

LGBT Older Adults in Long-Term Care Facilities



Stories from the Field

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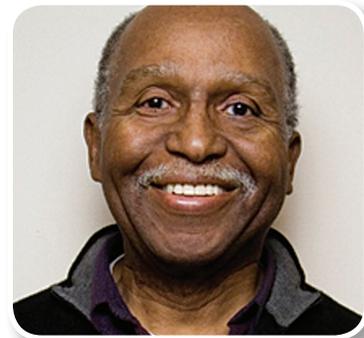
Acknowledgments

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The foundation also works to ensure conservation and respect for the great apes. Its financial support and commitment to the project made this report possible.

The following organizations worked together on this project and co-authored the report:

- National Senior Citizens Law Center
- National Gay and Lesbian Task Force
- Services & Advocacy for GLBT Elders (SAGE)
- Lambda Legal
- National Center for Lesbian Rights
- National Center for Transgender Equality



The study and report would not have been possible without the efforts of the National Council on Aging, AARP, Family Caregiver Alliance, and Old Lesbians Organizing for Change, who helped us disseminate information about the survey and garner respondents from their networks.

Last but far from least, our sincere thanks go to Trishala Deb, program officer at the Arcus Foundation, who requested funding and worked with us to implement this grant.

This report, along with video stories from some of the respondents, is also available online at <http://www.lgbtlongtermcare.org>.

Executive Summary

According to the groundbreaking policy report, *Improving the Lives of LGBT Older Adults* (March 2010), LGBT elders are more likely to be single, childless, estranged from their biological family, and reliant on families of choice, such as friends and other loved ones.

Without traditional support systems in place, many LGBT elders end up relying on nursing homes or other institutions providing long-term care.¹ Yet little information is available about the opinions and experiences of LGBT older adults in these settings.

This report is the result of a survey undertaken by six organizations seeking to better understand the experiences of LGBT older adults in long-term care settings. The survey also sought to capture personal comments that describe some of the varied experiences of LGBT older adults, their loved ones, and the providers who care for them.

Of the 769 individuals who completed the survey, 284 identified themselves as LGBT older adults, and 485 identified themselves as family members or friends, social service providers, legal services providers, or simply “other.” Social service providers included ombudsman program representatives, state staff of area agencies on aging, administrators of area agencies on aging, nursing home administrators, doctors, social workers, nurses, psychologists, hospice workers, and owners of and workers in home health care companies.

The concerns included in this report are mostly expressed in comments from the respondents themselves rather than in answers to closed-ended questions. At the same time, some of the findings, while not the product of a random sample or scientifically reliable, are telling. A majority, for example, believed that staff would discriminate against an LGBT elder who was open about his or her sexual orientation. More than half felt that staff would abuse or neglect an LGBT elder and other residents.

However, the most significant results of the survey are expressed in the hundreds of comments submitted, ranging from reports of staff harassment to staff refusals to provide basic services or care. Altogether, 328 people reported 853 instances of mistreatment. Instances were reported by those identifying themselves as LGBT older adults, family members, friends, social service providers, legal services providers, or other interested individuals.

Some of these comments point to possible violations of federal nursing home law, as noted in the section “Legal Rights of LGBT Residents,” while others signify that far more training and awareness by staff is needed. Additionally, policymakers would be well advised to consider the wide array of policy remedies that could be enacted to better support LGBT elders and the institutions where they reside and receive services. Based in large part on these comments, the recommendations made in this report are directed toward policymakers and consumers as well as long-term care providers.

¹ SAGE (Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders) and Movement Advancement Project. *Improving the Lives of LGBT Older Adults*. March 2010. Available at <http://www.sageusa.org> and <http://www.lgbtmap.org>.

Foreword

The survey was conducted online over a period of eight months, from October 2009 through June 2010. The findings speak only to the experiences of the survey respondents.

These responses should not be read as representative of the experiences of the broader U.S. population. Our hope is that this report provokes thought, raises critical questions, and compels future systematic research that can be used to dive deeper into the issues raised by these personal stories.

Based on the concerns outlined by individuals in this survey, we also believe that LGBT elders and those who care for them would be helped greatly by increased awareness of the protections in the Nursing Home Reform Act, as well as by a wide array of federal, state, and local regulations that could better support the rights of assisted living residents, specifically those who are LGBT older adults. A basic overview of legal rights for LGBT facility residents can be found at the end of this report, along with resources to help LGBT residents and those who care for them.



Key Findings from the Survey

Fear of Being Out and Vulnerable

Survey Question:

Do you feel that an LGBT older adult can be open with the staff of a nursing home, assisted living facility, or other long-term care facility about his/her sexual orientation and/or gender identity?

When asked whether LGBT older adults could be open with facility staff, only 22 percent of LGBT respondents answered “yes.” A smaller share of respondents, who did not identify as LGBT older adults, responded “yes,” as the table shows.

	LGBT Older Adults		Non-LGBT Older Adults	
	Number	Percent	Number	Percent
No or not sure	218	78%	390	84%
Yes	60	22%	76	16%
All responses	278	100%	466	100%

Quotes from Survey Respondents:

Within the next two weeks I will be going into assisted living. Due to my financial situation, I will have to share a room with another man. The thought of going back into a closet is making me ill. Frankly, I'm afraid of telling anyone that I'm gay.

—Anonymous, 73 years old, Sylmar, CA

Of the 289 service providers who answered the survey, 247 felt that LGBT older adults were not safe coming out or were not sure that they should come out.

I've not known anyone in a facility who has stated their alternative sexual orientation, which says a lot in itself.

—Katheryn J. C., 49 years old, MSW, Dept. of Social Services, Ashland, VA

I lived in a very rural, conservative state as a lesbian for 25 years and then transitioned from female to male. LGBT elders in (state withheld by request) are forced to remain hidden, and when placed in long-term care facilities, become even further isolated. I have done training for long-term care staff and administrators in this state, but most feel that there are no LGBT residents in their facilities.

—*Sam (last name withheld by request), 51 years old*

This story illustrates the theme of many comments:

Two friends of mine, Vera and Zayda, had been together for 58 years. When Vera's Alzheimer's became too much, Zayda moved her to an assisted living facility. Zayda could barely trust family or neighbors with the truth, let alone strangers, so she and Vera became "sisters." Much later, after Vera's death, Zayda needed to move into an assisted living facility herself. She had many, many photos of the love of her life, but dared not display them in her new home. The other residents would talk about husbands, children and grandchildren, but she felt too vulnerable to tell the truth. Zayda was in hiding and terribly isolated.

