Spring 7-19-2013

The Historical, Political, Social, and Individual Factors That Have Influenced the Development of Aging and Disability Resource Centers and Options Counseling

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by

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A thesis submitted in partial fulfillment of the
requirements for the degree of

Master of Urban Studies

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Portland State University
2013

Abstract

This thesis reports on the perspectives and experiences of policymakers, advocates, agency supervisors, and experts in the field of gerontology, about the development of Aging and Disability Resource Centers (ADRC) programs and Options Counseling (OC). By examining the foundations upon which ADRCs and OC are built, this study sought to inform future research about the effectiveness of existing practice, increase understanding of best practices, and clarify whether these emerging services are accomplishing original goals.

ADRCs and OC intend to address long-term care issues and healthcare needs by providing a single entry point to the social service system. ADRCs offer information, assistance, and OC to people of all ages, incomes, and disabilities, and promote long-term care options that honor independence and respect for the needs and preferences of individuals, their families, and caregivers. They are the latest iteration of policymakers' efforts to provide affordable home-and community-based care for older persons and their caregivers.

A total of fifteen qualitative interviews were conducted and analyzed using grounded theory methods. Key persons interviewed included experts in the area of aging, aging policy, and aging. Participants were recruited through referrals suggested by Portland State University's (PSU) Institute on Aging (IOA) staff. In addition, several key experts known to the researcher through affiliation with PSU's IOA agreed to be interviewed. Snowball sampling was then used to locate additional key experts.

Interview participants were classified as advocates, state decision makers, policy makers, or academicians. Advocates included national and state directors of agencies that promote the development and management of effective services to aging adults. State decision makers included state directors, ADRC directors and supervisors, and program analysts. Policy makers interviewed were national program directors responsible for shaping the future of developing programs to assist older adults. Academicians who participated in the study have been instrumental in developing and researching practices that promote well-being for the aging and the aged. These key experts were selected based on their knowledge and ability to inform the strengths, weakness, and development of ADRCs and Options Counseling. Many have been instrumental in health and aging policy and service development and research, and possess insider knowledge not available to the general public regarding attitudes and interests motivating the actors.

Findings indicate that ADRCs and OC are designed to manage within existing social service systems. They can benefit some individuals by providing more options and support in accessing public and private services. It remains to be seen whether they have the capacity to ameliorate some existing system-level problems. Findings highlight program strengths and weaknesses, sustainability issues, and policymakers, state decision makers', and providers' commitment to sustaining ADRCs and OC.

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Dedicated to the ones who teach me,
Especially
Brent, Sarah, and Jean

Acknowledgements

I am indebted to colleagues, friends, and family who have supported me in this endeavor. Diana White shared her office and endless patience. She has guided me into the fascinating world of research. Margaret Neal, through her steadfast support, has provided inspiration and opportunities. Her generosity has enabled me to grow both academically and personally. I am grateful to Paula Carder for her instruction, both in and out of the classroom, and volumes of the best literature. This study has benefited from her contributions. Katie Berg and Meriam Rahali have offered encouragement and support during times of excitement and discouragement on this mid-life journey and I am thankful for their friendship. Brent Elliott embraced added family responsibilities with generosity and humor. Without him, I would have been unable to accomplish this work. Lastly, I thank Sarah and Jean Elliott for the times we have studied together. Your determination motivates me to do my very best.

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Chapter 1

Introduction

In the United States, older adults have been recognized as deserving of public assistance, and social policies benefiting the aged have developed over time. Increasingly, however, federal and state governments face challenges in addressing the long-term care needs of this rapidly increasing aging population that totaled approximately 40.4 million in 2010 and represents over one in every eight individuals (AoA, 2011). The purpose of this research was to describe the Aging and Disability Resource Centers (ADRCs) program and a process called Options Counseling that are new approaches to long-term care policy. These programs are a collaborative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS). ADRCs were designed to rebalance the long-term care system by redirecting consumers away from institutional care to consumer-driven, home-and community-based service systems (AoA, 2003).

Long-term care (LTC) refers to assistance provided over a sustained period of time to people experiencing difficulty functioning due to a disability (Kane & Kane, 2003). Some LTC services include housing and home maintenance, nutrition, transportation, caregiving and respite, and financial security (Kemper, 2003). These services are largely supportive, although medical care is also included within LTC. They are designed to assist individuals who have functional or cognitive impairments that limit their ability to manage activities of daily living (ADLs), such as help with bathing, mobility and toileting, and instrumental Activities of Daily Living (IADLs) such as meal

preparation, housekeeping, and medication management (Oswald, et al., 2011). The United States Administration on Aging (2010) documented that persons reporting problems with two or more ADLs included 6% of those 65 years and older and 18.1% of those 85 years and older. Of those 85 years and older, 49.8% have difficulty with IADLs, especially self-care and mobility limitations (AoA, 2006). The study, *Aging into the 21st Century*, concluded that the number of moderately or severely disabled older persons will increase sharply over the next 40 years, perhaps as much as 350% (AoA, 2008).

With population aging, more elders require a greater number of LTC services, but not all in need have the resources to either learn about or obtain services (Kane et al., 2003). In addition, these individuals often do not know where to turn, and many need support in deciding about and managing a wide range of home-and community-based service (HCBS) options administered by complex social service systems that can be confusing to navigate (ACL, 2012). Accessing these services presents additional challenges due to physiological changes common in old age, including mobility limitations, cognitive changes, and greater need for medical care (Oswald et al., 2011). As a result, policymakers, state decision-makers, and researchers have examined the critical nature of developing LTC policies that will adequately address elders' increasing functional needs and related health care costs (Kemper, 2003).

Most LTC is provided to older adults and persons with disabilities by families (Connidis, 2010). For those who need formal LTC and lack financial resources to pay

privately, nursing homes have been the primary policy response. However, studies have found multiple benefits in shifting the emphasis from institutional to home-and community-based care, including cost effectiveness and older adults' preferences to remain at home (Lehning & Austin, 2010; O'Shaughnessy, 2008; Oswald, Schilling, Nygren, Fange, Sixsmith et al., 2007). Further, the Olmstead decision gave a mandate to states to shift the balance from institutional to community-based options (ADA, 2012). Many home-and community-based LTC programs, including those offered through public, not-for-profit, and for-profit agencies, are shaped by policies developed at the federal, state, and local levels. These policies were created in response to the increasing numbers and increased longevity of older adults, many of whom wish to avoid nursing home placement and instead, age at home. They address healthcare costs, information and access to HCBS, and issues related to chronic care needs common to old age (Lehning & Austin, 2010).

Older adults' limited financial resources can make sought-after services unaffordable. The median income of the 37.9 million persons age 65 and above reporting income in the U.S. in 2010 was $18,819. Older men had a median income of $25,704, and older women had a median income of $15,072 (AoA, 2011). Many of these individuals find it necessary to seek support from federal, state, and local social service providers to obtain help with healthcare and HCBS that allow them to age in place.

Aging and Disability Resource Center programs (ADRC) and Options Counseling (OC) programs intend to address LTC cost issues and healthcare needs by providing a single entry point to the social service system. These programs offer information, assistance, and OC to people of all ages, incomes, and disabilities, and they propose to promote a community-based environment that fosters independence and respect for the LTC needs and preferences of individuals, their families, and caregivers (ACL, 2012). They are the latest iteration of policymakers' efforts to provide affordable home-and community-based care for older persons and their caregivers.

Options Counseling (OC) represents a new model of publicly-funded long-term planning support available in the United States. OC is a core service offered through ADRCs and is intended to provide person-centered, interactive, decision-support to older adults and people with disabilities (known as consumers), their family members, and significant others. With OC, these individuals are supported in their attempts to identify and access appropriate LTC choices (AoA, 2010). Options Counselors are trained to respond to consumers' needs, preferences, values, and individual circumstances (AoA, 2011).

Although ADRCs do not provide services, some consumers were able to obtain them with the information and support they received from the program. In a study conducted by Portland State University's Institute on Aging for the state of Oregon, most survey participants found the information and access they received to the social service

system through the ADRC somewhat helpful or very helpful (81%, 2011-2012; 83%, 2012). Many agreed or strongly agreed the services or information they received would allow them to live in the place they most desire (80%, 2011-2012; 83%, 2012) (White & Elliott, 2013; White, Elliott, Carder & Luhr, 2012).

ADRCs and OC address the need to reduce LTC spending by providing information and easy access to what may appear to consumers to be a daunting array of social services (ACL, 2012). ADRCs and OC address some contemporary issues regarding the relative roles of government, individuals, and the private market in responding to older and disabled persons' needs (AoA, 2012).

Research questions

- Which historical, economic, political, social, and individual factors have influenced the development of ADRCs and OC?

- How do the various actors (Advocates, Policymakers and System Decision Makers) define the goals of OC?

- What are the economic, political, social, and individual advantages and disadvantages of ADRC and OC programs?

- Which theoretical constructs clarify the reasons for the development of ADRCs and OC?

Chapter 2

Literature Review

This study sought to answer questions regarding these new programs' effectiveness and sustainability, and to better inform the analysis and interpretation of ADRCs and OC. In addition, the study sought to determine whether the programs were realizing intended goals and to increase knowledge concerning what is needed to provide best practice. Research conducted to accomplish these goals included a review of literature tracing historical, political, and economic trends, a review of theoretical constructs in gerontology, and interviews with key informants. Reviewing current research findings on policy successes and failures in person-centered care models and examining attitudes regarding the use of public resources to assist older adults contributed to the existing literature and assisted in conceptualizing standards and practices more likely to serve consumers effectively and efficiently.

This literature review explored historical and political trends influencing the transition from institutional long-term care to home-and community- based care using a more person-centered approach in service delivery. Peer-reviewed journal articles and research findings and implications examined within the context of ADRCs and Options Counseling standards and practices clarified the programs' emergence and determined factors contributing to the programs' strengths and weaknesses. Topics investigated included social welfare policy and politics, person-centered long-term care history,

demographic trends in aging, older adults' needs and preferences, and the Aging Networks including Area Agencies on Aging.

Reviewing different types of evidence can be complementary (Charmaz, 2006), and examining both qualitative and quantitative published studies can contribute to answering questions more thoroughly and accurately (Light & Pillemer, 1984). To ensure that data are not constrained by predetermined analytical categories (Patton, 2002, p. 228) literature was examined before, during and after the key expert interviews to further refine inclusion and exclusion criteria.

Literature inclusion and exclusion

Criteria for inclusion and exclusion of literature were based on articles that informed the research questions and clarified the reasons for the development and implementation of ADRCs and OC. Some studies from each category were selected for review. Key words used to locate relevant articles include: Person-Centered Care; Home-and Community-Based Care; Ageism; Age Bias; Culture Change; Cultural Competence; Elders/Older Adults/Seniors Needs and Preferences; Quality of Life; Quality of life; Life Course and Aging; ADRCs; Options Counseling; Aging Policy; Funding, Healthcare, Aging, Aged; Long-term Care. The qualitative and quantitative studies reviewed discussed: older adults' needs and preferences with regard to aging in place and home-and community-based services; accessibility and affordability of services; whether or not older adults are satisfied with services and the reasons for their

satisfaction or dissatisfaction; social service providers' ability to provide necessary services to older adults in the ways they prefer.

Key categories within the topics are represented in the table below.

Table 1

Key Categories Within Topics				
Individual Factors	**Economic Factors**	**Political and Institutional Factors**	**Aging and Long-term Care Policy**	**Historical Factors**
Diversity of older adults needs and preferences	Federal policy shifts	Aging Network influence	Retrenchment	Social welfare policy trends
Demographic considerations	Rise in medical expenditures for the elderly	Attitudes toward the aged	Reduction in expenditures for domestic social programs	Long-term care history
Health needs	Healthcare costs	Public anxiety over increasing aging population	Social benevolence vs. individual responsibility	Person-centered care evolution
Healthcare needs	HCBS costs	Profit and not-for-profit group roles & influence	Decentralization of program authority and responsibility	
		Deregulation and devolution of federal authority		

Using key words to locate literature and identify categories within topics guaranteed representation for each topic, enabled the researcher to prune irrelevant literature, and minimize researcher bias (Light & Pillemer, 1984). To further ensure that current and emerging relevant literature would be examined, writings were reviewed on a continual basis throughout the study.

As new topics emerged during interviews with key experts, articles were examined that addressed those topics in order to clarify the discussions and answer the thesis questions more thoroughly and accurately. When some interview participants made reference to literature they wrote and studies they conducted, those references were investigated to gain better understanding of the responses to interview questions and for relevance to the research topic.

Theoretical Constructs That Clarify the Reasons for the Development of ADRC & OC

Theoretical Approaches

Bengtson, Burgess, & Parrott (1997) stated that empirical results in research should be presented within the context of more general explanations. Examining ADRCs and OC within the framework of three theoretical constructs, life-course perspective, social constructionist and political economy of aging lent credibility to the study. Further, it ensures criteria used to determine program outcomes were grounded, and would provide a contribution to understanding successful standards, best practices, and policy.

Life-course perspective. The life-course perspective incorporates the effects of history, social structure, and individual meaning, and attempts to explain aging populations and individuals over time (Settersten, 2005). The life-course perspective is dynamic; rather than focusing on one segment of the life of an individual or cohort, it

attempts to understand the life cycle in its entirety and allows for exploring deviations in expected trajectories (Tinker et al., 2004).

Within the context of the life-course perspective, the concept of cumulative advantage/disadvantage has theoretical and empirical connections as it relates to issues of heterogeneity and inequality among the aged (Settersten, 2005). Cumulative advantage/disadvantage can be defined as the interaction of forces that account for individual variation in a given characteristic (e.g., money, health, or status) with the passage of time, and exists independent of merit" (Dannefer, 2003, p. 328). These processes are responsible for increasing inequality and variability with age, and they label individuals. The labels, in turn, can influence how people experience the world, their ability to develop skills and opportunities, and often affect future life opportunities (Dannefer, 2003). The health-inequality relationship among individuals late in life provides an example. Low income minority people often have poor access to a safe environment, good quality food, and education. Often, they work in low-paying jobs that fail to offer health care benefits. As a result, these people enter old age in poorer health and with fewer resources than individuals who have experienced greater economic, educational, and social advantages (Geronimus, 2000; Oswald, Wahl, Schilling, Nygren, Fange, & Sixsmith, 2007). Dailey (2000) indicated that the more precarious financial status of Baby Boom women is the result of personal and economic factors that have influenced the life course, including intermittent work-force participation due to

childrearing, lower wages than men, and Social Security benefits that depend on spousal income. These circumstances place a greater percentage of old women in poverty.

According to Settersten (2005), comprehending the long-range effects of early life experiences in old people's present and future lives and experiences is necessary for understanding their needs and designing policy to meet those needs. This approach can increase societal understanding of each aging individual as unique with diverse sets of needs and experiences. Policymakers who understand the effects of cumulative advantage and disadvantage are more likely to be effective in developing programs that address the heterogeneity of this population (Settersten, 2005).

Options Counselors and service providers face challenges when addressing diverse qualities unique to the aging process and old age. The life-course perspective provides a tool to better understand the cumulative advantages and disadvantages influencing the diverse needs and preferences of older adults and their ability to obtain services. Without this perspective, OCs risk misinterpretation and use of prescribed standards in suggesting service options.

Social constructionist theory. Bengtson, Burgess, & Parrott (1997) indicated that social constructionist theory is useful because it can link individuals to social-structural context, and because it focuses on understanding the ways in which social definitions and social structures create beliefs about people or groups. These contexts, in turn, define attitudes, form stereotypes, and direct policy decisions. Understanding how

the social meaning of age directs feelings about the value of providing for aging individuals, ways in which those perceptions affect policymakers' decisions, and ways in which services are developed and allocated can clarify how service needs unique to old age are labeled.

Constructionist theory also emphasizes ways in which social reality and social roles change over time and how they influence life situations (Dannefer and Perlmutter, 1990; Kuipers & Bengtson, 1973). Connecting these changes in perception to attitudes regarding the aging population and its needs and to new developments in long-term care programs can provide an additional dimension to analyzing the development of ADRCs and Options Counseling. Examining these transitions within the context of policy shifts that favor decentralizing federal responsibility for service provisioning to state governments and individuals can illustrate who benefits most from the programs, and how.

Political economy of aging perspective. The political economy of aging perspective takes a structural and economic approach to questions of aging in guiding understanding, prediction, and control of aging services (Estes, 1979). This perspective attempts to explain how the interaction of economic and political forces determines how social resources are allocated and how variations in the treatment and status of groups can be understood by examining public policies, economic trends, and social-structural factors.

According to Estes (1979), socioeconomic and political constraints shape the experience of aging and result in the loss of power, autonomy, and influence for older persons. Life experiences are seen as patterned by age, class, gender, race, and ethnicity. These structural factors are often institutionalized and reinforced by economic and public policy, and affect experiences later in life. According to Bengston et al. (1997), such social-structural contexts, constraints, and construction are responsible for the precarious status and ageist treatment of the elderly in American society.

Political and Economic Factors That Have Influenced the Development of ADRCs & OC

Long-term Care Resources, Funding, and Distribution. The financing of LTC services is fragmented and consists of a variety of federal, state, and local government, and private-pay dollars. In 2009, Americans spent an estimated $182 - $196 billion on LTC services for the elderly (Lewin, 2010; AHRQ, 2013). This figure does not include estimates for unpaid care worth approximately $375 billion (Arno, Levine & Memmott, 1999; Neal & Hammer, 2007).

Several factors contribute to the recent policy preference for HCBS instead of institutional LTC, including limited funding for public benefits such as Medicaid, redistribution of responsibility to individuals to finance long-term care services, and increased desire to honor diverse needs and preferences for older adults wishing to age in place. According to Kane, Kane, & Ladd (1998), the United States has supported a long-term care system dominated by the nursing home model with funding made available

through the Medicaid program. Kane and colleagues found government focus to be shifting due to the growing aging population, consumer demand, and the high costs of institutional care. They indicated that challenges exist in achieving consensus on long-term care goals, and that various interest groups formed arguments for or against changing the system. For example, 67 percent of nursing homes are primarily for-profit entities interested in filling beds (Niles-Yokum & Wagner, 2011). Proponents of the Aging Network, which is the largest provider of HCBS for older adults and their caregivers (AoA, 2013), wish to increase HCBS using Aging Network programs (Carbonelle & Polivka, 2008).

Medicare provides national health insurance for most older adults. This insurance program pays 49 percent of medical care bills for people aged 65 and over, covering physician services, medications, nursing facilities, rehabilitation, home health and hospice. Medicare does not pay for most long-term care to assist people with support services, including activities of daily living such as dressing and bathing (Medicare, 2013). Most Medicare beneficiaries use private, supplemental insurance to help cover deductibles and fill the gaps in Medicare benefit (CMS, 2013; Stone & Benson, 2012).

Medicaid is the federally and state funded health insurance program for specific categories of persons of all ages with low incomes who meet income-eligibility guidelines. Funding is a joint commitment between the federal government and the states. The federal government provides an open-ended funding commitment and agrees

to match, at varying rates, whatever states choose to spend (Thompson & Burke, 2008). This public benefit costs the federal and state governments over $300 billion per year and provides health insurance to over fifty million low-income people (CMS, 2013). In addition, Medicaid provides supplemental insurance for 9 million Medicare enrollees. These individuals are labeled "dual-eligible." For dual-eligible beneficiaries Medicare as their primary source of health insurance while Medicaid provides supplemental coverage for premiums and services not covered by Medicare (Stone & Benson, 2012). Medicaid accounts for 49 percent of all LTC expenditures. Of that, nursing home care accounts for 73 percent of total Medicaid spending on LTC for elderly and disabled (Stone & Benson, 2012). Medicaid covers a large portion of LTC expenditures including doctor's services and prescription drugs, and provides additional healthcare and LTC beyond Medicare (CMS, 2010; Thompson & Burke, 2008).

