Building an LGBTQ+ Inclusive PACE Program

Key learnings on how the Program of All-Inclusive Care for the Elderly (PACE) model addresses the needs of LGBTQ+ older adults

Michael Adams and Ryn Skultety, PhD
Introduction

The population of lesbian, gay, bisexual, transgender, queer and questioning, and other self-identifying members of the community (LGBTQ+) older adults is growing, and as we age, it is imperative that we build systems of care that support aging in the communities we love.

Rather than being pushed aside or ignored, we must prioritize our need for connection to our chosen families and communities as we come to need more care. For over 40 years, SAGE has worked tirelessly on behalf of older LGBTQ+ people. In partnership with its constituents and allies, SAGE works to achieve a high quality of life for LGBTQ+ older people, supports and advocates for their rights, fosters a greater understanding of aging in all communities, and promotes positive images of LGBTQ+ life in later years. SAGE is committed to uplifting the voices of LGBTQ+ older people and developing solutions that allow us to remain with our loved ones and within our communities, even if we require increased care as we age. By refusing to be invisible, we can ensure that our unique needs are met and we receive the care and support we need.

SAGE is excited to share important insights into the Medicare/Medicaid PACE (Program of All-inclusive Care for the Elderly), which provides an effective solution for nursing home-eligible LGBTQ+ older adults to age within their community with their chosen family. PACE, commonly called “assisted living without walls,” utilizes an interdisciplinary approach that caters to the unique medical and social needs of older adults who qualify for nursing homes. PACE offers an alternative to traditional nursing home care, allowing nursing home eligible LGBTQ+ older adults to receive the necessary care while remaining within their communities and with their chosen families, enabling us dignity and comfort, and autonomy as we continue to age.

This paper documents SAGE’s active exploration to build an LGBTQ+ inclusive PACE center in New York City. SAGE is excited to share its learnings to encourage LGBTQ+ serving organizations to consider building PACE centers and existing PACE programs to become more inclusive and accommodating to LGBTQ+ older adults.
LGBTQ+ Older Adults Health Disparities and Challenges to Aging in Community

The United States population is rapidly growing older. According to the US Census Bureau projection, by 2034, 20% of the US population, or 1 in 5 residents, will be aged 65 and older.\(^1\) By 2030, studies project the population of LGBTQ+ people over 50 to reach 7 million. The LGBTQ+ aging population is unique and has a distinctive aging experience, which needs to be considered as LGBTQ+ aging populations continue to grow. LGBTQ+ older adults often lack supportive relationships with their families of origin, which limits their access to age-related informal caregiving and social support. In addition, LGBTQ+ older adults are four times less likely to be parents than older Americans in general and twice as likely to grow old single and living alone. Therefore, many LGBTQ+ older adults rely on their chosen families and community members to provide the support they need as they age.\(^2\)

LGBTQ+ aging is also characterized by a higher prevalence of health disparities, which can be attributed to a lifetime of discrimination experienced by LGBTQ+ older adults. The minority stressors\(^3\) experienced by LGBTQ+ older adults can take a significant toll on the physical and mental health of LGBTQ+ older adults and lead to chronic conditions, including heart disease, diabetes, and depression, as well as increased rates of substance abuse and suicide.\(^4,5,6\) Additionally, discrimination and stigma can make accessing health and social services difficult, leading to increased isolation and loneliness.\(^7,8,9\)

As a result of experiencing minority stressors over a lifetime, many LGBTQ+ older adults experience a “compression of morbidity,”\(^10\) which is the onset of more functional limitations at an earlier age compared to straight and cisgender adults 65+.\(^11\) Many LGBTQ+ older adults may need increased health services and become nursing home eligible at an earlier age.

