

**The Program of All-Inclusive Care for the Elderly:
A Qualitative Study on Three Sites in a Southwestern State**

Lucas Asher

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Jacqueline L. Angel
Lyndon B Johnson School of Public Affairs
Department of Sociology, College of Liberal Arts
Supervising Professor

Sheldon Ekland-Olson
Department of Sociology, College of Liberal Arts
Second Reader

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Chapter 1: Introduction

Projections of population growth and aging in the United States indicate the arrival of what might be called a silver-haired tsunami - a significant increase in the population over 65. By 2030, more than one in five (42 million) Americans will be 65 and older. This cohort is expected to double to 84 million by 2050, and would represent 21 percent of the population. Moreover, as the country ages, the population over 85 is estimated to triple in size to 18 million by 2050 (Ortman, Velokff, & Hogan, 2014).

In addition, the population over 65 will become more ethnically and racially diverse. As of 2012, blacks made up 9% of the older population followed by Hispanics at 7% and Asians at 4%. However, by 2050, the percentage of older Hispanics is projected to nearly triple to 18.5%, followed by African-Americans at 12% and Asians at 7%. Because nearly forty percent of the aging population will be minority by 2050, the US will face an entirely new set of social and health challenges (Ortman et al. 2014).

Meanwhile, due to increased longevity and the rapid growth of the aging population, spending on federal public assistance programs will continue to put fiscal strain on the national budget. In 2014, Medicare and Medicaid spending made up 25 percent of the budget at \$840 billion (Center on Budget and Policy Priorities, 2015). Through 2024, Medicare growth is expected to average 7.3 percent a year while federal Medicaid growth is expected to average 5.9 percent (Centers for Medicare and Medicaid Services, 2015). Furthermore, the cost of providing health care to people 65 and older is three to five times more costly than people younger than 65 (Centers for Disease Control and Prevention, 2013). Nearly all these costs are due to the fact that two-thirds of adults

over 65 have multiple chronic illnesses, such as Alzheimer's and diabetes (CDC, 2013). As the aging population grows and demands for health care services multiply, increased spending on these programs is inevitable. Given US population trends and the immense fiscal strain on federal public assistance programs like Medicare and Medicaid, the country's aging population faces vast financial and social challenges.

In Texas, the second most populous state, the aging population is expected to mirror national trends. In 2012, adults 60 and older made up 15.7% of the state's population and in 2030 this percentage is expected to rise to more than 20% (Administration on Aging, 2012). By 2050, it is anticipated that there will be 8 million Texans aged 65 years and over (The Office of the State Demographer, 2014). Meanwhile, Texas spends about \$25 billion on Medicaid, (jointly run with the federal government) which is more than a quarter of the state's total budget (Texas Health and Human Services Commission, 2015). Yet, Texas consistently ranks at the bottom of states for its health care system which takes into account, among other factors, the health of its citizens and health care access (Radley, McCarthy, Lippa, Hayes, & Schoen, 2014). Texas' swiftly aging population inevitably puts added strain on the Medicaid budget, yet the state is reluctant to invest more dollars into Medicaid and other long-term care programs, which is evident in the state's decision to not expand Medicaid under the Affordable Care Act.

As the state legislature explores options in long-term care for an increasingly frail and older population, the focus of this thesis, the Program of All-Inclusive Care for the Elderly, (PACE) offers the state a cost-effective alternative to delivering quality care to

some of its most frail and financially vulnerable older residents who would otherwise reside in nursing homes or assisted living facilities.

Local non-governmental groups integrated into their respective communities may be able to more efficiently and effectively spend Medicaid dollars than state regulatory government agencies with many responsibilities and competing priorities. The PACE program offers an opportunity for states to deliver social and health care services to its most vulnerable citizens using a capped number of state and federal funds. In my thesis, I will examine whether PACE is an ideal model of care to serve this frail population by comparing and contrasting three operating PACE sites in a Southwestern state.

In the next chapter, I present a systematic review of the literature on PACE; its history, where it exists, components of the program, who participates, what purpose it serves and barriers to growth.

Chapter 2: History of PACE

The Program of All-Inclusive Care for the Elderly originated in San Francisco, California in 1971 when On Lok Senior Services asked the Swedish health care consultant Marie-Louise Ansak to conduct a feasibility study of bringing senior care services to the Chinatown district. Given the financial difficulties of building and sustaining a nursing home and a cultural disdain for institutionalization in the Chinese-American community, Ms. Ansak devised an alternative model of care that would eventually develop into what is now known as the PACE model. Based on the British day hospital model, Ms. Ansak's model of comprehensive care combined housing, medical and social services to best serve the older, frail Chinese-American community. Moreover, in conjunction with the University of California, San Francisco, Ms. Ansak trained health care workers specifically to work with this vulnerable population in a community setting. By 1973, On Lok was established as one of the nation's first adult day care centers and began serving the community. The name "On Lok" translates in Cantonese to "peaceful, happy abode," which is fitting for a model of care that aims to provide the community with care that brings peace and happiness to residents in a setting that functions as their homes (National PACE Association, 2015).

A year after beginning its operations, On Lok received Medicaid reimbursement for adult day health services, thus broadening its reach in the community with the ability to serve more residents. Over the next few years, On Lok expanded its services to include home-delivered meals, home-health care and housing assistance. On Lok also expanded its medical care and social support services to nursing-home eligible participants, which is now a mandatory feature of the PACE model. By 1979, On Lok received a four year demonstration grant from the Department of Health and Human Services to develop a

comprehensive model of care to participants with long-term care needs. Because of On Lok's success, the federal government enacted legislation in 1986 that provided Medicare and Medicaid waivers to ten organizations that could apply to replicate the On Lok model of care (NPA, 2015)

In 1987, On Lok received financing from major foundations including the Robert Wood Johnson Foundation, the John A. Hartford Foundation and the Retirement Research Foundation. In addition to On Lok, the foundations provided funding and operational support to five providers who wished to replicate the On Lok model. Soon, they became the first official PACE sites. The sites were established all over the country, in Boston, Massachusetts; Portland, Oregon; Columbia, South Carolina; Milwaukee, Wisconsin and Denver, Colorado (Hirth, Baskins, & Dever-Bumba, 2009). In 1990, the original PACE sites received Medicare and Medicaid waivers to expand and sustain their operations. Through the next seven years, the PACE model of care continued to grow and gain support from various stakeholders, including the newly established National PACE Association (NPA, 2015).

The year 1997 was perhaps the most important in PACE's history. Tucked away in a landmark piece of legislation, HR 2015 (best known as "The Balanced Budget Act"), passed by a Republican Congress and signed by President Clinton, PACE was established as a permanent provider of care under Medicare and Medicaid (Hirth et al., 2009). No longer a conditional "waiver" program, PACE was formally written into a statute that was mostly focused on cutting health care costs. Interestingly, though the BBA cut Medicare and Medicaid spending significantly, (Moon, Gage, & Evans, 1997) PACE was legally amended to Title XVIII and Title XIX of the Social Security Act, which

established the Medicare and Medicaid programs in 1965. This resulted from PACE's appeal to the federal government as a new method of care that could achieve long-term Medicare and Medicaid savings. From its early beginnings as a novel concept in 1971, twenty-six years later, the idea of an all-inclusive model of care for the elderly was established in federal law, a remarkable feat given the program's beneficiaries are some of the most vulnerable in society.

Another significant year in PACE's development was 2005. As the PACE model of care continued to grow in the country, legislators saw a need for PACE services in rural areas. Under the Deficit Reduction Act, legislation again aimed at reducing the federal budget, \$7.5 million was awarded in competitive grants to fifteen rural health care providers to operate the PACE model in under-served parts of the country. Sites included Billings, Montana; Bismarck, North Dakota and Sioux City, Iowa (Mirth et al., 2009). However, the other sites established under the Act in Kahului, Hawaii and Colchester, Vermont are no longer in operation.

On August 5, 2015, the US Senate passed the PACE Innovation Act of 2015 (S.1362) and the House of Representatives passed a companion bill on October 21, 2015. President Obama signed the legislation into law on November 5, 2015. The Act authorizes the Secretary of Health and Human Services to waive certain Medicaid requirements so that PACE providers and others can develop demonstration projects for additional vulnerable populations, such as younger people with disabilities. The CEO of the National PACE Association called the Act a “milestone for the PACE model of care” and said that “PACE organizations are eager to demonstrate how its interdisciplinary, all-

inclusive approach can improve health outcomes and quality of life for younger individuals who qualify to enroll.” (NPA, 2015).

Chapter 3: Background - Organization and Program Characteristics

The Balanced Budget Act (BBA) defines PACE as a program that “provide(s) services to such enrollees (dual-eligible) through a comprehensive, multidisciplinary health and social services delivery system which integrates acute and long-term care services pursuant to regulations...” with the goal of enabling program participants to maintain their independence in their communities for as long as possible (1997, p. 280). PACE organizations are anchored through their PACE centers, which “combine the services of an adult day health center, primary care clinic, and rehabilitation facility into a single location” (Legislative Budget Board, 2015, p. 216). Coordination of all participant services occur at the PACE center. According to the NPA, about half of PACE organizations operate one adult day health center; other organizations provide care in two or more centers while the largest operates ten centers (2015).