Cost increases in Medicare and Medicaid spending and the already inflated costs of medical care in the United States (higher than those in any other in advanced industrial country) have expanded faster than the economy. Some predict that Medicare costs, if not contained, will drain the country's economic resources (Morgan, 2010). As a result, Medicare and Medicaid were targeted for reductions in spending (Stone & Benson, 2012).

When the President's Commission on Fiscal Responsibility released its report in December 2010, it included proposed cuts in Medicare and Medicaid "despite, or perhaps

because of the prospective entrance of tens of millions of baby boomers in these programs" (Binstock, 2012, p.398). A few weeks prior to this announcement, a private commission consisting of former Congressional Budget Office and the Office of Management and Budget leaders released a report calling for cost-sharing and premium increases to be paid by Medicare recipients, and a cap on the growth of federal Medicaid expenditures. To further contain costs, in 2009 most states reduced some part of their Medicaid programs (Binstock, 2012).

An important HCBS funding source, The Older Americans Act (OAA), subsidizes Aging Network services to states. Some services include meal programs, home modifications, help with ADLs and IADLs, transportation, respite, and other community-based services. Unlike Medicaid, all older adults aged 60 and above are eligible for benefits, regardless of means. OAA programs are administered through State Units on Aging (SUA) and Area Agencies on Aging (AAA), and the provisioning of services is tailored to fit area needs. On average 30 percent of each state's SUA budget comes from the OAA (Stone & Benson, 2012).

The Aging Network is extensive, community-based, and includes 56 SUAs, 655 AAAs, non-profit in-home services providers and volunteer and advocacy groups (Carbonelle & Polivka, 2008; Niles-Yokum & Wagner, 2011). According to Kunkel & Lackmeyer (2010), AAAs are diverse and flexible. These strengths empower them to provide a service system that is locally managed, person-centered and coordinated,

benefiting both public benefits-eligible individuals and older adults with chronic long-term functional limitations and disabilities who are not eligible for public programs (Doty, 2010). Many older adults rely on informal care and Aging Network services to supplement their LTC needs (Niles-Yokum & Wagner, 2011).

The Aging Network's strengths include the ability to develop and manage HCBS in a person-centered way, which is responsive to older peoples' needs and preferences, while existing on a limited budget. The Network operates at the local level to identify person-centered resources and has been critical in supporting informal caregiver roles (Carbonelle & Polivka, 2008). According to Carbonelle and Polivka (2003), "the Aging Services Network is poised to play a significant role" (p. 1) in developing a more flexible, balanced, person-directed LTC system.

Since the federal government has reduced funding for social services, increasing responsibility for providing those services has been placed on state and local government agencies already experiencing economic difficulties (Hudson, 2010). As previously mentioned, financial constraints are the result of medical care costs for Medicaid eligible people (Silverstein, Angelelli, & Parrott, 2001).

Back in 1981, Estes and Lee predicted that state-level changes, particularly limitations to Medicaid expenditures, are likely to have a profound effect on medical care for the elderly. They anticipated that three shifts in federal policy would affect the medical care of the elderly: "(1) A significant reduction in federal expenditures for

domestic social programs; (2) decentralization of program authority and responsibility to states, particularly through block grants; (3) deregulation and greater emphasis on market forces and competition to address the problem of continuing increases in the costs of medical care" (Estes & Lee, 1981, p. 511). They anticipated reductions in Medicaid eligibility and in scope of benefits, and the implementation of prescribed standards set to reduce hospital, nursing home, and physician reimbursement. These reductions, in turn, would lead to a decrease in physicians willing to treat Medicare recipients.

Estes' and Lee's predictions regarding Medicaid expenditures were accurate. In 1981, Congress adopted Section 1915 of the Social Security Act which granted a waiver that would reduce long-term care costs. Issued by the federal government, waivers authorized states to expand Medicaid-funded healthcare delivery beyond institutional settings to provide HCBS, including case management, homemaker, home health, personal care, adult day health, habitation, and respite care, and incorporate Medicaid payment systems to include managed care (Thompson & Burke, 2008).

The 1915c waivers reduced Medicaid costs by allowing state officials, with federal approval, to limit provision of Medicaid-approved HCBS to specific geographic areas rather than providing these services statewide, as was previously required by Medicaid law, creating an unequal distribution of services. Although waivers provided flexibility to increase the use of Medicaid funds to provide additional HCBS, they also permitted states to limit, or cap, the number of participants, and generate waiting lists for

HCBS (Thompson & Burke, 2008). Additionally, states were required to keep HCBS waiver costs at or below the cost of services provided in institutional settings for a comparable population. (Shirk, 2006).

With the proliferation of 1915c waivers that allow states to limit HCBS geographically, cap enrollments, and create waiting lists, states are no longer required to subsidize Medicaid services for all eligible individuals. Thompson and Burke (2008) argued that this feature has eroded Medicaid entitlement, since it limits the ability of many eligible consumers to receive services. They pointed out that in the past, factors such as difficulty accessing healthcare facilities, providers unwilling to take Medicaid patients, and complex enrollment procedures created roadblocks for enrollees. Waivers were distinguished by "their endorsement of rationing as a policy principle rather than as an undeclared subterranean outcome of the implementation process" (Thompson & Burke, 2010, p. 23). ADRC and OC programs will likely confront wait-listed consumers, who are hoping to find alternative service options, in geographic areas where limited HCBS are further reduced.

Reduction in Medicaid services and increased Medicare premiums result in increased costs and limited services for consumers (Thompson & Burke, 2010). In offering easy, one-stop shop access to shrinking, more costly services, ADRCs could be confronted with the reality that consumers might not be able to afford to do more than window shop. That is, they can see what is available, but be unable to afford the things

that they require to remain healthy at home. It is within this economic climate that ADRCs and OC were conceived.

Aging Policy. According to Hacker (2004), economic, political, and social pressures have caused a reduction in social services to older adults and people with disabilities. He believes that these reductions have been achieved, in part, through unpublicized political processes and strategies that policymakers and other actors adopt when attempting to transform policy regulations. These practices are significant, since analyses of the consequences of social policy transitions often reveal only the more visible politics of large-scale reform (Hacker, 2004). One way this type of transformation is achieved is through the process of retrenchment.

Pierson (1994) discussed retrenchment as spending cuts that move government social welfare responsibility to a more residual role. In this process, government decreases social expenditures and restructures programs to place greater responsibility on individuals or "enhances the probability such outcomes can occur in the future" (Pierson, 1994, p.1). In other words, retrenchment means that, in an effort to reduce spending, a government introduces deflationary fiscal measures designed to reduce costs related to and economic crisis. One way retrenchment is achieved is by limiting funding for public services. Although many public social programs in the United States have resisted retrenchment, they have failed to offer protection against several risks that individuals and families confront (Hudson, 2010), such as reduced income and access to fewer

resources (Hacker, 2004). For example, some public programs have been restructured to restrict eligibility or reduce benefits. In the private sector, retrenchment occurs when employment-based benefits such as health insurance require higher co-pays and deductibles (Harrington Meyer, 2010).

Hacker (2004) argued that some policies have led to formal reform, replacement or revision of a policy but, more importantly, sources which have occurred with less public awareness or significant alteration to public policy have had a greater impact. For example, the privatization of social policies that have reduced retirement and healthcare benefits coverage shift risk in the form of higher costs and income challenges to families and individuals, and away from social service providers and employers. Viewed from a life-course perspective, the trajectories created by these risks result in fewer resources and increased social service needs for people facing old age, especially for those who are poor.

Hacker (2004) found that decentralization, the federalist tendency to redistribute power and resources from central to state and local government, has also played a role in the emergence of risk privatization. As a result, changes have taken place in formal policies that require state and local government with funding shortfalls to shoulder greater responsibility and risk for funding social services. At the individual level, reduced or eliminated retirement pensions and health insurance coverage have shifted

financial responsibility for financing healthcare from employers and government entities onto individual and families (Harrington-Meyer, 2010).

Families struggle to pay for LTC. In 2010 nursing home costs averaged between $72,000 to $79,000. Estimated median annual out-of pocket expenditures on nursing homecare is $12,680 and for HCBC, $6,648 (Stone & Benson, 2012). Many older adults needing support with ADLs and IADLs and who choose to age in place use their own resources to pay a portion of healthcare expenses (Lewin Group, 2010).

This is the environment in which ADRCs and OC have evolved. To understand their relevance to the programs' development, sustainability, and overall success in meeting individuals' long-term care needs and reducing healthcare costs, the effects of risk privatization and decentralization need to be examined and analyzed within the context of social factor

Societal Factors That Have Influenced the Development of ADRCs & OC

Person-Centered Care. Person-centered care has been adopted throughout LTC, including nursing homes, assisted living, home health, and, most recently, OC. The emergence of person-centered care service models reflects a shift from regarding older adults and people with disabilities as a group in need of guidance and protection to a growing acknowledgement and respect for these individuals' capabilities, autonomy, and personal rights (Powers & Sowers, 2006). This shift in attitude acknowledges that older adults prefer making choices independently rather than accepting decisions made by

family members and providers regarding their care needs. According to Mead and Bower (2000), a person-centered approach to service delivery for older adults and people with disabilities is increasingly regarded as essential in meeting the needs of this rapidly growing and diverse population. Consequently, individuals are regarded as "consumers" rather than "patients" or "clients," and providers discuss service options in the context of individual needs and preferences rather than offering prescribed solutions based on their clinical expertise or social service protocol.

Language can vary among different person-directed service models targeted to different types of disabilities and age groups, yet these models appear to have similar philosophies and service elements. Each provides a range of flexible service options permitting customers (or consumers) to explore a wide variety of HBCS that they believe will sustain or promote their preferences, health, and quality of life (Powers & Sowers, 2006).

Person-centered care concepts are permeating all aspects of health and long-term care (Pioneer Network, 2013; White, Newton-Curtis & Lyons, 2008). Carder (2004) found that LTC providers believe that offering older persons choices increases their independence, even those requiring a great deal of assistance. Further, she found that assisted living providers use consumer discourse in order to create a sense of autonomy and might reduce the stigma of dependency while still providing assistance. The philosophy of person direction recognizes the capacity of individuals to determine their

needs, identify how those needs should be met, and monitor the quality of services they receive" (Law & Britten, 1995, p. 520). According to Mead and Bower (2000), all person-centered care includes six components: exploring the disease and illness experience; understanding the person's individuality; finding common ground regarding management; incorporating both prevention and health promotion; enhancing the provider-consumer relationship; and realizing personal limitations such as the availability of time and resources. Interpersonal aspects of care are primary determinants of patient satisfaction, and patients report valuing such attributes as service providers' respect and empathy, being given sufficient information and time, being treated as individuals, being involved in decision-making, and aspects of the relationship with the provider such as mutual trust (Mead & Bower, 2000). These concepts were clearly present in the development of ADRCs generally and, more specifically, in OC which offers decision support that honors individuals' needs and preferences.

Attitudes Toward Aging and Old Age. Kemper (2003) found that conflicting societal attitudes toward the aged are manifest in a lack of shared values concerning long-term care funding and practice. He found that views about entitlement programs, health care, and other policies developed to assist elders vary depending on individuals' and groups' ages, interests, and attitudes. For example, some individuals are in favor of increasing funding to provide necessary aging services, while others are resistant to further straining already financially challenged health care and social service systems

(Hacker, 2004). Some feel the costs are greater than the benefits in allocating a large portion of public funding for people they consider to be continually declining in health, arguing that that financial support is greatly needed for other social programs (Connidis, 2010).

Discussions of the 76 million aging Baby Boomers often address the financial burden of maintaining old-age policies and programs rather than examining the lives of all Americans as family policy issues needing broad understanding and support (Connidis, 2010; Shultz & Binstock, 2006). Some fail to acknowledge that adequate income allocated through social insurance programs such as Social Security enables aging individuals to avoid poverty and drain family resources. For example, Schultz and Binstock have argued that, "the financial costs of not investing in old age are great for families and societies" (Shultz & Binstock, 2006, p .21).

Addressing aging policy concerns is complex since people define quality of life according to personal experience and values and attitudes about what constitutes need (Kemper, 2003). According to Hudson (2010), these differences make addressing aging issues at a personal, societal, and political level difficult. Additionally, personal fears about aging and dying affect individuals' and policymakers' willingness to focus on age-related service needs and create long-term care policies that respond to those needs (Binstock, 2010; Kemper, 2003).

According to Connidis (2009), societal attitudes toward aging can affect the way in which individuals view the elderly, influence policy decisions, and construct societal norms regarding their value. For example, Myles (2001) discussed ways in which old people are portrayed by some as draining the economy, straining the health care system, and threatening the future of the country. Research conducted by Carder (2002) found that there is a tendency of assisted living proponents to define people who require medical care have personally failed in some way (Carder, 2002). These attitudes are especially prevalent among those who wish to deregulate the welfare state. Miles reported that socially constructed portrayals such as these influence discussion about the amount of responsibility individuals, families, and government should assume and the expectations concerning the extent of care and types of services needed to maintain quality of life for the aged.

Kemper (2003) argued that because the functional limitations due to chronic health conditions associated with age are not dramatic or life threatening, providing funding and implementing policy to support increases in long-term care services are not prioritized. He found that since many older adults with chronic illness are able to manage ADLs and IADLs and family members assume the role of unpaid caregivers, their needs are sometimes not visible to policymakers.

Older adults are diverse, with greatly varying abilities and disabilities and cultural, ethnic, class, and gender differences that make prescribed solutions insufficient

for meeting their varying needs and preferences (Binstock, 2010). A wide range of supports and policy solutions will be necessary in order to address the functional needs and enhance the quality of life for all elders (Binstock, 2010). For these reasons, older adults can benefit from strong and stable political organizations that advocate for their interests (Binstock & Quadagno, 2001) as they manage age-related disabilities, obtain limited financial assistance for HCBC services, and receive care from family members who often have limited time and constrained resources.

Individual Factors That Have Influenced the Development of ADRCs & OC

Phelan (2004) found that most older adults have thought about aging and about aging successfully; her study of elders' views of the importance of healthy aging that found attributes regarded by older adults as important in achieving successful aging to fall into several categories including physical, functional, psychological, and social. Further, she concluded that older adults' views of aging appear to be multidimensional, emphasizing physical health, freedom from disease, and active engagement with life (Phelan, 2004).

A study conducted by Tinker, McCreadie, Stuchberry, Turner-Smith, Cowan, and colleagues (2004), found that quality of life for older adults is directly linked to remaining at home, and independence. Additionally, most elders prefer to age in place and want their personal preferences and their right to self-determination honored (Tinker et al., 2004; Sherman & Dasher, 2005). Moreover, Settersten (2005) reported that

honoring elders' preference to remain safely at home and in the community will positively affect not only the elders themselves, but their family, and society as well.

Care at home is generally the goal for all but the most highly incapacitated elders (Rowles & Chaudhury, 2005); thus, aging in place represents a critical consideration for policymakers, service providers, and researchers within the aging network (Settersten, 2005). Quality care, however, is not available to all, with community-based systems depending heavily on the availability of secure housing and family caregivers (Tinker et al., 2004).

The ability to perform ADLs, IADLs, and mobility tasks necessary for independent living affects older adults' ability to age in place (Guralnik & Simonsick 1993; Kaplan, 2001). ADLs (bathing, dressing, toileting, eating, moving around the house) and IADLs (preparing meals, shopping, managing money, using the telephone, doing housework, getting around outside, taking medications) can be used as reference points for ascertaining an elderly person's physical functioning (AOA 2002). These factors and can provide guidelines for Options Counselors in addressing older persons' LTC needs, and offering appropriate service options.

Elderly living in rural areas face additional challenges, including lack of transportation, geographic isolation, and limited health and social services. According to the National Advisory Committee on Rural Health and Human Services (NACRHHS) (2011), rural elderly are more likely to have limitations in ADLs and suffer from higher

rates of chronic disease than non-rural elderly. These individuals are also more likely to be poor, with 10.3 percent of the non-metro elderly population living in poverty compared to 8.7 percent of the metro elderly population (U.S. Department of Agriculture, 2011). Rural Medicare beneficiaries are more likely to report being in poor health (12 percent vs. 9 percent), make up approximately 25 percent of the Medicare population, and 30 percent qualify for Medicaid as dual-eligibles (Medicare Payment Advisory Commission, 2011).

The NACRHHS (2011) pointed out that ADRCs require an understanding of the unique challenges faced by rural-dwelling older adults, including coordinating access to support programs that are more financially limited due to higher costs of service to a smaller population distributed over a large geographic area. This was the experience in Oregon, as found in a recent study by White, Carder, and Elliott (2012) when ADRC and OC providers noted that in rural areas, resources may simply not be available to people, regardless of their ability to pay. Information and assistance workers noted that in some counties there are fewer resources and that it is important to ask which county a consumer is calling from before offering services that are unavailable in that area **.** Similarly, State agency leaders reported a dearth of services in Oregon's many rural communities, and a need to fill in gaps in services through public and private partnerships. Concerted efforts aimed at resource development and flexibility in ADRC structure and staffing were found to be needed to accommodate different community

needs (White, Carder & Elliott, 2012). Community partners interviewed indicated that the ability to provide services to individuals with limited resources had not improved with the implementation of the ADRC, and the ability to support aging rural residents remained difficult (Elliott & White, 2012).

Family members face several challenges in caring for their aging relatives. Historically, women have assumed the role of unpaid primary care providers, and as more women have entered the paid labor force, finding adequate time to offer care has become a major issue (Neal & Hammer, 2007). Fifty-nine percent of working age women in the United States were employed in 2009, an increase from 43 percent in the 1960s (Bureau of Labor Statistics 2011**).** Neal and Hammer (2007) found that the stress inherent in balancing work, family life, and caregiving duties can affect working caregivers' physical and psychological well-being.

The supply of informal caregivers is affected by current transformations in family networks. Since caregiving is often delivered within a broad family network that includes parents, children, grandchildren and others, households composed of divorced and single parents may have decreased spousal involvement. With less support, greater caregiver burden is placed on care providers (Connidis, 2010). As birth rates continue to decrease, the supply of children available to care for aging family members becomes more limited. Consequently, as the proportion of old to young grows, fewer family members will be available to meet the increasing caregiving needs of a growing number

of old people with chronic care needs (Connidis, 2010). This can be problematic for families who are already experiencing time and financial constraints.

Most HCBC services are not covered by conventional health insurance, however, and many low-income and impoverished individuals and families cannot afford them (Hacker, 2004; Myles, 2001; O'Shaughnessy, 2008). Medicare offers acute care coverage but does not provide HCBC services to meet the needs of those aging and aged individuals who wish to age in place (Kemper, 2003). As caregiving needs for older adults grow and caregiver availability is reduced the problem of finding and financing care becomes increasingly more complex.

According to Brach & VanSwearingen (2002), women and minority elders are the most likely to be impaired and in need of long-term care assistance. They found these individuals are also more likely to live in poverty, face greater service needs due to decrease in physical functioning, and have fewer resources to access costly services. These factors increase the possible loss of independent living status (Brach & VanSwearingen, 2002; Kane et al., 2003).

ADRCs and OC programs are intended to go beyond traditional information and referral services to help consumers identify goals and learn about the range of public and private sector resources available to meet their needs and preferences, and live independently (AoA, 2011).

