Prepared by: Mev Miller, Ed.D.

SAGE-RI spent one year assessing and interviewing lesbian elders and healthcare professionals in an effort to explore barriers and identify educational gaps related to healthcare and the lesbian-elder community. This report summarizes the results from both groups including response comparisons and key findings.
Executive Summary

In 2012, with funding from the Women’s Fund of Rhode Island, SAGE-RI initiated a project to transform healthcare. Our efforts focused around transforming healthcare from one that often repels lesbian elders due to its lack of awareness and knowledge to one that imbues in lesbian elders a sense of confidence and conviction in accessing healthcare. To create such a social change, SAGE/RI spent an amazing year assessing and interviewing lesbian elders and healthcare professionals in an effort to explore barriers and identify educational gaps related to healthcare and the lesbian-elder community.

In order to understand the attitudes, concerns, and ideas around healthcare delivery and LGBT sensitivity, SAGE-RI created two sets of specific questions to assess two unique groups of individuals: 1) lesbian elders and 2) healthcare workers. The assessments were distributed electronically using a web-based tool by Zoomerang and printed copies were available as well.

As a result, between May and July of 2012, SAGE-RI received immediate feedback and engagement from lesbian elders and a large group of healthcare professionals. The information was analyzed; and, the following key concepts were culled from the responses:

- There exists a general lack of awareness and information —for both lesbian elders and healthcare providers — that lesbian elders do have unique, medical concerns. Both populations could benefit from information and/or education.
- Lesbian elders desire more information about specific, healthcare providers to whom they can be open about their sexual identity and receive competent, non-discriminatory care.
- Lesbian elders in Rhode Island have higher-than-average percentages of certain health factors, specifically arthritis and joint pain, obesity, high blood pressure and other common ailments for aging women.
- Lesbian elders show considerable concern about who will care for them as they age and can no longer care for themselves. They need information about seeking services and support from providers who understand their situation and needs.
- While the majority of healthcare providers in RI claim to be “lesbian-friendly,” their knowledge, practices, and policies reflect limited (or no) competency in the areas of lesbian-specific health issues or cultural needs. Evidence of the lack in good practice is embedded in statements from providers such as, “we don’t ask [about sexual orientation]” or “we treat them like all patients.” Most providers still offer only heteronormative terms on their intake forms (married, single, divorce).
- Providers are not informed about or aware of agency non-discrimination policies, specifically as they relate to LGBT clients. Providers could benefit from more sensitivity-awareness training.
- Providers generally have no way of knowing how many LGBT people they are serving. Providers are tracking other demographics for the populations they serve including
gender, age, race, language, and healthcare issues. Sexual orientation should also be included.

As change toward a more welcoming and culturally competent healthcare environment emerges, encouraging elder lesbians to engage in the health system will be crucial. Helping individuals move from a place of resisting critical healthcare services to feeling confident and supported in accessing health services is the shift in individual behavior that SAGE-RI is seeking. The full, Final Report presents an in-depth review of all assessment responses including the details supporting the previous statements above.

SAGE-RI would like to express its sincere gratitude to the amazing people, partners and collaborators who have supported our work.

Special thanks to Marcia Cone at whose inspiration and gift of leadership constantly calls and challenges us into a greater awareness of each other’s needs.

. . . . .

There are projects on which we embark, hopeful of what will be accomplished but uncertain of how they will end. Mev Miller took an idea and made it into a work of art! Her brilliance, hard work and diligence made this report something beyond our wildest imaginings. Many, many thanks, Mev for your long hours.

. . . . .

Thanks to Gail Patry & Melissa Miranda at Healthcentric Advisors for supporting SAGE-RI and who always find new and better ways to make the world a better place. “I think it’s a quality improvement thing!”

. . . . .

To the great SAGE-RI Steering and Advisory Committee members, who volunteer their precious time, freely offer their expertise but most of all share their hearts.

Patricia Burbank, Marie Esposito, Peter Fournier, Jodi Glass, Cathy Gorman, Sally Ann Hay, David Lima, David McElroy, Marguerite McLaughlin, Ted Platt, Dianna Shaw, Delores Walters
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Chapter 1: Responses to the Lesbian Elder Assessment

Assessment Design

Many women describe their sexual orientation or identity using different words such as lesbian, gay woman, or woman who prefers/prioritizes companionship of women, bisexual, dyke, femme/butch, queer, homosexual, and so on. SAGE-RI sought responses from any woman who has had a primary affectionate and/or sexual relationship with women or who uses any of these terms to describe herself.