According to PACE regulations, providers must have the following services, at a minimum: interdisciplinary assessment and treatment planning, primary care services, social work, restorative therapies, personal care and supportive services, nutritional counseling, recreational therapy, transportation, meals, medical specialty services, laboratory tests, x-rays, drugs and biologicals, prosthetic and durable medical equipment, corrective vision devices, hearing aids, dentures, acute inpatient care and nursing facility care (Beauchamp et al., 2008). The number and complexity of services that PACE organizations must provide illustrate how comprehensive the program is.

I. Financing

A key component of the program that makes it unique among health care providers is its funding mechanism. Unlike traditional fee-for-service payments, PACE operates through capitated Medicare and Medicaid funds. In fact, “PACE is the only statutory program that integrates services covered by Medicare and Medicaid through a system of capitation payments from both programs” (Ghosh, Orfield, & Schmitz, 2014, p. 1). The Center for Medicare and Medicaid Services (CMS) calculates a frailty level risk score for each program participant to determine the amount of funds that Medicare pays the PACE provider. Importantly, according to federal law, “Such amount under such an agreement shall be computed in a manner so that the total payment level for all PACE program eligible individuals enrolled under a program is less than the projected payment under this title for a comparable population not enrolled under a PACE program” (BBA, 1997, p. 283). It is easily discernible why PACE was a part of the Balanced Budget Act, as cost-savings are written into the program requirements. For all PACE providers, the universal rule applies that they will receive less Medicare dollars to care for a participant than other care providers that serve the same population, such as nursing homes receive.

Though the Medicare capitated rate is set by the federal government, the BBA asserts that the state in which the PACE provider operates in is responsible for setting the Medicaid rate. Importantly, the capitated amount must be specified in the PACE program agreement with the state administering agency on an annual basis (BBA, 1997, p. 293). Similar to the Medicare rate rules, the Medicaid rate that the state pays the PACE provider must be less than what the state would pay a provider serving a similar population. This is in keeping with the program's objective of delivering similar services

as other care providers at lower costs to the federal and state governments. The fact that the state has control over the Medicaid rate process results in differences among PACE providers across the states as their Medicaid rates depend on the state's spending, regulatory and political environment. Because each state has the latitude to operate their respective Medicaid programs differently within approved federal guidelines, PACE providers' relationship with their state administering agency varies across states.

The fact that PACE providers take on full financial risk of their participant, as explicitly outlined in the Balanced Budget Act, is another important component of the program. First, it serves as an incentive for providers to deliver the best possible care to their participants because once participants are enrolled in PACE, the provider assumes responsibility for all their medical needs. Thus, PACE providers must work tirelessly on prevention measures to avoid added costs to their programs. Although, the literature shows that assuming full financial risk is a component of the model that may deter potential providers from beginning PACE, as organizations must have significant resources to assume full financial risk to hundreds of frail older adults (Gross, Temkin-Greener, Kunitz, & Mukamel, 2004).

II. Organization

The second key component of the PACE model is the interdisciplinary team (IDT). Unlike other teams in medical care settings, the IDT is larger, more comprehensive and responsible for participants' care 24/7, even though most participants reside in their own residences. In addition to primary care physicians, registered nurses and social workers, the IDT must include physical and occupational therapists,

recreational therapists (or activity coordinators), dieticians, PACE day center coordinators, home care coordinators, personal care attendants (or their representative), and drivers (or their representative). PACE sites can also choose to include additional staff in their IDTs, such as pharmacists and chaplains. (Mukamel et al., 1998, p. 228). PACE is unique in that it includes paraprofessionals in addition to professionals and that their opinions are equally valuable. As Mukamel et al. (2006) write, “The PACE philosophy recognizes that often it is these care providers who are the most intimately acquainted with patients and their families and are therefore most knowledgeable about their needs and the barriers and difficulties they face” (p. 228).

The IDT embraces a holistic approach to participants' health, to meet all their physical, psycho-social and functional needs (NPA, 2013). PACE's unique service structure also encourages programs to deliver better health results to their participants. Specifically, the use of IDTs encourages PACE programs to reduce hospital use. Louise A. Meret-Hanke (2011) writes, “This approach reduces hospitalization due to ambulatory sensitive conditions. Second, the interdisciplinary teams are responsible for managing enrollees' care across all settings, which facilitates transitions between settings and reduces rehospitalizations” (p. 775).

IDT meetings are not necessarily comprised of fifty staff members. Attendance at the meetings depends on the participants that the team discusses that day. Ordinarily, physicians, the director of nursing and other staff that see all participants will be involved in all IDT meetings and staff who oversee certain participants will attend meetings when their participants are discussed. In the IDT meetings, participants' cases are discussed if they experienced a recent hospitalization, developed an illness, were placed in a nursing

home, their family expressed concerns or other immediate issues (Mukamel et al., 2006). Moreover, IDTs occur during initial intake of the program participant; “The (initial) assessment must cover a range of health and social issues, and be used as a basis to develop an integrated plan of care that will meet the participants’ medical, physical, emotional, and social needs” (Beauchamp et al., 2008, p. 38).

IDT meetings are also done every six months to reevaluate a participant's case and make any necessary changes to their care plan. All IDT meetings are facilitated by one team member to ensure the meeting runs efficiently and so all staff have input on participants' care. What makes the PACE IDT model unique is that teams have incentives to collaborate to make decisions that are in the best interest of the patients' well-being. Any hospitalizations, expensive procedures or excessive treatment are borne by the PACE provider. Because the provider receives a capitated amount of Medicare and Medicaid funds, any preventable illness or hospitalization will take a financial toll on the provider. Thus, the IDT understands that staff must always put the participant's interests ahead of their own interests, in order for their employer to succeed.

PACE programs are also required under CMS regulations to implement marketing guidelines. “Each PACE organization must establish implement, and maintain a documented marketing plan with measurable enrollment objectives and a system for tracking its effectiveness” (CMS, 2013).

Another component of PACE is its emphasis on quality assurance and stringent patient safeguards. The BBA outlines that at a minimum, PACE providers must have “a written plan of quality assurance and improvement” and “written safeguards of the rights of enrolled participants (including a patient bill of rights and procedures for grievances

and appeals) in accordance with regulations...that are designed for the protection of patients” (1997, p. 281). Because the population PACE cares for is frail, very old and sick, patient safeguards are strictly enforced by the state administering agency and by CMS. Moreover, because of these regulations, many PACE sites employ a staff member solely dedicated to overseeing quality assurance and patient safeguards.

III. Coverage

All PACE programs are required to provide participants with transportation to and from the PACE centers. Moreover, if a participant needs to be transported to medical appointments, the PACE program is responsible for providing that transportation (NPA, 2015). According to the NPA (2015), “Providing transportation also places a driver, who has been trained to observe cues, in the home of the PACE participant. Drivers can then report these cues that may signal a change in health status or other changes that should be monitored.”

Another significant component of PACE is that when participants enroll, they must drop their current care providers and only receive medical care at the PACE center or other PACE approved specialists (Gross et al., 2004). Until disenrollment or death, the PACE provider is responsible for all of the participant's medical and social needs. The requirement that participants end their relationship with their primary care physician ensures that all the participants' care is integrated, coordinated and individualized by the IDT. While this integration is crucial to the PACE model, the requirement that participants drop their primary care physicians may also be a barrier to enrollment growth. In interviews with staff at PACE sites, Gross et al. (2004) found that this

requirement was the third most important barrier to program enrollment growth. As an example, they write, “At one PACE program, of the 255 individuals who were referred to the program in 2001 but did not enroll, 42 (16 percent) specifically cited not wanting to change physicians, and another 42 stated more generally that they did not wish to give up their fee-for-service care” (p. 273).

PACE providers can only disenroll participants in two circumstances; if the participant fails to pay his/her premium on time (if applicable) or if the participant engages in disruptive or threatening behavior as outlined in regulations agreed to between the PACE provider and the state administering agency (BBA, 1997, p. 282). According to the NPA (2015), less than two percent of participants were involuntarily disenrolled from PACE. Because most participants are dual-eligibles and do not pay premiums, disenrollment over failure to pay a premium is very unlikely. Further study is needed to determine how many participants are disenrolled due to behavioral issues. Given that many participants have dementia and other cognitive issues, the regulations that dictate disenrollment must be strict and stipulate that the provider is responsible for caring for participants with behavioral problems. Thus, except for extraordinary cases, most participants are enrolled in PACE until they pass away.

IV. Advocacy

Lastly, the National PACE Association plays an essential role in the operation of PACE programs. The NPA is the trade organization that supports and advocates for PACE programs through federal policy and advocacy, education and communication, data and research (NPA). They lend crucial support to organizations that are interested in

becoming PACE providers, providing resources and helping them navigate through the start-up and application process.

V. Eligibility

While participants must be age 55 or older to enroll in PACE, the average age of participants is 80. Approximately 75% of participants are female (NPA, 2015). The typical PACE participant also has an average of eight acute and chronic medical problems, primarily heart disease, diabetes and respiratory disease. The typical PACE participant has three activities of daily living dependencies, such as walking, toileting, bathing and dressing. Importantly, PACE participants must be nursing home eligible in the state they reside, as PACE was created as an alternative model of care to provide for older adults who otherwise would reside in nursing homes. Lastly, the PACE participant has to live in the service area of the PACE provider and be able to live safely in the community at the time of enrollment (Hirth et al., 2009).