Ways in which Various Actors (Advocates, Policymakers, and System Decision Makers) Define the Goals of OC

OC and other home-and community-based, LTC programs, including those offered through public, not-for-profit, and for-profit agencies, are shaped by policies developed at the federal, state, and local levels. Policies and services that support information and access to HCBS were created in response to the increasing numbers and increased longevity of older adults, and the fact that old people typically wish to avoid nursing home placement and instead, age at home (Lehning & Austin, 2010). Policymakers, state decision-makers, and researchers indicate that multiple benefits exist in shifting the emphasis from institutional to home-and community-based care (HCBC), including cost effectiveness and older adults' preferences to remain at home (Lehning & Austin, 2010; O'Shaughnessy, 2008; Oswald et al., 2007). Surveys of older adults, even those in substandard housing, reveal that more than 90 percent want to stay in their homes for as long as possible (AARP, 2006), and that nursing homes represent settings of last resort for most older individuals (Vasunilashorn, Steinman, Liebig, & Jon, 2012).

Six competency areas for OC have been identified by AoA (2012) including: determine the need for Options Counseling; assess needs, values, and preferences; understand public and private sector resources; demonstrate respect for self-determination; encourage a future orientation; and follow-up all require a person-centered approach. This is especially true for three areas: assess needs, values, and

preferences; demonstrate respect for self-determination; and encourage a future orientation. Arguably, the three remaining areas (determine the need for OC; understand public and private sector resources; and follow-up) also require a person-centered focus to be applied effectively.

In Oregon, these six competency areas served as a starting point for a systematic job analysis, which was used to develop professional standards for Options Counselors, refine the OC training program, and design and conduct an evaluation of the ADRC and OC program. In 2010, Portland State University received a contract from the Oregon Department of Human Services to conduct this systematic job analysis using subject matter experts to identify core job tasks and associated job requirements (i.e., knowledge, skills, abilities, and other traits) related to the six competency areas (White, Foucek-Tressider, Carder, Truxillo, Barios, & Jackson, 2012). Person-centered care concepts are central to these standards. For example, in assessing needs, values, and preferences, the Options Counselor identifies the consumer's situation and issues, preferences about where to live, perspectives of needs and values, level of knowledge about options, and functional limitations. Each competency is complex, with numerous components, and standards were constructed to support Options Counselors in developing person-centered support skills (White et al., 2012).

Since the aging experience is shaped by social context, cultural meaning, socioeconomic status, and social structure (Rowles & Chaudhury, 2005; Schultz &

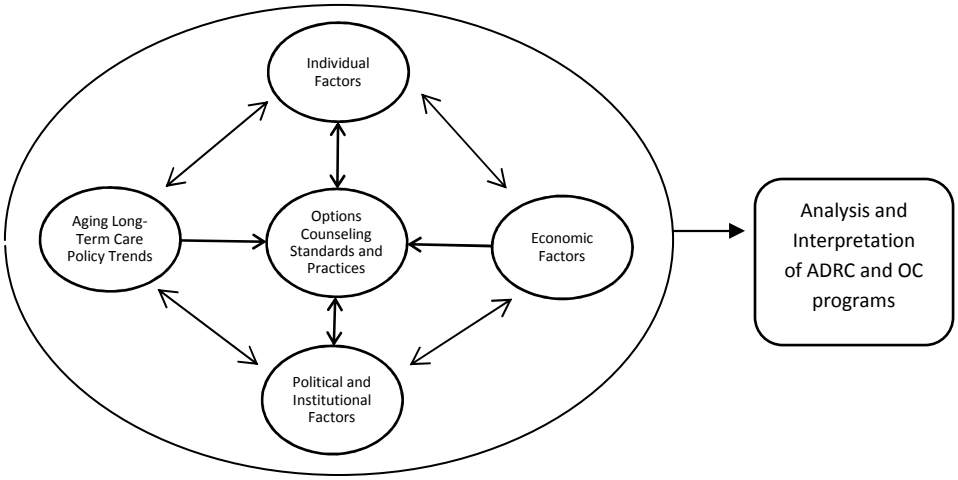
Binstock, 2006; Setterstein, 2005), perhaps the core components of Options Counseling (ease of site accessibility, personalization, knowledge, empowerment, and guidance) will minimize the effects of unequal resource distribution on older adults and people with disabilities. Perhaps public policies, driven by economic factors and the positive aspects of a neo-liberal climate that values independence and freedom of choice, can equalize and reshape the experience of aging to ensure that more older adults are able to maintain health and quality of life (Schultz & Binstock, 2006).

At every level, challenges to develop cost-effective LTC options for older adults are evident (Carbonelle & Polivka, 2008). Aging and Disability Resource Centers, person-centered care models, and Options Counselors address these challenges by offering guidance to older adults and people with disabilities in meeting service needs while accounting for individual needs and preferences. This literature review has offered a snapshot of the economic, political, social, individual, and historical trends in gerontology and the theoretical constructs that will be used to inform the analysis of ADRCs and OC.

The concept model below was constructed during and after the literature review, and provides a visual representation of the interrelationship of the historical, individual, and political factors influencing ADRCs and OC, and indicates the way in which these components guided the study's research. Originally, the study intended to analyze and interpret OC, without addressing ADRCs, and the box outside of the circle read

"Analysis and Interpretation of OC." However, after the literature review was completed, it was evident that OC exists as a core function of ADRCs, and must be analyzed within the context of that program. Furthermore, the two programs were conceived together, and the outcome of each depends on the other. For instance, if a consumer is in need of additional assistance after discussing service needs with an ADRC information and referral worker, the consumer is referred to an Options Counselor for additional support. Thus, ADRC analysis and interpretation was necessary.

Figure 1: Concept Model



Chapter 3

Methods

Aging and Disability Resource Centers and Options Counseling claim to rebalance the long-term care system by providing easy access to HCBS, thereby reducing preference for institutional care. In addition, the programs claim to promote equality by suggesting LTC service options to all people, regardless of means. This study was designed examine these claims by analyzing factors that have influenced the programs' development, and by determining whether the programs are in a position to accomplish intended goals. Because ADRCs and OC are relatively new programs, this research is considered to be exploratory in nature. Developing and using a study guide that consisted of open-ended responses and probing, allowed flexibility to explore interview participants' perspectives regarding the nature of the programs' evolution and implementation. Using grounded theory method allowed flexibility to code and recode to unify participants' ideas analytically, and to code and recode as new meaning and insights emerged.

Data Collection

Primary data were collected using semi-standardized, in-depth interviews conducted either in person or over the telephone. Telephone interviews were conducted with out-of-state participants and with some participants residing locally due to work and

time constraints. Two state decision makers and two academicians chose to participate in face-to-face interviews. These were conducted at PSU in a private office space. A total of 15 interviews were completed. All were audio recorded and transcribed.

Sample

Key persons interviewed were experts in the area of aging, aging policy, and/or aging services. These included advocates, system decision makers, policy makers, and academicians.

Initially four participants in each category were to be recruited through referrals suggested by Portland State University's (PSU) Institute on Aging (IOA) staff. All were experts in the areas of aging, aging policy, and/or aging services. In addition, several key experts known to the researcher through their affiliation with PSU's IOA agreed to be interviewed. These experts were selected based on their knowledge and ability to inform the strengths, weakness, and development of ADRCs and Options Counseling. Many of the experts interviewed have been instrumental in health and aging policy and service development and research and possess insider knowledge not available to the general public regarding attitudes and interests motivating the actors. They brought years of experience and insights about aging politics and research and therefore provided a unique historical perspective in understanding factors that influenced the development of Options Counseling. Snowball sampling was then used to locate additional key experts.

With the help of one federal policymaker, the researcher was able to obtain interviews with key experts involved in ADRC policy implementation.

With two exceptions, all key experts asked to participate were interviewed. One director in the area of elder advocacy who agreed to an interview was contacted numerous times but could not find the time to commit. One was contacted by email, and several phone messages were left requesting an interview, but calls and email were not returned. However, interview participants holding dual roles as researcher/advocate or as academician/advocate and two federal policymakers provided interviews that yielded rich data to inform topics that the two unavailable recruits would address. A fifth state decision maker was recruited because, after conducting a number of interviews, the researcher found it necessary to add the perspective of an additional state decision maker with front line experience.

The table below provides a breakdown of the participants' roles in aging services and their positions. Interviewees are identified only by their roles when they are quoted in the findings section. Roles were attributed to comments rather than individuals' names or titles because while some participants were willing to allow comments to be associated with their names, others were not. To avoid confusion and to provide a consistent format, roles were used for all participants. Further, two of the participants asked that the researcher use care when attributing their names to certain responses and not others. Roles were assigned to all participants since it would have been difficult to determine

which responses to quote, which to avoid, and what "use care" meant. In addition, providing roles rather than names when presenting the results informed the data, provided context, and identified how different roles are related to views about the topic.

Table 2. Interview participants

Sample (N=15)			
Interviewer participant roles and titles			
Federal policymakers	**State (Oregon) decision makers**	**Academicians**	**Advocates**
Centers for Medicare and Medicaid Services (CMS) Director	State Units on Aging (SUA) manager	Researcher//academician	Culture change advocate
Federal director//evaluator	ADRC Program Analyst	Political scientist/academician	Researcher// elder advocate
Deputy Assistant Secretary	Department of Human Services (DHS) Program Analyst	Director/academician	Senior Vice President (SVP) analyst/advocate
Senior policy analyst-Department of Health and Human Services (DHHS)	Area Agency on Aging (AAA) program manager		
	County program manager		

Interview protocol

The interview guide included eight questions and can be found in Appendix A. Topics included those related directly to the research areas, and to the concept model. Probing beyond the prepared questions was done to gain a detailed understanding of each individual's experiences and expectations of the ADRCs and Options Counseling.

Interview documentation

All interviews were audio recorded and then transcribed by the researcher. The time of the interview, date, and interviewee name were documented, and notes were taken. Recordings are stored on the interviewer's PSU hard drive. Back-up copies are stored on a flash drive in the interviewer's office, which is locked when unoccupied.

Analysis and Interpretation

Coding procedure. After transcription, each interview was re-read and placed in a Word document table for coding, where line-by-line coding was conducted. The interview text was deconstructed and classified to reveal preliminary categories and themes then moved to Excel for selective coding, analysis, and final coding.

Qualitative data analysis using a constructivist approach in grounded theory (comparative analysis- making comparisons between data, codes, and categories to compare ideas and topics discussed among interview participants) (Charmaz, 2006) tested emergent concepts. Cross-case analysis to locate patterns and themes common to each topic was conducted throughout the process. Emergent factors were then aggregated thematically by respondent and question. Next, these themes were incorporated into summaries where recurrent words were highlighted, counted, and reorganized into categories and sub-categories for further analysis. Relationships among categories were then analyzed, an outline produced, and a first draft written. A detailed outline of the coding procedure can be found in Appendix B.

Individual interviews were transcribed then coded using open coding. Text was examined line by line, using the constant comparative approach, which involves making comparisons during each stage of the analysis (Charmaz, 2006). This approach was employed during this study to provide systematic rigor throughout the research process and minimize bias effects (Patton, 2002).

Next, categories were developed, and the text was scrutinized to ensure all data informing the category were included. Quotable quotes were highlighted and organized by category. Differences and similarities in views, feelings, and examples were noted, and the most significant and recurring codes were highlighted.

Participants' responses were organized by interview question and placed on separate Excel sheets for final coding. Responses from each question were compared, and relationships were established among concepts. Like responses and outliers were grouped. Then, responses were compared and grouped by category and summarized. Repeated words, phrases, and themes were counted and organized by category and sub-category. Relationships among categories were examined and outlined.

The first draft discussed patterns and connections found in interview participants' responses to determine ways in which the data were connected, and the extent to which responses answered the research questions. The final draft was then constructed. It clarified central issues and concerns, opposing views, areas of agreement and argument, and generated and introduced contrasting theories to increase understanding of the topic.

Researcher bias. Use of data triangulation (Patton, 2002) (i.e. interview guides, literature, policy papers) and theory triangulation (Patton, 2002) (i.e. life-course perspective, political economy, social constructionist) minimized bias in the study, since literature was drawn from several areas. In addition, the study's development was monitored by thesis committee members who are experts in gerontological research. Agreements and disagreements within the literature were examined so that divergent findings and their implications would be understood (Light & Pillemer, 1984).

Interviews

The interviews, conducted by the researcher, addressed the individual, economic, political and institutional factors, and aging long-term care policy issues relevant to the development of ADRCs and Options Counseling. Probing follow-up questions yielded further detailed information.

Analysis

During the initial analysis, related concepts and themes emerged across all eight interview guide questions. As a result, it became necessary to group and analyze data within the context of the four research questions to determine relevant patterns and connections, clarify central issues and concerns, and examine areas of agreement and argument.

The results of the study are presented in four sections. At the end of each section, the results are summarized and compared to the literature review to determine

similar and dissimilar views. In the first section, the analysis of participants' responses that address the research question about historical, economic, political, social, and individual factors that have influenced the development of OC is presented. Second, the analysis of participants' responses to the research question about how the various actors (advocates, policymakers, and system decision makers) define the goals of Options Counseling is presented, summarized, and compared to the literature review. Third, analysis of participants' responses that address the research question about which theoretical constructs clarify the reasons for the development of OC is presented, summarized, and compared to the literature review, as were the first two questions. The fourth and last question is presented in the discussion section. This question addresses the economic, political, social, and individual advantages and disadvantages of ADRCs and OC.

Chapter 4

Results

Factors That Have Influenced the Development of ADRCs & OC

This section covers participants' perceptions of the evolution of ADRC and OC programs from 2003 to present. Discussions include the political and economic motivation for the partnership between AoA and CMS to fund the programs; ways in which the Older Americans Act and the Centers for Medicare and Medicaid Services' intended goals in offering information and assistance to all older adults influenced ADRC development; the shift in preference from institutional to home-and community-based services in long-term care; and the shift from discretionary funding to national standards program requirements.

Historical, Economic, and Political Factors. According to interview participants, the ADRCs and OC were key components in the federal effort to "rebalance long-term support systems," and create "an effectively managed, consumer-driven system of long-term support."

Three of the interview participants in this research project were architects of the 2003 ADRC proposal and constructed the program for nationwide distribution. Although the ADRC concept was originally formed as part of Title III of the Older Americans Act in 1987 (termed Aging Resource Centers for Help (ARCHES), the one-stop shop model

emerged in its current form with the 2003 and the subsequent 2010 and 2012 grant announcements that provided the means to expand the program. Interview participants' responses regarding the history of ADRC development follow and provide a historical context for federal policymakers' motivation in creating and promoting the program, state decision-makers' interest and attitudes toward the program's implementation, and academicians' and advocates' insights about the reasons for ADRC development.

Interview participants reported that the rapidly increasing aging population and long-term care service costs motivated the federal government to find ways to streamline access to the social service system and to expand opportunities for older adults to age in place. All recognized that as older adults' service needs continue to increase, it is necessary to reduce the cost of long-term care provided with public funds such as Medicaid nursing home placement. "There is an undercurrent in the motivation for ADRC development to slow the cost of publicly funded programs like Medicaid nursing home placement," a state decision maker reported.

An academician reported that national data confirm that from an economic standpoint it makes sense to assist aging individuals with functional limitations to remain in the community for as long as possible. "This approach," the person noted, "reduces institutional long-term care costs." According to the federal policymaker:

> This goal (in creating ADRCs) was to prevent people from entering nursing homes prematurely… It was believed that if individuals could be diverted from nursing homes for some time there is a dual benefit of meeting individuals'

> preference to age at home, and reduce the significant cost associated with institutional long-term care.

A federal policymaker confirmed that the motivation to create ADRCs was two pronged:

> It's what people want and it is more cost effective. In study after study we found the average costs in the community were less that the average institutional cost …On average, overall it's much more cost effective and it supports all of the principles that everyone was in favor of – personal dignity, person centered care, person directedness, community participation.

Policymakers' motivation in developing and expanding ADRCs. According to a federal policymaker, both the Administration on Aging (AoA) and the Center for Medicaid Services (CMS) recognized that information and assistance programs were insufficient to inform consumers of available public and private service options. As a result, AoA and CMS forged a partnership to implement a more centralized approach to providing information and access to the long-term care (LTC) system.

Federal policymakers who were interviewed identified the partnership as the first significant AoA and CMS program intervention initiative. This is consistent with the reasons cited in the literature review for the programs' creation (AoA, 2011). ADRCs and OC programs developed as a result of this partnership. The collaboration was considered to be both politically and financially beneficial, and presented an opportunity to enhance nursing home diversion, coordinate care and resources, and provide a place for consumers to easily access to the social service system. According to an academician:

> The [ADRC policy] agenda was essentially designed to elevate and strengthen the role of the Aging Network in long-term care, building on [its] success over a 20 plus year period when it had played a leadership role in most states in creating home-and community-based care systems. Our perception was that we needed to build on that foundation and take the Aging Network to the next level in creating a more fully coordinated long-term care system…that puts home-and community-based systems and nursing home care together under the aging network apparatus, both at the state and service delivery levels.

This partnership, he said, was considered essential in achieving a more prominent role for the Aging Network in managing long-term care. This statement is consistent with literature discussed in the literature review regarding the ability of the Aging Network to manage a wide range of HCBS with limited funding (Carbonelle & Polivka, 2008).

> A federal policymaker added the following perspective:
> The Assistant Secretary for Aging at AOA sought to forge a partnership with The Centers for Medicare and Medicaid [recognizing] the need to engage the Medicaid agency at all levels [federal, state, local] if AoA was to play a meaningful role in long-term care.

The Role of the Older Americans Act in shaping ADRC concepts. Core ADRC and OC functions include providing easy access and information to the service system (AoA, 2011). These functions first emerged in the mid-1960s, when information and assistance and consumer counseling services for older adults were prioritized by the federal government under the Older Americans Act (OAA), according to a state decision maker. These services, she said, have always existed as core functions under the OAA, and the federal funding match has been integral to Aging Network functioning.

Originally, she explained, the goal was to assist older adults of all income levels in accessing public and private social services, but instead the focus was placed on serving only Medicaid eligible recipients. “So the 90-plus percent of the population that will never need to access a public benefit hasn’t had a good, robust system to engage with in order to understand with a private paid dollar, how to plan for their long-term services and support needs,” she said.

Aging Network services are funded jointly with federal and state dollars. State interview participants all acknowledged that the OAA never proposed to use federal money to fully fund information and assistance, and expected local engagement and local support to sustain those services. As the older population grew and service needs increased, however, federal funding remained flat, placing increasingly greater responsibility on states. A state decision maker described the difficulties that resulted:

> [The federal government intended] the program would be a model of incentivizing a local area to provide [a] service. They still, I think, were remiss in at least not keeping up with inflation. I mean, the funding has fallen behind over the years. [What they provide] is like a matching grant and they would provide a dollar and the local community would provide a dollar and together you would have two dollars to fully fund the service. Now it provides a dollar and you need about three dollars of local funding to provide the service.

Yet, the federal government has been hesitant to increase funding to OAA programs. The state decision maker pointed out that the OAA is funded without restrictions, and successful measurement outcomes are not required. As a result, Aging Network services such as information and assistance, and meal programs provided to

older adults through the Aging Network have not been assessed to determine whether they are cost effective and meet intended goals. “The time has passed to be able to secure funding and commitment on the part of policymakers with anecdotal stories,” a state decision maker warned. She believes that ADRCs have been embraced by federal policymakers because the program is required to measure performance and outcomes.