The term, lesbian, was used in this assessment to include all options of sexual identity as described above (also, see Section 1, Question 8). The term, partner, was used in this assessment as to include life-time companion, girlfriend, lover or other descriptions for a sexual, intimate relationship.

At what age does one become a lesbian elder? There is no actual consensus among lesbians, or even those who sponsored this assessment. It was agreed that for the purpose of the assessment, the age of a lesbian elder is 65+ years of age, born in or before 1947. However, responses were also requested from lesbians 55+ years of age, born in or before 1957; because they are already considering the issues of elder healthcare.

Outreach to the appropriate audience crucial. SAGE-RI promoted the assessment through the following venues to reach lesbian elders in RI:

- SAGE-RI mailing list
- SAGE-RI website/Facebook page
- RILGBT Listserv
- “Options Magazine”
- RI Gay Pride
- Lifespan Professional Development - event
- Personal connections

The assessment was organized into five sections:

- General Demographics
- Health & Well Being - Part 1, Specific Health Issues
- Health & Well-Being - Part 2, Experiences with Providers
- Healthcare Economics/Legal/Cultural
- Elder Care Services & Related Aging Concerns

The following pages are a summary of the responses organized by section. For general ease of reading, responses were combined thematically for each question.
Section 1: Demographics

Data revealed the assessment was reviewed a total of 172 times and was completed online by 43 people. Additionally, six, completed assessments were submitted by mail, which were entered into the Zoomerang web tool by the researcher to ensure consistency and reliability of the data. In total, 49 completed assessments were collected and analyzed.

Since responses were submitted confidentially, the researcher was unable to determine whether respondents completed more than one assessment, which would create duplicative responses. The only required data included birth year and geographic location. Partially completed assessments were not included in this data summary.

The following information includes responses for the 20 questions found in Section 1.

**Question 1: City/Town in RI**

<table>
<thead>
<tr>
<th>City &amp; Zip code</th>
<th># of replies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrington, 02806</td>
<td>1</td>
</tr>
<tr>
<td>Bristol, 02809</td>
<td>1</td>
</tr>
<tr>
<td>Coventry, 02816</td>
<td>2</td>
</tr>
<tr>
<td>Cranston, 02905</td>
<td>3</td>
</tr>
<tr>
<td>Cranston, 02910</td>
<td>1</td>
</tr>
<tr>
<td>Cumberland, 02864</td>
<td>2</td>
</tr>
<tr>
<td>East Providence, 02914</td>
<td>1</td>
</tr>
<tr>
<td>Foster, 02825</td>
<td>1</td>
</tr>
<tr>
<td>Lincoln, 02865</td>
<td>2</td>
</tr>
<tr>
<td>Narragansett, 02882</td>
<td>5</td>
</tr>
<tr>
<td>No Kingstown, 02852</td>
<td>2</td>
</tr>
<tr>
<td>No Providence, 02904</td>
<td>2</td>
</tr>
<tr>
<td>Pawtucket, 02860</td>
<td>4</td>
</tr>
<tr>
<td>Providence, 02903</td>
<td>2</td>
</tr>
<tr>
<td>Providence, 02904</td>
<td>1</td>
</tr>
<tr>
<td>Providence, 02906</td>
<td>5</td>
</tr>
<tr>
<td>Richmond, 02892</td>
<td>1</td>
</tr>
<tr>
<td>Smithfield, 02917</td>
<td>1</td>
</tr>
<tr>
<td>So Kingstown, 02879</td>
<td>1</td>
</tr>
<tr>
<td>Wakefield, 02879</td>
<td>2</td>
</tr>
<tr>
<td>Warwick, 02886</td>
<td>3</td>
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<tr>
<td>Warwick, 02888</td>
<td>1</td>
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<tr>
<td>Warwick, 02889</td>
<td>2</td>
</tr>
<tr>
<td>W Warwick, 02893</td>
<td>1</td>
</tr>
</tbody>
</table>

**Question 2: Non-Rhode Island Residents**

<table>
<thead>
<tr>
<th>State &amp; Zip code</th>
<th># of replies</th>
</tr>
</thead>
<tbody>
<tr>
<td>California, 91601 (Receiving healthcare in Providence)</td>
<td>1</td>
</tr>
<tr>
<td>Massachusetts, 02760 (Receiving healthcare in Providence)</td>
<td>1</td>
</tr>
</tbody>
</table>
Question 3: Birth Year

Of the 49 responses, 55% (27) were 65-years of age or older (born in or before 1947). The oldest respondent was 84 years of age.