—*Nina L., Carlsbad, CA*

Some respondents developed an unspoken understanding with staff. Several individuals offered comments like this one:

My partner was in a nursing home for 10 years until she passed away. I visited several times a week. We have never mentioned our relationship though I think everyone except perhaps the direct care workers figured it out. They do have a big picture of the two of us together hanging on the wall.

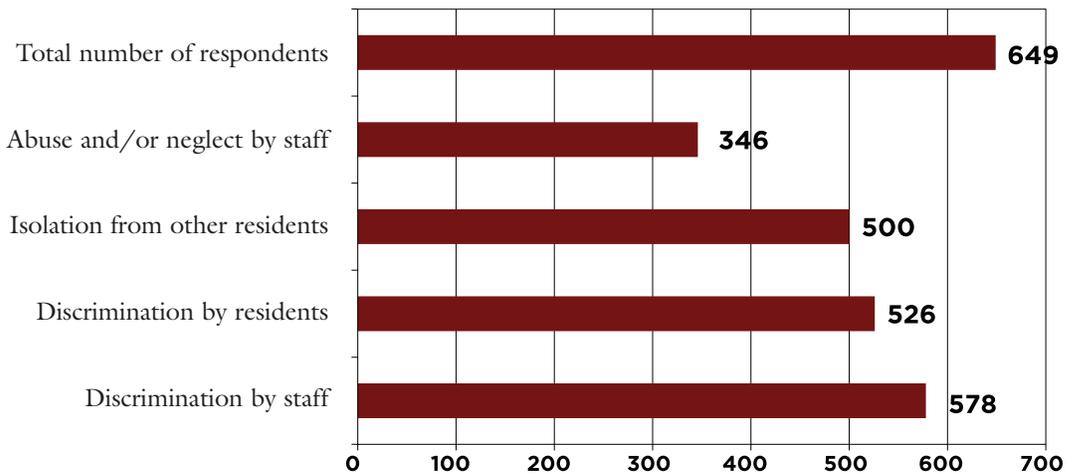
—*Patricia H., Congers, NY*



What Survey Respondents Expect

What issues do you feel an LGBT older adult faces or might face if open about his/her sexual orientation and/or gender identity? List all that apply: abuse and/or neglect by staff; isolation from other residents; discrimination by residents; discrimination by staff.

Possible Issues Affecting LGBT Older Adults



A majority of respondents (578 of the 649 respondents or 89%) predicted that staff would discriminate against an LGBT elder who was out of the closet. A majority also thought that other residents would discriminate (526 or 81%) and, more specifically, that other residents would isolate an LGBT resident (500 or 77%). More than half also predicted that staff would abuse or neglect the person (346 or 53%).

What Survey Respondents Experience

Altogether, 328 respondents (43%) reported 853 instances of mistreatment. Of those who reported instances of mistreatment, 124 were LGBT older adults. The forms of mistreatment are reported below in order of frequency. The results are compiled from four questions on the survey:

Have you, a loved one or a client ever experienced any of the following because of actual or perceived sexual orientation and/or gender identity? Refusal of admission, abrupt discharge, attempted discharge, refusal of readmission; restriction of visitors; none of the above; other/comments.

Has the staff of a facility that you, a loved one or a client lived in ever done any of the following? Refused to provide basic services; verbally or physically harassed or ostracized you/client/loved one; refused to refer to a transgender resident with his or her preferred name or pronoun; refused to let the spouse, partner, or person with the medical power of attorney or other health care directive make decisions for an LGBT resident?

Have you, a loved one or a client ever experienced verbal harassment or other abuse by residents because of your/his/her actual or perceived sexual orientation and/or gender identity?

Has the staff of a long-term care facility denied you, a loved one or a client medical treatment because of actual or perceived sexual orientation and/or gender identity?

Experiences Related to Resident's Real or Perceived Sexual Orientation and/or Gender Identity	Number of Instances	Percent of All Instances
Verbal or Physical Harassment From Other Residents	200	23%
Refused Admission or Re-admission, Attempted or Abrupt Discharge	169	20%
Verbal or Physical Harassment From Staff	116	14%
Staff Refused to Accept Medical Power of Attorney from Resident's Spouse or Partner	97	11%
Restriction of Visitors	93	11%
Staff Refused to Refer to Transgender Resident by Preferred Name or Pronoun	80	9%
Staff Refused to Provide Basic Services or Care	51	6%
Staff Denied Medical Treatment	47	6%
Total	853	100%

Verbal or Physical Harassment by Residents

Negative treatment from other residents was the most frequently reported problem. *Improving the Lives of LGBT Older Adults* cited research showing that LGBT people experience chronic stress due to social stigmatization, discrimination and violence [cite, p. 5].

A gay couple moved into my mother's facility. The residents kept talking about: "Which one is the man and which one is the woman?" They moved out in a couple of months."

—Frances C., Pima, AZ

Several residents' offhand comments about gays and fags make me (and any gays) uncomfortable.

—Bob C., 88, LGBT friend, retired from Ford Motor Company, Ann Arbor, MI

Others report a more complex experience.

It is difficult for some elderly residents here to accept me as a gay male and my partner, who is a F to M transitioning person. Some reluctantly call him by his male name, having known him for years as a female. Generally, though, we and other GLBTQs in the complex are accepted and not bothered, even with HRC, pro-Gay Marriage, Task Force, PFLAG, AIDS, Rainbow flag and other stickers in our windows and apartments.

—Denny M., New York City, NY

Verbal or Physical Harassment by Staff

Negative treatment by staff was the second most frequently reported problem.

There were known gay and transgender residents at the nursing home where I used to work. Some employees made inappropriate remarks towards the residents, some were spreading rumors, and some were telling other employees that the residents are gay/transgender without a respectful manner. I am also gay.

—Yoshi M., St. Paul, MN

Only a few residents have been out in the nursing homes where I have worked, and I have worked in nursing homes for more than 25 years. For those perceived as LGBT there are comments, whispers and gossip about the residents amongst staff and other residents.

—Mary Blanchett, Licensed Nursing Home Administrator and President of Mary Blanchett & Associates Inc., Brooklyn, NY

My partner was in the long-term skilled nursing facility for 30 days—it was a difficult time for both of us, but particularly because of some staff who seemed to “resent” our relationship and my advocacy on his behalf.

—John D., 83, San Francisco, CA

Several respondents also reported being “prayed over” or being told that they would “go to hell” for their sexual orientation or gender identity.

As one respondent described it, “Insisting on praying for me feels like harassment.” He added, “It took a lot of work to get staff to stop asking me about a wife; especially because I have children from a heterosexual marriage. I have been in my same-gender relationship for over 30 years.”

