/ valued, feel accepted by)
5. How good do you feel at the Facility? in the community?
6. Tell me about your neighborhood? (access to and knowledge of)
7. How much control over the activities and policy at the Facility?
8. Satisfaction with the Facility:
 - A. How would you rate the Facility?
 - B. How often do you wait for staff at the Facility?
 - C. What suggestions do you have for the Facility?

Post/Follow up: How much of the change in your life do attribute to life skills and self-advocacy training?

APPENDIX B

INSTITUTIONAL REVIEW BOARD APPROVAL

INSTITUTION REVIEW BOARD , OFFICE OF INTEGRITY AND
ASSURANCE

Project: The Impact of Moving toward a Culture of Empowerment in the Lives of
Residents of Assisted Living Centers

Approval Date: 04/05/11

To: Maria Napoli
UCENT

for From: Mark Roosa, Chair *SM*
Soc Beh IRB

Date: 04/05/2011

Committee Action: **Expedited Approval**

Approval Date: 04/05/2011

Review Type: Expedited F7

IRB Protocol #: 1103006252

Study Title: The Impact of "Moving toward a Culture of Empowerment" on the Lives of Residents in Assisted Living

Expiration Date: 04/03/2012

The above-referenced protocol was approved following expedited review by the Institutional Review Board.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date. You may not continue any research activity beyond the expiration date without approval by the Institutional Review Board.

Adverse Reactions: If any untoward incidents or severe reactions should develop as a result of this study, you are required to notify the Soc Beh IRB immediately. If necessary a member of the IRB will be assigned to look into the matter. If the problem is serious, approval may be withdrawn pending IRB review.

Amendments: If you wish to change any aspect of this study, such as the procedures, the consent forms, or the investigators, please communicate your requested changes to the Soc Beh IRB. The new procedure is not to be initiated until the IRB approval has been given.

Please retain a copy of this letter with your approved protocol.