According to the NPA (2015), 30% of enrolled participants live with family members, 22% live independently, 17% live in senior housing and 16% live in senior housing with medical services such as assisted living. Only ten percent of PACE participants permanently reside in nursing facilities. The top five sources for participant referrals are assisted living facilities, friends and family of participants, churches and community organizations, senior housing and health care providers (NPA, 2015). While Medicaid eligibility is not required to participate in PACE, 90% of PACE participants are dual-eligibles, meaning they qualify for both Medicaid and Medicare. Fifty percent of participants have diagnoses of dementia (NPA, 2013). Thus, the average PACE

participant is very old, frail, poor and demand considerable medical attention. PACE providers are serving some of the most vulnerable members of society, while assuming full financial risk and providing for all their medical and social needs, which makes PACE highly unique among medical care providers for the elderly.

VI. Availability

There are currently 116 PACE programs operating 210 centers in 32 states. PACE programs serve 34,413 participants as of October 1, 2015. Pennsylvania leads the nation in the number of sites with 19, followed by California and North Carolina with 11, Michigan with nine, Massachusetts and New York with eight and Virginia with seven. The following states do not have a PACE program: Alaska, Arizona, Connecticut, District of Columbia, Georgia, Hawaii, Idaho, Illinois, Kentucky, Maine, Minnesota, Mississippi, Montana, Nevada, New Hampshire, South Dakota, Utah, Vermont, and West Virginia (NPA, 2015). As of 2013, the average size of PACE organizations operational for one year or more is 285 participants while the average size of PACE organizations operational less than one year is 40 participants. The largest PACE organization serves 3,265 participants (NPA).

VII. Cost-Effectiveness and Health Outcomes

Overall, national studies on PACE have shown that the program is a cost-effective alternative that delivers more health benefits to participants than if they were in other long-term care programs, such as nursing homes. White (1998) and Bodeheimer (1999) found that “Costs for PACE enrollees are 16-38 percent lower than Medicare fee-for-

service costs for a frail elderly population, and 5-15 percent lower than costs for comparable Medicaid beneficiaries” (as cited in Petigara, Tanaz, & Anderson, 2009, p. 1). In a review of the literature on PACE, Hirth et al. (2009) detailed many positive outcomes from participating in PACE; they include: “greater adult day health care use, lower skilled home health visits, fewer hospitalizations, fewer nursing home admissions, higher contact with primary care, longer survival rates, an increased number of days in the community, better health, better quality of life, greater satisfaction with overall care arrangements, and better functional status.”

In a study assessing the effects of PACE on hospital use, Meret-Hanke (2011) found PACE reduces hospital use compared to a comparable population of seniors not enrolled in PACE. She found “that although PACE enrollees had higher hospital use in the six months before baseline, they had substantially lower use during the two-year follow-up period. PACE enrollees spent an estimated average of 0.2 days in the hospital per month alive compared with an estimated average of 0.8 days in the hospital per month alive by matched-comparison subjects or an estimated PACE effect of 0.6 days in the hospital per month alive per enrollee” (p. 781). While her study did not definitively confirm that PACE is cost effective through reduced hospital use, she estimates potential savings per PACE enrollee is about \$520 per month alive in hospital costs (p. 782). Thus, reduced hospital use among the PACE participants not only benefits participants' health but also offers PACE programs and governments the chance to save health care dollars.

In a comparison of Medicaid costs between PACE participants and a comparable population in fee-for-service long-term care, Weiland, Kinosian, Stallard, & Boland (2013) found that PACE's capitation model resulted in significant savings for Medicaid

compared to outlays in the traditional fee-for-service model. Segelman, Cai, Reenen, & Temkin-Greener (2015) found that compared with Section 1915(c) waiver program enrollees, PACE enrollees had 31% lower risk of long-term nursing-home admission. Importantly, PACE enrollees were at lower risk even though they were overall more cognitively impaired. The authors concluded that “PACE may be more effective than 1915(c) aged and aged and disabled waiver programs in reducing long-term NH use and may be particularly well suited to supporting cognitively impaired individuals, enabling them to remain in the community longer” (p. 1) Beauchamp et al. (2008) also found a positive correlation between enrollment in PACE and health quality. The researchers compared PACE enrollee survey results to responses from a similar cohort enrolled in Section 1915(c) waiver programs in the same states. Overall, their results showed, “PACE improved health management outcomes, increased preventive care, and reduced hospital use” (p. 93). Moreover, “PACE participants had better self-reported health status; the same levels of functioning, and fewer depressive symptoms than HCBS participants” (p. 93). Nonetheless, the authors reported weak evidence “as to whether participation in PACE improved physical or mental health status” (p. 94).

While most national studies on PACE indicate that the program benefits participants' health in a cost-effective way, it is important to acknowledge that there isn't uniformity among researchers on PACE. The best example of this is Mathematica Policy Research's report to the U.S. Department of Health and Human Services in 2014. Based on a comprehensive review of existing literature on PACE, the report found mixed evidence as to whether PACE improves health quality while controlling costs. First, the authors found that “PACE has no significant effect on Medicare costs, but it is associated

with significantly higher Medicaid costs, with the Medicaid spending gap between PACE and matched comparison enrollees decreasing over time” (p. v). Contrary to findings that PACE saves Medicaid costs through its capitation financing model, Mathematica found that Medicaid expenditures are actually higher for PACE participants than for a comparable group not enrolled in PACE. The study also found that “PACE enrollees have fewer inpatient hospitalizations than their fee-for-service counterparts, but they appear to have higher rates of NH admission” (p. v). The authors do admit that that the high rates of nursing-home admissions could be a result from PACE programs substituting short-term nursing home use for hospitalizations. Still, this finding is curious given that the guiding principle behind PACE is to enable older adults to live independently as long as possible.

The authors only found “some evidence” that PACE improves quality of care (such as pain management) and reduces participants' mortality rates. The only positive health outcome that the authors found strong evidence for was reduced inpatient hospitalizations. The authors do acknowledge limitations to their review. They write, “Several studies included in this review have significant limitations in terms of external validity or the generalizability of their findings and in their continued relevance for assessing the current PACE model” (p. v). Specifically, the report points to Medicare capitation as an important limitation as “...findings from prior evaluations looking at potential cost savings under PACE are likely to be outdated, given changes to the PACE financing structure over time...” (p. vi). However, even with the study limitations, the Mathematica Study reveals a profound disagreement among researchers on whether

PACE participants experience better health outcomes than if they were in a fee-for-service program and if PACE is a cost-effective alternative to traditional models of care.

VIII. Barriers to Growth

Some may ask that if PACE is indeed an ideal model of care for frail, low-income adults, why aren't there more programs in operation? The relatively slow growth of PACE is one of the biggest challenges facing supporters of the model today. Without more programs in existence, it is exceedingly difficult to encourage various stakeholders that PACE should be expanded. PACE is regulated differently than traditional Medicare and Medicaid providers as the number of programs is capped by the Balanced Budget Act. Though the BBA authorized PACE to grow by 20 programs each year after enactment, the number of existing programs remains far below the legislative cap (Gross et al., 2004). Today, there are 116 programs in operation though the legislative cap is at 400 programs, meaning the cap is nearly three and half times higher than the growth of programs.

One of the earliest barriers to growth was the federal regulatory environment. Because PACE regulations were not finalized until two years after passage of the BBA, providers could not accept dual-eligible participants, who make up a majority of the program's participants (Gross et al., 2004). Thus, regulatory uncertainty following passage of the BBA prevented potential providers from opening PACE sites. The state regulatory climate is another important barrier to growth. Because of the state's role in dispensing Medicaid funds, the state must be willing to invest time and money in regulating PACE providers. Gross et al. (2004) write, "States must determine whether

new legislation is required, the licensure or certification that providers will need, and whether any financial requirements beyond those stipulated by the federal government will be necessary in view of the state's regulations” (p. 265). Because states play a significant role in the operation of PACE programs, the growth of programs nationwide is highly dependent on the state's interest in seeing the program succeed. This helps explain the variation in the number of programs nationwide; states with the highest number of programs indicates “their relatively generous state home and community-based benefits, as well as their political willingness to adopt innovative social programs” (Gross et al., 2004, p. 265). Population density is another important factor as the states with the most PACE programs have a higher population density than states without programs. Because attendance at the PACE day center is required and PACE providers must provide transportation to and from the center, operating PACE in rural areas is more difficult than in areas with dense populations (Gross et al., 2004)

Funding is perhaps the largest barrier to program growth as establishing a PACE site requires significant upfront investments. Potential providers need an estimated \$3-\$5 million in start-up funding, which is difficult for non-profit organizations to secure. (Texas Department of Aging and Disabilities Services, 2014). In PACE's early history, national foundations provided grants that covered more than 70% of start-up costs for the first eight demonstration sites. However, because PACE is a permanent provider of care, grants are no longer available for potential providers. Today, most PACE programs are sponsored by health systems, hospitals, nursing homes and other health care organizations (Gross et al, 2004). The fact that no for-profit providers have opened PACE sites illustrates the difficulty in making a profit from the PACE model of care.