Unfortunately, LGBTQ+ older adults face significant discrimination and bias, which limits their ability and the likelihood of entering an assisted living or nursing home facility, even when becoming eligible for long-term care. For example, many LGBTQ+ older adults are hesitant to live in retirement communities or long-term care facilities due to fear of experiencing homophobia or transphobia.\(^12\) Many LGBTQ+ adults have reported feeling unwelcome or uncomfortable in these types of settings or have faced discrimination or mistreatment from staff, residents, or other caregivers. LGBTQ+ older adults also have concerns about being able to express their gender identity or sexual orientation openly or being in an environment that is not culturally competent or sensitive to the needs of LGBTQ+ individuals. This can result in many LGBTQ+ older adults choosing to remain in their homes without adequate care or support and relying on informal support networks rather than seeking out more structured or institutionalized forms of care. While informal support networks, like chosen families, are crucial for fostering resilience and a sense of community among LGBTQ+ people of all ages, they may not fully address the challenges faced by LGBTQ+ older adults. These challenges include limited access to healthcare and other critical resources necessary for healthy aging.\(^13\)
PACE Model and Ways It Could Address the Challenges for Nursing Home-Eligible LGBTQ+ Older Adults

A model for LGBTQ+ older adults who wish to age in community may be found in Medicare/Medicaid Program of All-Inclusive Care for the Elderly (PACE). PACE provides a comprehensive range of medical and social services for Medicare and Medicaid recipients aged 55+ who are eligible for nursing home care. Being “nursing home eligible” means that an individual likely can no longer live independently due to age, illness, or disability. To meet the criteria for nursing home eligibility in PACE, an individual typically must have a chronic medical condition or disability that requires skilled nursing care and assistance with daily activities such as bathing, dressing, and eating. Examples of conditions that may make someone nursing home eligible include Alzheimer’s disease, Parkinson’s disease, stroke, and severe arthritis.

Since many LGBTQ+ older adults may become nursing home-eligible at an earlier age, PACE offers an interdisciplinary approach to care that provides comprehensive, coordinated services to nursing home-eligible older adults who require a level of care like that provided in nursing homes but who wish to remain in their homes and communities. The interdisciplinary approach offered by PACE can benefit LGBTQ+ older adults, who may have unique healthcare needs due to their sexual orientation or gender experiences. PACE’s team-based approach involves healthcare professionals from different disciplines, which allows for a holistic approach to care that considers each individual’s diverse needs. For example, in an LGBTQ+ inclusive PACE program, an interdisciplinary team would work to address the fear-based care avoidance of many LGBTQ+ older adults by providing culturally competent care that respects and celebrates different sexual orientations and gender experiences.

The interdisciplinary approach offered by PACE can benefit LGBTQ+ older adults, who may have unique healthcare needs due to their sexual orientation or gender experiences.

In addition, LGBTQ+ older adults often have unique social support challenges, such as isolation due to discrimination, lack of familial support, or limited access to LGBTQ+ community resources. PACE’s interdisciplinary team can work to address these needs by providing social support services such as LGBTQ+ support groups, peer mentoring, and assistance with accessing community resources. Overall, building an LGBTQ+-oriented or LGBTQ+-inclusive PACE program appears very promising because such a program would provide personalized, culturally competent care that addresses the unique healthcare and social support needs of nursing home eligible LGBTQ+ older adults.

The Work Done Already

Although it is clear that the PACE model has immense potential to meet the unique needs of LGBTQ+ older adults, for a variety of reasons, there has yet to be a PACE program created specifically with this population in mind. For example, there is limited, if any, data that addresses the utilization of PACE by LGBTQ+ older adults; Medicare and Medicaid fail to collect sexual orientation and gender identity (SOGI) data on PACE participants. In addition, it is clear that an LGBTQ+ oriented PACE program would be challenging for many LGBTQ+ organizations to launch because of financial and institutional constraints. In the experience of SAGE, relatively few nursing home-eligible LGBTQ+ older adults currently are enrolled or utilizing the PACE model. However, according to focus group data, nursing home-eligible LGBTQ+ older adults would likely embrace PACE services if they were available and LGBTQ+ inclusive.
In 1971, to create a model of care for nursing home-eligible Chinese American older adults in San Francisco who wished to age at home and in community, On Lok founded the PACE model as a special population program and thereafter became a pioneering organization leading a pilot project that turned PACE into a national model. Today, Openhouse, a leading local organization for LGBTQ+ older adults in San Francisco, has worked with On Lok to open a community-based adult day program for LGBTQ+ older adults as part of a larger effort to make On Lok’s existing PACE offerings LGBTQ+ inclusive. The Community Day Services program was designed for LGBTQ+ older adults to bring much-needed services to San Francisco’s growing LGBTQ+ community that needs better long-term care. In addition, the Community Day Services program serves as an alternate care site for one of On Lok’s existing PACE centers with the goal of increasing enrollment of LGBTQ+ older adults and increasing awareness of the PACE model for this population.