Reexamining the Medicaid mindset. A federal policymaker emphasized that Medicaid favored funding long-term care in institutional settings since nursing homes provided a range of services and housing in a convenient, accessible package. This “Medicaid-only mindset” was fueled further since Medicaid is the largest healthcare funder. He provided the following example:

> … when a hospital discharge planner is… looking for a convenient discharge plan, or when a family is struggling with an elder or other family member who they’ve been trying to support in their own home, [attempting to] manage an array of services…the nursing home has been a convenient one-stop package where the funding was available, the packaging was available, the convenience was there, and so over time we ended up with most of the folks who required high levels of supportive care to be cared for in the nursing homes.

Furthermore, if Medicaid recipients preferred to remain at home, public benefits to assist them were limited and difficult to find making institutional placement more convenient, especially during times of healthcare crisis. A federal policymaker provided the following example:

> If an individual went into a hospital, coming out in a wheelchair, there was no ability to get them back home because they would need a ramp, plumbing cut out for the sink, [and] a variety of other services that no program paid for.

All interview participants recognized that for private pay individuals who did not qualify for public benefits, obtaining long-term care services was difficult. Families were required to put complex service packages together without support, a federal policymaker pointed out, and this process was time consuming, requiring sophistication and extensive family management.

Eventually, several interview participants said, providing long-term care in nursing homes created budget shortfalls at the state and federal levels and policymakers were required to seek alternative methods of long-term care.

Home-and Community-Based Long-Term Care (HCBC) Expansion. According to an advocate, since the 1980's HCBS expansion at the federal level has included a one-stop shop concept for all states and has been intended to incorporate aging and disability service, communities, and resources. The Aging Network was in favor of this coordination.

As the need for affordable HCBS became apparent, the federal government developed The Home-and Community-Based Waiver Program in 1981. A federal policymaker reported that the waivers allowed states to divert Medicaid funds normally used to provide institutional care to provide additional HCBS. According to a federal policymaker, the program exhibited positive outcomes. In the almost eighteen years that it was administered, the older adult population in Wisconsin, for example, increased by

32 percent, but the census of Medicaid individuals in nursing homes decreased yearly. By 1999 nursing home admissions were 19 percent lower despite the population increase. "The key factor was the greater availability of community opportunities through the (waiver) program," the federal policymaker maintained. He provided the following example:

> Neighbors that would volunteer to take the elderly person or disabled person who was enrolled in the [waiver program] and take them to the doctor, but they needed gas money and Medicaid would not pay for gas money, but it's much more cost effective than to hire a personal care aid to take someone to the appointment where you're paying a salary to the aide as well as transportation expenses. We could just pay the neighbor the gas money so that's what we did with Community Options, and for the first time with the HCBS waiver Medicaid legislation Medicaid said, 'Hey, that's a good idea we'll allow states to use Medicaid money to do what Wisconsin and Oregon are doing right now.'

He acknowledged that implementing the program "was a struggle every step of the way because it was a threat to the NH industry." He and other state decision makers worked with these institutions, reassuring them that their intention was to offer better community choices, create an affordable long-term care system, and not to drive the [nursing home] industry into the ground. They proceeded gradually. Many nursing home providers opposed the transition while others favored offering broader long-term care choices.

As waiver programs implementation expanded to more states, federal concerns surfaced quickly. According to a federal policymaker, The Office of Management and Budget was very concerned about woodwork effect, a topic addressed earlier in the

literature review (Silverstein & Parrott, 2001, National Alliance of Caregivers, 2011), where more people will use HCBS if they are expanded and publicly funded since HCBS are more attractive than institutional placement to most consumers, "so it was war for most of the 1980s as parts of the federal government and states worked to show that community care could be cost effective as well as what people wanted."

The advantages and disadvantages of waivers were discussed in the literature review and include concerns about the ability of states to limit provision of Medicaid approved HCBS to specific areas, or to cap enrollment and generate waiting lists (Thompson & Burke, 2008). Although these practices help to increase HCBS options, the number of eligible individuals receiving services is decreased since states can cap enrollment and generate waiting lists.

One-stop Shop Access to the Long-Term Care System. The social service system, interview participants agreed, has been confusing and overwhelming for consumers to navigate. Most believe ADRCs and OC address these issues by providing easy access to the home-and community-based long-term care (LTC) network. All but two participants emphasized offering easy access, information and assistance, and Options Counseling would enable consumers to preserve resources and postpone or avoid spend-down to Medicaid and nursing home placement. A Federal policymaker discussed the need to increase awareness of available services:

> It was believed in many circles that in some ways the provision of HCBS was almost accidental. If people happened to find out about the availability of services it was provided to them, but there didn't seem to be any formal significant, organized approach to (informing) populations and communities (about) a full range of CBS and targeting counseling about those services.

All interview participants further recognized the importance of providing easy access to the service system through a single entry point for older adults of all income levels and their caregivers. By locating lower cost, community-based alternatives to nursing homes, seven participants believed that both public-benefit eligible and private-pay consumers could preserve personal resources and avoid crises that result in the need for institutional care. A state decision maker confirmed the benefit of early intervention and provided the following example:

> We have worked with clients that have experienced savings. We know they have, because we've moved people out of the nursing facilities. There was one individual that our options counselor worked with that had very unique needs, and facilities tend to add on different charges depending on what the needs are. So this person was paying even more than the standard private pay rate. An options counselor worked with him and the family to set up an in-home plan at private pay and it was half what the person was paying in the nursing home.

As the need to provide streamlined access became clear, interest in developing a policy agenda for ADRCs heightened. An academician pointed out, "One of the things we found extremely appealing right off the bat in another state was that the ADRCs were not just for poor, Medicaid elderly, but all elderly and their families." He provided this example:

> [The Federal Assistant Secretary for Aging] said…In [this city] half the families end up tearing their hair out because they don't know where to go. They keep getting shuttled from one place to another. But that was not happening in [another state], so for private pay and people likely to be publicly supported, this was the go to place and that's precisely what we wanted.

A state decision maker found that although people are hungry for information about long-term care and are concerned about rising healthcare costs, many public benefits-eligible consumers, private-pay consumers, and their families are unaware of available services that allow them to age at home. Two participants described personal experiences where they were asked for professional advice on these topics in social situations. A state decision maker provided the following example.

> We have one employee that lives in a place where it has a high concentration of retired folks, and she used to say, "I can't go for walks at night because they all come out and grab me and ask me questions.

A state decision maker experienced a similar situation:

> I was at a wedding shower once and ended up talking with somebody that I didn't know, and in the course of the conversation (we) asked each other what we did for a career, and as soon as I said that I work for senior services, that's the person I talked to for the rest of the evening because…they were so desperate for information on how to care for their older parent…and that has happened over and over again. I talk to colleagues and (it's) the same thing, so it's pretty well known that our system has been confusing to navigate.

According to a federal policymaker**,** people attempting to gain information and access to public benefits become overwhelmed with the daunting array of long- term care service options and service benefits. He felt that ADRCs want to address this issue. A federal policymaker confirmed that observation and provided the following statement:

> ADRCs were created to minimize consumer confusion about long-term care services and supports, assist aging consumers and their families in navigating the fragmented service system, make informed choices about services that honor needs and preferences, and enable these individuals to age in place.

A state decision maker had a similar response regarding ADRC goals. She said, "(ADRCs) offer a no wrong door, highly visible, robust front-end service with high quality, professional guidance for individuals of all income levels needing to navigate the numerous choices available for long-term service supports."

Another state decision maker provided a personal example of her difficulty in finding services for an out-of-state aging relative:

> I was trying to access OAA services. It literally took me all afternoon. I started thinking this was a hidden service because they didn't really want people to access it and… I've been here [at senior and disability services] for seventeen years; I even know the key words to search for.

State systems managers realized that the long-term care service system was confusing to consumers and, according to a federal policymaker, decided to create an entity whereby all admissions to any public program could be accessed easily. As a result, the "one-stop shop" model that was absent from home-and community-based services was developed. He described ADRC core functions as providing unbiased information and access about both community and nursing home options free of charge to consumers and their families. This description is consistent with the ADRC and OC program literature (ACL, 2013).

Motivation for CMS and AoA Partnership. Nine interview participants reported that the need to reduce healthcare costs for older adults was heightened as the country fell deeper into recession. As the federal government sought ways to decrease expensive nursing home placement, the AoA proposed a solution to reduce LTC costs and strengthen the Aging Network's role in providing HCBS (AoA, 2003).

A federal policymaker stated that he and the Federal Assistant Secretary for Aging at AOA recognized that if the Aging Network were to play a meaningful leadership role in the future of long-term care, the Medicaid agency must be involved at the federal, state, and local level, since these institutions provide the largest public payment for long-term care. "Without them at best you can play a marginal role," he said. For this reason, the Federal Assistant Secretary sought to form a partnership with CMS/Medicaid. Together with a federal policymaker, she approached CMS hoping to develop a partnership with CMS to fund HCBC services.

Within the area of LTC these policymakers could have concentrated on many things, a federal policymaker pointed out. They chose to develop ADRCs since discussions of the need to provide more efficient access to the service delivery system surfaced repeatedly in public meetings and in "every serious analysis of issues affecting the elderly." After examining some states that had developed or started to develop one-stop shop entry points to long-term care, they chose the Wisconsin model since it served

not just Medicaid eligible individuals, but older adults of all income levels, according to a federal policymaker.

During that time, an architect of the Wisconsin ADRC was managing the adult care side of CMS. He was approached by the Assistant Secretary for Aging and a federal policymaker and asked to partner with them in developing an ADRC policy proposal. The federal policymaker had participated in the evolution of the Wisconsin program's successes and readily agreed to collaborate. The following comment expresses the pride and excitement a federal policymaker described the way in which the team was formed:

> The lead person at CMS… and I were the key staff who cooked this thing up, so the two of us were equal in status within our organizations and formulated the strategy that we then presented to our respective bosses who then went to the Secretary and moved it forward.

Together the partners educated CMS about the value of the program. The AOA understood and supported the one-stop shop concepts, while CMS needed education and encouragement from a federal policymaker to provide funding for the program he had so successfully administered in another state. He reported:

> [The Assistant Secretary for Aging] went out and looked at the ADRC in Milwaukee and she came back just very enthused. We started planning, and frankly, I was trying to educate people at CMS, but AoA people understood the concepts better than I could get other folks here at CMS to understand, so I put up 5 million dollars and AoA matched it. AoA coordinated that new money in the ADRCs, so the synergy was fantastic.

A federal policymaker was the ADRC Program Evaluator at the time. He identified an additional key person in the program's evolution who provided expert advice and was instrumental in obtaining ADRC funding in 2003. The additional key person is an academician; he provided an additional perspective on national ADRC development. He confirmed that the Assistant Secretary for Aging at AoA asked for his assistance in the program's creation in July of 2002. This academician rekindled the original OAA agenda to "organize the front end" of the long-term care system and emphasized that the AoA/CMS partnership would strengthen Aging Network HCB services and build on previous successes through the implementation of ADRCs. He visited Wisconsin to examine the state's ADRC with the Federal Assistant Secretary and federal policymaker and provided the following insight:

> We went [to the state] and … were extremely impressed that they had done this, had organized both the front end of the system, intake, referral, assessment process and the Family Care [HCBS for consumers], which includes care management organizations as well.

Upon their return to Washington, D.C., this team developed an ADRC grant proposal based on the Wisconsin program, other work in long-term care, and discussions with experts in the Aging Network. The academician, the federal policymaker**,** and the Assistant Secretary presented it to CMS. The team had the good fortune of addressing the federal policymaker directly. "The [federal policymaker]**,** who was one of the architects of Family Care, was there, and so it got picked up by CMS," an academician

explained. He indicated that the effort between CMS and AoA represented a critically important partnership, was the first major program intervention between the two agencies, and "a really big deal." As a result, states received demonstration grants in 2003. "Forty plus states were in the demonstration phase with the AoA/CMS grant. And that's how it occurred," he said.

The development of national performance standards for ADRCs and OC. A federal policymaker was a key figure in the program's implementation. He maintained that since he was in charge of performance measurement at the federal level, he brought knowledge and resources to assist AoA in implementing higher performance measurement standards. He discussed his association with ADRC policymakers and the significance of his role and stated, "This [involvement] represented an important step in strengthening Aging Network funding, since the AoA had lost favor with the Hill for not proposing quality performance measurement for programs."

With a federal policymaker's support in applying measurement standards, the Aging Network could demonstrate successful outcomes, receive credit for accomplishments, and procure ADRC funding. Yet, accomplishing these goals proved difficult for several reasons. Although the federal budget processers were supportive of the request for ADRC funding, policymakers were limited in their ability to increase HCBS funding for older adults, since there were massive expenditures for elderly LTC services in the form of Medicaid and Medicare. The budget examiner questioned the

ability of the Aging Network to divert funds in institutional LTC. A federal policymaker paraphrased the federal budget examiner's reaction to this proposal:

> Look, little AoA and your little Aging Network…and they wouldn't say this disrespectfully, but the rationale behind it [is…] 'We respect what you have done. We respect the performance you have been getting out of this really small network over the last X number of years. That's one of the reasons we have increased your resources even this much, but we don't believe your Network has the capacity to have this significant effect economically on Medicare and Medicaid.'

He believed this absence of trust reflected the lack of understanding of the Aging Network's prior experience administering Medicaid LTC services, and of the potential and the scope of the network to manage and to administer this large an investment. A federal policymaker found the federal budget examiner's reaction to be reasonable. "To be perfectly honest, it's hard to argue with a lot of it," he said.

The budget examiner then required the ADRCs to demonstrate reduction in long-term care costs for the program in order to obtain necessary funds. The budget examiner's office informed Aging Network advocates that it had increased discretionary budgets to implement ADRCs and OC, but it was not willing to increase further unless positive outcomes were demonstrated. They told AoA ADRC policymakers, "…we just can't go all the way with you people until you prove it will generate results." This attitude became problematic, since ADRCs and OC were not fully implemented. Therefore, random control trials to compare groups and determine which were successful in preventing or delaying institutional use were not possible to perform. "You didn't have

a situation where ADRCs through the federal program were implemented fully anywhere," a federal policymaker pointed out. He discussed the roadblock this created:

> You would have to have the two systems in place or at a minimum you would have had to have a circumstance where ADRCs were fully implemented in one place, and then you could do a cross. You could do a comparison across areas, but none of that was possible because the level of implementation didn't allow for that.

Also, randomized control trials require time, and a federal policymaker suggested that this type of research is more than is necessary to determine ADRC and OC outcomes. Yet, if ADRCs and Options Counselors hoped to obtain the additional funding to expand the programs, they would have to implement performance standards developed by the federal government.

ADRC and OC program expansion. Since the 2003funding announcement, federal policymakers have refined ADRC program requirements and now require OC standards development. A federal policymaker clarified the developments. Originally, with the 2003 announcement, he said, ADRC program specifications addressed the States' Balancing Incentive Program which offered a Medicaid federal dollar match for states creating more community-based, long-term care options for Medicaid eligible individuals who wished to age in place.

In 2010, CMS/Medicaid expanded the criteria and announced that an ADRC, no wrong door program could serve both Medicaid and non-Medicaid individuals. For a state to qualify for the federal match, a federal policymaker explained, it was required to

commit to three structural changes: Create a statewide, single-entry point system; standardize the state assessment process; and provide Options Counseling.

To implement these changes, a federal policymaker explained, CMS and AoA developed ADRCs that serve both Medicaid and non-Medicaid eligible individuals. He said that the rationale for including all consumers was to avoid the need for private-pay individuals to spend down to Medicaid and require more costly nursing home services. As a result, all consumers could access long-term care services funded through the Balance Incentive Program, and states could use federal Medicaid funds to pay for the ADRC and OC operational costs. According to a federal policymaker**,** a long-term financing strategy was created and made available to all states, whether or not they received additional 2012 grant funding to expand ADRCs statewide. "That is the future," he emphasized.

The 2012 ADRC grant provided eight states with funding to expand the program statewide. As stated in the literature review, the state of Oregon was one of the eight states to obtain a grant, receiving $2.3 million over three years (ACL, CMS, VHA, 2012). A federal policymaker questioned whether the grant funds will be sufficient to actually provide and expand ADRC services with this budget. He expressed the following concern:

> Does anybody really think that 2.3 million dollars is enough for a state to take ADRCs statewide? 2.3 million dollars in any state is not going to allow that state to take ADRCs statewide. It's just not. Obviously, people who work in

> government are very, very practical. 'I'll take whatever money I can get.' But I don't see those resources being adequate for any state.

A federal policymaker provided this perspective on long-term care regarding the preference to provide LTC in institutional settings:

> Forty-five years after Medicaid and Medicare, most of our rhetoric is framed in terms of promoting independence, and freedom, and community participation for individuals; however, the actual public investments have gone in the opposite direction, with much more investment in providing LTC in institutional settings, rather than supporting people to live and participate in their own communities.

Summary. The findings indicate that originally, in 1965, the Aging Network intended to offer information and assistance for long-term care services to all older adults regardless of means. This goal was not prioritized, however, and most Medicaid-eligible older adults needing long-term care went to nursing homes. Medicaid was well funded, and nursing homes provided an easily accessible, structured, coordinated system where services existed as a comprehensive package. Older Americans Act funding for information and assistance and HCBS was more limited, with fragmented systems that were confusing and difficult to access. Seven participants discussed the need to increase information and access to the public and private long-term care system. All reported that this need was a primary consideration in ADRC development.

Of the 15 interview participants, nine discussed aspects relating to the Medicaid mindset. All were in agreement that this preference for institutional placement was reexamined as the aging population, long-term care costs, and budget shortfalls increased. Although six participants said that increasing HCBS and limiting nursing home

placement had a dual purpose of honoring older adults' preferences to age at home, more emphasis was placed on HBCS as a solution to reduce long-term care costs for Medicaid eligible individuals. Four participants discussed the AoA and CMS partnership. Three agreed that the two agencies joined forces to strengthen the Aging Network services and reduce Medicaid healthcare costs by granting funds to states to implement ADRCs. One, the federal policymaker, said the federal government did not believe the Aging Network had the capacity to manage HCBS for an increasing number of aging individuals and reduce enormous Medicaid budget shortfalls.

Although providing easier access to the social service system in the form of a one-stop shop, single entry point is presented as a primary reason for ADRC and OC implementation, it appears that the need to reduce public benefit program spending was the primary impetus for the AoA/CMS partnership in developing the program and making grants to fund its implementation..

Social Factors

Person-directed methods of service transform the consumer's identity from need based to consumer based (Carder, 2004). This section covers the transition in LTC policy from using prescribed methods of care to considering individual needs and preferences when providing long-term healthcare solutions. Specifically, I summarize the growth of the culture change movement and person-centered care; equity issues manifest in resource availability and distribution; and ways in which unequal distribution of

resources affects long-term care options and the ability of older adults to age within their communities.

Culture change and Person-centered care. According to an advocate, Options Counseling stems from a growing recognition of the need to honor individual preferences in offering long-term care services to individuals. An advocate reported that although OC emerged from the disability and culture change movements, the practice has become more pronounced and focused in the current form.

A state decision maker reported that OC emerged from the culture change movement when providers recognized that individuals should be part of the decision making process. State decision makers and two federal policymakers interviewed confirmed that the culture change movement and the concept of person directed-care contributed to the implementation of programs such as OC that emphasize offering services that honor individuals' needs and preferences. An advocate reported the movement developed primarily because service workers, consumers, and family members became aware of the need for change. According to her, economic considerations were secondary concerns. "You get passion first, and then the organization of it, and the "how to" comes next. (It) hasn't anything to do, in my opinion, with finances," she stated.