Chapter 4: Objectives and Methodology

My thesis aims to answer the following objectives:

- to understand the history, development, management, finances and operations of three PACE sites in a Southwestern state
- to learn the benefits and challenges of operating PACE in the state
- to understand the working relationship between PACE sites and the State Administering Agency (SAA)
- to understand the regulatory framework and operational management of PACE sites from the state's perspective
- to learn if models in the state have participant results in line with national studies on PACE
- to learn if PACE is an ideal model of community-based, integrated care for frail, low-income older adults in the state
- to learn if PACE can fulfill the need in the state for comprehensive, cost-effective services for a growing elderly population

I. Researcher's Role

To answer these objectives, I completed the University of Texas at Austin's Office of Research Support Institutional Review Board (IRB) training for human subjects research. Following the training, I submitted an IRB proposal to interview persons relevant to my research. The proposal included a detailed document outlining goals and objectives, an interview guide and a consent form for research participants. After

receiving IRB approval, I contacted PACE executives to introduce myself, explain my research project and asked if I could travel to their sites to conduct in-person interviews with executive staff members. Correspondence was done through e-mail and phone. After receiving permission to visit all three PACE sites, I applied for travel funds through the Humanities Program in the College of Liberal Arts. I proposed a detailed budget outlining all travel related costs (including flights, food, rental car and hotel stays) to the cities where PACE sites are located. I was awarded a \$1,500 stipend to complete my travel. After receiving my stipend, I made all necessary travel arrangements to the PACE cities.

I traveled to the PACE sites to conduct interviews in June of 2015. Because of time and geographic constraints, I completed travel to the sites on two separate trips. I visited two sites on June 2 and 3, 2015 given their proximity to one another. I made a separate trip to the third site from June 8-9, 2015. Because the third site is much larger than the other sites, (greater number of facilities spread-out in the city) I spent a day and a half touring the sites and conducting interviews.

II. Data Collection

During my travel to the PACE sites, I collected qualitative data through personal on-site interviews which were recorded using my personal tablet. Though I received interviewees' consent for their names to be identified in my thesis and for their interviews to be recorded (audio only), I decided to de-identify my sources in the thesis as a precaution. With interviewees' permission, I also took photographs of the exterior and

interior of the sites using my tablet to illustrate the physical resources that are necessary to operate PACE.

III. Units of Analysis

In order to maintain a narrow scope with my research and to understand PACE program operations in depth, I chose to only interview the Executive Directors and their leadership staff. They are the major decision makers who are responsible for medical, financial, regulatory and support operations.

PACE A – City 1: Interviews conducted on June 2, 2015

- Executive Director
- Director of Clinical Services
- Director of Social Services

PACE B – City 2: Interviews conducted on June 3, 2015

- Chief Financial Officer
- Director of Quality Management and Compliance
- Medical Officer
- Program Director

PACE C – City 3: Interviews conducted on June 8-9, 2015

- Executive Director
- Vice President of Center Operations

- Medical Director
- Vice President of Support Operations
- Senior Vice President of Finance

IV. Analytic Strategy

The interviews I conducted were semi-structured. I developed a formal questionnaire (see Appendix I) which I used in the interviews but I also provided interviewees with opportunities to expand on topics. Following the interviews, I transcribed interviewees' responses from audio to written word. I coded responses based on recurring patterns and themes. I compared cost-effectiveness, measurement of quality of care and patient satisfaction and working relationship with regulatory agencies across three sites based on interview responses.

V. Sample Size

PACE A – City 1:

According to the Executive Director, the site was named for a physician in the community who was very involved in caring for the elderly population in the late 1970's. He wanted to look at ways to provide community-based care in place of nursing homes. After the center opened on July 5, 1978, he died unexpectedly in August and the board of directors decided to name the center after him. The Executive Director visited PACE C and after realizing her site provided very similar services, she began the application process to become a PACE provider, receiving state and CMS approval in 2004. It is the only adult day health center in City 1, filling an important gap in services in the

community. The center has 142 PACE participants as of June 2015. The site opened a memory care unit in 2010 which serves 20-25 participants on a given day. The ED described her organization's mission to "provide the best possible care in an atmosphere of fellowship and love for elderly and disabled adults in the community." PACE A has very little turnover as many of the staff have been there ten years or longer, making it an organization deeply rooted in the community.

PACE B – City 2:

PACE B is a division of a parent health system which is a community health care network that "provides services for adults, children and adolescents who have a diagnosis of mental illness, developmental disabilities or substance abuse." The parent company was created in February 1964. In addition to PACE, the parent company provides a number of different services, including substance abuse treatment and short-term psychiatric crisis stabilization. This makes PACE B unique among PACE providers as it is the only site in the country that is operated by a community health center. The CEO of PACE B saw a gap in services for the aging population in City 2 and believed a PACE program would fill this crucial need. PACE B became a PACE provider in December 2010 and has a census of 115 participants, making it the newest and smallest PACE site in the state. PACE B's stated mission is to "provide quality medical care and support services to people with health challenges, ensuring they are able to live at home and be part of the community."

PACE C – City 3:

PACE C was established as a private non-profit 501(c)(3) organization in 1987 and became a PACE provider in 1992. The Executive Director traveled to San Francisco to tour On Lok, the first PACE site in the country, before opening her own PACE organization. PACE C is the largest and oldest PACE site in the state, with a staff of 560 employees serving 855 participants at three centers throughout the service area. PACE C was an important resource for the other sites when they began the application process to become PACE providers. The ED also serves as president of the state's PACE association which advocates for PACE providers at the state legislature and represents the providers in discussions with the SAA. Because of PACE C's history as the first PACE provider in the state and the large number of participants it serves, it is regarded as the most influential PACE site in the state and stands out as a national model.

Approximately six percent of PACE C's participants reside in nursing homes, less than the national average of ten percent. PACE C is unique among PACE providers given that 80-90% of participants are Spanish speaking and are three times as frail as the average Medicare enrollee. PACE C also has a residential memory care unit, an on-site pharmacy and a facility solely dedicated to maintenance and support services. PACE C's mission is to "enable frail elderly persons to remain independent and reside in their own homes and communities for as long as it is desired and medically possible."

Chapter 5: Findings

I. Benefits

The Director of Clinical Services (DCS) at PACE A oversees nurse managers, licensed vocational nurses and the program's two physicians. She also manages quality insurance and infection control which is usually under the purview of an additional staff member at other PACE programs. Lastly, she facilitates care plan meetings. Because PACE A is a smaller program, she wears many hats. She said that “Normally, three people do what I do.” When asked, “What do you see as the greatest benefit of the PACE model, compared to traditional forms of medical care for the elderly, such as nursing homes,” the DCS responded that PACE was “Managed care in truest sense of form” because before enrolling in PACE, participants had no central authority managing their care. She noted how hard it is to manage our health care system as a “competent young adult” so for frail, low-income older adults, navigating the system is nearly impossible.

The DCS said another benefit of the model was that the PACE center acted as a “wheel hub” that referred participants out to specialists when necessary. As the hub of operations, the PACE center staff can coordinate and manage all participant care as the program's nurse managers and physician are in constant communication with specialists. All aspects of the participant's visit with the specialists are relayed back to program staff without requiring the participant to do anything. For instance, if a cardiologist wrote a prescription for the participant, he/she would fax the prescription to the program staff instead of giving it to the participant. This enables the participant to receive the medication faster and enables coordination and communication between the specialist

and PACE program staff. The participant's care is managed without the participant providing information about the specialist visit to PACE staff and filling the prescription on his/her own. This aspect of PACE that manages the participant's care in a coordinated way is what she most appreciates about the model.

The DCS also told a story that is indicative of the huge impact PACE can have on participants' lives. A couple was experiencing strain in their relationship because one spouse had Alzheimer's disease and the other was frustrated that he could not help her. The illness took a toll on their relationship until the woman was able to enroll in PACE and attend the memory care center during the week. This took a huge burden off the man who told the director that he "learned to love again." This story vividly illustrates the way that PACE can relieve caregiver burden and improve personal relationships. The Executive Director of PACE A commented that the greatest benefit of the PACE model was that her staff could coordinate care for a "forgotten population" and help them maintain their independence and provide a higher quality of life. She agreed with the DCS that the program acts as a managed care program because of the coordination across all medical disciplines. She loves coming to work every day, knows the participants well and attributed the joy of engaging with participants to what makes her "tick."

The Director of Social Services (DSS) at PACE A is responsible for supervising the other social worker on staff and ensuring all the psychosocial needs of the participants are met. Social workers are an integral part of the PACE model and are the first people whom participants go to when they need help. The duties of the position include intake of new participants, acting as a liaison to the local Medicaid office and coordinating home visits to conduct psychosocial assessments. Additional duties include assessing and

monitoring participants' mental health, home environment, finances, activities, socialization and transportation needs. Many times, the social worker helps participants obtain basic necessities such as clothing and food, a sign that many PACE participants are severely financially vulnerable. She has moved a participant from an infested home environment to a cleaner and secure environment. Social services also assist in participants' palliative and spiritual care.

She said that the greatest benefit to the PACE model is that it allows staff to address all participant needs and reduces barriers that patients have. Another benefit of the program is the participant advocacy committee which brings participant grievances and concerns to the attention of staff members. This provides participants with a sense of autonomy over their care. The social services director embraces providing participants with any services they need. She likes being a “motivator” and “getting her hands dirty.” There has never been a day at work where she sits and does nothing. In the PACE model, she feels she is more of an advocate than when she worked in nursing homes.