In 2021 SAGE joined forces with The New Jewish Home (TNJH), one of New York City’s major long-term care providers, to explore building an LGBTQ+ oriented PACE program from the ground up. The collaborative exploration between SAGE and TNJH was founded on a long-standing relationship between the two organizations. Over time, SAGE has played a vital role in supporting TNJH to become LGBTQ+ culturally competent and affirming; TNJH has provided quality care to a number of SAGE constituents. From creating vibrant, welcoming facilities to organizing Pride-themed events and campaigns, TNJH has shown a strong commitment to LGBTQ+ inclusivity and diversity.

Together, SAGE and TNJH recognized a potential opportunity to create an LGBTQ+ inclusive PACE center that aligned with overarching organizational priorities. SAGE seeks to provide greater support for LGBTQ+ elders who otherwise would be denied the opportunity to age in community and is prioritizing the creation of new mission-based program models that are financially self-sustaining and profitable over time. The TNJH plans to build a new Center of Excellence that will provide a range of long-term care services; TNJH believed this location could be an ideal spot for a PACE program.
The two organizations worked together to conduct a needs assessment of LGBTQ+ older adults and a feasibility and market analysis of the New York City area. Based on the results of the analysis, and with their combined expertise, SAGE and TNJH developed a business plan for building an LGBTQ+ oriented PACE center. The organizations also engaged in conversations with local and state-level policy experts in PACE and relevant governmental officials and started preparing an initial application to Medicare.

Eventually, SAGE and TNJH realized they had differing timelines for proceeding with a PACE application. SAGE wished to move forward on a more accelerated timeline than TNJH, and they mutually agreed that a joint venture would be unfeasible at this time. Nonetheless, the two organizations continue to be thought partners committed to supporting PACE expansion for LGBTQ+ older adults and are actively collaborating on other initiatives, such as supporting SAGE clients enrolling in TNJH’s medical adult day program. SAGE is currently exploring a new path to pursue the construction of an LGBTQ+ inclusive PACE center.

While SAGE has not yet submitted its PACE application or opened its PACE center, SAGE has already gained valuable insights through its extensive exploration to date and work in collaboration with TNJH. To explore these insights for the purpose of sharing them with the aging policy and practice sector, SAGE interviewed key stakeholders from both organizations to document key learnings. SAGE believes it’s important to share the lessons learned to encourage LGBTQ+ organizations to consider what roles they can play in catalyzing the creation of LGBTQ+-oriented PACE centers and to encourage existing PACE programs to become more LGBTQ+-inclusive.

Currently, SAGE is exploring a new path to pursue the construction of an LGBTQ+ inclusive PACE center.

SAGE believes it’s important to share the lessons learned to encourage LGBTQ+ organizations to consider what roles they can play in catalyzing the creation of LGBTQ+-oriented PACE centers and to encourage existing PACE programs to become more LGBTQ+-inclusive.

Learnings from Key Stakeholder Interviews

**FINANCIAL VIABILITY**

A challenge for some LGBTQ+ serving organizations seeking to establish a PACE program is regulatory and licensing requirements which may be difficult for organizations already strained for resources. Establishing a PACE program is expensive, with costs ranging from $8-15 million, including constructing or leasing a physical center large enough to house a PACE program, creating a business plan, hiring staff, and managing administrative and operational expenses. While successful PACE programs earn this investment back over time, success is not guaranteed, and it takes a number of years (depending on the specifics of the business plan) to recoup the investment. The initial premise of conversations between SAGE and TNJH was that the two organizations could share the cost of building a physical PACE center and cover startup costs for an LGBTQ+ oriented program, reducing each organization’s financial risk. Moreover, it’s possible that SAGE’s expertise and networks in LGBTQ+ inclusive social service delivery and TNJH’s expertise in building a talent pool for medical care could have resulted in greater efficiencies in building, staffing, and managing an LGBTQ+ oriented PACE center.