Staff Refusal to Accept Medical Power of Attorney

A Medical Power of Attorney, also known as a Health Care Proxy, is a legally binding document that allows individuals to designate an agent to make health-care decisions on their behalf should they become incapacitated. This document protects a resident from mistreatment by biological family members who may make medical decisions contrary to their wants and needs.

Brian was hit by a car when they stopped to help a stranded motorist. He and his partner had no health-care power of attorney in place. Brian’s family took over his care at the hospital, excluded his partner, and tried to convert Brian back to being straight. Luckily, this couple had registered as domestic partners years before in Kings County, Washington, and we were able to petition for a change in guardianship. This case took litigation and a lot of money to fix. It could have been obviated with a health-care power of attorney. Even a simple document available online at an estate planning site would have done the job.

—Richard Sayre, elder law attorney, Spokane, WA

Individual comments highlighted the importance of planning for a medical emergency, particularly giving someone a health-care power of attorney.

One individual comments that he still has to advocate to ensure that providers recognize and follow what the health-care power of attorney says. Even so, this document is critical to better ensuring that an individual’s wishes will be respected.

Some tend to discount or conveniently forget that my life partner has medical say-so about my care. I keep our medical directive in the nightstand for easy access.”

—Anonymous, 68 years old, Washington, DC

The study did not ask about the need for a medical power of attorney to protect an LGBT elder from hostile actions by family members to whom decision-making power devolves by default. Still, several individuals said having one is important.

I have been haunted for years by what happened to two lesbian friends of mine. They had been “married” for more than 50 years, when they both fell ill. Their families sent them to separate nursing facilities despite all protests. They each shortly passed away. It was heartbreaking!

*—Vicky Esperanza, wife of a minister,
Metropolitan Community Church, Des Moines, IA*

A woman died shortly after I started as a floor nurse in a nursing facility in 2002, and I learned her story from other staff. The woman came to the nursing home after having a stroke. She was unable to communicate. The family decided that her partner of 50+ years had no rights to their property, or to see or make decisions for the patient. The family sold the home and got a restraining order against the partner. These ladies were retired schoolteachers in their 80's and had never considered being “out.” They had no legal protections in place. The partner of the patient had severe health issues herself. She would call the nursing home occasionally on the night shift to see if a kind nurse would be willing to break the rules and tell her if her partner was still alive and how she was doing. It was a sad situation.

—Michelle F., Riverview, FL

I have a friend who served in the Army for 28 years and was also a civilian employee of the Army Reserve. All that time, he was more or less “in the closet.” He very much looked forward to retirement when he would finally be able to be out and open. That day came, and he had a huge retirement party, inviting gay friends, relatives, and nearly everyone he knew. It was an elaborate “coming out” for a man of 60. Within a year, and after months of increasing mental confusion, he was diagnosed with a deadly brain tumor. He was operated on, and then spent the better part of a year in hospitals and convalescent-therapy facilities. Sadly, he lost the ability to think clearly and care for himself. He was placed in a permanent long-term care nursing home, where he remains.

Although some of his gay friends believed he had given them his Power of Attorney, there was no documentation. And after his operation, my friend could no longer speak for himself. His “next of kin”—his brother—was determined to be in charge of my friend's fate. In accordance with State law, his brother was assigned Power of Attorney. His brother was and is very homophobic and they had little to do with each other until this situation arose.

For his own convenience, his brother moved my friend to a nursing home in southern New Jersey where he lives, far from gay friends in New York City. In the first year, we had phone contact and my friend was even brought to NYC by his gay synagogue for holiday events. All that seemed to anger his homophobic brother, who, as legal guardian, cut off phone service and prohibited all trips out of the facility. My friend is now totally isolated from his gay life. While he is severely incapacitated mentally, I believe he is “aware” of his isolation and feels emotional pain.

—Denny M., New York, NY

Restriction of Visitors

Ninety-three (93) individuals checked that they, a loved one, or a client had experienced restriction of visitors; however, none provided follow-up comments. Individuals who responded to the survey could have experienced or know about restrictions on either side of the relational equation, either as a visitor or a resident. This is an area of research that should be considered in the future.

Staff Refusal to Refer or Use Preferred Name or Pronoun

According to a national survey by the National Center for Transgender Equality and the National Gay and Lesbian Task Force, discrimination against transgender people in housing, health care, and public accommodations is pervasive. One in five transgender adults reports being turned away by a health care provider because of his or her gender identity, one in five reports being turned away from a home or apartment, and nearly half have been denied equal treatment or service in at least one place of public accommodation.²

Transgender older adults—including those who have made a gender transition and those who have not—are particularly vulnerable in nursing homes and assisted living facilities. For many, hiding is not an option. Transgender children of a nursing home resident are also likely to experience hostility and mistreatment from the staff as they try to care and advocate for their parents. In our survey, eighty (80) individuals reported that they, a loved one or a client had experienced a refusal by staff to refer to a resident by his or her preferred name and/or pronoun.

² Grant, Jaime M., Lisa A. Mottet, Justin Tanis, Jack Harrison, Jody L. Herman, and Mara Keisling. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011. http://endtransdiscrimination.org/PDFs/NTDS_Report.pdf.

My lesbian friend, whose given name is “Hazel,” has gone by the name “Rusty” her entire adult life (she is in her 80s). The staff in the skilled nursing facility insists on calling her “Hazel.” Mentally, she is very astute, but it is rare that other residents or staff interact or make conversation with her. I feel that she has been excluded or isolated often. My friend has been transferred from place to place several times.

—Eddie W., 62, San Francisco, CA

I was already living 24/7 as a female ... when I checked my Mom into a nursing facility in 2008. However, my legal name was still in a masculine form. I thought that information was confidential. As soon as my Mom was checked in and I left the building, the head social worker called all staff together to inform them of my gender identity and sexual orientation. In retrospect, I better understand a number of incidents with staff members when they made odd comments to me or referred to me by the wrong gender.

—Kerrie Ellen W., Susquehanna, PA

Staff Refusal to Provide Basic Services or Care

Depending on someone for bathing, toileting, and feeding who deeply disapproves of who you are can be an extremely stressful experience. Several respondents commented on personal care staff that refused to touch LGBT residents for fear of contracting a disease. Fifty-one people reported that staff had refused to provide such basic care. Here is one example:

Two years ago, Jack was in the SNF [skilled nursing facility] for some 16 days before he was finally taken in for a shower by a staff member with empathy, and my “screaming” insistence. This time, I check him out of the SNF (which is in the same building in which we have an independent living apartment) and bring him up to the apartment where he can shower and shave without the assistance of an aide who may or may not be “comfortable” helping a Gay man bathe.

