

LGBT Aging Policy Task Force Format

Case Statement: LGBT Seniors and Dementia Care

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Introduction: San Francisco's *Strategy for Excellence in Dementia Care*, published in 2009, was developed under the auspices of the Long Term Care Coordinating Council in collaboration with the San Francisco Department of Aging and Adult Services (DAAS). The recommendations included in that strategic plan are now being implemented by the Dementia Care Excellence Oversight Committee, also in collaboration with DAAS. Accordingly, the implementation of any recommendations included in this report should be overseen by the Dementia Care Excellence Oversight Committee as it continues in its working relationship with DAAS.

1. Statement of Problem to be addressed (one sentence).

LGBT older adults are reluctant to access existing Alzheimer's and dementia care services.

2. Statement of Solution/Recommendation including sub-parts (one sentence for each).

Create an LGBT targeted dementia education and awareness campaign.

Increase availability of exclusive LGBT support groups for caregivers and insure they are provided in LGBT friendly environments.

Create an informational campaign about the importance of advanced care planning.

Create cultural competency training for first responders specific to LGBT seniors living with dementia and their caregivers

Develop a training module for senior care facilities around LGBT senior issues and concerns, specifically as they relate to dementia care.

Encourage LGBT organizations to collaborate on dementia care. Create a coalition of LGBT organizations serving LGBT older adults, eg. Shanti, Openhouse, Maitri, Black Coalition on AIDS, Lyon-Martin, etc.

3. Factual Background of Problem (one page max).

It has been estimated, by 2020, the total population of older adults in San Francisco living with Alzheimer's disease will be 26,774 older adults (*San Francisco Strategy for Excellence in Dementia Care*, 2009). Using the city's 12% estimate of the LGBT senior population, it can be extrapolated that, by 2020, approximately 3,213 LGBT seniors will be living with Alzheimer's disease.

This estimate is specifically related to Alzheimer's. The Alzheimer's Association estimates that Alzheimer's accounts for approximately 60% of all dementias. Accordingly this estimate is low in regard to the total number of LGBT older adults in San Francisco with all forms of dementia.

"LGBT seniors with dementia as well as their caregivers are reluctant to access support services in San Francisco. Fear of discrimination keeps these seniors from coming out in our support groups. The older the LGBT person is between 65 to 90, the less likely they are to be out in the Alzheimer's Association support groups. There are 2,200 to 2,700 participants in our groups, approximately 700 to 800 people a month. Approximately 2 to 5 % of support group participants may be LGBT at any one time but the percent "out" is smaller than that. Level of outness, who they are comfortable being out with is what makes the difference." (Heather Gray, Alzheimer's Association, Northern California Regional Director, Caregiver Support Groups).

Service providers report that fear of discrimination is a primary reason that LGBT seniors and their caregivers are reluctant to utilize senior services for all older adults in San Francisco. “One of the biggest challenge LGBT seniors and their caregivers have is **access** to support services.” (Heather Gray, Alzheimer’s Association) “There is a level of mistrust of service and service providers. LGBT seniors and their caregivers are often fearful of people coming into their world..” Erika Erney, LCSW, Facilitator, LGBT dementia caregiver support group, Alzheimer’s Association and Openhouse.

LGBT seniors, 70 years of age or older, grew up and became adults in the pre-liberation era when disclosure invariably meant rejection, loss and possibly incarceration. Consequently, LGBT seniors often fear for their safety if they invite service providers into their lives and their homes. LGBT seniors often go back into the closet to access needed services or at the risk of jeopardizing their health and well being do not access these services at all.

Alzheimer’s disease and other forms of dementia are still little understood by many people, and there is much stigma associated with dementia. “LGBT seniors are vulnerable to the dual stigma associated with dementia and being LGBT.” (Erney)

Mainstream seniors rely on the assistance of a spouse, adult children, and other family members to access long term services and supports. But research has found that San Francisco LGBT seniors are more likely than heterosexual seniors to be childless, single, and live alone (Karen Fredrikson-Goldsen et. al, 2013, Diana Jensen, 2012, Adelman et. al, 2006). These factors have important implications for care and support for LGBT seniors since having children and/or a partner reduces the likelihood of poverty, and increases access to services and care in old age.

Discrimination, fear of discrimination and living alone increases the risk of isolation in LGBT seniors. These factors are compounded when a person is challenged by a chronic illness. This is especially true for persons with Alzheimer/dementia. “Unlike other illnesses, the person with dementia cannot be the individual asking for help. If you don’t have a plan in place, you can easily be in trouble and become isolated.” (Janice Wallace, Elder Coach, small business owner).