Most state and federal decision maker participants agree that the baby boomer cohort is more preference oriented than the Great Depression era cohort, and more

assertive about defining individuals' service needs. This newer cohort of older adults, participants noted, is somewhat more highly educated, with a greater capacity to absorb information and make informed choices. As a result, participants reported that these individuals demand more information regarding long-term care for themselves and their family members and are not willing to accept prescribed solutions.

Their determination with which the Baby Boom cohort demand long-term care treatment methods that honor personal and family members' needs and preferences has directed trends toward service options that are tailored to individual preferences. An advocate pointed out that they are more willing to be very vocal about their preference. According to her, providers have responded by becoming increasingly aware that the older adults are able, for the most part, to make their own decisions and have responded by offering elders greater choice in how care is delivered. She indicated that even people with cognitive impairment have potential to determine their needs and preferences either alone or through a proxy.

An academician and two state decision makers identified shifting social norms to have further prompted the transition from prescribed care methods to person-centered care. These interview participants identified societal trends such as the women's movement, the veteran's movement, the disabilities movement, and the self-help movement as cultivating the growth of personal choice and person-centered planning. A decision maker noted that since baby boomers are more accustomed to participating in

care decisions, they choose to operate in partnership with providers and direct care methods toward better treatment for themselves and family members.

Equity Issues and Resource Availability. ADRCs and Options Counselors offer service options that enable consumers to be in control of their care decisions and, according to most interviewees, have been important in elevating consumer awareness about non-institutional LTC options. However, several questioned the value of providing older adults with information about options when federal and state funds for public services are limited, some individuals are unable to afford supports, or services are not available. When options are neither available, affordable nor accessible within the community, many believed that the significance of ADRCs' streamlined access and OCs' long-term care options, designed to assist older adults of all income levels, are diminished.

For example, an advocate said that even if wealthier private pay individuals are more able to pay for services that honor needs and preferences, ADRCs support is beneficial only if those services are available in the community. Concerning individuals without financial means, participants noted that discussing accessible options might increase awareness of HCBS, but if those elders lack financial resources obtain them, the ability of ADRCs and Options Counselors to prevent spend down to Medicaid and nursing home placement is reduced, and potential for frustration and stress is increased.

An academician cautioned that ADRCs could decline in relevance if resources are not available, because "it will be the place to go and that's it." He pointed to wait lists for community-based waiver services in one state that are in excess of 5,000 to 6,000 and asserted:

> The state will not make efforts to increase revenue base for the foreseeable future, and the state is undergoing a very, very slow recovery. And at the same time, the population needing help is steadily growing, so that's a recipe for growing waitlists.

A state decision maker noted that ADRCs are not mandated to finance caregiving or other services, and. according to a federal policymaker, "It [the ADRC program] is inherently superior to narrowly defined counseling approaches that focus only on what's available by that particular provider." Yet, if more resources exist, there is a greater possibility that providers can offer choices to individuals of all income levels, an advocate argued. She made the following observation. "In theory, Options Counseling assists people with determining service needs, and service options are available to those who can afford them, but when personal and public resources are limited, the ability to meet needs and preferences becomes more difficult, she said." She maintained that OC can be successful if infrastructure is in place that assists consumers in making good choices and if Options Counselors are able to include consumer preferences into the resource distribution process. A state decision maker added that a means to address resource-poor rural areas needs to be included in program development.

A state decision maker addressed an additional issue that can influence the value of ADRCs and Options Counselors to all older adults. She found that distribution of resources in different communities and the number of service options available varies depending on area. She indicated that in Oregon, existing services are being evaluated to determine ways to reduce costs, but in most places in the state "there isn't anything left to cut, especially in the rural communities."

Some states have been successful in matching ADRC and OC assistance with the ability to deliver services. However, according to a federal policymaker, a number of those states have had to decrease funding for resources due to the ongoing recession. An advocate pointed out that in constrained economic times fewer public resources are available, particularly those used for home-and community-based options.

At the consumer level many older individuals' retirement savings were lost when the economy failed and, as a result, they must revise their retirement plans, an academician reported. He explained that most Baby Boomers are unprepared for their future long-term care needs and will be unable to afford services to remain self-sufficient and age in place.

Distributing community-based resources presented additional concerns, since service delivery is dependent on availability. A state decision maker pointed out that even if the economy were strong, community resources in rural areas that assist older adults to age in place would be lacking. "It's just really difficult," she said, since

community services have diminished, and waiting lists for programs that provide in-home services free of charge or on a sliding scale to older adults who are not eligible for Medicaid services are long. “Providers struggle to find ways to do less and maintain a positive attitude about providing service,” the state decision maker pointed out.

An advocate reported that pressure is placed on agencies with scarce resources to assist consumers. A federal policymaker addressed the problem with the following example:

> We could go out and do comprehensive assessments of people’s needs and wants and preferences, but then we would have to say, ‘Okay, we know the 10 things that you really need, and here are the three that we can actually pay for.’ So OC is necessary [but] needs to be aligned and matched by the ability to actually fulfill chosen options.

An advocate responded that OC ability to identify community supports and prevent institutional use is contingent on what options are available to allow “people of like levels of disability to remain in the community.” A federal policymaker **r**eported that numerous factors contribute to issues surrounding resource availability. He noted, “These problems cannot be remedied with a well-developed (ADRC) system that makes it easy for individuals to learn about and access services that meet needs and preferences alone.”

Most participants realized that ADRCs’ and Options Counselors’ value is diminished in an environment where service choices are limited and unaffordable to

many. An academician expressed concern that many private pay consumers struggle to remain at home and maintain quality of life without public support. A state decision maker pointed out that as the elder population increases many private payers are left out of the social service net.

Both federal and state-level decision makers who were interviewed noted that federal motivation to streamline access to services through ADRCs and assisting consumers with future orientation through OC is linked to the need to reduce spending for public insurance programs. The federal policymaker indicated that states will use the ADRC and OC programs to rebalance their long-term care social service systems and discussed the desired program outcomes. "Their systems [will be] more person-centered, more efficient, and more supportive of community living. This rebalancing process is advantageous for both public agencies wishing to reduce spending and for consumers who wish to age in place."

Summary. Four participants discussed culture change as an important transition in long-term care delivery. Three discussed the more preference-oriented Baby Boom cohort as an impetus for the shift in focus from prescribed methods of treatment in long-term care to a more person-centered approach. Thirteen noted that person directed-care contributed to the implementation of OC that emphasizes offering services that honor individuals' needs and preferences.

Participants recognized that providing information and access to all people, regardless of their means, does not necessarily make it easier for all to obtain resources. Twelve of the fifteen participants addressed resource affordability and resource availability and agreed that ADRC and OC relevance is diminished when recommended services are unaffordable to the consumer or unavailable in the community. Two federal participants added that although resource distribution issues cannot be remedied with ADRC and OC services, the program has value because it increases awareness of long-term care options. One participant feared that ADRCs will decline in relevance if the program is not tied to resource distribution. Eight discussed the increasing number of private-pay individuals with limited resources who are without a safety net and unable to afford needed HCBS LTC services.

Individual Factors

This section covers the issue of responsibility for funding long-term care; individuals' ability to pay for desired long-term care services; perceived need regarding crisis and retaining resources; and the importance of family ties in caring for aging loved ones.

Responsibility. Some interview participants cautioned that requiring states and individuals to take a greater share of responsibility in funding long-term care raises concerns about equity and can highlight unequal distribution of wealth at the state and local levels. According to an advocate**,** questions about access, equity, and funding are

raised when resource-rich states and counties functioning with limited federal support are more able to provide services to a larger number of residents than resource- poor communities. A state decision maker found that weak economic factors highlight inequity among states, counties, and individuals. "Consumers are out of work, and the tax base is further decreased. Counties are attempting to climb out of recession with limited resources, (and) resource poor counties and cities must cut a great number of services," she said.

Further issues regarding unequal distribution of resources were discussed within the context of service cost to individuals. Several state and federal participants pointed out that since state programs do not have a federal match for home-and community-based services, there are tremendous variations in program availability and affordability nationally.

Several other factors regarding resource availability were also addressed by federal policymakers. An advocate suggested that rhetoric surrounding meeting individual needs and preferences might be "greater than the reality in implementation," since the more constrained the resources are, the more difficult it becomes to meet consumers' needs and preferences. A federal policymaker noted:

> OC by itself, I would argue, is necessary and not sufficient. What is the point of doing a better job helping people to understand their options about what is possible without matching that counseling with what you can deliver? Over time

> this issue is being addressed at the federal level and some states have been successful in matching ADRCs, OC, and services.

He recognized, however, that offering one-stop shopping access and information about services is more difficult in times of recession, when public and private resources are more limited.

Interview participants discussed whether the burden of responsibility for financing long-term care services found through ADRCs and OC should be placed on individuals, family members and caregivers, or on government agencies. An academician indicated that privatization of public sector services began in the 1980s with the election of Ronald Reagan as president. During this decade, corporate-sector support from government increase, as it reduced financial support for public services. He provided the following observation:

> The Reagan [era began the] road to destruction [of public programs and services]. What you had was a steady drum beat for almost 30 years, and that has affected [social service funding and distribution.] Privatization of the public sector, beginning with Regan's famous statement that the public sector" is not the solution, it's the problem"…That [received] corporate support because the corporate sector has a number of opportunities through privatization to make a lot of money in some areas of public policy…

A state decision maker questioned whether private-pay consumers would prefer to deal with "bureaucratic complexities" in obtaining means-tested services or to remain independent, make independent choices, and fund their own care. "Perhaps most individuals prefer to use their own resources," she suggested.

A state decision maker pointed out, however, that consumers must first perceive they are able to afford the long-term care services they need before they choose to access public resources or use personal funds. She has found that some consumers are unwilling to spend personal savings to fund needed services because they lack understanding about the importance of paying for services that enable them to live at home safely before crisis occurs. She provided the following example:

> Consumers say, 'That's our rainy day fund,' and they don't recognize that this IS their rainy day. They're fine with getting [services] if somebody else is going to pay for it, but a lot of them hold out. They don't recognize that they really need that care, and its preventative. They're not having to lean over and clean their bathtub, for instance, and do the heavy cleaning in their house, and they could maybe fall.

Some participants questioned the advantages of providing easier access to resources through ADRCs and OC without funding them and questioned placing financial responsibility on the ballooning population of aging baby boomers who are without means to pay. An advocate addressed this issue with the following comment:

> ADRCs have to operate in the reality of what is going on, and you can talk about all the wonderful things that they might be able to do, and yes they might be able to do them, and some can do it better than others and some have better infrastructure. Some have better resources, but it's got to be understood within the context of the larger [economic and political] issues.

An academician noted political concerns, surrounding the rapidly increasing Medicaid costs, as one of the larger issues impacting ADRCs' success. He suggested that controlling those costs as a federal government priority, since spending for these

programs influences the amount of funding allocated to other services such as transportation, education, child welfare, and the mentally ill. "These all are pressing social policy issues as well," he said, and indicated that they diminish policymakers' focus on aging issues and older adults. He described the political climate in the following way:

> In this political and budgetary environment, aging and LTC policy is not a priority issue for most people. There is an increasing need for services of all types, and funding to provide those services is limited. It's a negative sum game, and it's getting very nasty at the state level.

A federal policymaker discussed the limited ability of policymakers to fund HCBS for older adults when "there were such massive expenditures for elderly LTC services" (Medicare/Medicaid) as it was. Medicaid costs and shortfalls in all public benefits programs are enormous and represent larger political issues, according to an academician**.** He argued that these issues present obstacles to continued funding of ADRCs and other HCBS programs, since public benefits require huge funding increases for continued sustainability. He described the impact this has on government, families, and individuals:

> We have massive shortfalls in anything from Social Security financing, Medicare, Medicaid. All these programs are running out of money. We would have to spend hundreds and hundreds of billions of dollars to get these programs where they need to be financially, so whether we want it or not, more and more of the burden is going to fall on individuals, and very few boomers are financially prepared. In twenty years from now, where the government says, 'We don't have money to pay for any of this anymore,' and to have individuals find that they don't have money either can be very, very hard.

He argued that the burden of responsibility for long-term care costs will fall on caregivers. Two federal policymakers, two academicians, and a state decision maker who were interviewed highlighted the importance of formal and informal caregiver roles in helping older adults to age in place and reducing long-term care costs. An academician provided the following example:

> This is very established in the literature. In other fields we have seen for every dollar spent, you (save) 22% keeping people out of homes and facilities. For instance, Arno came up with a figure of $163 billion each year spent on informal care. That has almost doubled. We also know that 80% of care is provided informally by friends, family, and neighbors, and it's unpaid.

A state decision maker pointed out that when formal caregivers assist consumers with ADLs and IADLs within their homes, long-term care costs are reduced for both individuals and service agencies. Informal caregivers further reduce government expenditures for long-term care, since family members often pay to provide services for loved ones out of pocket, and according to an advocate, are increasingly required to absorb costs of care for their frail elders. She provided the following comment:

> It's going to bounce back on the family, and all of these programs are already predicated on family. They're not generous. They're not covering everything. They're always predicated on having a family member there.

An academician further contended that the majority the aging population has strong family ties, but that a public policy incentive structure has not been constructed to

reinforce those bonds, since policies do not adequately address caregivers and their needs.

The question remains, then, that if families are limited in their ability to provide necessary levels of supports, or if services are not available in their communities, how beneficial will offering access and information be? Of what value is streamlining access to services that consumers are unable or unwilling to pay for?

Summary. Interview participants discussed equity issues that arise when resources are unequally distributed. Two participants indicated that variations in affordability and availability highlight inequity among and within states and among individuals. Five participants indicated that weak economic factors increase these variations, and seven believed that during times of recession ADRCs and Options Counselors have more difficulty addressing consumer needs. Six participants reported that additional responsibility is being placed on individuals and families to fund LTC services. Seven highlighted that as public service support declines, the financial burden to pay for LTC HCBS is redistributed to individuals and families, and they are required to absorb costs of care. Three participants reported that public policy does not support family ties, and seven questioned the sustainability of programs that link information, access, and options but do not provide the means to obtain them. Five interview participants believed that scarce resources fail to foster a climate of collaboration and

partnership among state agencies, since each provider struggles to do more with less and desires to retain their own dwindling resources.

Ways In Which Various Actors Define the Goals of ADRCs & OC

Options Counseling competency standards are complex, with numerous components designed to offer person-centered support skills. For example, in assessing needs, values, and preferences, the Options Counselor identifies the consumers' situation and issues, preferences about where to live, perspectives of needs and values, level of knowledge about options, and functional limitations (White et al., 2012). Interview participants discussed factors that contribute to the success and sustainability of the practice.

Future orientation. Future orientation, specifically assisting consumers with planning for long-term care service needs, was considered by all interview participants to be essential in delaying or preventing institutional use, and most acknowledged that providing information about available resources with OC is critical in assisting consumers with future planning efforts.

According to a state decision maker, the public system is currently crisis management oriented, not future oriented, and aging consumers wishing to age in place could do so for a longer period if they used HCBS services earlier, before crises occurred. She reported that for consumer planning efforts to be effective in retaining personal resources to age at home, older adults and their families must first be aware of a broad

range of service options available in the community. A state decision maker discussed the importance of OC services in facilitating this process:

> Having a primary Options Counselor on staff who understands consumer needs and fears regarding financing long-term care has a positive impact on lives. Consumers fear future crisis and are resistant to using personal resources. There's always this 'What-if?' in the backs of their mind…

A state decision maker maintained that consumers' use of personal savings to pay for services such as paid caregiving can enable them to remain at home for as long as possible. She provided this example. "I think about elder care lawyers who assist consumers in preserving resources, ways they prefer to spend down to Medicaid, and ways to remain at home as long as possible. [(This] represents what ADRCs are trying to do," she said

Offering information about future orientation can also enable older adults to preserve resources, which is a core function of OC. A state decision maker provided the following example:

> …a resident [in a residential care facility] had a health crisis that caused him to be hospitalized. He was discharged to a skilled nursing facility. He no longer progressed enough to remain at the facility under his Medicare stay but thought that was the only place he could stay. He ended up using all of his assets to privately pay for the nursing facility. Now he is in a residential care facility with the hope that he can get back to his house. Hypothetically, if he had good Options Counseling after his skilled stay, even if he couldn't have gone back home he could have gone to the less expensive residential care facility rather than spending those days at the nursing facility at four or five hundred dollars a day and could have preserved his nest egg or discussed even other options with his family.

A federal policymaker pointed out that without ADRCs and OC, the public service system "will encounter people when they have exhausted resources, and intervention to forestall Medicaid dependency will be too late." According to him, federal policymakers determined that access to a fragmented system and the need to reduce healthcare costs were the most significant issue faced by older adults.

As federal grant funds to provide services become more limited, some participants reported that finding ways to assist consumers in using resources wisely is increasingly important. Several discussed future orientation within the context of the federal government's concern about draining public resources and believed Options Counselors can assist consumers in maintaining quality of life while delaying or avoiding the need to use public services. A federal policymaker stressed the importance of counseling consumers about planning for their futures since federal government funds are limited:

> Previously, the federal government gave grants to states to develop ADRC programs. Now, the federal government is aware that discretionary funding will become scarcer. Helping people make informed decisions before they spend down to Medicaid and before they reach a crisis that requires them to go to a nursing home will preserve resources for all parties. The ADRC is a preventative strategy that enables people to make informed decisions about how to use resources.

Decision Support. Three state decision makers, an advocate, and two federal policymakers addressed the importance of OC's role to empower individuals in determining and achieving long-term care goals and stressed the significance of

considering consumer preferences over provider direction. A state decision maker explained:

> (In) Options Counseling, the decision support is key…It's all about the individual consumer and what they want. We had never been able to do that with private-pay individuals…to go (to a) home and spend an hour or two with the consumer and their family and talk about their specific needs and their specific wants and desires for long- term care.

Several federal policymakers discussed the importance of building person directed relationships with consumers. Both a federal policymaker and an advocate found this process provides more support to consumers who wish to age in place within their communities, and others stressed the importance of person directed support in elevating consumer awareness about affordable non-institutional LTC options. These findings are consistent with literature review discussions of the importance of person-centered care, and the evolution of culture change (Powers et al., 2006).

Options Counselor Competency. The focus on person-centered care was considered a key component of OC by all interview participants. According to an advocate**,** person-centered care represents a difference in philosophy from previous forms of service delivery by emphasizing the consumer perspective and by evaluating how preferred options relate to individuals' circumstances. A federal policymaker reported that person-centered care approaches such as OC are more efficient than previous methods, more cost effective, and more supportive of community living.

A federal policymaker stressed the importance of building relationships with consumers when evaluating needs and preferences. She provided a personal example where a hospital case manager made a recommendation to move her parents to an assisted living facility:

> She [the case manager] said, 'Don't you want your parents to be someplace you'll feel certain they're secure and taken care of , close to an exit from the turnpike, and will be quick for you when you drive in?' [I told her] 'I think it's more important to them that they be close to the church they've gone to for 50 years and that their friends can come and see them. If I have to spend an extra 10 minutes on the highway when I come to visit, I don't consider that a major sacrifice.' The point is [this is] part of what you want, I think, in an Options Counselor. And this is why it is very hard - this whole other dimension to things. I think it's a little hard to get it from a stranger. Things are misinterpreted. Like in my mother's case, I would tease her, and we would talk about why she wanted to go there (to a nursing home) and whether that was literally what she meant…What she was saying was, 'I want to be taken care of.' She was feeling bad, and she wanted people to wait on her and do stuff for her, and I had to gently remind her that was not what would happen in a nursing home.