—John D., 83, San Francisco, CA

The resident who is transgendered was prevented to eat (sic) with other residents, talk with them or be involved in the social/recreational activities with other residents.

—Anonymous, Ombudsman, CA

In some cases, facilities refuse to recognize an individual's gender identity. This may include refusing to assist a transgender resident in dressing consistently with his or her gender identity, or requiring that intimate tasks be performed by a member of the resident's birth-assigned gender (e.g., male staff bathing an older transgender woman). These can be extremely demeaning and traumatizing experiences for transgender residents.

The law is clear regarding the facility's obligation to provide necessary care in both nursing homes and assisted living facilities.³ In either type of facility, staff must be able to provide care without regard to individual prejudices.

Failure to Provide Proper Medical Care

Twenty-four (24) elders (12 percent) reported direct experience or knowledge of someone who was denied medical treatment because of their actual or perceived sexual orientation or gender identity. In addition, almost half (46 percent) of LGBT older adults who responded said that they, a loved one, or a client were not comfortable self-identifying with medical staff.

My lover, Johnny Jones, was in a skilled nursing facility for four days in 2007. The first day the nursing staff “accidentally” pulled out his feeding tube. The second day they “accidentally” injured his urethra after pulling out the catheter or inserting it too forcefully. Johnny had to go to the ER twice in the four days: the first time to treat his damaged urethra and the second time after he was found unresponsive following the trip back from the ER. After that, Johnny’s family and I moved him to a bigger hospital in Ann Arbor. I don’t know whether the poor care Johnny received was because he is black, or because we are a gay couple. I was at his side all day every day, only leaving to sleep. The bad things happened at night, when I couldn’t see what was going on.

—Jean-Luc D., Maybee, MI

I went for nine days without heart medication during a rehabilitation stay in a nursing home. For 17 days I received another, inappropriate, medication. Even though I had been out for many years, I was so dependent on the nurses that I became afraid. It took all the courage I could muster up to keep pushing the staff to solve the problem.

—C., Columbia, SC

³ See “Legal Rights of Facility Residents in the Appendix for more discussion on this topic.

Abrupt or Attempted Discharge, Refusal to Admit or Re-Admit

Has the staff of a long-term care facility that you, a loved one or client has lived in ever done any of the following because of actual or perceived sexual orientation or gender identity?

Admission and Discharge	All Instances	Number Reported by LGBT Older Adults
Attempted Discharge	58	18
Refused Admission	50	22
Abrupt Discharge	36	18
Refused Re-Admission	25	8
	169	66

No admission or discharge decision should ever be made on the basis of a resident’s actual or perceived sexual orientation or gender identity.

In the very few instances of my office becoming aware of discrimination of LGBT residents, administrative staff usually quickly resolve the problem. ... However, I have been told that some facilities would choose to not have the problem by denying admission of the LGBT resident.

—Anonymous, Ombudsman, CA

Good Care is Possible

A small group of individuals sent in comments and stories about receiving compassionate care. Here is one example that inspires hope:

Carly is a 64-year-old transgender woman. Her mother, Lucy, lived in an assisted living facility in Central Oregon until she was 102. About two years before Lucy died, Carly came out to her for the first time as a woman. Carly was deeply touched by the level of support the staff provided to her and to Lucy as she was coming out.

[My mother] had just turned 100 years old and she was very confused [about what this transition meant]. While I was trying to explain to her who I was, a young woman who worked there came in. I explained the situation. She said “not to worry, I get it and I will help your mother understand.” A couple of other hospice people and staff people worked with my mother to help her understand who I was. It turned into a positive thing for both of us when these people who worked with my mother everyday were able to help her see. And they didn’t bat an eyelash. Where my mother lived was kind of a conservative town, but these people were very compassionate and caring.

Carly reported that there was a little bit of confusion at first about her gender, but after correcting them she does not remember “a single slip up” among staff regarding the proper pronoun. Carly felt that the other residents were supportive of her, even though they may not have known who she was. Carly herself hopes to move to this facility if she ever needs long-term care.



Recommendations

This report is part of a much larger national conversation about fair treatment, dignity and respect for sexual orientation and gender identity, and compassionate care for everyone. Every actor in the long-term care story can use these findings to advance that conversation and take steps in their own domains:

- Nursing home and assisted living facility operators can raise staff awareness and conduct self-assessments of their facility's culture and quality of care.
- Ombudsman programs can develop measures of resident safety and educational programs for facilities and for their programs.
- Researchers can frame more in-depth studies of resident experiences. In particular, researchers can identify the sexual orientation and gender identity of survey respondents and compare the experiences of LGBT and non-LGBT residents as well as transgender residents with lesbian, gay, and bisexual residents who are not transgender.
- LGBT older adults and their loved ones can use the questions in this report as a guide to help assess whether a facility is welcoming.
- Policymakers can use this report to support more funding for research, more programs that train nursing home staff to provide culturally competent care, and clearer policies to protect LGBT residents.
- States and local communities, especially those with human rights provisions, covering sexual orientation and/or gender identity can mandate cultural competency training and others steps to promote better care.
- States and local communities can pass health or aging services regulations identifying LGBT elders as a vulnerable aging population, and they can mandate cultural competency programs for any agency receiving local funds.
- State agencies on aging can help local area agencies examine their long-term care planning programs and add resources for LGBT clients and providers alike.
- Aging and Disability Resource Centers (ADRCs), which are designed to provide a single point of entry into the public long-term care system, can assess their programs, the quality of information given, and their intake systems.

As the nation moves toward full inclusion of LGBT people, the older adults in nursing homes and assisted living facilities across the country need to be heard and included. It is our hope that improvements won for LGBT older adults will ultimately benefit all residents in long-term care facilities, and that this report inspires action.

About the Survey Respondents

Survey Question:

I am (check as many as apply): An LGBT older adult, a legal services provider, a social service provider, a family member or friend of an LGBT older adult, other (please specify).

Of the 769 individuals who completed the survey, 760 responded to this question. Of those, 284 identified themselves as LGBT older adults.

Since respondents could check more than one box, there is some overlap among categories—a strategy that we suggest future studies avoid. Of the 284 individuals who checked “LGBT older adult,” 82 individuals also checked “family member or friend,” 56 also checked “social service provider,” and 8 checked “legal services providers.” We grouped together all responses from those who identified as LGBT older adults, including any who checked multiple categories.