The program director of PACE B said that the greatest benefit to the model was its holistic approach which includes home care, medication and physical therapy. She said, “You get to treat the whole person and know everything about them.” Because PACE coordinates all participant care and provides all medical and social services, staff members are able to learn a lot about their participants; with greater knowledge, the staff is able to provide higher quality care. The director said that program participants and staff become family and that she is “happy to be a part of it” because they are able to make a difference in people’s lives. For instance, participants have gone up to her and told her that they would not know what to do without the program. In her first few days at the

center, the director heard a couple of participants laughing when one participant expressed bewilderment at her daughter who thought she dumped her at PACE, when she is actually “having the time of my life.” Another example of how much participants love the model is when participants express concern after enrollment that they have to live at the PACE center (which they can't) and then weeks later, they want to live at the center because they are so happy. She explained that given participants' frailty and financial vulnerability, they have not experienced the best luck. She believes they are “special” and deserve the best possible care. If participants are not satisfied, her staff will do everything to fix the problem. Participant surveys have shown high satisfaction with the program; however food quality is the biggest concern.

Approximately 56-57 participants attend the center five days a week which illustrates the need for PACE in City 2. The program director believes PACE is “absolutely” an ideal model of care. She explained that her mother was exhausted caring for her ill father and that if they lived in the program’s catchment area, she “would have put my father in program in a minute.” Then, her mother could have been a wife instead of a caregiver; this is another example of how PACE has the potential to reduce caregiver burden. She believes PACE has a bright future in elder care and that there is no reason to have nursing homes. She explained, “Have you heard anyone say, I want to get old and live in a nursing home? Why would we have those? They go there to die and it's horrible...This program doesn't throw older adults away.” The director said that this program is what she has spent her career preparing for and that she “feels amazing to be a part of it.”

The Director of Quality Management and Compliance at PACE B believes a great benefit of PACE is making prescription medication accessible and affordable for participants. Also, the variety of social activities that the program offers benefits the participant's physical and psychological well-being. She had always hoped that this program would be viable because she believes in the model and sees great value. She loves the fact that participants are able to get good care at PACE B and points to an example of a woman who, after enrolling her mother in the program, said “This is the mom who I grew up with.” She believes PACE is “absolutely” an ideal model of care that the state should embrace and expand.

The physician at PACE B was unavailable for an interview so in order to understand the medical benefits of the PACE model, I interviewed the medical officer. The medical officer is a physician's assistant, operates the medical clinic and is the primary medical professional who interacts with participants. He appreciates the coordination and integration that the PACE model provides. For instance, he describes a hypothetical scenario where he can see a patient with a painful knee in the morning, evaluate it, inject it with a steroid, send the participant to the physical therapist for heat treatment and then to the occupational therapist to be evaluated for lifestyle changes. What would normally take weeks to accomplish, including referrals to different specialists, can be done in a few hours because all the participant's health care providers are under one roof.

The medical officer described the typical participant (when first enrolled) as someone on many medications from various physicians with no designated person overseeing their care. That is when the PACE team comes in; with the integration of

different disciplines, participants receive more consistent care and consecutive lab work which keeps them out of hospital and in their homes. He explained that “We had patients going to the ER every three weeks. Now, patients haven’t been in hospitals in over a year or two. They can call a nurse 24/7, the nurse can go to their house and call me and I can make a decision at 11 PM instead of the participant taking a trip to the ER.” With this system of care, PACE is able to not only cut costs for the overall health system but also saves patients the burden and time that comes with prolonged illnesses. In terms of cost-effectiveness, he says that PACE is a cost-effective model because the program takes people who would normally be in nursing homes and enables them to stay in their homes with their families. The medical officer cited statistics to justify his opinion that because most Medicare costs are spent on the last three to four years of an older adult's life, it is cost-effective for the government to put the risk on PACE. Thus, PACE staff have to develop very good managerial skills to prevent unnecessary hospitalizations and emergency room visits.

All three PACE A staff who were interviewed also commented on their program's contribution to their community as another benefit of the PACE model. PACE A fills a crucial need in City 1 as the only adult day care center. Because the city lacks affordable assisted living facilities and there are no alternatives to nursing home care to provide for the long-term care needs of older residents, according to program staff, their PACE program is a vital provider in the community. The need is highlighted by the fact that participants have moved into City 1 from the outlying areas just to participate in PACE. PACE A also receives great community and philanthropic support and enjoys a good reputation in the city. Within the community, people know PACE A as a “happy place to

be.” This includes the support of a state representative of City 1, who is a huge supporter of PACE and has advocated for the existing sites and the expansion of PACE at the Legislature. In fact, the ED said that PACE enjoys bipartisan support from most state legislators.

II. Interaction with family members

The DSS at PACE A interacts with participants' family members the most out of other staff members. When asked, “How do you interact with and include family members in your IDT?,” she responded that the majority of participants' families are not very involved and that the staff is so close to participants that they become their family. However, most families that are involved with their loved one's care are supportive of PACE. She said the staff loves families to be involved but there are “times when they can be a pain.” For example, some family members are in complete denial of the disease process and forget that their loved ones have chronic conditions, many of which went untreated for years. She explains that the staff tries to ensure participants have a medical power of attorney as they want participants to make their own decisions, with their families as backup support. PACE A staff strive to educate and to provide support to families but ultimately will make decisions that are in the best interests of the participants. Because PACE is such a complex program, PACE A staff make sure family members know what PACE is and ask them to verbalize their understanding before signing the enrollment form.

At PACE B, the medical officer interacts with family members on a regular basis and is very upfront with family members as to what the program can and cannot do

medically. This concern is similar to what the DSS at PACE A expressed about family members being in denial of the disease process. The medical officer also points out to family members that the organization is not a dumping ground for their loved ones. The PACE staff do not exist to “babysit” the participants but instead through the IDT, will evaluate the number of days the participants need to come to the PACE center to receive the appropriate amount of care. Family members are invited to attend IDT meetings with the participants.

III. Measuring Quality of Care

“How do you assess quality of care you provide to enrollees?” The DCS at PACE A responded that PACE programs are required to report vaccines, grievances, appeals, enrollments, disenrollments and deaths to CMS. She said she also measures sudden deaths to learn if her staff missed something in participant care and if the death could have been prevented. When the program witnessed a high number of urinary tract infections, she began to wonder if nurses and caregivers were properly trained. She then began an education program around urinary tract infections which helped reduce the number of participant cases. Similarly, when the program experienced a high number of emergency room visits that weren't resulting in hospitalizations, (visits were unnecessary) she educated the participants on calling the on-call nurse who is available 24/7. The director reported that emergency room visits were significantly reduced as a result of educating participants of the program resources available to them. Because PACE programs assume the full financial risk of the participants, they are incentivized to

prevent illnesses and emergency visits which is why she implemented various educational programs.

The director also emphasized that there are many aspects of PACE that cannot be measured. For example, a participant could ask a nurse about taking an allergy pill and the nurse tells the participant not to take it because of the negative interaction it would produce with other drugs. Thus, measuring the prevention of a medical error is difficult and is an aspect of the PACE model that cannot be reported to CMS. Because participants have access to nurses and physicians at all times while at the PACE center, interactions as the director described occur frequently. As a model of care that emphasizes prevention, it is challenging to measure preventative services that participants receive.

The ED at PACE A also commented on aspects of quality that are difficult to measure. For example, there are many participants who attend the center five days a week and are provided with breakfast, lunch and a snack before leaving for home. Thus, participants are saving money on groceries. The socialization that participants experience at PACE A is another aspect of care that is immeasurable. Participants enjoy a wide range of activities in the day center, become friends with each other and look forward to going to the center. The ED said given the holistic model of PACE, “How do you attach a price tag to what we do here every day?” There are many aspects of the model, such as socialization that cannot be measured but are vital to the quality of care that is provided to participants.

The medical officer at PACE B responded that “Bad things are what everyone looks at to measure,” such as hospitalizations, rehospitalizations, falls, smoking cessation, emergency room visits and other medical problems. He said that we are “always

measured on negativity.” He rhetorically asked, “How can you stop a gallbladder from going bad?” Because the average participant has several chronic illnesses, the development of gallbladder disease is likely, which will inevitably lead to hospitalizations. Thus, his team works very hard to heavily monitor the participants so that they can treat illnesses before they require hospitalizations. The medical officer also commented that there are aspects of PACE that the federal government does not measure, such as sewing and art classes available to participants at the PACE center. These are activities that the frail participants would not partake in if they resided in nursing homes or stayed home all day.

When asked “How do you hire physicians, who studies show, are more reluctant to participate in alternative models of care, such as PACE?” he responded that “The reality is it takes money and you have to offer a good salary.” Luckily, if it is difficult to hire a full-time physician in a rural area, programs can contract out with physicians as PACE B’s medical director and sole physician work on contract. Similarly, programs can hire other medical professionals such as physicians' assistants to carry out the majority of medical operations with participants.

IV. Growing Pains

As the newest PACE site, the leadership staff at PACE B reported having the most difficulty in meeting enrollment thresholds and took years before they were able to find steady ground and serve the community from the strongest position possible. PACE B’s experience speaks to the challenges new PACE providers face after approval from the state and federal governments. Unlike the other PACE providers in the state, PACE B

began their PACE program from the ground up which required a “grassroots buildup.” The Director of Quality and Compliance (DQC) and the Chief Financial Officer (CFO) described the process as “quite a struggle.” At the beginning of program operations, they did not have enough people on staff to offset the start-up costs so the program began \$1.4 million in the hole. Even though PACE B is a division of a parent company, they did not have the ability to take money from the company's other programs to put into PACE. Despite the fact that they work directly for the parent company, they devoted a lot of their time and effort to ensuring the PACE program could become successful. They visited PACE A many times for guidance as they and other staff were “lost trying to begin operations.” The DQC exemplifies the steep learning curve of the program given that she owns three PACE manuals; one on her work desk, one in her work bag and one at home. Whenever she had the opportunity, she tried to read the manual to make sure she was well-versed in the program. She said that both her and the CFO had to learn about PACE spontaneously and that they are still learning about program. She also commented that “If you’re not committed to it, you can find it overwhelming pretty quickly.”