Options Counselor attributes considered most valuable in determining long-term care options that honor consumers' needs and preferences were knowledge and understanding of long-term care service options, assisting consumers and family members with future orientation, and creativity in locating affordable services that honor individuals' needs and preferences.

State decision makers reported that Options Counselors' knowledge of community resources benefits both Medicaid-eligible and private-pay individuals searching for service options. This attribute, most participants believed, helps consumers

to use their resources wisely to remain healthier at home and delay or avoid more costly institutional placement. According to a federal policymaker:

> Options Counselors' knowledge of the full range of long-term support service options available through federal, state, and local public and private resources has brought greater discipline and organization to the utilization and provisioning of HCBS.

Interview participants noted that offering more organized, streamlined access to the social service system and providing information by an Options Counselor knowledgeable about community resources can empower older adults to make informed choices.

Creativity in locating services, state decision makers found, is a necessary Options Counselor skill. One state decision maker stressed that in a constrained economy, **c**reativity in locating services increases Options Counselors' ability to find resources that honor consumers' needs and preferences. Several state decision-makers indicated that Options Counselors who understand the need to think outside the box in finding community resources are most skillful in linking consumers to services before crisis occurs. An advocate suggested that in the face of diminishing public funds, an Options Counselor's awareness not only of individual needs and preferences but also the ability to link consumers to non-government resources will determine OC success.

State-level decision makers and two federal policy makers consider Options Counselors' ability to honor individuals' diverse needs and preferences to require

complex competencies, including observation, oral communication, and interpersonal skills. According to an advocate**,** "Professionals in the aging field should be educated and have greater skill in offering person-centered care options." She and other state and federal interview participants maintained that Options Counselors require a complex set of abilities to meet standards, including the ability to offer choices and to interpret consumers' desires based on awareness of cohort differences, cultural differences, cognitive abilities, and language interpretation. An academician advised that Options Counselors' competencies are diverse and multifaceted and asked the following questions:

> How good is the information the people are giving out? How good is the advice they're giving out? Do they know the resources in the community? Are they making the right connections? Are they coordinating? Are they getting people from nursing and social work and nutrition together on behalf of clients, or are they unable to do that either out of ignorance or out of lack of resources?

Knowledge of community resources and interpreting consumer needs and preferences accurately can then facilitate implementation of a wide range of public and private service options, according to a state decision maker**.** "They [Options Counselors] provide a vehicle to better coordinate assessments, service plans, and determine eligibility," she advised. A federal policymaker reported that, "Eligibility determinations for people appropriate for public long-term social service programs are streamlined."

Participants were in disagreement about the necessity of setting national standards to ensure Options Counselors exhibit these skills. Some believed that standard

requirements will ensure Options Counselors' proficiency, hold Counselors accountable and make program outcomes easier to achieve and assess. They acknowledged that if Options Counselors lack the capacity to interpret consumers' desires and offer a wide range of choices that maintain or increase quality of life, then the ability of the program to be successful diminishes. Others, however, fear that requiring Options Counselors to follow a prescribed set of standards will limit their ability to address regional needs and issues unique to their population and area.

A federal policymaker described the pros and cons of requiring Options Counselors to meet standards in the following way:

> The downside of [not requiring standards] is that there are probably [Options Counselors] out there that are not really cutting the mustard by any standard, so a lack of national standards means you can have some very, very low performers. The up side is the concept of tailoring the system to local conditions and local needs, since every state LTC system is different, and there's so much discretionary authority for Medicaid programs. Then anything you design has to conform or relate the system it is trying to help you to get into. So there would have to be differences.

A state decision maker stressed the necessity of standards requirements. She found that state goals of establishing criteria to determine Options Counselor competency to be a highlight of ADRC and OC development in Oregon. "This topic should have been included in the Oregon discussion earlier on," she suggested.

Knowledge, Skills, Abilities and Other Traits. Although ADRCs and Options Counselors do not fund or distribute the HCBS they recommend, most interview

participants found that the benefit of offering information about affordable service options increased consumers' ability to plan for the future and to feel more in control of their lives. Three state decision makers interviewed found that listening and offering support "without judgment and preconceived notions" has merit. One state decision maker observed, "There's a sense of personal dignity when you're able to know what you can and cannot do and then make the choice for yourself."

An advocate stated that OC has been important, "if nothing else, symbolic," in heightening awareness that other choices for long-term care exist beyond nursing homes.

A federal policymaker believed that offering one-stop shop information and access through ADRCs without actually providing the means to obtain services is equitable because it presents consumers of all income groups with a more convenient way to acquire desired services. He stated:

> It's generating public support and it's a public service, and that public service pays off in terms of [offering support t] more consumers and families. [It's] more cost effective and [with] consumer-preferred choices, people understand that they have more options than many of the more expensive choices that end up getting advertised. In particular community services [have merit], because people are pretty well aware of the institutional options that are available but they are much less aware of the cost- effective community services and supports that can be available to help people stay in their own homes.

Program assessment. State decision makers, academicians and two federal policymakers reported that assessing program outcomes is critical for ADRCs and OC to receive ongoing federal funding. State decision makers believe infrastructure allowing

states to collect and analyze data will assist in understanding the ways in which service outcomes impact consumer lives, direct healthcare spending, and reduce the number of nursing home placements. A state decision maker indicated that if providers invest in assessing program adequacy and are able to determine consumer satisfaction, the programs will be considered successful by legislators and policymakers, and funding is more likely to continue. Another state decision maker added that if people remain at home as long as possible, Medicaid costs will be reduced, since nursing homes are the most costly LTC options. She believes a measure must be implemented to show a decrease in the quantity of consumers utilizing public assistance and Medicaid. Yet, another state decision maker suggested that if the data collection system is easily utilized in the field, it will be possible to track OC consumers and Medicaid recipients to determine their ability to avoid institutional placement. "If data indicate that Medicaid-eligible individuals with limited resources are maintaining quality of life at home after having received OC, then the program can be considered successful," she said. An advocate pointed out that another benefit of program assessment includes holding providers and contractors accountable for meeting service standards and determining whether outcomes meet intended goals.

Participants expressed concern that existing state measurement systems are weak. A state decision maker reported that state data systems are not reliable, and that the tracking of OC recipients to determine whether they have remained at home or are

relying on Medicaid will be a difficult and complex task. She expressed concern that at this time OC recipients are few, and that in a consumer satisfaction survey conducted by Portland State University for the state of Oregon in 2012, consumer self-report data indicated that some consumers might be receiving information from multiple services and providers; therefore, the data may not represent the impact of the ADRC and OC (White et al., 2012).

State decision makers identified Area Agency on Aging (AAA) attitudes as problematic when the agencies are required to demonstrate successful program outcomes. According to a state decision makers**,** measuring program outcomes were absent in the past, and agencies were not required meet goals and achieve outcomes to obtain government funding. She found that many AAAs in Oregon struggle with lack of understanding about the ADRC concept and are challenged to meet evaluation and performance measures.

Additional conflicts existed with federal policymakers who were not convinced that HCBS programs were cost effective. A federal policymaker discussed the apprehensions felt by the federal government resulting from the lack of state and local accountability for programs they funded. He said that without assurance that they would reduce institutionalization, HCBSs were considered too great a financial risk. A federal policymaker identified a roadblock he and his colleagues encountered as they sought funding to develop ADRCs:

> [We encountered difficulties] in the Office of Management and Budget review... They would cite former studies which had suggested that if you offer HCBS [instead of nursing homes], the result wasn't, in fact, the reduction in cost … there was an increase…They would talk about the 'woodwork effect.' So we had a very, very difficult time getting a strong commitment to [fund ADRC programs]. They would say, 'We know you guys want this; we know you're supportive of this, but the evidence does not seem to support your contention that it will necessarily reduce [long-term care costs].' They would go back to saying that; therefore, we cannot take this risk [to adequately fund the programs].

An academician acknowledged that the programs' ability to achieve goals is dependent on measuring and comparing outcomes to determine the number of people remaining at home and the number of people served through ADRCs and OC. He added, however, that it is difficult to quantify the benefits of consumer-directed care:

> I heard some great stories about how these Options Counselors call around and really dig to the bottom of the issue… Stuff like that is incredibly hard to quantify. The benefit to [a consumer] staying at home is huge. How do you quantify those social benefits? How much better off she is? How much better off we are as a society?

An advocate felt that programs such as OC, where person-directed care is prioritized, have merit beyond cost benefits. In her experience, "Small efforts to honor needs and preferences have positive outcomes in terms physical and emotional development." She reported that she has seen these aspects of care positively affect clinical outcomes and increase older adults' quality of life.

Outreach and marketing. Several state and federal participants found that outreach and marketing to engage community partners and elevate awareness of the program is critical to OC success and sustainability. Elevating awareness of OC to the

community must be a “continuous and persistent” effort, according to a state decision maker, so that partner agencies remember to use ADRC services, and consumers are offered support before crisis occurs and care needs increase. She has found most community agencies to be receptive to working together in providing consumers with more resource options, but that that partners need to be reminded that ADRCs and Options Counselors exist.

A state decision maker emphasized the importance of reaching and educating older adults with diverse needs about available resources and their costs. She believes that AAAs need to find ways to gain the attention of all consumers and family members before they reach crisis.

A federal policymaker emphasized the importance of using both formal and informal sources when assisting consumers in their decision-making process, since informal caregivers often provide services to family members. She acknowledged the importance of coordinating Options Counselors, Information and Assistance workers, and community partners in supporting diverse needs and preferences of individuals and caregivers. She indicated that the importance of establishing connections with consumers and partner agencies cannot be overemphasized.

The need to increase sharing and collaboration among state agencies is considered essential by state decision makers and some federal policymakers interviewed. According to a state decision maker, agencies facing funding and staff cuts are required

to partner during economically constrained times to reduce the duplication of services. She emphasized that organizations struggling with funding, and must be creative in finding meeting service needs in the current economy. For example, she emphasized that AAAs and partner agencies such as Centers for Independent Living all provide information and assistance/referral, which is one of the ADRC components. Each partner receives a funding and staffing allotment for the service. She suggested:

> If several groups in the same location perform a similar task, it becomes more efficient to coordinate rather than duplicate. "You take a day or two, but you don't have to do it all, all three or four of you; that's just total duplication of services.

Yet, AAAs are often resistant to sharing their resources. According to a state decision maker, state agencies in Oregon have been unsuccessful in creating regional programs. She provided the following example:

> It is rare that two counties agree to share or combine resources to provide better quality services to more people.[They] are determined to work independently of other AAAs even though they are not able to meet state expectations, and [they] prefer to manage programs differently because they have different personalities.

A state decision maker suggested this attitude creates confusion for consumers, limits the ability to reduce spending, and makes it difficult to implement standards statewide. She and other state decision makers expressed frustration that counties are determined to work independently, even though they are not able to meet state expectations. They indicated that convincing some AAAs to collaborate to support ADRC development and accept the need for OC standards and training has been difficult.

A federal policymaker addressed the confusion arising when AAAs function without statewide standards with the following example:

> This [state administrator] had checked the elder locator [for the city], called the AAA, went to their website, and discovered that nowhere did they mention the existence of in-home supportive services. He asked how they could be claiming to run an eldercare locator if they don't tell people about the existence of the major public program…which is an entitlement, so if you qualify you are not going to be on a waiting list; you are going to get it right away. So I called my colleagues in AoA and said 'Uh, does this strike you as strange?' They explained to me that the elder care locator, which I had imagined was a nationally standardized system, was not. They said, 'No, it's just whatever advice and referral the local AAAs give you. It's completely up to them what they want to put in it.' I said, "Doesn't it strike you a little odd that they aren't mentioning the big Medicaid program?" They said, 'You have to understand that they're grantees. We can't tell them what to do, and we can't take their grant away if they don't do what we want them to do, either.' So I thought, 'No wonder they say there's so much variability in the quality of the AAAs.'

An advocate suggested a solution to the problem is linking public health services together by imposing requirements on AAAs so that ADRC service could be maximized and costs reduced. A state decision maker recommended that since most AAAs are structured differently, a variety of models should be examined to determine what aspects are the most effective in accessing consumers, providing services, and using funds wisely.

Summary. Six interview participants discussed the importance of providing consumers with support in planning for their futures since the public system is currently crisis management oriented, not future oriented. They indicated that it is important to reach consumers before crisis so that they are aware of available supports that can enable

them to remain at home and preserve resources. Eight participants discussed the importance of supporting consumers to use their resources wisely, since federal grant funds to provide services will become increasingly limited. Six reported that Options Counselors can use the decision support process to empower consumers in maintaining quality of life while delaying or avoiding the need to use public services. They addressed the importance of the Options Counselor's role to empower individuals in determining and achieving long-term care goals and stressed the significance of considering consumer preferences over provider direction. Eleven pointed out that policymakers and providers were required to examine ways to address older adults' service needs in a more person-centered way when confronted with the more preference oriented Baby Boom cohort.

Person-centered care was addressed as a key component of OC by all interview participants. Options Counselor attributes considered most valuable in empowering older adults to make informed choices, retain savings, and age in place were knowledge and understanding of long-term care service options, assisting consumers and family members with future orientation, and creativity in locating affordable services that honor individuals' needs and preferences. Nine believe that national competency standards will ensure Options Counselor proficiency, hold Options Counselors accountable, and make program outcomes easier to achieve and assess. These participants reported that assessment is critical if ADRCs and OC are to receive ongoing federal funding and be a federal and state priority. Seven reported that programs such as OC where person-

directed care is prioritized have merit beyond cost benefits. Regarding outreach and marketing, six participants addressed the importance of engaging partners to elevate awareness of ADRC and OC programs and increase service options.

Ways in which Theoretical Constructs Inform the Development of ADRCs & OC

The strength of the three theoretical constructs, life course perspective, social constructionsim, and political economy, became evident during the analysis. In ways consistent with these constructs, interview participants addressed topics including consumer needs and preferences, family values, societal attitudes toward aging, and ways in which aging policy issues are constructed and resolved.

Life course perspective

Recall that the life-course perspective considers the life cycle in its entirety (Tinker et al, 2004) and explores the effects of individual circumstance, life trajectories, socioeconomic status, and cohort on an individual's aging process (Bengston et al., 1997; Hoomyman and Kiyak, 2008; Connidis, 2010). Within the context of the life-course perspective, the concept of cumulative advantage/disadvantage was especially useful when examining OC. Individual differences in wealth, health, and status that accumulate over time, contribute to individual differences in wealth, health, and status, explain much of the heterogeneity and inequality among the aged (Dannefer, 2003; Settersten, 2005).

When a state decision maker described family support, the effects of cumulative advantage and disadvantage was apparent. Healthy or unhealthy family support affects

an individual's quality of life and quality of care over time. She argued that highly functioning families who remain connected over the life course can be more supportive of older family members' decision-making process and are more able to assist in obtaining services that respect needs and preferences. Fragmented, conflicted families, she implied, are more likely to dismiss older family members' needs and project personal interests regarding what is best for their family member. An advocate indicated that family members often do not honor elders' independence throughout the life course, and that coaching and support is necessary. "[There is] unawareness or lack of appreciation of independence throughout life, so you need to get education going to expand awareness in those areas," she advised.

When family relationships are healthy, a state decision maker reported, families "become creative in finding ways to meet service needs," and provide paid and volunteer services for older family members in need of assistance. Another stated that people become creative in finding ways to meet service needs, especially if neighborhood and family relations are functional.

Life circumstances that magnify the effects of cumulative advantage and disadvantage can be further influenced by policy decisions. An academician provided an example. He reported that one popular solution to resolving Social Security and Medicare funding shortfalls is to increase the retirement age. He pointed out that this remedy is problematic, since socioeconomic factors are linked to longevity. Educated,

affluent people possess more resources and tend to live longer, while most laborers' life expectancy is shorter, and a greater number of these individuals do not reach retirement age. If retirement age is increased, he explained, equity issues are raised, since it is likely that a greater number of lower-income individuals will not realize Social Security benefits or will experience hardships while waiting for them. He summarized, "It's a complicated picture, and raising the age is the popular policy option. It may not be the best policy option."

A state decision maker discussed the importance of assessing consumer needs. She stressed that developing state Options Counselor practice standards and requiring training enables providers to understand, acknowledge, and honor individual circumstances and differences resulting from a lifetime of experiences. She provided the following example:

> [OC] involves a person-centered assessment, getting to know the person really well, getting to know what their goals and values are, who they've been in their life, and what they want to do - if they want to stay in their home, what kind of natural support they have, who their family is, and their own resources, what their challenges and their barriers are to being able to use those and to do those kinds of things - and then help connect them with their resources in the community that will fit their unique situation and their resources, so that they can stay in their home as long as they're able to and as long as they want to.

Most interview participants noted that a primary goal of OC is assisting individuals to age in place. However, a federal policymaker argued that the emphasis on nursing home diversion fails to acknowledge that some individuals' needs might be met

better in an institutional setting and that language used to describe ADRC goals and current policy trends favoring HCBS fail to recognize diverse healthcare needs. Research that supports this view, and is discussed in the literature review, indicated that some assisted living proponents define those in need of medical care to have failed in some way and reinforces a gerontophobic view (Carder, 2002). The federal policymaker advised:

> I would personally not phrase the goal that way. I would say that it would be to help someone reach the best decision for them weighing all the factors. The way [the goal is] stated sort of puts it like 'at all costs,' or that keeping someone out of a nursing home or an institution is the be all and end all of OC, right? Whereas there are times when I think it's appropriate for old people to be in a nursing home, and it may be the best thing for them.

In her research, this federal policymaker found the effects of cumulative advantage and disadvantage such as socioeconomic status, education, and income to be important factors in determining care needs and housing choices. She reported findings from a study she conducted confirming that people with more financial resources have a wider range of choices:

> Avoiding nursing home placement is tied to understanding options and having more resources. This is a rational decision process. [Research participants in the study] explored options that were less restrictive but selected housing based on need, or availability, or preferred choice.

Another interview participant further questioned the ADRC goal to offer information and counseling to all regardless of means, and then to provide the means to access services. She doubted the appropriateness of this language, since the statement

implied that services could be available and affordable to all individuals, when in reality, some qualify for public programs, and others are required to finance recommended services using personal resources. This statement, she maintained, raises concerns about equity, since the ability to obtain services varies depending on individual and local resources.

Individuals able to accumulate resources throughout the life course are in a better position to address age-related functional limitations and healthcare issues and maintain or increase quality of life. ADRCs and Options Counselors are challenged to provide the means to access affordable services that meet all individuals' needs and preferences when societal conditions increase the ability of some to obtain preferred services while limiting the ability of others to do so, (Settersten, 2005), as indicated in the literature reviews. The advocate provided an example of the way in which unequal distribution of resources fosters inequity among states:

> In constrained times, when budgets are being cut, social services are some of the first to be cut. You start to see that this variation leads to tremendous inequity across the country. Why should somebody in Mississippi not have access to the same things that somebody in N.Y. has, for example? We have to realize that this decentralized approach, depending where we come at this, raises real questions around equity and access…

She provided another example of the way in which an individual's ability to accumulate resources reflects inequality:

> Private-pay people buy in the market. They look at what they want, what's best for them, what's cheapest. But when you're in a publicly subsidized program,

> that's when it becomes more of a balance between individual choice and preference and what can be made available and how do you distribute resources in constrained economies?

Evaluation of program outcomes are needed to determine whether providing a one-stop shop to older adults of all income levels is equally advantageous to all, regardless of means. It can then be established whether standards that require Options Counselors to support consumers in finding options that respect cultural, socioeconomic, and health differences is fostering or decreasing inequality among the aged.