LGBT seniors rely on their family of choice for support and assistance. But families of choice are more often than not people of similar age and so are aging at the same time. Friends may well need services themselves when a senior is in need of assistance. Further, families of choice exist outside of legal support and are challenged by legal obstacles when providing care. Clearly LGBT seniors are in need of more formal support systems to assist them in accessing needed care

4. Policy Rational for solution/recommendation (one page max).

"San Francisco is facing a crisis in dementia care... Dementia is expected to skyrocket in coming decades. .. there is no cure and treatments can only slow dementia’s progression, not stop it or ease its symptoms, and not eliminate them. Age is the strongest risk factor for the development of dementia. Seniors make up a higher proportion of the city's population (17.6% at the time of the 2000 Census) than they do statewide or nationally (14% and 16.5% nationally). In the Bay Area, one out of every three people 85+ has some type of dementia.” From: *San Francisco's Strategy for Excellence in Dementia Care*, December, 2009.

While stigma, denial, lack of information and lack of family members to provide informal care may impede any one from accessing dementia care services, LGBT seniors are further challenged by discrimination and fear of discrimination. Discrimination exacerbates feelings of vulnerability and increases the risk of isolation.

Every effort needs to be made to integrate LGBT seniors into the existing network of dementia care services. Any delay in the transition to less costly, community-based in-home care, to more expensive institutional settings would significantly reduce costs to the City and County of San Francisco. The proposed recommendations would facilitate integration of services and provide the LGBT community with the information and resources to live in community for as long as possible.

Major issues confronting LGBT seniors:

- Isolation
- History of discrimination, discrimination, and fear of discrimination
- Dual Stigma - LGBT & dementia
- Lack of family support
- Lack of informal caregiver support
- Lack of information about dementia
- Denial
- Complications from HIV/AIDS
- Lack of advanced care planning

It is recommended that mainstream dementia and senior services expand service to LGBT seniors by mandating cultural competency LGBT dementia care training for service providers – primary care doctors, nurses, senior service providers, mental health workers, senior serving institutions—nursing homes, senior housing, etc., and first responders – fire and police. Cultural competency training will increase and broaden expertise in working with LGBT seniors with dementia and facilitate LGBT senior integration into the dementia care network.

Without a cure for dementia and with the exponential increase in people living with dementia, it will be important to integrate LGBT dementia care as much as possible into existing long term care services. In turn, all LGBT senior and health services need to be dementia capable.

Unlike the AID epidemic, the coming dementia epidemic is well documented and the disease is well understood. Consequently, a coalition of LGBT organizations that could provide direct services to LGBT older adults, e.g. Openhouse, Shanti, Maitri, Lyon-Martin, and the Black Coalition on AIDS, would reduce the risk of service duplication, increase cost-effectiveness, and allow funding to be channeled in the most expeditious way.

It is recommended that educational programs, resource tools and a community awareness campaign be funded by the city to increase outreach to the LGBT community about Alzheimer/dementia and dementia resources. Education is needed to increase knowledge about dementia and to assist the LGBT community, individuals and couples to better plan for the future. Presently there are few tools available for service providers, first responders or the LGBT community. One of the tools available is the Alzheimer's Association brochure for LGBT Caregiver Concerns. This is a good start. But other tools are needed for people with dementia, their caregivers and service providers.

5. Discussion of potential funding sources (half page max)

Potential funding sources include: the Department of Aging and Adult Services, the San Francisco Foundation, the MetLife Foundation, the Metta Fund, the California Healthcare Foundation, and local health care organizations such as Kaiser Permanente, and California Pacific Medical Center and its foundation, and the Horizons Foundation. Opportunities for public-private partnerships should be explored to develop culturally appropriate resources and funding.

Potential recommendations to Health and Human Services Work Group:

1. Create an LGBT targeted education and awareness campaign about dementia and the issues it presents to LGBT persons. This would include topics and information on:
 - Risk reduction
 - Early identification of dementia
 - What to expect as the disease progresses
 - Services and resources
 - Caregiver wellness and support
 - Disease management for mild, moderate & advanced dementia, including end of life
 - Advanced care planning
 - Ethical issues
 - Emergency preparedness and safety.
2. Create an informational campaign about the importance of advanced care planning, including:
 - What is advanced care planning (ACP)
 - Why is it especially important that people with dementia engage in ACP
 - Who should be involved in the ACP process and why
 - What specific issues should be covered during ACP:
 - Identification of a surrogate or decision-maker
 - Preferences regarding life support and CPR
 - Hospice and palliative care
 - What steps are involved in ACP
 - What is POLST (physician order for life sustaining treatment)
 - Code status while in hospital
3. Work to create new and strengthen existing LGBT-specific dementia caregiver services.
4. Work to enhance other dementia caregiver services so they are sensitive to the unique issues and concerns of LGBT seniors.
5. Create cultural competency training for first responders tailored to LGBT seniors living with dementia and their caregivers.
6. Develop a training module for senior care facilities around LGBT senior issues and concerns, specifically as they relate to dementia care.
7. Seek ways to involve LGBT organizations in senior issues including dementia care.
8. All of these recommendations should be explored and implemented, when possible, in collaboration with the Alzheimer's Association of Northern California and Northern Nevada.