According to SAGE’s conversations with key stakeholders, the combination of high financial costs and other regulatory requirements presents potential hurdles for LGBTQ+ serving organizations seeking to build an LGBTQ+ oriented PACE program. For example, the PACE center application process also requires a physical address for a qualified PACE site upfront, which can be challenging for organizations without a deep brick-and-mortar history and who may find it difficult to make the substantial investment of time and money to make a site PACE-ready as well as equipped with necessities to be a fully operational medical facility.
Enrolling a sufficient number of PACE program participants is essential for the financial success of a PACE program. PACE organizations receive capitated payments from Medicare for each enrollee, meaning PACE centers are paid a fixed monthly amount to cover all the enrollee’s healthcare needs. By enrolling enough eligible individuals, PACE organizations can ensure a stable revenue stream to cover the costs of comprehensive care and services. The relative lack of SOGI data makes it impossible to know precisely how large the LGBTQ+ nursing home-eligible population is. However, SAGE and TNJH worked with the Williams Institute at UCLA, the country’s leading research and think tank on LGBTQ+ issues, to extrapolate localized New York City enrollment estimates by combining census estimates of the LGBTQ+ 65+ population with existing information on the percentages of people with health challenges. This analysis suggested a significant PACE-eligible LGBTQ+ population in the New York area. Specifically, the data reveal that in New York, Kings, Queens, and Bronx counties the number of individuals who are anticipated to meet the age, financial, and level of care requirements for PACE, not considering LGBTQ+ status, exceeds 10,000. In addition, in many zip codes (where data was available) the analysis suggests a high concentration (a minimum of 500 people per zip code) of LGBTQ+ people over 65 who have an income less than $36,000. This estimate, along with SAGE’s existing relationship with thousands of LGBTQ+ older adults in New York City, suggested that the PACE center could be financially viable within the term of the venture’s business plan. Our stakeholder interviews and learnings indicate that enrollment may be an initial hurdle for some LGBTQ+ serving organizations to build a PACE program. However, depending on the specifics of the organization, it is not an insurmountable obstacle. Moreover, once people are enrolled in a PACE program, disenrollment rates are estimated to be as low as 7%.⁷ Not only this, a wealth of data shows that people who are enrolled in PACE are very satisfied with the services.¹⁸ Despite the likelihood that nursing home-eligible older adults would be happy in a PACE program, there are entrenched sociopolitical challenges stemming from heterosexual-centric practices and bureaucratic structures, along with consumer mistrust of providers, that in SAGE’s experience inhibits nursing home-eligible LGBTQ+ populations from enrolling in general PACE programs. In general, LGBTQ+ older adults demonstrate high levels of mistrust of care providers and frequently avoid necessary care for fear of mistreatment.¹⁹,²⁰

More specific to PACE, the model’s integration of all care and services requires participants to place all of their eggs in the PACE basket, which poses unique challenges for a consumer population that is often suspicious of care providers. Placing this level of reliance in a single PACE center requires a high level of trust that often is not present since PACE programs can be unwelcoming in their practices. For example, PACE programs can take restrictive and non-inclusive approaches to who is recognized as a family caregiver, relying on traditional biological notions about who can perform enrollment functions, such as filling out forms or dropping someone off at a center. Furthermore, since the financial viability of PACE programs hinges on enrollment, creating LGBTQ+ oriented systems and practices that are welcoming to LGBTQ+ elders and knowledgeable about their lived experience and their care eco-systems, including chosen family, is critical to the long-term success of LGBTQ+ oriented or inclusive PACE programs.

According to SAGE’s conversations with key stakeholders, the combination of high financial costs and other regulatory requirements presents potential hurdles for LGBTQ+ serving organizations seeking to build an LGBTQ+ oriented PACE program.