Social Constructionist Theory

Social constructionist theory explores ways in which norms, prevailing attitudes, and societal beliefs about aging emerge, and how those attitudes and beliefs direct feelings about providing for the aged. Perceptions about aging, formed by those in power, affect policy decisions and social service distribution. Understanding the social meaning of age can clarify how service needs unique to old age are labeled and how beliefs about responsibility for an increasing aging population are formed (Bengtson et al., 1997; Powell, 2009), as indicated in literature review articles. For example, popular terms such as greedy geezers, and the aging tsunami reflect socially constructed attitudes that the growing aging population is destructive, draining resources, and harmful to other cohorts. Yet, at different times, older adults have been considered deserving poor or, more recently, as greedy geezers. As noted in the literature review, Hudson (2010) found

the aged have been labeled as a unique, indulged beneficiary group, denying others in need of their rightful share. In past decades, attitudes toward aging and older adults were more positive. For example, Social Security was created in the 1930's, when many more aging individuals lived in poverty and were considered to be the deserving poor (Binstock, 2010; Polivka & Estes, 2010). This article was addressed in the literature review. An academician explained the influence of these beliefs:

> What's happened with this demonization of the public sector is that the notion has become prevalent that they [older adults] are just lazy, and of low character. Why would we help them? I come to that all the time here. That is a bad sign for future policy years and for American civilization. Ageism is in the culture.

This academician pointed out that contemporary beliefs about older adults that suggest programs and policies supporting children and grandchildren are being robbed by baby boomers' entitlements are "more myth than reality." She contended that policies set for the aged protect multiple generations, and that both young and old benefit. Framing the financing of all programs so that people view them as beneficial to all generations rather than stealing from one to provide for another is critical, she believed, in reducing the potential for intergenerational conflict.

This interview participant discussed conflicting views in federal policy regarding Medicaid and Social Security shortfalls. One proposal suggests adding a percentage to the Social Security and Medicare payroll tax that is paid over the lifetime. Another, he

said, expressed the attitude that elders should be held personally responsible for age-related, end-of-life heath issues and should not be entitled to public support.

An academician confirmed that long-term healthcare discussions for the aged in the United States fail to recognize long-term care social insurance as a solution. He indicated that disinterest reflects socially constructed beliefs about the importance of independence, the conservative attitude that individuals should be responsible for aging family members, and the conviction that government should not be required to provide supplemental support. He reported that attitudes such as these are directing policy choices at the federal level. He noted that conservative government believes it should provide a voucher and then not be involved in providing any additional support. He pointed to a study examining why the increasing demand for providing LTC care for family members with chronic care needs has not generated more aggressive policy intervention. The study participants, he said, were asked whether they had considered insurance programs like Medicare for long-term care. Generally, they responded that the concept had not occurred to them, but that they were not opposed to it. An academician went on to discuss the findings from that study in the context of social construction theory:

> [Due to] the construction of the problems in the U.S., the idea that you have a Social Security program for LTC is just not on anybody's mind. So it's really very interesting how we construct social problems and, in turn, how we recognize possible solutions.

A state decision maker discussed the ways in which negative attitudes toward aging affect individuals. Society, she maintained, possesses a "fatalistic" view of aging that is difficult to overcome. As a result, the state decision maker noted, people avoid planning ahead, accessing services early, and addressing increasing age-related healthcare needs. She suggested that educating people aged 40 and above about their future LTC needs has the dual benefit of helping family members determine older relatives' needs and to plan for their own future needs.

A state decision maker recognized that independence is highly valued in the United States and that interdependence and dependence on others are considered to be a loss of freedom. This perception, she said, is culturally determined. She added that negative attitudes regarding loss of independence cause consumers to avoid future orientation and addressing long-term care needs because they equate those needs to loss of freedom and nursing home placement.

If societal attitudes toward the aged are driven by cultural beliefs about independence and caring for family and reinforced by policymakers, then family members of all socioeconomic statuses are reasoned to be responsible for aging relatives. In this neoliberal climate, ignited during the Regan era, fueled by the Bush years, and reinforced with the economic downturn and dire predictions of fiscal cliffs and financial shortfalls, some believe this is what families should be required to do. As an advocate explained:

> It's still going to bounce back on the family, and all of these programs are already predicated on family. They're not generous. They're not covering everything. It's always predicated on having a family member there. This is just the reality.

Political Economy

Political economy theory is concerned with explaining how and why social resources are unequally distributed (Bengtson et al., 1997), and this was discussed in the literature review. A central focus of research stemming from the political economy tradition describes ways in which public policies reproduce existing forms of inequality **(**Quadagno,2002), and how economic and bureaucratic activity promoting profit making fosters elder dependency through control and distribution of resources such as medical services (Estes, 1989).

A academician believed the conflict existing between the federally and state-funded Aging Network programs and profit-driven HMOs interested in expanding HCBSs could influence the likelihood that ADRCs and OC will successfully evolve and expand nationwide since they will have a greater capacity to not only offer information and access to services, but actually provide them. Estes and Lee (1981) expressed similar concerns and predicted a greater emphasis on market forces and competition to address the problem of continuing increases in the costs of medical care. Hacker (2004) reported that risk-privatization of social policies have reduced benefits coverage and increased the

risk faced by individuals. These conflicts and concerns were addressed by Estes, Lee, and Hacker in this literature review.

Since ADRCs are limited to offering information and access to the service system, linking consumers to a variety of not-for-profit, for- profit, and volunteer resources can enable them to obtain the services they need, but cannot actually provide the services. The academician expressed concern that with their powerful National lobby, HMOs could slowly dominate the HCBS industry and marginalize more affordable Aging Network HCBS services. He maintained:

> The Aging Network is being squeezed [out]. I think there is a tremendous political issue here in terms of who's in charge and what's going to happen to the ADRC structure as HMOs move to control the entire LTC system.

Conservative government policymakers, he added, support HMOs and prefer to privatize healthcare services. These powerful, profit-driven systems, he stated, provide no evidence that they are more capable than the Aging Network of coordinating long-term care programs, yet the Medicaid and Medicare offices of CMS are confident that HMOs can produce better outcomes. He believes healthcare costs will increase as for-profit HMOs procure a greater share of the LTC HCBC services. Harrington-Meyer (2010, p.23) presented two prevailing arguments regarding public programs and market-based programs with the following example:

> Therefore, some contend that government funded policies addressing collective needs place unrealistic financial burdens on government, consumers and businesses. In contrast, those with a collectivist view stress that corporate and

> market-based programs place too much financial responsibility on people with limited incomes.

An advocate questioned the ADRCs' ability to evolve if managed care organizations play a progressively larger role in healthcare deliver. She asked:

> What's going to happen in the next couple of years as states get more aggressively into turning over their programs to managed care, and what is the role of the ADRC as being a part of that?

An academician reasoned that, in this political and economic climate, privatization can be the preferred choice. He explained:

> You've got these horrible projections about budget deficits and fiscal cliffs, and you know, the government's going to go bankrupt… the Medicaid money might get not eliminated, but obviously the growth rate would go down. And states simply don't have any money, so what's the logic? You've got sort of a classic formulation. You've got public and private services, and you've got formal and informal services. In this environment, things are going from public to private as everybody tries to privatize one thing or another.

If HMOs prevail, the academician believes that healthcare insurance costs will increase, but service quality will decline, and community and family involvement in the form of volunteerism and public services that support informal caregivers will decrease. He provided the following example of the "disastrous effects" a profit-driven system produces:

> Look at hospice care across the country. It was nonprofit until twelve or thirteen years ago. Now two-thirds is run by corporate entities driving up cost and lowering quality of care provided…For-profit corporations have driven up cost steadily for past ten years. They feel that the only way to get on top of it is to become as prescriptive as they can, and it's changing the nature of the hospice

> experience, which is a huge loss. You cannot have a humane, efficient corporate-operated healthcare system. It is absurd.

Providing added support for this view, a federal policymaker supported this sentiment and offered a personal example of the way in which prescribed care weakens hospice care:

> Each time the hospice people would come, they would say something like, 'You understand that we are from hospice and this means that you have agreed (this is not the way they said it but it sounded like this to the hospice patient) you're going to die, and we are not going do anything to stop you from dying, and you will be dead in six months.' [The patient's wife] would take them aside and say, 'Must you read that thing? Can you just accept that he knows who you are and what hospice means? Do you have to constantly shove it in his face?' They [the hospice workers] would say… 'That this is our policy, our protocol. We need to make absolutely sure that he is in agreement with this.' Now, there is a tactful ways of doing this, and then there's clueless, by the book, paint-by-numbers ways of doing it. A couple of times when they came [the patient] blew up at them and told them to leave, so they didn't even do what they were there to do. Then, part of [his wife's] caregiver stress was she would have to get them to come back out because the alternative was that he was going to go to a hospital and be stuck full of tubes.

Political preference for HMOs can affect ADRC relevance in offering HCBS options. An academician emphasized that HMO expansion into offering HCBS programs currently managed through the Aging Network is important to acknowledge, since powerful, profit-driven HMOs could become the front-runner in HCBS service provisioning, and could marginalize more cost efficient Aging Network functions. This participant felt that the Aging Network is pressured by a "Medicare/Medicaid coordination obsession" from the Obama administration and is affected by grants to states

that support HMOs in coordinating Medicare and Medicaid services. ADRCs, as part of the Aging Network, struggle to grow in this climate, he contended. He warned, "That's the larger context in which the ADRCs exist and will evolve in the years ahead, but there needs to be much more attention to that larger picture."

This issue was not addressed specifically by other interview participants, but an academician and two federal policymakers instrumental in ADRC implementation emphasized that the relationship forged between AoA and CMS strengthened the Aging Network by providing more options. Yet, a federal policymaker pointed out insufficient funding to expand the programs statewide could affect sustainability.

It will be important to evaluate ways in which policymakers' decisions and their outcomes strengthen or weaken ADRC program functions, since continued funding can be dependent on ADRCs ability to reduce long-term care costs and compete with for-profit healthcare providers. Further, if certain public policies have the potential to recreate existing forms of inequality, as Political Economy theory suggests, it is important to assess whether ADRCs and OC are able to overcome the effects of cumulative advantage and disadvantage by offering equitable access, or whether the programs foster the inequity they hope to eliminate. Thus, establishing whether the Aging Network has the ability to compete with HMOs (or any private healthcare provider) and offer a greater range of more affordable HCBS to a larger, more diverse

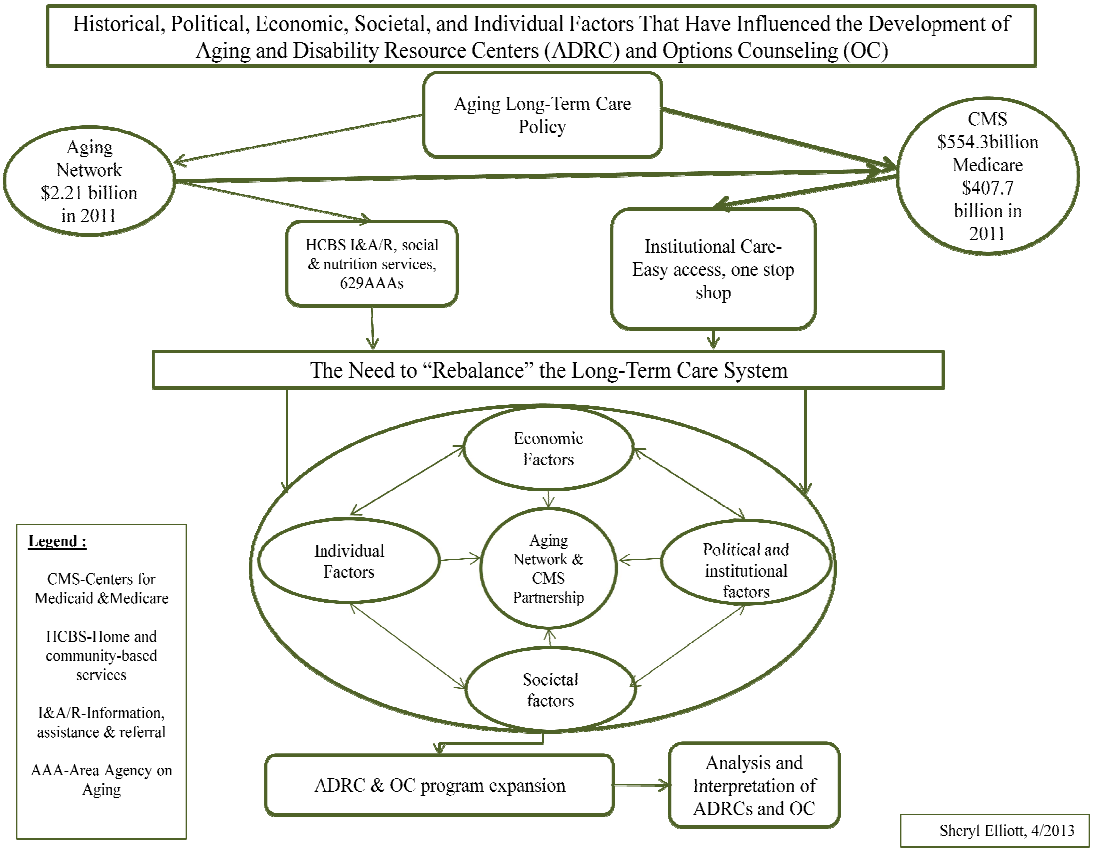
population can provide evidence of Aging Network strengths and reinforce emphasize program legitimacy.

Summary. Three theoretical constructs increase understanding of the evolution and practice of ADRCs and OC. First, equity issues are regarded from a life-course perspective as OC standards and practices seek to address the effects of cumulative advantage and disadvantage, including individuals' social status, health, and individuals' perception of needs and preferences. Second, social constructionist theory clarifies the ways in which issues related to aging are perceived and solutions addressed. For instance, negative attitudes about the increasing healthcare costs can affect aging individuals' desire to plan for their futures and society's willingness to provide adequate public health benefits. Third, Political Economy theory explains the possible conflict between profit-driven healthcare providers and publicly-funded Aging Network HCBSs, and the effects prescribed standards can have on person-centered, decision-support processes. Evaluating ADRCs and OC advantages and disadvantages from these three constructs can inform the programs' potential to sustain and expand in offering long-term care options that honor needs and preferences to a diverse population of both public-benefits eligible and private-pay consumers.

The revised concept model, represented below, reflects the way in which this study evolved from the original design, and provides a frame of reference for the following discussion section. The original model explored the political, economic,

social, and individual factors that have influence the development of ADRCs and OC. In the revised model, a section has been added examining LTC policy, and the influence this factor had on two agencies, the Aging Network, and The Centers for Medicare and Medicaid, and on this study. The revision further examines the strength with which CMS influenced LTC provisioning to favor institutional placement, and on placing Aging Network service functions in a secondary position. The revised model reflects the importance of LTC in framing and guiding this study.

Figure 2: Revised Concept Model



Chapter 5

Discussion

The Economic, Political, Social, and Individual Advantages of the Model

In what ways will ADRCs and OC influence long-term care and existing social service functions? According to the candid comments of one interview participant, the life of a new policy is dependent on the motivation of those who design and implement it. If they are interested in enmeshing and strengthening a program within a system to improve that system, the program's life is most likely dependent on the power of those who administer it. If the program was created to elevate the policymaker to the next rung on their career ladder, the program is more likely to be sidelined when its creator moves on. Analysis indicates that policymakers who developed ADRCs and OC are resolute in their investment to address enormous long-term care costs and provisioning issues with the expansion of these two programs.

ADRC and OC Evolution. The need to contain LTC costs has directed policy efforts toward providing more affordable HCBS options to older adults who are eligible for Medicaid services. One attempt to accomplish this goal is through the expansion of ADRCs and OC programs designed, in part, to reduce public benefits costs for LTC by providing information and access to HCBS services. These programs have been cultivated in the reality of massive budget shortfalls in public insurance programs, rising

healthcare costs, and a ballooning aging population with limited budgets and increasing healthcare needs. ADRCs and OC are evolving in fifty-four states and territories that are required to take greater financial responsibility for providing services due to federal spending reductions.

Financial Risk and Responsibility. As the federal government shifts financial support toward HCBS and away from institutional care, greater financial risk and responsibility for obtaining services is shouldered by states, individuals, their families, and care providers through various federal programs such as federal Medicaid waivers (Estes & Lee, 1981p511; Shirk 2006, p10; Thompson & Burke, 2008). Waivers result in both benefits and costs to eligible individuals. They offer more flexibility and options by partially funding HCBS, but the new standards allow states to cap Medicaid enrollment (previous regulations did not allow this), and generate waiting lists. As waiting lists for services grow due to waiver restrictions, some Medicaid-eligible people without HCBS could be more susceptible to decreased quality of life and healthcare decline, resulting in costly hospital care, nursing home placement, and rehabilitation (Thompson & Burke, 2008). States can offer services with state, Aging Network, and grant money, but this patchwork of funding sources is inadequate to address provider staffing needs and individual service needs (Stone & Benson, 2012). The federal policymaker's comment indicated that "government employees are very practical and will take what they can get"

highlights the determination with which state employees struggle to address aging populating demands with insufficient resources.

Equity issues. At the individual level, with reliable infrastructure in place, Options Counselors can help people make good choices (Stone & Benson, 2008), and this study's findings indicate that building preferences into the resource distribution process does broaden awareness of options. In reality, however, choices are limited when resources are not available or affordable to all, and ADRCs and OC are likely to foster inequality in access to services since they fail to address unequal distribution of resources and wealth. Hudson (1997) noted that moving away from means-tested eligibility requirements in public programs does not resolve issues concerning equity; it only presents us with different equity considerations depending how need is defined. Clearly, concern for parity can be examined when considering that ADRCs provide "equal" access, and OC offers options to honor "diverse" needs and preferences of all consumers "regardless of means" (AoA, 2011). According to Kutza (1981) values implicit in social policy include four components: equality, equity, adequacy, and efficiency. Policymakers usually judge the success of programs they created by one or more of these values. Furthermore, satisfaction with outcomes varies depending on the values held by the analyst (Kutza, 1981).

In the case of ADRCs and OC, determination of outcome satisfaction might be like the blindfolded men who were asked to describe the elephant. Each described the

elephant differently (by the ear, by the trunk, by the tail) depending on where they stood and what they felt. From the policymakers' perspective, if the outcomes indicate that programs provide easy access and offer person-centered options, perhaps they are satisfied that all four values, including equity, are achieved. Yet, when agencies' funding is insufficient to add another employee to an already depleted staff roster, requiring overworked employees to add OC duties raises issues of adequacy and efficiency in meeting agency, staff, and consumer needs. Further, staff could find such requirements unfair and unrealistic, as some Information and Assistance/Referral workers and Options Counselors during focus groups conducted for the state of Oregon did (White, Elliott, & Carder, 2012). Similarly, consumers who were able to obtain services after accessing the ADRC might think they have been treated in an equitable way, whereas others who did not receive desired supports might think they were treated unfairly. In a consumer satisfaction survey, some consumers responded with comments such as, "They should listen better," and "They should think about the whole person and not put everyone in a box." These comments raise questions about the perception of ADRCs and Options Counselors as providing equal, adequate treatment (White et al., 2012).