<table>
<thead>
<tr>
<th>Year</th>
<th>Age</th>
<th># of replies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1928</td>
<td>84</td>
<td>2</td>
</tr>
<tr>
<td>1932</td>
<td>80</td>
<td>1</td>
</tr>
<tr>
<td>1935</td>
<td>77</td>
<td>1</td>
</tr>
<tr>
<td>1939</td>
<td>73</td>
<td>2</td>
</tr>
<tr>
<td>1940</td>
<td>72</td>
<td>1</td>
</tr>
<tr>
<td>1941</td>
<td>71</td>
<td>1</td>
</tr>
<tr>
<td>1942</td>
<td>70</td>
<td>1</td>
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<tr>
<td>1943</td>
<td>69</td>
<td>4</td>
</tr>
<tr>
<td>1944</td>
<td>68</td>
<td>7</td>
</tr>
<tr>
<td>1945</td>
<td>67</td>
<td>1</td>
</tr>
<tr>
<td>1946</td>
<td>66</td>
<td>4</td>
</tr>
<tr>
<td>1947</td>
<td>65</td>
<td>2</td>
</tr>
</tbody>
</table>

TOTAL: 27

Of the remaining 22 responses, 91% (20) were aged between 64 – 57 (1948-1955), and 10% (2) were younger than 55 years of age with the youngest respondent being 51 years of age.

<table>
<thead>
<tr>
<th>Year</th>
<th>Age</th>
<th># of replies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1948</td>
<td>64</td>
<td>4</td>
</tr>
<tr>
<td>1949</td>
<td>63</td>
<td>1</td>
</tr>
<tr>
<td>1950</td>
<td>62</td>
<td>2</td>
</tr>
<tr>
<td>1951</td>
<td>61</td>
<td>4</td>
</tr>
<tr>
<td>1952</td>
<td>60</td>
<td>2</td>
</tr>
<tr>
<td>1953</td>
<td>59</td>
<td>4</td>
</tr>
<tr>
<td>1954</td>
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<td>1</td>
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<tr>
<td>1955</td>
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<td>2</td>
</tr>
<tr>
<td>1960</td>
<td>52</td>
<td>1</td>
</tr>
<tr>
<td>1961</td>
<td>51</td>
<td>1</td>
</tr>
</tbody>
</table>

TOTAL: 22

Question 4: Primary race/ethnicity

Of the 49 responses, 48 (98%) identified themselves as White (European) and 2% (1) identified themselves as Black (African.)

Questions 5 – 7, 16:

Employment: Of the responses, 37% (18) were retired while everyone else was working in either a full-or part-time capacity (see Figure 1). Retirees ranged in age from 64 – 82. The oldest full-time worker was a 69-year-old educator. Five of the nine part-time workers were primarily contract workers or self-employed. One claimed to be retired but still working as a part-time, self-employed worker.
**Occupation:** The respondents’ occupations were primarily located in three sectors: healthcare, education, and social services. Healthcare workers included five nurses and a range of positions including administration, research, nursing assistant, psychotherapist, and audiologist. Educators included college professors, administrators, classroom teachers, and reading/literacy specialists. Social work and services included generalized social workers, substance abuse counselors, clinical and psychiatric social work, an administrator and a minister. Additional occupations outside of those three areas included: electronics technician, policy specialist, ice skating coach, writers, motion picture sound editor, government administration, community activist, and caterer.

**Income:** Respondents reported on their INDIVIDUAL, current income (see Figure 2). One retired respondent reported making less than $10,000 annually while two other retirees reported $10,000 - $19,999. However, 58% of respondents (both retired and working) reported making more than $50,000 a year.

**Education:** Those who responded to the assessment appear to be highly educated. Those with post-graduate degrees made up 71% (35) of the respondents and those with some college (14%) or college degrees (12%) rating next. One respondent said she had a high school diploma (or GED) and there were no responses from those with trade or technical school or those without a high school diploma or lower.
Question 8 – 9:

**Sexual identity:** Of the 49 who responded to the assessment, 46 (94%) identified themselves by using the term “lesbian.” Of those, 74% preferred to use ONLY lesbian. The remaining 12 also used multiple identifiers such as gay, bisexual, woman who prefers companionship with women, other labels—Dyke, Femme/Butch, Queer, or Homosexual, and non-op trans.