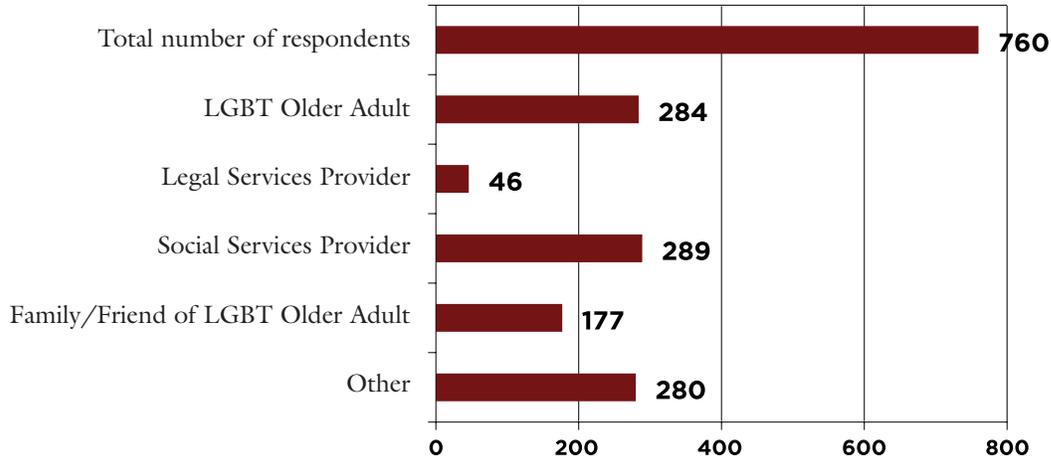
We did not ask for more detailed demographic data—in hindsight, a decision we would change. We recommend that future studies create mutually exclusive categories, that they include questions on race and ethnicity, and that they differentiate among lesbians, gay men, bisexual and heterosexual individuals, and between transgender and non-transgender individuals.⁴

The 289 individuals who identified as social service providers included ombudsman program representatives, state staff of area agencies on aging, administrators of area agencies on aging, nursing home administrators, doctors, social workers, nurses, psychologists, hospice workers, and owners of and workers in home health care companies.



⁴ Some researchers on LGBT issues have developed standards for data collection that will enable greater comparison across studies. For further information, see the Williams Institute, *Best Practices for Asking Questions about Sexual Orientation on Surveys* (November 2009) at http://www.law.ucla.edu/williamsinstitute/pdf/SMART_WI_FINAL.pdf.

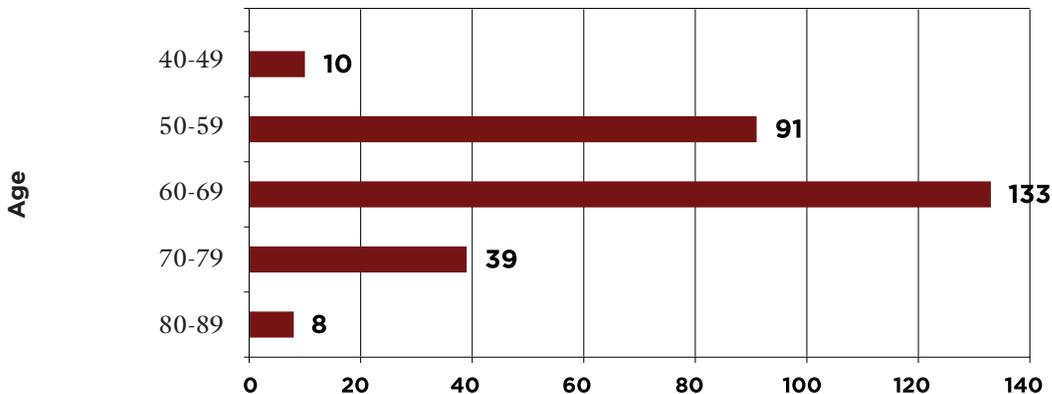
Who Answered the Survey



People in 44 states plus the District of Columbia responded to the survey. Of these, 41 percent are from three states: California (129), Michigan (79), and New York (52). The number of responses from the other 42 states and the District of Columbia ranged from 25 to 1.

The mean age of the LGBT older adult respondents was 63 (total responses: 281).

Distribution by Age Range, LGBT Older Adults



Appendices

Legal Rights of Facility Residents

Nursing home residents, regardless of sexual orientation or gender identity, are protected by the federal Nursing Home Reform Act (NHRA).⁵ The NHRA is a comprehensive federal statute that creates a minimum set of standards of care and rights for people living in federally certified nursing homes.⁶ Among other things, the NHRA requires a nursing home to “provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.”⁷

The NHRA, and the regulations for its implementation, encompass a wide breadth of rights, including the right to be treated with “dignity” and “respect,” “to be free from physical or mental abuse” or “involuntary seclusion,” and to make personal decisions, such as what to wear.⁸ Discrimination, abuse, or neglect against LGBT older adults would violate the NHRA’s standards of care.

Residents of assisted living facilities generally have some of the same rights, but because assisted living laws are set by the states and not by the federal government, there is significant variation in the strength of consumer protections across states.

Based on the concerns outlined by residents and their family members—such as fear of discrimination, mistreatment by staff, or even about being open while living in a long-term care facility—LGBT elders and their families, friends, caregivers, and advocates would be helped greatly by increased awareness of the protections for residents under federal and state law. LGBT older adults still need explicit protections against discrimination and bias on the basis of sexual orientation and gender identity.

This section outlines legal protections for LGBT older adults in long-term care facilities and provides basic information about procedures for seeking relief if a problem occurs.

Federal and State Anti-Discrimination Laws

The federal Fair Housing Act (FHA), which covers residential care facilities such as nursing homes and assisted living facilities, prohibits discrimination based on sex. The FHA is administered by the Department of Housing and Urban Development, which has found that discrimination against a resident or applicant because he or she is transgender or fails to conform to gender stereotypes may violate the

⁵ 42 U.S.C. § 1396r (2009). Section 1396r applies to Medicaid-certified nursing homes. A virtually identical section, applicable to Medicare-certified nursing homes, is located at 42 U.S.C. § 1395i-3.

⁶ 42 U.S.C. § 1396r(a).

⁷ 42 U.S.C. § 1396r (b)(2).

⁸ 42 U.S.C. § 1396r (c)(i)(a)(2); 42 CFR §§ 483.15; 483.25.