The Administration on Aging and Center for Medicaid Partnership Considerations

The evolution of the joint AoA/CMS partnership, considered by some interview participants to be the first of its kind, provides an historical perspective of ways in which the two agencies have influenced one another and steered the direction of LTC service

delivery preferences. The Aging Network, some interviewees reported, lost sight of its original goal to provide all older adults with information, referral, and access to HCBS and shifted resources to address Medicaid-eligible individuals' needs. Medicaid was appealing since it was more heavily funded than HCBS Aging Network programs, and offered the more convenient, visible, one-stop access to services provided in nursing homes. The Medicaid mindset became more established, since CMS funding was directed toward institutional services rather than HCBS.

As discussed earlier, with fiscal healthcare crisis predictions looming, then Secretary Carbonelle took her ADRC proposal team to CMS. The meeting between AoA and CMS was well timed and fortuitous. One of the ADRC architects for the Wisconsin program had taken a federal position at CMS and advocated for the program's national expansion. His superior, who was governor of Wisconsin during the ADRC Wisconsin development, had taken the position as U.S. Secretary of Health and Human Services. The program was ripe for development under the Bush Administration. It was, according to one interview participant, budget neutral (offering information and access is cheaper than offering services), and it had been proven to reduce institutional costs (Mitchell, Salmon, & Polivka 2003). In addition, it promoted person-centered care practices, favorable to the Baby Boom "tsunami" and was consistent with the increasingly valued Pioneer Network and Culture Change practices taking place in residential LTC settings (Binstock, 2010; Pioneer Network, 2013; Powers & Sowers, 2006).

With the AoA/CMS partnership, the Aging Network had the opportunity to take greater responsibility for the provisioning of HCBS and realize the original goal of providing information, assistance, and access to social services for all older adults. The ADRC and OC programs provided the additional benefit of increasing Network practices that value person-centered approach to care. Some interview participants questioned whether the Aging Network can realize its goal to assume a more central role in providing LTC, however, or whether the agency will again be marginalized by more heavily funded, structured healthcare systems.

The evolution and expansion of Managed Care Organizations (MCOs) that develop and manage a network of LTC services and supports (WDHS, 2013) could marginalize the Aging Network. ADRCs and OC could also be made less relevant if they are functioning outside of more heavily funded and subsidized programs. Although MCOs provide both information and services, questions about lower cost and quality of care arise with managed care (Binstock, 2001; Polivka & Zayac, 2008), and both ADRCs and MCOs should be evaluated to determine the strengths and weaknesses of each in providing good quality, person-centered, affordable care.

The findings from this study indicate that control over the HCBS network will be determined by who has a larger, more sustainable funding source that drains dwindling public resources the least. Although two federal policymakers interviewed emphasized the “dual benefits” of cost reduction and person-centered care with ADRCs and Options

Counselors, the emphasis (within the contexts of responsibility, resource distribution, quality of life, and quality of care) was most often placed on the need to reduce costs and avoid expensive "crisis" situations. Options Counseling standards and person-directed care are significant but can be offered in a variety of settings, not necessary through ADRCs.

The question remains whether the Aging Network can continue to manage increasingly complex long-term care issues more efficiently and effectively than other public or private healthcare systems, as some of the literature (Carbonelle & Polivka, 2008) and some interview participants claim it can. Perhaps political favoritism and adequate resources are the determining factors in any agency's ability to assume the leadership role providing HCBS. Yet, as CMS has shown, leadership does not ensure responsible money management, or the avoidance of financial crisis.

Local Government Issues

Independence is highly valued in this neoliberal climate that favors caring for one's self and ones' own at both the individual and provider level (Estes, 1979; Harvey, 2007). Some interview participants reported that Area Agencies on Aging take pride in their ability to tailor their functions and services to local personalities and local needs and wish to remain free of federal restrictions. Since resources are unequally distributed between and within states, as data from this study indicate, it makes sense to allow flexibility to local agencies in meeting community needs. Requiring agencies to meet

performance standards, however, can assist federal, state, and local government in assessing whether outcomes have successfully addressed program goals. Furthermore, in this climate where providers struggle to do more with less, stubbornly independent AAAs could benefit from partnering with other agencies to coordinate redundant programs and reduce costs. As one interview participant pointed out, Information and Referral/Assistance services are sometimes offered by four different public agencies in the same county.

ADRC and OC Language

The ADRC literature defines those in need of LTC services as "consumers" offered a "one-stop shopping" experience that "provides the means" to "access" programs of choice, thereby enabling those individuals to avoid "crisis" and retain "resources." Further, ADRC and OC are available to all consumers, "regardless of income" (AoA, 2003; CMS, 2013). This language recognizes the difficulties and confusion most people experience when looking for services. It addresses the need for information and access to long-term care for older adults and their families, services formerly available only to public benefits-eligible people. Providing information about a wider range of HCBS recognizes the needs of individuals at all income levels, but the language also implies personal responsibility for "purchasing" resources.

Some with low-income are not eligible for public benefits but are incapable of obtaining services without public support (O'Shaughnessy, 2008). Although some

research suggests that most people benefit from having their needs and preferences acknowledged (Pioneer Network, 2013; White et al., 2008), more study is needed to determine whether equal access benefits all equally, or if the effects of cumulative advantage and disadvantage throughout the life course (Settersten, 2005) make ADRC programs and OC more beneficial to those who are able to obtain desired services than those who are able to obtain information alone.

ADRCs and OC language endorses equality by offering support to all people regardless of means and by employing person-centered practices that honor diverse needs and preferences. Questions are raised, based on the findings from this study, about the programs' capacity to confront the realities of unequal resource distribution and service needs that not all can afford to address and whether ADRCs and OC programs reproduce the existing forms of inequality they intend to reduce.

ADRC and OC language has both positive and negative implications regarding older adults' capabilities, suggests feelings about providing for the aged, and reflects prevailing attitudes about aging experience (Binstock, 2010, Binstock & Quadango, 2001). The language implies older adults are capable of addressing their needs and are entitled to a decision-support process that honors their preferences rather than requiring prescribed care provider recommendations.

The Social Construction of Crisis

Future orientation is a critical OC function that helps older adults plan for their future needs, retain their resources, and avoid healthcare "crises" such as falls that can require expensive hospitalization and nursing home placement. Helping older adults to remain healthy at home is a positive outcome of future orientation efforts (White et al., 2012), but constructing the potential need for higher levels of care as crisis should be reevaluated. Older adults' functional limitations that can create the need for higher levels of care are naturally occurring, age-related events that might be more effectively addressed as part of the aging process rather than defined as crisis that can "drain the public coffers" (Binstock, 2012). Further, beliefs about what constitutes crisis are subjective and determined by a variety of societal influences, including media coverage, personal experience, and "anxieties generated by predictions and possibilities" (Slovic, Firschhoff & Lictenstein, 2002, p. 231). Perhaps framing the benefits of future orientation as a process that can enhance a better quality of life for a longer period of time, rather than planning to avoid the disastrous consequences of crisis related to aging, could help to reduce negative perceptions about healthcare needs and aging.

Limitations

It was unlikely that available data would be adequate to address all aspects of the research questions, since ADRCs and OC models are newly developed, and a limited amount of literature exists on the emerging programs and their outcomes. Examining several divergent theories compensated somewhat to provide a more complete and informed awareness from several perspectives. There also exists a risk of applying data from similar studies incorrectly (Patton, 2002). However, guidance from gerontologists and thesis committee members skilled in research development, data collection, and analysis, provided assurance that relevant data were located, interpreted, and applied accurately.

Chapter 6

Recommendations for Policy and Practice

This section presents several recommendations for the continued development and practice of Aging and Disability Resource Centers (ADRC) and Options Counseling (OC). The first focuses on rebalancing the long-term care system, making it more sustainable for HCBS in general, and ADRCs and OC in particular. A second recommendation is to establish a sustainable, evidenced based infrastructure to support ADRC and OC expansion. This infrastructure will build on an adequate funding stream and is based on an assessment process that includes consumer satisfaction with program services, OC competency, and LTC cost savings. Third, increased advocacy and outreach efforts are needed to engage consumers, families, and community partners. Finally, suggestions are offered for an equitable National Healthcare program that is free of selection bias, providing equal access to the LTC system, and affordable services to all.

Rebalancing the Long-term Care System

ADRC policy language emphasizes the need to rebalance the LTC service system by increasing access to home-and community-based services (HCBS), and elevating consumer awareness about a wide range of service options. To do so, the Aging Network and CMS will need to consider creating a balance between institutional placement and aging at home with the use of HCBS. They must also find ways to increase Aging

Network capacity to administer HCBS, thereby rebalancing federal funding distribution. The Department of Health and Human Services (DHHS) funds the Aging Network's HCBS programs. However, this funding is inadequate to address older adults' LTC needs. DHHS should increase funding so that the Aging Network can administer more HCBS thereby enabling this program to share greater responsibility with CMS in providing LTC services. This will ensure a balance between Aging Network and CMS in both funding and LTC provisioning.

For the federal government to provide the funds necessary to sustain ADRCs and OC, these programs will need to demonstrate cost savings by delaying or diverting consumers from institutional settings. More research is needed to establish the specific ADRC practices or characteristics that lead to desired outcomes, including reduced costs and improved consumer satisfaction. Savings, then, can be accomplished by requiring the programs to meet national performance standards that have been found to reduce costs and promote consumer satisfaction. However, as this study has determined, regional needs vary due to resource availability, population, and geography. A public policy package that includes core national standards, with flexible provisions that address state and regional differences, is needed.

Core standards should be based on 1). Program evaluation across ADRCs to determine which standards lead to desired outcomes, and 2). To identify variations in approach and organizational structures that enable ADRCs and OC programs to achieve

success. To determine flexible provisions, states that have implemented ADRC and OC programs could conduct research to determine which AAAs are demonstrating positive consumer satisfaction and cost-saving outcomes. Then, program factors could be evaluated independently to determine which aspects determine success. Determining aspects of successful consumer, family, and caregiver outcomes that demonstrate both satisfaction and cost savings can sustain future funding for ADRCs and OC, provide financial incentives for AAAs to accept national performance standards, determine areas of cost saving regionally, and tailor standards to areas based on regional need.

Infrastructure

In the current economic climate, federal and state governments, and individuals face financial hardship in providing LTC for older adults and people with disabilities. The federal government faces fiscal crisis and must reduce spending. State budgets are constricted due to reduced federal spending and the recent recession. Aging adults face crisis due to increased healthcare costs, depleted retirement savings, and the effects of functional limitations that place them at-risk for injury and disease.

This study has addressed several economic issues related to the aging population. Foremost among these issues is the need for more services and supports to ameliorate age-related functional limitations. To delay or avoid nursing home placement, adequate HCBS resources and supports that enable older adults to age in place need to be made available. If CMS hopes to reduce the number of people transitioning to nursing homes,

the agency must provide adequate funding for HCBS. For example, federal waivers could be more effective in meeting LTC demands if they were to provide the same entitlements to HCBS as nursing homes. In their current form, waivers have advantages. Like OC, they offer options for services that enable older people to remain at home. Unlike OC, waivers link options with funds for services to consumers who qualify based on financial and medical criteria. However, as this study's literature review indicates, the funding is insufficient, and waitlists for services are long. The federal government, if it is serious about reducing LTC institutional costs, should consider revising this policy, and those like it, to either increase funding or provide additional service options. If services to support older persons safely at home are not available or affordable, many individuals will experience health crisis, costly hospital placement, rehabilitation services, and nursing home placement. For the ADRC and OC to establish a meaningful role in the provision of HCBS, resources must be available that link information, access, and a full range of quality, affordable services.

It is important to reexamine expectations regarding diverting more consumers from nursing home placement in favor of long-term care at home. Although nursing homes are increasingly used for short-term, post-acute care, a subset of adults with critical healthcare needs might be best served in institutional settings, especially if HCBS options are unavailable in their community. Without resources, and with caps on entitlement spending, ADRC and OC programs designed to increase the likelihood that

institutional care will be avoided or delayed are almost certain to fail in achieving this goal. In fact, without a supportive infrastructure to expand the supply of HCBS to those at greatest risk, these individuals might be better served in nursing homes.

Options Counselors play a vital role in the future success of ADRCs. One important OC standard, assisting consumers in planning efforts to avoid depleting resources and delay or avoid costly hospital services and nursing home placement is a required competency component for OC. Yet, in order for people to plan for their futures with OC support, they must first be willing, and have the ability, to contact the ADRC to be referred to OC assistance. This is the case for private pay and public benefits eligible consumers alike. Thus, information about ADRCs must be broadly communicated to families and consumers, including those who are not yet experiencing a health-related crisis.

Further, in order to benefit from the decision support process offered through OC, services that have been determined to meet the consumer's needs and preferences must be affordable and available. For the decision support process to be effective, relevant, and sustainable, it is necessary to ensure Options Counselors are aware of community resources, can guide consumers in determining their needs and preferences, and offer appropriate options.

Advocacy and Outreach

Advocacy and outreach efforts should target consumers, providers, state legislators, and federal policymakers. At the consumer and provider level, Options Counselor advocacy efforts should be increased by providing support to consumers transitioning from hospital to home. Care transitions is an OC service that educates hospitalized Medicaid and Medicare beneficiaries about risks associated with their condition, informs those consumers and their families about LTC options, and provides assistance with obtaining HCBS. Expanding outreach efforts to hospitals has several benefits. Elevating consumer awareness about HCBS can decrease public benefits costs by reducing expensive hospital readmissions and avoiding unnecessary nursing home stays. In addition, providing more options increases the likelihood that consumer needs and preferences will be honored.

State legislative support is necessary to sustain ADRCs and OC. One interview participant in this study pointed out that without legislative support at the state level, programs "dry up and go away." Therefore, state decision-makers have an important role in sustaining ADRCs and OC by advocating for them during legislative sessions and by providing proof of consumer satisfaction, positive measurement outcomes, and cost savings.

Advocating for ADRC program expansion is also necessary at the federal level. By partnering with CMS in developing ADRCs, the Aging Network hopes to increase its

capacity to administer LTC services. Yet, the federal government lacks confidence in the Aging Network's ability to administer Medicare and Medicaid entitlements, divert people from nursing homes, and provide affordable HCBS on the massive scale needed to reduce public benefits costs. One reason for this, as one federal policymaker who was interviewed for this study emphasized, is that the federal government is unaware that many AAAs already successfully administer Medicaid entitlements and HCBS. Therefore, the AoA must continue efforts to increase awareness of Aging Network functions and advocate for additional funding so that the Aging Network has the capacity to administer more LTC services.

National Healthcare

Although ADRCs intend to provide information and access to all individuals regardless of their means, the voluntary nature of the program raises concerns about selection bias and equity. As noted earlier, some individuals are more capable than others of contacting ADRCs to ask for help. People who are more educated and who have fewer healthcare limitations are more likely to both seek and obtain support and services. Further, some older adults who fear loss of independence may be apprehensive about informing providers of their functional limitations and increased need for support. A mandatory public insurance program could more effectively address public and private benefits issues including access, affordability, and resource distribution issues. In

addition, the stigma associated with needing public healthcare benefits could be reduced with a program that offers not only options, but services to all regardless of means.

ADRCs and OC are important programs. They offer person-centered LTC choices to all consumers, families, and caregivers. They have the potential to reduce LTC costs to both individuals and government agencies by providing access to a wide range of HCBS. Following these recommendations can ensure the sustainability and expansion of ADRCs and OC.

Chapter 7

Conclusion

This research has made two important contributions to ADRC and OC programs. First, through interviews with key experts, the study offers a comprehensive understanding of ADRC and OC programs. In gathering data from key informants in several levels of government, and from academicians knowledgeable in aging policy and practice, this study provides a multifaceted understanding of ADRCs and OC. With this broad perspective, policymakers, decision makers, and providers alike can more effectively examine all aspects of the programs, and develop solutions to enhance programs strengths, and more effectively address program weaknesses.

In addition, this research provides a theoretical framework with which the programs can be viewed and understood. Theory guided this research and offered insight regarding the programs' capacity to address complex issues, consumers' diverse needs and preferences, the effects of societal attitudes on program functions, and ways in which aging policy issues influence ADRC and OC policy development. Further, examining data within theoretical constructs ensures criteria used to determine program outcomes are grounded and provides guidance for implementing successful ADRC and OC standards, best practices, and policy.

Final Thoughts

ADRCs and OC can benefit some individuals by providing more options and support in accessing public and private services (White et al., 2012). It remains to be seen whether they have the capacity to improve some existing system-level problems, however.

The programs' strengths lay in their capacity to positively impact older adults' ability to understand existing services and choose options that best fit their social and financial circumstances. OC accounts for individual diversity and life-course events and explores service options that honor older adults' needs and preferences. Literature and discussions with interview participants indicate that, at this point, the programs are realizing their intended goals (AoA, 2013; White et al., 2012; Wisconsin Department of Health Services, 2013). According to this study's findings, the programs are limited by their ability to satisfactorily address long-term care funding, resource distribution issues, and federal motivation to reduce public benefits costs by placing greater responsibility for those costs on state and local government, and on individuals. The program sustainability depends on numerous factors including, positive measurement outcomes, a consistent funding source, increased consumer, provider, and community partner engagement, and the ability of the Aging Network to maintain a strong presence in the provisioning of home-and community-based services. With these in place, ADRCs and OC will emerge as a robust, sustainable system where consumers can obtain information,

access, and the services they need age in the manner that best meets their needs and preferences.

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Appendix A

Interview Guide

1. From your perspective, why do you think ADRCs have been created? [PROBE: political reasons, economic considerations, attitudes about the increasing aging population].

2. A major component of the ADRC is Options Counseling (OC). What is your understanding of the roles and functions of Options Counseling? How does OC differ from the way previous social support service systems are organized and delivered? [PROBE: What do you think prompted this change? What is the likelihood of success for OC? What are the challenges?]

3. Greater responsibility for financing delivery of social services to seniors and people with disabilities has been placed on state and local government. What do you see as the advantages and disadvantages of this decentralized approach to service delivery? [PROBE: How has this decentralized approach to providing services affected the ability of agencies to address the needs of the increasing aging population?]

4. How do you think we will know if Options Counseling is successful? [PROBE: To find affordable services that enables individuals to age in place and maintain their quality of life. Is OC a more effective form of service delivery?]

5. One goal of ADRCs and OC is to help people identify community supports and prevent institutional use. What do you think about the ability of the program to meet this goal in the current economic climate? [PROBE: Do ADRCs and OCs address service gaps and stretch consumer resources, and shrinking state budgets?]

6. Are there roadblocks to success for ADRCs and OC? What do you think those are? [PROBE: Ageism at the federal and societal level; defining individuals as consumers].

7. What do you think these words mean: Options Counseling; person-centered care; consumers? What about this new way of looking at providing services and those receiving services?

8. What do you think are the next steps in the development of this service?

Appendix B

Coding Procedure

1. Transcription- Individual interviews were transcribed then coded using focused coding
    a. Open coding: line by line
        i. Text was examined using the constant comparative approach
            1. Quotable quotes were organized by category
        ii. Developed categories were scrutinized to ensure all data informing the category was included
        iii. Differences in views, feelings, and examples were noted
        iv. The most significant and recurring codes were noted
2. Final Coding
    a. Excel format
        i. Participants responses were organized by interview question
        ii. Responses were compared and relationships established among concepts
        iii. Like responses and outliers were grouped
3. Responses were compared and grouped category and summarized
4. Repeated words, phrases and themes were counted and merged
    a. Organized by category and sub-category
    b. Relationships among categories were noted
    c. An outline was created
5. A first draft was composed
    a. Discussed patterns and connections found in interview participants responses to determine ways in which the data is connected, and the extent to which responses answer the research questions.
6. The final draft was constructed
    a. Clarified central issues and concerns, opposing views, areas of agreement and argument
    b. Generated and introduced contrasting theories to increase understanding of the topic