Our stakeholder interviews and learnings indicate that enrollment may be an initial hurdle for some LGBTQ+ serving organizations to build a PACE program. However, depending on the specifics of the organization, it is not an insurmountable obstacle. Moreover, once people are enrolled in a PACE program, disenrollment rates are estimated to be as low as 7%.⁷ Not only this, a wealth of data shows that people who are enrolled in PACE are very satisfied with the services.¹⁸ Despite the likelihood that nursing home-eligible older adults would be happy in a PACE program, there are entrenched sociopolitical challenges stemming from heterosexual-centric practices and bureaucratic structures, along with consumer mistrust of providers, that in SAGE’s experience inhibits nursing home-eligible LGBTQ+ populations from enrolling in general PACE programs. In general, LGBTQ+ older adults demonstrate high levels of mistrust of care providers and frequently avoid necessary care for fear of mistreatment.¹⁹,²⁰

More specific to PACE, the model’s integration of all care and services requires participants to place all of their eggs in the PACE basket, which poses unique challenges for a consumer population that is often suspicious of care providers. Placing this level of reliance in a single PACE center requires a high level of trust that often is not present since PACE programs can be unwelcoming in their practices. For example, PACE programs can take restrictive and non-inclusive approaches to who is recognized as a family caregiver, relying on traditional biological notions about who can perform enrollment functions, such as filling out forms or dropping someone off at a center. Furthermore, since the financial viability of PACE programs hinges on enrollment, creating LGBTQ+ oriented systems and practices that are welcoming to LGBTQ+ elders and knowledgeable about their lived experience and their care eco-systems, including chosen family, is critical to the long-term success of LGBTQ+ oriented or inclusive PACE programs.

STRUCTURE OF PARTNERSHIPS AND COLLABORATIVE RELATIONSHIPS

Collaboration and partnerships may offer a promising solution to the financial and enrollment constraints associated with building and staffing an LGBTQ+ oriented PACE program. Working together, organizations may be able to pool their resources to not only build and staff an LGBTQ+ oriented PACE center but also to secure enough enrollees to sustain the program financially. When SAGE began exploring a partnership with TNJH for PACE, both organizations assumed it would take the form of a 50-50 joint venture. Moreover, SAGE would bring its expertise in LGBTQ+ inclusive social services, while TNJH would provide its share of LGBTQ+ inclusive medical care.
An important learning from the SAGE/TNJH PACE exploration and SAGE’s conversations with key stakeholders is that it might not be necessary nor advantageous for LGBTQ+ serving organizations to approach a PACE partnership as a 50-50 collaboration or even a joint venture at all.

Depending on the situation, establishing a PACE program as a sole initiative led by an LGBTQ+ organization with support from secondary partners who do not have decision-making power or financial investment could be just as promising or even more promising than a partnership. Shared decision-making and financial arrangements can present an array of risks embedded in the unknowns of a new business partnership, including differing priorities over time, differing financial circumstances, differing cultural frameworks, and evolving organizational perspectives and priorities. For example, problems can arise if there are significant leadership changes at one partnered organization or if one of the organizations faces unexpected difficulties that impact its capacities or incentives. These are among the reasons why, per below, deep trust and mutual respect are so important if a joint venture is under consideration.

Based on SAGE’s discussions with stakeholders at SAGE and TNJH, establishing a sole or predominant owner for an LGBTQ+ oriented PACE center with secondary partners may be advantageous, assuming the owner has deep cultural competency and trust within the targeted LGBTQ+ older adult population. An LGBTQ+ serving organization with sufficient capacity and community experience could form its own PACE program and provide services within its expertise while contracting out for various services. This means an LGBTQ+ serving organization could not only partner with other LGBTQ+ and allied organizations but also with vendors to deliver services in an LGBTQ+ oriented PACE program. For example, if an LGBTQ+ serving agency has a large enough organizational capacity to construct a physical PACE center, they could serve as the primary partner and provide all the social and care coordination services while contracting out to vendors or partners for primary medical care, occupational care, as well as nursing and other home-based services.

Similarly, an LGBTQ+ serving organization could play a secondary or even third-party collaborator role, given that securing highly specific expert talent and large amounts of funding are so essential to building a PACE program. For LGBTQ+ serving organizations with limited organizational capacity, it may be advantageous to consider becoming secondary partners to new or existing PACE programs. By partnering with an established PACE program, organizations would be able to leverage the program’s expertise, infrastructure, and resources. Additionally, partnering with an existing PACE program and building stronger relationships with other healthcare providers and community organizations may be a route for LGBTQ+ organizations with a limited capacity to reach a larger audience.

