Partnership by design: new project aims to improve LGBTQ elders’ lives

Interview by Tim R. Johnston

San Francisco’s Openhouse (www.openhouse-sf.org) and On Lok (www.onlok.org) are partnering to help the city’s LGBTQ older adults age with dignity, independence and pride. The two non-profits are co-designing a program that addresses two critical issues in this community: accessing much needed aging services, and ameliorating the LGBTQ elders’ fears that life in a nursing home would drive them back into the closet.

Tim R. Johnston, director of national projects at SAGE, talks with Openhouse Executive Director Karyn Skultety and On Lok CEO Grace Li.

Tim Johnston (TJ): How will this partnership address the fear of being mistreated in a nursing home environment and an inability to access necessary services?

Karyn Skultety (KS): Programs like PACE (Program of All-Inclusive Care for the Elderly), which was pioneered by On Lok, and adult daycare programs are specifically meant for people at risk of institutionalization, but who want to continue living in the community. We’re studying those models of care, being careful not to just adopt these models as is for our LGBTQ older adults. These programs already exist in San Francisco and we know they’re being underutilized by LGBTQ older adults. We’re looking to build upon those models, which typically provide engagement through art, learning and other activities, such as lunch, transportation and assistance with day-to-day activities, to create a program that provides those services but meets the needs of LGBTQ older adults.

We might provide an art activity focused around Harvey Milk’s birthday or a reminiscence group about activism or someone’s first Pride Parade. Transgender older adults in particular have had negative experiences in healthcare settings and avoid utilization of aging services. We’re hopeful that this program will have a positive impact on transgender older adults who will be entering a facility where there are all-gender restrooms, have staff that use the correct pronouns to greet them and embody a community ready to embrace them as who they are.

Grace Li (GL): It’s important to understand and address whatever is driving access limitations. In addition to services, part of the intention is to educate people about the aging process. Without that knowledge, some people might not know what they need. If we can keep people in the community, especially LGBTQ older adults who may face bullying and discrimination in institutionalized care, we also want to make sure that the risks of isolation do not increase.

This is even more critical in the LGBTQ population, many of whom haven’t raised children who would become their family support system. Our aim is to decrease the chance of depression and other adverse clinical outcomes. It’s important that people who are at risk of declining health can access services while being monitored for changes in condition so they can quickly receive the services they need. Catching changes early is critical to maintaining independence for as long as possible.
**TJ:** How did you get the idea to partner, and what does the program design process look like?

**GL:** Openhouse understands the needs of LGBTQ older adults focused on staying in the community. On Lok has a strong background in serving a wide range of diversity, in particular ethnic and linguistic diversity, as well as sensitivities to cultural norms. I have known Karyn for many years and, as we both stepped into leadership roles at our respective organizations, we recognized an opportunity to leverage our expertise for the benefit of Openhouse’s new site.

**KS:** The design process is one that is careful, intentional and community-driven. For example, Dr. Jason Flatt, a researcher at the University of California, San Francisco (see his article on page 11), is conducting focus groups with LGBTQ older adults and caregivers. We’re also drawing on the methods of cultural anthropology to conduct a wide range of interviews. This will help ensure the process includes community members, as well as the caregivers for those with dementia. The programming, which will be available most days of the week, will be offered in the community center of our new location at 75 Laguna Street.

**GL:** We’re applying a well-defined design thinking approach, one that has been widely adopted in the world of products, and one that puts the “user” of the program at the center of the design. We are so focused on the experience of the older adults as they find out about the program, as they seek out the service and talk to staff to learn more and possibly join. We care about their experience in the program and throughout their day with us. A consistently positive experience is the key to opening up access to these services, as well as creating not just a center, but a center brimming with community.

**TJ:** How did you go about forming this partnership?

**GL:** On Lok is working with Openhouse to assess our readiness to serve the LGBTQ senior community. We’re committed to an organizational readiness that will create a safe, supportive setting for LGBTQ older adults. We’re also committed to training and program design that will support our staff in providing sensitive care, helping to ensure we aren’t bringing any of our own biases or lack of education to the partnership.

**KS:** During the planning process, we spent time with the management and boards of both organizations discussing guidelines and shared values. Openhouse has a long history of providing cultural humility training to aging service providers to help improve their care of LGBTQ older adults. While the training is highly regarded and impacts the knowledge of providers, it has not been sufficient in changing the engagement of LGBTQ older adults and fully meeting their needs. We believe that the On Lok and Openhouse partnership goes beyond training, to transforming existing models of care.

**GL:** Early conversations brought forward some challenging issues. We worked through them because we’re aligned on our goals. A project like this has many layers—from identity to dependencies to vulnerabilities—so we hope to be advocates helping people use their voices and stay in their communities.

**TJ:** What are some challenges you are working through?

**KS:** One challenge is thinking fully about the diverse communities that On Lok serves. There are important intersectional conversations to be had about being an LGBTQ elder in the Asian and Pacific Islander communities, or about being LGBTQ and Latinx. Having these conversations, though they may be complicated, presents a unique opportunity.

**TJ:** Are there plans to share what you learn through this process?

**KS:** We’re engaging in active documentation of the process: writing thoughtful notes, videotaping design sessions, recording transcripts from focus groups, etc., in order to produce a model of how we can become a transformational organization by working with other partners to change the system of care.
GL: Part of On Lok’s history and legacy is sharing our innovations with a broad audience—our colleagues in healthcare, private foundations, elected officials and government, as well as our fellow community stakeholders. If we can share what we’re doing here in San Francisco, and what we’re doing here can work in other communities, that makes us all stronger.

TJ: How can members of the community, in San Francisco and across the country, get involved?

KS: We’d love to hear their stories. Reach out to us at info@openhouse-sf.org or through our website at www.openhouse-sf.org. What do they think is important? What are they struggling with as an LGBTQ older adult or caregiver? The other way people can help is to get the word out that LGBTQ older adults are underutilizing existing services. That’s very true in San Francisco, and if it’s happening in San Francisco, it is likely happening in other places across the country.