Through the first two years of PACE B’s operations, the DQC and CFO were overwhelmed by the difficulty in getting the program off the ground. In the beginning, the program suffered from heavy turnover; three medical directors and six program directors came and went in a very short amount of time. Because PACE programs have to report a “professions list” and have program directors, PACE B was out of compliance with the SAA and CMS because of their turnover problems. With this heavy turnover, the program was unable to grow enrollment and as a result, the SAA took their slots away. Thus, their enrollment cap dropped from 150 to 115 because the program was not

enrolling enough participants and was out of compliance in other areas. They described this time as a “painstaking ordeal.” When PACE B’s slots were taken away, the program was held back for five months and the SAA was causing the program to lose money, according to the DQC and CFO.

However, with the support of friendly legislators and the lobbying efforts of the state PACE association, they received their slots back. This was especially due to the efforts of a former state representative of the area where PACE B is located, who is now a lobbyist for the state’s PACE association. The National PACE Association also provides support to the site through program assistance, lobbying and advocacy. PACE B pays an annual due of \$25,000 to belong to the NPA. However, there is a ton of work to do to raise enrollment to the new cap. In terms of community support, PACE B developed a great relationship with a local bank that was willing to give them a line of credit based on how quickly the program could build up to 150 slots. In the first three years of the loan, PACE B did not pay interest. They also received a building loan, operations loan and a line of credit. After growing pains in which the program was losing a lot of money, PACE B had a surplus in the last fiscal year.

V. PACE C

As the oldest and largest PACE site in the state, (one of the oldest in the country as well) PACE C stands out in the scope of services offered and in the great size and beautiful architecture of its facilities. Its largest facility houses corporate headquarters and two adult day care centers. Though, only one center is in operation as the building will be undergoing renovations. The center is 12 years old and has 300 participants

assigned to it. An average of 90 participants attends the center daily. PACE C has 560 employees, including seven full-time physicians, serving nearly 900 participants. It provides 24/7 on call service, hospice, dental services and has a residential memory care unit with 44 beds. PACE C also has an in-house pharmacy that fills 700 prescriptions a day.

The Vice President of Center Operations pointed out the color scheme of the building which represents the Rio Grande. He explained that the Executive Director was responsible and extremely invested in every detail of the organization's operations, including the building design. When I expressed my wonder as to how PACE C could afford such an aesthetically pleasing facility, he responded that the organization did not start off with this building and that it took many years of strategic planning and investments to afford such an impressive facility. In his role, the VP coordinates with state and federal regulators, directs business development, center operations, responds to emergencies, directs center managers and completes other tasks as directed by the ED. He is completely enamored by the PACE model and never wants to return to his previous work for a for-profit hospital. He believes the PACE model is "truly altruistic" because it provides care to people who need the most help and that "no one follows the individual in the community like we do." He said he could not ask for a better boss and gives all the credit to the program's success to the ED.

The Vice President of Support Operations is responsible for the support center facility which opened two and half years ago. It houses the following departments: home health, purchasing, transportation and durable medical equipment. The support center is the hub for all of the services that are provided at the three centers. PACE C utilizes

electronic systems in a number of departments that monitor supply and costs and allow for more efficient operations. He explained that technology is something PACE C has adopted wholeheartedly because of the positive effects it has on the organization's operations and care provided to participants. The home health department has 120 employees and is housed in an open concept office design, which helps foster collaboration among nurses and other support staff. One tenth of PACE C's participants are on hospice and a quarter of all participants receive home health services. Participants receive an average of 10-15 hours a week of care. PACE C staff provide care as early as 6 AM and as late as 7 PM. The transportation department has 48 buses taking 700 trips per day, shuttling participants from their homes to the centers as well as medical appointments. An electronic system is used to plan and monitor the bus routes.

PACE C buys and refurbishes medical equipment as a way to cut costs. For example, when a participant passes away, his/her wheelchair is properly cleaned and refurbished for another participant. The only equipment that is outsourced is respiratory-related. PACE C owns about \$1 million worth of durable medical equipment. Again, an electronic system exists to monitor the purchasing and costs of medical equipment. Because PACE C is such a large site, it has implemented a number of procedures and technology enhancements to ensure that costs are in control since providing care for almost 900 frail elders can become expensive very quickly. Given that the organization receives a capitated rate, it is incentivized to innovate and do more with less, while still maintaining high-quality care standards because of stringent PACE regulations.

I asked the executive officers at PACE C to explain their organization's progression over nearly thirty years. They explained the important task is to find

efficiencies within the organization, understand and project program costs and build reserves overtime. Through their experience, they learned how to manage their population better and keep them out of the hospital. One has to manage the organization like any other business in order to be successful. However, since PACE C is a nonprofit, any surplus is reinvested in the organization for future growth. Though, as time has gone by, PACE C's reimbursement rates have gone down so they had to adapt and become even more efficient in their operations, such as implementing electronic systems. PACE C received financial support for their central facility from City 3 and the NPA. The funds for their brand new building, which opened in the spring of 2015, came from reserves and the refinancing of bonds. The building is in the process of becoming LEED certified (Leadership in Energy & Environmental Design). The ED wanted the organization's newest building to have a green footprint because "Contaminants are the last things an elderly person should worry about. I always have the mentality that you can do a lot of good while doing a lot of good."

The CFO explained that the Part D prescription drug program established in 2006 helped PACE C financially. Since 92% of their population is dual-eligible, when their medications are reimbursed, the organization can earn a return and cover administrative costs. The executive officers and other leadership staff are constantly searching for new ways to control costs and maximize revenue, especially since PACE is unlike other health care organizations which can pass costs onto their patients.

Chapter 6: Challenges and Prospects

I. Regulatory Environment

Despite the many benefits of the PACE model that the interviewees explained, interviewees at all sites expressed many common challenges that their organizations face, most of which are with the SAA of PACE. The ED of PACE A explained that the biggest challenge for her site was getting the SAA to follow the mandates of the Legislature, which has been supportive of PACE. She said that the agency has not been supportive of expanding PACE and in setting reasonable reimbursement rates for the newly authorized sites. She made it clear that the contract PACE A has with the state provides for adequate reimbursements but is concerned that the new sites will not be successful if the rates are not higher than currently proposed.

PACE is also highly regulated by CMS as the application process to become a site takes “well over a year” and that the process is “not for sissies.” In fact, the application process is so arduous that she would not apply to become a PACE provider from scratch. (PACE A was already a licensed adult day care center and had many components of PACE in place at the time of their application process). Some would ask, given the difficult regulatory environment, why an organization would want to operate a PACE site. All of my interviews revealed that operating PACE requires passion and a determination to deliver high-quality care to frail older adults. Every staff member, from the executive director to the van driver, has to be invested in the PACE model in order for the organization to succeed.

The DCS at PACE A believes her greatest challenge is the state's unfamiliarity with PACE which hampers the program's operations. She said that every time the site has a contact from the SAA who develops an understanding of PACE, a new liaison is brought on who lacks knowledge about PACE. She also said federal regulations are inconsistent and up to interpretation. One year, an auditor came and deemed the site deficient. When a different auditor came the next year, the site was considered deficiency free. According to the DCS, The regulators make their own inferences based on their professional backgrounds instead of applying one set of standards.

Perhaps more than the two other sites, PACE B staff reported the most frustrations with the regulatory environment. First, the CFO and DQM commented that the program is more regulated than the parent company's methadone and psychiatric units, which signifies how highly-regulated the PACE program is. In terms of the Medicaid reimbursement rate, the CFO commented that PACE B receives the lowest reimbursement of the three sites. City 1 has higher rates even though they are 100 miles away and are similar geographically and demographically. He communicates to the state that this is unfair because they are providing the same services to the same population as the other sites. More tellingly, the CFO believes the state has not been transparent in explaining to him and other staff how the agency calculates their rate. He thinks that comparing the PACE sites to MCOs is unfair because of all the added features that PACE provides, including the certainty that participants have with their care which "is immeasurable." To be sure, he believes a reevaluation of PACE rates is needed in order to produce rates that are both fair and transparent.

PACE B staff emphasized that their program is not in competition with the other sites but that if they are providing the same services to similar populations, they should be reimbursed the same amount. They want to see all PACE sites succeed and know “with volume, we become stronger.” They said that regulations add more costs and that the program needs many different licenses and certificates but have to spend the money for their personnel to stay in compliance. For example, PACE B pays \$25,000 to an actuary to perform tasks related to Medicare Part D compliance. The program is costly but so many components are necessary to ensure it is in compliance with state and federal regulations.

Similar to the concerns expressed by PACE A, PACE B staff believe the state and federal regulators lack sufficient knowledge of PACE. As an example, a CMS auditor went out to the site and did not know what the PACE program was. The auditor had to speak to her supervisors to learn about the program even though SAA regulators work in the same building. In the middle of the audit, “she was told to leave to get clarification to why she was there.” It took five months to resolve the issue that the auditor came to resolve initially. This example shows a lack of knowledge and communication among regulators about PACE program requirements.