Regardless of the role of partners and collaborating organizations, SAGE’s learnings and conversations with key project stakeholders showed us that involving the right people who are deeply committed to the mission of LGBTQ+ inclusivity is essential. Success with an LGBTQ+-oriented or LGBTQ+-inclusive PACE program depends on having people with the right professional background, knowledge, and commitment to design a program that meets the unique needs of the LGBTQ+ community. Team members should be fully committed and knowledgeable about LGBTQ+ inclusivity, including addressing homophobia and transphobia in medical care and the importance of chosen families.

**TRUST AND MUTUAL RESPECT**

While SAGE is now moving in a different direction, it initially conceptualized its PACE exploration as a joint venture with TNJH. SAGE’s interviews with key stakeholders involved in the PACE exploration emphasized the significant role of trust and mutual respect in the construction of an LGBTQ+ PACE center through a strong partnership where decision-making is shared among the top-level management of all parties involved, and financial commitments and risks are extensively intertwined across two or more venture partners.

SAGE and TNJH have built a strong level of trust at the leadership and staff levels over a decade of growing collaboration. SAGE has provided ongoing training and technical assistance to TNJH. TNJH has demonstrated its organizational commitment to this work by funding SAGE training and technical assistance. SAGE supported TNJH in earlier efforts to create an LGBTQ+-oriented “greenhouse” model and publicly honored TNJH for its commitment to the community.
TNJH made specialized care and support for LGBTQ+ older adults a centerpiece of its business transformation plans. At the leadership level, the CEOs of each organization have invested substantial time in building a mutually respectful relationship, learning from each other, and developing a shared vision. Through all these activities, over an extended period of time, SAGE and TNJH have built deep levels of trust across the two organizations at multiple levels. This trust repeatedly proved invaluable during the lengthy exploratory process undertaken by the two organizations. This trust was instrumental in the organizations reaching a mutual, amicable decision to close down the joint exploration, with TNJH pledging to continue supporting SAGE’s efforts to move forward with a PACE center and SAGE pledging to continue working closely with TNJH on other fronts.

To build an LGBTQ+ inclusive PACE program, partnering organizations must understand the LGBTQ+ experience and past discrimination.

SAGE’s conversations with key stakeholders also highlighted the importance of mutual recognition of expertise. PACE programs are complex and require specialized knowledge in medical care delivery. While SAGE is an expert in the social and cultural dynamics of LGBTQ+ aging and in the delivery of community-based services, the organization lacks medical and geriatric care expertise. By contrast, while TNJH has deep experience in long-term care and has built its LGBTQ+ cultural competency over time, it lacks the depth and breadth of SAGE’s experience working directly with LGBTQ+ older adults and decades of experience providing community-based services. Therefore, the explorational partnership between SAGE and TNJH was facilitated by the synergy of mutual trust, LGBTQ+ cultural competency, and mutual knowledge and recognition of each organization’s complementary capacities.

To build an LGBTQ+ inclusive PACE program, partnering organizations must understand the LGBTQ+ experience and past discrimination. Merely having medical or aging expertise is insufficient if the partner lacks cultural competency in LGBTQ+ issues. All staff, including specialists and front and back-end employees, must be LGBTQ+ culturally competent.

To succeed, organizations must prioritize ongoing education and commitment to LGBTQ+ inclusivity when selecting partners for an LGBTQ+ inclusive PACE program. Failure to do so risks creating an unwelcoming PACE facility and reputational damage, ultimately undermining the program’s success.

PACE EXPANSION, UTILIZATION, AND SOGI DATA GAP

The number of people aging into Medicare greatly surpasses the number of people in PACE programs every day, but the number of PACE centers remains small (260 centers across 31 states). However, the 2015 expansion of Medicare and Medicaid has created an opportunity to build and launch LGBTQ+ oriented PACE programs.

SAGE’s feasibility study documents significant concentrations of LGBTQ+ individuals in New York City who may be eligible for nursing home care and could potentially enroll in an LGBTQ+ focused PACE center. However, New York City presents particular circumstances, including unusually high population density. We believe it is necessary to conduct a market-specific analysis to determine the viability of establishing an LGBTQ+ focused PACE Center in a given city or region. In many regions, this may be extremely challenging due to a lack of data on LGBTQ+ older people, especially in regions where it is not safe for individuals to reveal their SOGI. In these cases, it is recommended to work with community organizations who are serving LGBTQ+ people (particularly those in lower income brackets) to help map zip codes where LGBTQ+ densities may be higher based on community gathered data. This information can then be mapped onto data about the size of the eligible PACE population in each zip code to identify the best potential locations. This process can be very challenging and even in New York, it is not possible to map estimates of LGBTQ+ people over 65 in many zip codes. However, we do recommend investing time and effort to utilize even limited available data on LGBTQ+ people to help consider locations that will encourage the community to engage with PACE.