FHA.⁹ In addition, state and local laws in some jurisdictions expressly prohibit discrimination based on sexual orientation and gender identity in housing and/or public accommodations. If you live in a state that lacks a nondiscrimination law, check to see if your city or county has passed an LGBT-inclusive ordinance. These can provide comparable protections.¹⁰

Nursing Home Residents

The federal Nursing Home Reform Act (NHRA) applies to any nursing home that accepts reimbursement from Medicare or Medicaid (or both) and therefore covers more than 96 percent of the nursing homes in the country. In addition to the NHRA, federal law has established Long-Term Care Ombudsman Programs to provide assistance for consumers having problems with long-term care facilities. Also, individuals can bring a complaint to the state survey board or file a lawsuit. See below for more details.

Helping residents reach the highest practicable level of functioning. The cornerstone of the NHRA is the requirement that a nursing home provide the care needed so that the resident can reach the highest practicable level of functioning. Care should never begin with the assumption that a nursing home resident is destined to do nothing more than decline and then die. Instead, the resident should receive necessary nursing care and therapy services, in an environment that respects the resident's right to make choices about daily living. For LGBT residents, acceptance is a critical component of reaching the highest level of functioning, as many of the comments in this report point out.

Individual assessment and comprehensive care plan. In a nursing home, care should be provided based upon a careful assessment of the resident's health and capabilities, as translated into a comprehensive care plan. This care plan is developed by an interdisciplinary team that includes the resident and the resident's representative, as well as nurses and other nursing home staff members. Ideally, the care plan will meld the staff's health care expertise with the resident's individual preferences. In development of the care plan and in the provision of care generally, the nursing home must reasonably accommodate a resident's individual preferences. A care plan for an LGBT older adult should include protections against bias by staff or residents and accommodations for needs based on sexual orientation or gender identity. A transgender resident should be cared for by staff who are sensitive to gender identity. If double occupancies are the norm, that resident should be housed with someone who will treat him or her with dignity and respect.

⁹ HUD, *HUD Issues Guidance on LGBT Housing, Discrimination Complaints*, HUD Press Release No. 10-139 (July 1, 2010), available at http://portal.hud.gov/hudportal/HUD?src=/press/press_releases_media_advisories/2010/HUDNo.10-139.

¹⁰ See, e.g., Equality Florida, *Winning Equality* (2010) at 5 (despite the lack of a statewide nondiscrimination ordinance, sexual orientation and gender identity-inclusive nondiscrimination laws have been passed in numerous counties).

Freedom from interference, coercion, discrimination, and reprisal for exercising rights. Under the NHRA’s regulations, a “resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights.”¹¹ Federal guidelines for this right instruct government inspectors to “[p]ay close attention to resident or staff remarks and staff behavior that may represent deliberate actions to promote or to limit a resident’s autonomy or choice, particularly in ways that affect independent functioning.”¹² Although there is no explicit mention of sexual orientation and gender identity in the NHRA and its regulations and guidelines, these provisions should be interpreted to cover negative treatment of LGBT older adults.

Dignity and respect. The federal regulations implementing the NHRA state that a nursing home “must promote care for residents in a manner and in an environment that maintains or enhances each resident’s dignity and respect in full recognition of his or her individuality.”¹³ Biased treatment of LGBT older adults, including verbal and physical harassment by staff, thus is prohibited.

Visitor access. Under the NHRA, a nursing home must “permit immediate access to a resident, subject to the resident’s right to deny or withdraw consent at any time, by immediate family or other relatives of the resident.”¹⁴ Thus, a resident’s family member can visit at any hour of the day or night, without regard to any visiting hours established by the nursing home. If a visitor is not a family member, however, the “immediate access” is “subject to reasonable restrictions and the resident’s right to deny or withdraw consent at any time.”¹⁵ These “reasonable restrictions” include reasonable visiting hours. Under these rules, an LGBT family member or friend cannot be excluded or limited to visiting hours that are different from those offered to other visitors.

Despite recent advances in visitation rights, it is recommended that couples—whether in legally recognized relationships or not—complete a hospital visitation authorization. This document allows you to designate who you would like to be able to visit you in the hospital if you are no longer able to communicate this yourself. For more information about these forms, please contact any of the advocacy organizations listed in the Resource Section at the back of this report.

¹¹ 42 C.F.R. § 483.10(a)(2).

¹² Surveyor’s Guideline to 42 C.F.R. § 483.10(a)(2), Appendix PP to CMS State Operations Manual.

¹³ 42 C.F.R. § 483.15(a).

¹⁴ 42 U.S.C. §§ 1395i-3(c)(3)(B), 1396r(c)(3)(B).

¹⁵ 42 C.F.R. § 483.10(j)(viii).

Limits on evictions. The NHRA sharply limits a facility's ability to evict a resident. There are very limited justifications for eviction: nonpayment; the nursing home going out of business; or the resident needing a higher level of care, no longer needing nursing facility care, or endangering the health or safety of others. Thus, evictions on the basis of sexual orientation or gender identity are not authorized. There are explicit procedures in the law designed to protect a resident from arbitrary eviction. A nursing home must give written notice of eviction, generally at least 30 days before the proposed eviction date. A resident can appeal and have the issue determined by an administrative law judge.

Advocacy mechanisms in the law. The resident may wish to obtain the assistance of the Long-Term Care Ombudsman Program in negotiating with the nursing home. There are nearly 600 ombudsman programs in 53 states and territories. To learn more about ombudsman programs, visit the website of the National Long-Term Care Ombudsman Resource Center, located with Consumer Voice at <http://www.theconsumervoice.org/>.

If informal negotiations with the facility do not work, the resident can file a complaint with the state's nursing home survey agency (often a licensing and certification division of the state's health department), which has authority to fine or take other actions against nursing homes that violate the law.¹⁶ If the survey agency finds a violation, it should at a minimum require the nursing home to correct the situation. Finally, an individual has the right to sue a nursing home in court. In some circumstances, a resident may be well advised to file a lawsuit against an offending nursing home. See the **Resource Section** for information about how to reach legal advocates for LGBT people who may be able to assist.

Assisted Living Residents

Assisted living standards are set by state licensure law, which varies significantly from state to state. Even so, some generalizations are possible. State assisted living standards generally include a resident's right to self-determination and dignity. Also, a facility likely will have an obligation to assess a resident's condition and to plan and provide care in accordance with that assessment. A state's laws generally include some right to have visitors and to access the community outside the assisted living facility, although the extent of such rights varies from state to state.

Generally, state assisted living laws limit a facility's ability to evict residents. The allowed justifications for eviction, however, tend to be looser than the justifications for nursing home evictions, and state assisted living laws are generally somewhat vague as to a resident's appeal rights.