Another example of what PACE providers believe are onerous regulations is that CMS has to approve all advertising including brochures and videos. Even the font size has to be a certain size to be in compliance with regulations. Unlike the MCOs, PACE cannot advertise by knocking on potential participants' doors, which made it difficult for PACE B to grow after opening their doors. Another challenge is that their participants will get phone calls from Medicare advantage plans, seeking to persuade them from

PACE even though they are supposed to be on a “no target list.” The program director has a different relationship with the SAA than the CFO and DQM though it is important to note, she came to PACE B after the tumultuous first two years. She said that their account manager is an “amazing woman” and a “team player.” If there is anything she needs from the SAA, she calls the manager for help. The program director admits the site did a sloppy job in beginning, and because of that, regulators were dissatisfied with the program.

The DQM and CFO of PACE B suggested the SAA could improve in responding more quickly to approve participants’ enrollment once PACE B sends the necessary information over. Currently, the process takes a minimum of six weeks which makes it difficult for the program to grow. Moreover, the process has to start over if the participant is not timely in producing the necessary documents to become enrolled. One improvement CMS could make is to loosen the marketing guidelines which are stringent and hamper the program’s ability to advertise itself to the community.

II. State Support

When asked what improvements to PACE the state could make, the ED of PACE A responds that the state should expand the number of programs so the financial benefit to the state becomes clearer. Others argue that the state cannot afford to invest in unproven models of care at a time of intense fiscal pressures. However, she wants the SAA to understand that PACE is in the business to provide high-quality care at a set cost which saves the state money compared to managed care organizations which are large publicly traded organizations in the business to make money. PACE is very “black and

white” for the state as the capitated rate only lets the SAA see upfront costs and not the long-term savings that she believes the program provides the state. She also wants to see the state embrace open enrollment in which the PACE program can grow naturally without caps on the number of participants that the programs can serve. She said that states where PACE has succeeded, such as California, have open enrollment. PACE is a statewide model of care in California and in others so she expressed exasperation as to why the southwestern state “doesn’t get it” and is making it more difficult for PACE to expand.

The ED of PACE C said that the state promotes HMOs at the expense of PACE. She believes that given the new Health and Human Services Commissioner's background, preferential treatment will be provided to the state’s Medicaid managed care program. The ED believes there are “vested interests incorporated within the bureaucracy” that do not want to see PACE become an established model of care in the state. She believes this is also related to the state’s unwillingness to expand Medicaid under the Affordable Care Act. With billions more dollars flowing into the state, she believes it would provide the state more flexibility in expanding PACE.

According to the ED, the Legislature has been supportive of PACE for a very long time. As far back as 2001, the Legislature authorized PACE to expand to sixteen sites. However, the ED notes that “legislators come and go and the bureaucracy stays and perpetuates itself.” The state should be able to look at costs under traditional long-term care and see how much PACE is saving them especially since the state achieves a minimum five percent savings relative to its average expenditure for long-term care. She believes if the SAA dealt with reimbursement mechanisms on an equal footing with other

programs, PACE would be comparable to a HMO. She explains, “We wouldn’t function like one, wouldn’t be entitled to some opportunities but we wouldn’t be penalized.”

Similar to the other EDs, she wants the state to allow for natural growth in participants. She knows the need is in the community but PACE cannot serve them because of the cap. She infers that the state has caps in place because “They are controlling a system they don’t want. Some people prefer demise, but if you can’t get rid of it, you control it in very devious ways.” Obviously, the ED is frustrated with the way PACE is highly regulated and treated compared to other health care organizations in the state. Because PACE serves such a small sliver of dual-eligibles, PACE C and the other PACE organizations do not have the influence to tell the SAA they should be put on equal footing with the HMOs.

The CFO of PACE C explained that his organization takes on a lot more risk than HMOs and do not reap financial benefits. He has explained to the SAA and the Legislature that it is more expensive for a participant to be in nursing home than in PACE. He estimates that PACE C saves the state \$16 million annually, were their participants to reside in nursing homes instead of in their own homes. That is a significant number given the relatively small population the program serves. However, if PACE C could serve more participants and if more PACE sites existed in the state, it would see tremendous savings. The ED explained that neighboring states see PACE as solution because of the flexibility provided but that the state where her program operates views cost savings in a specific moment in time, such as enrollment. However, when PACE enrolls participants and their health deteriorates in the ensuing years, the cost to the state will not increase since the provider takes full financial risk.

As the ED put it, “We also know that annual Medicare surveys results have shown that Medicare respondents rate PACE services more favorably than any other service delivery system. If the state can establish how much a comparable population is costing them versus what they are paying PACE, PACE providers would not be obligated to submit unit cost and number of units of services provided.”

Though PACE C still has challenges in its dealings with CMS, the ED believes they are more flexible and objective than the state. She is concerned about the new sites' proposed rates, especially since City 3 has the highest proposed rates. She feels guilty about the situation but as president of the state's PACE association, she will fight for the other sites and push an agenda that helps all providers. She explained the camaraderie within the TPA and that exhibiting solidarity is “The PACE way.” She noted that the biggest surprise to everyone in health care was that in 2000, people thought the system was going to be overwhelmed with baby-boomers but that it didn't happen because the baby-boomers got healthier. She noted that “Now the wave is coming” and though PACE is the ideal model of care that could help baby-boomers, the state has hindered their ability to provide high-quality care at lower costs.

Chapter 7: Conclusions

I. Background of PACE in the Southwestern state

Learning about the history and regulatory features of PACE in the state is essential to understanding PACE provider concerns and frustrations with the SAA. First, the demographics of PACE participants in the state differ greatly from the national average as most participants are female Hispanics (LBB, 2015). Also, the state's PACE participants are more medically fragile than their national counterparts. According to the state's PACE Association, PACE participants in the state have a higher average risk score compared to all PACE sites. Acute hospital admissions per member are 0.81 in the state compared to 2.409 in all PACE sites. The average number of diagnoses is 23 in the state compared to 13 in all PACE sites. The prevalence of diabetes diagnoses is 55 percent compared to 36 percent nationally. The prevalence of dementia diagnoses is 55 percent in the state compared to 50 percent nationally. Finally, the state's participants took an average of nine prescription medications per month compared to eight nationally (LBB, 2015). Evidently, the state's PACE providers are caring for a more vulnerable population than their national counterparts. This could explain the provider's frustration with the insufficient Medicaid funds they receive from the state.

In 2001, the Legislature directed the SAA to have six PACE sites in operation in 2002, 11 sites in 2003 and 16 sites in 2004 (LBB, 2015). However, more than ten years later, there are still only three PACE sites in operation. This speaks to provider concerns about the SAA not devoting enough efforts in developing PACE into an established statewide model of care. In the 2014-2015 Legislative session, legislation was passed to

authorize the SAA to raise the enrollment cap and allow 96 additional participants to enroll across all three PACE sites (LBB, 2015). The General Appropriations Act also authorized the SAA to add three additional PACE sites with 150 participants each, which would tentatively begin enrolling participants in August or October of 2015. The SAA has completed its Request for Proposals (RFP) process and awarded three PACE designations. Importantly, the Legislature did not authorize additional funds for the SAA to serve more participants. Instead, if the allocated funds are insufficient to serve PACE participants, the Health and Human Services Commission (HHSC) is authorized to “transfer up to \$369,839 in General Revenue Funds in fiscal year 2014 and \$3.4 million in General Revenue Funds in fiscal year 2015 from Medicaid to PACE” (LBB, 2015).

Though three new sites have been authorized, they are still not established PACE providers because of ongoing negotiations with the state over Medicaid reimbursement rates. In the state, the rates are set by HHSC, the parent agency of the SAA. As expressed in interviews with existing PACE provider staff, they believe the proposed rates are insufficient for the new organizations to deliver PACE services while sustaining operations. Though CMS regulations authorize states to create their own rate-setting methodologies, the rate paid to PACE providers must be below the rates paid to other health care providers serving a comparable population under Medicaid (LBB, 2015). The rates also have to “take into account the comparative frailty of PACE participants, be a fixed amount regardless of changes in the participant’s health status, and can be renegotiated on an annual basis” (LBB, 2015). The state sets its rates by calculating three Upper Payment Limits for each type of PACE participant (Medicare only, Medicaid only, dual-eligible).

As the Legislation Budget Board writes,

“The UPLs for Medicaid-only clients and dual-eligible clients are currently calculated using historical costs derived from fee-for-service claims data for clients age 55 and older receiving nursing facility services or Community-based Alternatives (CBA) services in the counties served by each PACE contract. The UPL for QMBs is determined on a statewide basis using the average cost incurred by Medicaid for Medicare co-insurance and deductibles. Second, the Medicaid rates for the three client categories for each PACE contract are determined by multiplying the UPLs for each PACE contract by a factor no greater than 0.95” (2015). Importantly, the factor can be reduced due to available funds and the rates are set every two years when the Legislature is in session.

The SAA estimates that establishing a new PACE site takes 18-36 months and requires around \$3 million - \$5 million in start-up costs. The newly authorized PACE providers are still in the early part of the process because of the stalled rate negotiations. The new sites cannot submit their applications to CMS for approval until HHSC and the sites agree on the Medicaid rates. Only after CMS approval, which can take 3-6 months, can the PACE providers enter a three-way agreement with CMS and the SAA, and provide services.