Beyond quantitative population and health data, in our experience, gathering qualitative data about the attitudes of potential LGBTQ+ older adult users of PACE are essential, and this qualitative data is likely to produce different results in different communities based on different local histories.
For example, the 40+ year existence of SAGE as a well-known community institution providing support for LGBTQ+ older adults is relatively unique given the lack of similar organizations in most parts of the country. These kinds of local permutations will be important in ascertaining what would be necessary to build consumer interest and trust for an LGBTQ+-focused PACE Center.

Despite emergent data about the population size of LGBTQ+ older adults, the exact size and geographic dispersion of nursing home-eligible LGBTQ+ older adults are currently unknown. The lack of comprehensive national SOGI data makes it challenging to systematically determine the locations where LGBTQ+ oriented PACE programs should be established. Here, again, it is important to emphasize that building new PACE centers that are LGBTQ+ oriented is not the only option. To the contrary, it is essential that existing PACE centers create LGBTQ+ inclusive services from the inside out. All PACE centers should be LGBTQ+ inclusive. In areas where the LGBTQ+ older adult population is likely too dispersed to support the creation of an LGBTQ+ oriented PACE program, an LGBTQ+ inclusive approach is likely the best option if LGBTQ+ elders all across the country are to avail themselves of the considerable benefits offered by PACE.

Conclusion

Nursing home-eligible LGBTQ+ older adults face challenges including being displaced from the community and discrimination within healthcare settings. However, LGBTQ+ oriented, and LGBTQ+ inclusive Programs of All-Inclusive Care for the Elderly (PACE) can provide an alternative to traditional nursing homes, allowing individuals to age in place within their community with their chosen families while receiving dignified, affirming, and appropriate care.

The exploration started by SAGE and TNJH, and continued by SAGE, provides promising information to other LGBTQ+ serving organizations who might consider building their own PACE centers or collaborating to ensure that new and existing PACE centers are LGBTQ+ inclusive.

During its PACE exploration, SAGE has identified challenges to building LGBTQ+ oriented PACE Centers. The PACE model is logistically complicated, and establishing an LGBTQ+ oriented PACE program is a significant financial and operational undertaking. In addition, the lack of government attention to LGBTQ+ aging and the relative absence of SOGI data pose practical barriers to evaluating LGBTQ+ enrollment potential for PACE.

Nevertheless, SAGE’s exploration to date has revealed that none of these obstacles are insurmountable. Properly situated LGBTQ+ serving organizations can reasonably consider creating LGBTQ+ oriented PACE centers. SAGE’s findings to date also offer a framework for LGBTQ+ organizations to work with allied organizations and existing PACE programs to ensure LGBTQ+ inclusivity in care delivery for nursing home-eligible LGBTQ+ older adults. Organizations seeking to build LGBTQ+ oriented PACE centers or collaborate in the inclusive operation of existing centers must prioritize cultural competency and form partnerships based on shared values, mission, and goals of providing inclusive and affirming care to nursing home-eligible LGBTQ+ older adults.

The lack of comprehensive national SOGI data makes it challenging to systematically determine the locations where LGBTQ+ oriented PACE programs should be established.

As the number of LGBTQ+ older adults continues to increase, their needs must be prioritized in healthcare, including in PACE programs. With collective efforts, LGBTQ+ organizations and their allies can work to ensure that nursing home-eligible LGBTQ+ older adults can access culturally competent, high-quality care that upholds their dignity and respect while allowing these highly vulnerable elders to age in their community.
Notes


16. Ibid.


18. Ibid.


ACKNOWLEDGMENTS

SAGE is grateful for the generous support from The John A. Hartford Foundation, a private philanthropy dedicated to improving the care of older adults, and the National PACE Association that made this white paper possible. We hope it encourages deeper engagement with the PACE model by LGBTQ+ organizations and aging providers.