When an assisted living facility provides substandard care, a resident can take advocacy steps comparable to those recommended above for nursing home residents. The resident often will benefit from the assistance of a partner, family member, or friend. The first step is to speak to a responsible person at the facility,

¹⁶ Contact information for state survey agencies is available from the federal Centers for Medicare & Medicaid Services at <http://www.cms.gov/SurveyCertificationGenInfo/Downloads/Complaintcontacts.pdf>

explaining the problem and (ideally) identifying the state assisted living regulation and/or anti-discrimination law that the facility is violating.

If speaking with the facility representative does not bear fruit, a next step is to obtain the assistance of the state's Long-Term Care Ombudsman Program, which, as explained above, is set up to help residents of long-term care facilities. Ombudsman Programs in most states, however, primarily deal with nursing home issues, and a significant number are not prepared to help assisted living residents.

A resident can file a complaint with the state agency that inspects and licenses assisted living facilities. The agency likely will have authority to fine or otherwise punish an offending assisted living facility, although procedures will vary from state to state. At a minimum, if the state agency finds a legal violation, the agency will require the facility to correct the situation. As was mentioned in the discussion of advocacy for nursing home residents, a lawsuit may be advisable for problems that cannot be resolved otherwise.

If a problem is related to discrimination in violation of the Fair Housing Act or state anti-discrimination law, the resident may obtain relief by making a complaint with HUD or with the relevant state anti-discrimination agency, respectively.

More information about specific states' assisted living laws is available on the website of the Assisted Living Consumer Alliance, <http://www.assistedlivingconsumers.org>. Another helpful resource is *Critical Issues in Assisted Living*, an examination of how state assisted living laws address important issues such as the type of residents admitted, conditions for eviction, and standards for staff members. See www.NSCLC.org for more information.

Health Care Powers of Attorney

Health care decision-making rules are set by state law, but there is much similarity from state to state. A competent adult is responsible for his or her own health care decisions. If an adult becomes incapable of making those decisions—due to a dementia, for example—the decisions are made by the person's agent as designated in the person's health care power of attorney document.

The problem is that only a minority of persons have completed a power of attorney document.¹⁷ If a person *without* a power of attorney becomes unable to make health care decisions, there can be confusion about who should step in and make the decisions. Some state laws have default priority orders that tend to focus on marriage and blood relations. A typical priority order would be spouse, then parent, then sibling, with state law determining whether a partner can be considered a spouse for purposes of health care decisions. This type of priority order tends to be followed informally even when the state's law does not have a default priority order.

As a result, it is particularly important that LGBT older adults have health care powers of attorney. Depending on the state, an unmarried partner may have little authority over an incapacitated resident's health care decisions, unless the partner has been named as agent in a health care power of attorney.

¹⁷ See, e.g., Elisabeth Belmont et al., *A Guide to Legal Issues in Life-Limiting Conditions*, 38 J. Health L. 145 (Foreword, By Ira R. Byock, M.D.) (2005).

Glossary of Terms

Bisexual: A person who has an emotional, romantic, and/or physical attraction to more than one sex or gender. The capacity for attraction may or may not manifest itself in terms of sexual interaction.¹⁸

Gender Identity: An individual’s internal sense of being male, female, or something else. Since gender identity is internal, one’s gender identity is not necessarily visible to others.

Intersex: A term used for people who are born with external genitalia, chromosomes, or internal reproductive systems that are not traditionally associated with either a “standard” male or female.¹⁹

Transgender: A term for people whose gender identity, expression, or behavior is different from those typically associated with their assigned sex at birth, including but not limited to transsexuals, cross-dressers, androgynous people, gender queers, and gender non-conforming people. Transgender is a broad term and is good for non-transgender people to use. “Trans” is shorthand for “transgender.”²⁰

Transgender Man: A person who was assigned female at birth, but identifies and lives as a male.²¹

Transgender Woman: A person who was assigned male at birth, but identifies and lives as a female.²²

¹⁸ Miller, M. et al. *Bisexual health: An introduction and model practices for HIV/STI prevention programming*. National Gay and Lesbian Task Force, 2007. p. 10. http://www.thetaskforce.org/downloads/reports/reports/bi_health_5_07_b.pdf

¹⁹ *Transgender Terminology*. National Center for Transgender Equality. May 2009. http://transequality.org/Resources/NCTE_TransTerminology.pdf

²⁰ Ibid.

²¹ Ibid.

²² Ibid.

Resources

Online Resource Centers

The National Resource Center on LGBT Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual, and transgender (LGBT) older adults. Established in 2010 through a federal grant from the U.S. Department of Health and Human Services, the National Resource Center on LGBT Aging provides training, technical assistance, and educational resources to aging providers, LGBT organizations, and LGBT older adults <http://www.lgbtagingcenter.org/>.

The LGBT Aging Issues Network (LAIN), a constituent group of the American Society on Aging, works to raise awareness about the concerns of lesbian, gay, bisexual, and transgender (LGBT) elders and about the unique barriers they encounter in gaining access to housing, health care, long-term care, and other needed services. LAIN seeks to foster professional development, multidisciplinary research, and wide-ranging dialogue on LGBT issues in the field of aging through publications, conferences, and cosponsored events. http://asaging.org/constituent_groups/lain/index.cfm.

Legal Organizations Offering Assistance

Lambda Legal represents individuals who are experiencing discrimination related to sexual orientation, gender identity, and expression and HIV status. It also maintains a national network of volunteer Cooperating Attorneys, which widens the scope of its legal work and allows attorneys, legal workers, and law students to become involved in helping members of the LGBT community. If you or someone you care about has been discriminated against, or feels threatened or unsafe, because of sexual orientation or gender identity, please contact our Help Desk at 212-809-8585 or 1-866-542-8336. For additional information about Lambda Legal, see <http://www.lambdalegal.org> and Lambda Legal's Help Desk.

National Center for Lesbian Rights established the first permanent Elder Law Project in 1999 as the first wave of baby boomers became senior citizens. The Elder Law Project advocates for policies and legislation to protect the medical and financial rights of LGBT elders, and it educates the professionals who are charged with assisting them. For additional legal information or assistance finding an LGBT-friendly attorney, please contact our Legal Information Helpline through <http://www.nclrights.org> or at info@nclrights.org or 800-528-6257.

Local Organizations Offering Assistance

These organizations have agreed to provide information and referrals to local advocates to individuals who face bias or discrimination in a nursing home or assisted living facility.

This is a growing list, and there may be more resources in your community. Also, please check the national resources described in this section.