II. Interviews with SAA staff

After interviewing executives at the state’s PACE sites and hearing their concerns and frustrations with the SAA, I believed my thesis would be incomplete without getting a response from the agency. Thus, I set up interviews with agency staff responsible for overseeing PACE. The interviewees occupy the following positions:

- Director of Community Services and Program Operations
- Manager of Hospice Policy and PACE Operations
- Account Manager

The account manager has been working with PACE since 2010 when PACE B was approved as a PACE provider. Prior to two years ago, she was the only PACE staff person. Now, there are three SAA staff directly involved in PACE. When asked, “Does the SAA have a role to play in encouraging various stakeholders to establish PACE sites?” she responded that the RFP process is “fair and equitable” and that “We cannot encourage anyone organization to start PACE.” She explained that they are working with the sites to move beyond the impasse on rates. She estimates that after agreement on the rates and after sites receive CMS and SAA approval, the new sites will open in January of 2017.

When asked “How are you involved in establishing, regulating and overseeing PACE sites in the state,” the account manager responded that she is in contact with PACE B more than once per day through e-mail. She helps the site with enrollment and housing issues. She works with two account managers in CMS and is responsible for quarterly calls. There are audits of the sites every two years unless there is an urgent issue. There are not scheduled meetings with each PACE site; instead everything is done on as needed basis. The director of community services and program operations said the SAA staff work collectively with PACE staff and have a good rapport. She explained that each site is like a “well-oiled machine” that knows how to operate smoothly.

When asked, “What are some challenges you face in regulating the PACE sites,” the director responded that in other agency programs her staff has control over the enrollment process and plan of care but that PACE organizations have responsibility for these tasks. Because the SAA is removed from that process, they “have to rely on them to follow rules and ensure people are getting what they need.” Also, the director said that HHSC asks PACE sites for cost reports but have not received them. Thus, they are unable to calculate whether it is more cost-effective than providing long-term care services outside of PACE. She believes the PACE sites are not over-regulated despite their contention and in fact the agency takes steps to lessen regulation; she explained for example that the state does contract monitoring in conjunction with CMS which eases compliance for the PACE providers. In terms of the lack of growth of PACE sites in the state, the director said that the Legislature is the only entity in the state with the authority to establish PACE providers and raise enrollment caps. This makes the state unique in that other state legislatures do not have to explicitly authorize PACE providers. She says that “PACE is not an entitlement in the state” though “We would love for to be one.”

The SAA staff who I interviewed all believe in PACE and its potential to become an ideal model of care for low-income elders. When asked, “Would you like to see more PACE sites established in the state? If so, what steps can your agency take to enable faster growth in establishing more sites,” the director said that “PACE is rather new in the state. We’re very hopeful new sites will open soon in metro areas. With more calls to legislators, and more stakeholders expressing interest, PACE will gain more momentum.” The manager of PACE Operations said one of the problems is that “so many people haven’t heard of it” but once the state and the sites get past the rate hurdle and the new

sites are established, “Ten years from now, we will be laughing at this conversation because PACE will look so different.” She credits the ED of PACE C and her lobbying efforts for the recent authorization of the three new PACE sites. The manager said PACE is “a beautiful program.” The account manager said “most people say this looks too good to be true” and that the “facilities speak for themselves.” As an example of how dedicated providers are to their participants, she recalled a snow storm that hit City 1. The roads were impassable but PACE A staff went to the participants' homes to make sure they were safe.

III. New legislation

One of the reasons why expansion of PACE in the state has been sluggish is that the state lacks cost and quality outcome data compared to other Medicaid programs that serve a comparable population. The state’s Medicaid program which has transitioned to a managed care model is similar to PACE as it integrates acute care and long-term services. However, without comparable data, the state has not been able to determine whether PACE is a cost-effective alternative to managed care. The General Appropriations Act allows the SAA to transfer funds from managed care to PACE to serve more participants but without evidence that PACE costs less than managed care, the state will be reluctant to transfer funds.

Finally, though, the state will be able to compare PACE outcomes with its managed care program because of new legislation that passed in the 2014-2015 Legislative session. The legislation would “link the reimbursement rates of PACE to those of the Medicaid program, modify the methods for collecting PACE and Medicaid

program data, and require an evaluation of the PACE program to compare PACE costs and care outcomes to Medicaid program outcomes” (House Research Organization, 2015). Supporters of the legislation believe it will yield important data that will provide evidence to the state that PACE should be expanded to serve more participants (HRO, 2015). Supporters are also pleased that the legislation “contains provisions that ensure that the Medicaid reimbursement rates for PACE are sufficient to sustain the program but also would not be enough to exceed what is necessary and reasonable to operate the program” (HRO, 2015).

IV. Interview with the Commissioner of the SAA

In addition to interviewing the SAA staff directly involved in PACE, I also had the opportunity to hear the Commissioner of the agency speak about PACE to me and my peers. When asked about the sometimes adversarial relationship between PACE providers and the SAA, he responded, “This is not an uncommon issue for regulatory agencies, not just us (SAA). The job of regulators is to enforce these rules, they have to come out and inspect and they come out unannounced some times. You want it to be collaborative but it's never going to be as collaborative as providers might want.” However, the commissioner also expressed the challenge of applying consistent regulations across a large state with different regional offices. He expressed that the agency “can always do a better job of communicating with providers about the rules.” He acknowledged PACE provider concerns about regulators lacking sufficient knowledge of the program and said the agency may need to utilize more “targeted training” of its regulators as it relates to PACE.

When asked about provider concerns with the proposed reimbursement rates, he said that HHSC cannot raise the reimbursement rates without more funding from the Legislature but that “They’re trying to do as generous a rate as they can with the appropriations they’ve got.” Ultimately, the commissioner believes the reason for sluggish PACE expansion in the state lies with the program’s significant administrative and regulatory costs and competing priorities for legislative appropriations.

V. PACE’s future in the state

With a growing aging population and significant budget constraints, the Southwestern state faces real challenges in providing high-quality care for medically and financially vulnerable older adults. The PACE program offers the state a unique alternative to save costs by providing integrated community-based care using capitated Medicare and Medicaid funds. However, unlike in other states, such as California, PACE faces an uphill climb in expanding in the state. This is due to many factors, from the Legislature's tight control over the RFP process to the adversarial relationship between the SAA and PACE providers and an overall regulatory and political environment that has not expressed the support needed to expand PACE in the state. Though PACE participants experience better health outcomes than in traditional fee-for-service programs and participant care costs less to federal and state governments, the prospect of expansion in the state is bleak.

The silver-haired tsunami is quickly approaching and PACE could help fill the gap in services for a vulnerable older population. However, enrollment caps and insufficient support from the state make it exceedingly difficult for the program to

provide care for the millions in the state who will need supportive health and social services in order to maintain their independence and live safely in their communities.

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Appendix I

Questionnaire Guide

PACE Sites:

How would you describe your mission?

What do you see as the greatest benefit of the PACE model, compared to traditional forms of medical care for the elderly, such as nursing homes?

What do you see as your main contributions to your community?

Is your site different in any way from the other PACE sites? How so?

What are some of the challenges your site faces?

How do you measure satisfaction among your PACE enrollees?

How do you interact with and include family members in your IDT?

What was the process like of establishing your PACE site?

What type of support, if any, did you receive from CMS, the State Administering Agency, the city and other stakeholders?

How did you acquire the necessary capital to establish your program?

How do you hire physicians, who studies show, are more reluctant to participate in alternative models of care, such as PACE?

What would you advise other organizations that are interested in establishing the PACE model?

How do you maintain an operating profit given that PACE model is not as profitable compared to other models of medical care for older adults?

Administrators of PACE sites report that the primary roadblock to growth is competition with other care providers. How much competition for services do you face from other providers?

How do you measure the quality of care you provide to enrollees?

What is the regulatory/compliance environment like?

What actions, if any, could the state or federal government take to make your operations more effective?

Given that there are less PACE sites than permitted by law, what can be done to enable faster growth in establishing PACE models in the state?

How can you grow your site to accept more enrollees?

How do you see your site's commitment in the future to providing care, given the rapid growth of the aging population and the need for comprehensive care?

State Administering Agency:

How are you involved in establishing, regulating and overseeing PACE sites in the state?

Does the SAA have a role to play in encouraging various stakeholders to establish PACE sites?

Would you like to see more PACE sites established in the state? If so, what steps can your agency take to enable faster growth in establishing more sites in the state?

Do you think PACE is an ideal model of comprehensive care for low-income elders in the state? If so, why?

I have learned from my interviews with PACE administrators that their sites operate under the strict supervision of the SAA. What can be done to improve the regulatory framework to smooth operations and enable more growth?

How does the SAA interact with CMS to establish PACE sites?

Studies show PACE is more difficult to establish because of the capital required and the financial risk involved. Can the agency take any actions to make it easier for organizations to get their sites off the ground?

Because PACE is financed by capitated payments from Medicaid, some studies show PACE is less expensive for states than more traditional forms of medical care. In the state, is PACE saving the SAA money and how do you measure “cost-effectiveness” compared to other forms of care?

How does the SAA support the existing PACE sites?

What are some challenges you face in regulating the PACE sites?

Do you believe PACE is a more preferable alternative to nursing homes?

How do you calculate the Medicaid reimbursement rates and ensure they are high enough for the sites to continue their operations?