Azteca Project

P.O. Box 7678
Chula Vista, CA 91912
619-426-6736
<http://www.aztecaproject.org>
Contact person: John Acosta

WISE & Healthy Aging Long-Term Care Ombudsman Program

1527 4th St., 2nd Floor
Santa Monica, CA 90401
800-334-9473 intake line
<http://www.wiselandhealthyaging.org>
Contact person: Intake Staff

Old Lesbians Organizing For Change, Long Beach

3735 Albury Avenue
Long Beach, CA 90808
<http://www.oloc.org>
Contact person: Mina K. Meyer,
Co-Director

Pennsylvania Human Relations Commission

301 Chestnut Street, Suite 300
Harrisburg, PA 17101
717-787-4410
<http://www.phrc.state.pa.us>
Contact person: Stephen A. Glassman,
Chairman

Philadelphia Commission on Human Relations and Fair Housing Commission

The Curtis Building, 601 Walnut
Street, Suite 300 South
Philadelphia, PA 19106
215-686-4670
<http://www.phila.gov/humanrelations>
Contact person: Rosemary Branigan,
(215) 686-4687

FORGE Transgender Aging Network

P.O. Box 1272
Milwaukee, WI 53201
414-559-2123
<http://www.forge-forward.org/tan>
<http://www.grayprideparade.com>
Contact person: Loree Cook-Daniels or
Michael Munson



Publications

20 Common Nursing Home Problems—and How to Resolve Them, published by the National Senior Citizens Law Center and revised in 2010. Consumer booklet provides information about how to advocate for better care and how to identify common violations of the Nursing Home Reform Law. Visit the NSCLC website, <http://www.nslc.org>.

Critical Issues in Assisted Living, an examination of how state assisted living laws address important issues such as the type of residents admitted, conditions for eviction, and standards for staff members. The Critical Issues report is published by the National Senior Citizens Law Center and available at <http://www.nslc.org>.

Improving the Lives of LGBT Older Adults was published in March 2010. LGBT elders are more likely to live in poverty, face social and community isolation, and lack appropriate health care and long-term care. This groundbreaking report outlines the issues and offers solutions, making it a much-needed roadmap for LGBT and aging advocates, policymakers, and anyone interested in ensuring that all Americans have the opportunity to age with dignity and respect. The report represents the first major collaboration between LGBT advocacy organizations and mainstream aging organizations to comprehensively examine the issues facing LGBT older adults. A free copy can be downloaded at <http://www.lgbtmap.org/improving-the-lives-of-lgbt-older-adults.html>.

Our Maturing Movement: State-by-State LGBT Aging Policy and Recommendations provides a state-by-state analysis of each state's anti-discrimination laws both related to LGBT people and to aging. Included are descriptions of each state's mechanisms for funding and opportunities for activists to get involved in changing policies to improve the lives of LGBT seniors and elders. http://thetaskforce.org/reports_and_research/our_maturing_movement

Outing Age 2010: Public Policy Issues Affecting Lesbian, Gay, Bisexual and Transgender (LGBT) Elders is an update to the groundbreaking *Outing Age* report issued in 2000. Like its predecessor, *Outing Age 2010* presents an in-depth look at public policy issues and challenges facing millions of lesbian, gay, bisexual, and transgender people in the United States as they get older. It also includes detailed policy recommendations. A free copy can be downloaded at http://www.thetaskforce.org/reports_and_research/outing_age_2010

Planning with Purpose; Legal Basics for LGBT Elders from the National Center for Lesbian Rights. This free guide provides basic information about select areas of the law that are important to LGBT elders, especially individuals and couples who are age 55 and over. Several other related publications are on their website, <http://www.nclrights.org>.

Take the Power is a free guide to life and estate planning for LGBT people seeking to protect themselves and their loved ones from the potentially devastating effects of a biased system. It includes a section on important legal documents to have in place, and it discusses the changing legal landscape for same-sex couples. Written by Lambda Legal, it's available at <http://www.lambdalegal.org>.

About the Co-Authors

The National Senior Citizens Law Center (NSCLC) is a non-profit organization whose principal mission is to protect the rights of low-income older adults. Through advocacy, litigation, and the education and counseling of local advocates, we seek to ensure the health and economic security of those with limited income and resources, and access to the courts for all. For more information, visit our website at <http://www.nsclc.org>.

The National Gay and Lesbian Task Force (NGLTF) builds the political power of the lesbian, gay, bisexual, and transgender (LGBT) community from the ground up. We do this by training activists, by organizing broad-based campaigns to defeat anti-LGBT referenda and advance pro-LGBT legislation, and by building the organizational capacity of our movement. The Task Force provides research and policy analysis to support the struggle for complete equality. As part of a broader social justice movement, we work to create a nation that respects the diversity of human expression and identity and creates opportunity for all. For more information visit our website, <http://www.thetaskforce.org>.

SAGE (Services and Advocacy for LGBT Elders) is the country's largest and oldest organization dedicated to improving the lives of LGBT older adults. Since its inception, SAGE has pioneered programs and services for the aging LGBT community, provided technical assistance and training to expand opportunities for LGBT older people across the country, and provided a national voice on LGBT aging issues. In 2005, SAGE became the first official LGBT delegate at a White House Conference on Aging. In 2010, SAGE was awarded a three-year \$900,000 grant from the U.S. Department of Health and Human Services and the Administration on Aging to create the nation's only National Resource Center on LGBT Aging, launched in October 2010. For more information, go to <http://www.sageusa.org> and <http://www.lgbtagingcenter.org>.

Lambda Legal is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender individuals, and people with HIV through impact litigation, education, and public policy work. If you or someone you care about has been discriminated against, or feels threatened or unsafe, because of sexual orientation or gender identity, or seeks additional legal information, please contact our Help Desk at 212-809-8585 or 1-866-542-8336. For additional information about Lambda Legal, see <http://www.lambdalegal.org>.

The National Center for Lesbian Rights (NCLR) is a national non-profit legal organization committed to advancing the civil and human rights of lesbian, gay, bisexual, and transgender (LGBT) people and their families through litigation, public policy advocacy, and education. Since 1999, NCLR's Elder Law Project has been empowering lesbian, gay, bisexual, and transgender (LGBT) elders to protect themselves and advocating for equal treatment of LGBT elders in law, public policy, health, and social services. For additional legal information or assistance finding an LGBT-friendly attorney, please contact our Legal Information Helpline through <http://www.nclrights.org> or at info@nclrights.org or 800-528-6257.

The National Center for Transgender Equality is a national social justice organization devoted to ending discrimination and violence against transgender people through education and advocacy on national issues of importance to transgender people. By empowering transgender people and our allies to educate and influence policymakers and others, NCTE facilitates a strong and clear voice for transgender equality in our nation's capital and around the country. For more information, visit <http://transequality.org>.

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