**Orientation:** The three women who did not use the self-identifier, lesbian, preferred to identify themselves as gay or bisexual.

**Willingness to be “out”:** With 51% of the respondents claiming to be “out” in all situations (see Figure 3), being “out” did not seem to correspond with age, occupation or income, or whether one identified as lesbian or some other sexual orientation. As you will see later, though, there is some discrepancy with being “out” in general and being “out” to healthcare providers.

Question 10 – 15: Relational Situations

The women in this assessment reported a variety of relational experiences. Those who had (by choice) been sexually active with or married to a man numbered 78% (38). Of those 38 women, 12 (32%) have given birth to children. The 11 women (22%) who have had no chosen relationship with men also did not have children. Of the 49 respondents, nearly one-quarter (24%) had given birth to children (see Figure 4).

Of the 49 respondents, 12 (24%) reported themselves to be single, while one woman identified herself as celibate, and another chose non-monogamous/polyamourous. Two women noted they are partnered and monogamous in practice, but non-monogamous/polyamourous in philosophy. All others (67%) reported themselves in monogamous relationships, though one noted she is widowed.
Of the 38 women (78%) who reported they are currently in a relationship with only one woman, the majority of them (35 for 92%) described that relationship as a lifetime partnership. As of this writing in 2012, it is not legal to be married in Rhode Island, though civil unions and affidavits of domestic partnerships are recognized. Therefore, we asked women in lifetime relationships to identify the ways in which they have formalized (legally or in some other ways) their commitments to each other (see Figure 5).

They could choose more than one option. The additional comments (see Figure 5, last column) indicated that women were legally married in Massachusetts (11 total) and California (1 total). One woman responded she was holding out for marriage rights in RI. Age did not seem to be a factor in these legal decisions, though the oldest respondent (born 1928) marked no formal acknowledgement, but noted she has been with her partner for 30 years.

*Figure 5: Formalized Commitments*

**Question 17: Religious or Spiritual Affiliation**

Generally, the predominant religious affiliation in Rhode Island is Roman Catholic. In our assessment, there were 47 responses to the question of religious practices. Four women (9%) claimed to be Catholic while three mentioned having been raised Catholic, but explored or converted to other practices. Thirteen women (28%) stated they have no religions affiliation; and, there was representation of Jewish, spiritual/pagan, and Unitarian practices.
All of the responses indicated that individual’s religious affiliation(s) has no impact on their healthcare choices. However, here, and in a later question, two different respondents did mention that they specifically avoid religion-based healthcare facilities due to the RI Corvese Amendment¹ and attitudes towards homosexuality.

**Question 18: Elevated Risk**

While LGBT elders, in general, share many of the same health challenges as aging adults, LGBT elders have the added burden of coming “out” to providers, who assume patients are heterosexual. As a result, elders may not disclose their sexuality or choose not to seek healthcare at all, further compromising their healthcare needs. Secondly, “…there is currently no public health infrastructure for funding and supporting research on the LGBT communities.”² This reality, however, is changing. In recent years, calls for proposals on LGBT health have been released from NIH and there is a dramatic increase in research with this population. Although it has been slow to come, more studies are being published and are underway.

Primary healthcare issues for LGBT elders exist.³ Question 18 in Section 1 was derived from those health care indicators. SAGE-RI questioned RI lesbians’ awareness of these issues. Risks included were: breast cancer, HIV/AIDS, mental distress, substance abuse, depression due to isolation, hate violence, abuse and neglect at the hands of caregivers, access to affordable healthcare, loss of home or savings by one partner due to Medicaid restrictions, and age discrimination (see Figure 6). This was one of the only three, mandatory questions on the assessment. This mandatory question was also included the assessment for health providers (see Section 4 of this report for comparison findings from both assessments.

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1 Corvese Amendment (RI) - amends H6103 (RI Civil Union bill) to allow any religiously connected entity to ignore the legal import of a civil union for any purpose.


Question 19: Greatest Healthcare Concerns:

When asked about the biggest concerns and needs related to healthcare issues and services for lesbians in RI, responses included concerns about long-term care, partner involvement, insurance, equity and sensitivity. The following information is the specific comments from respondents:

**Long-term care and support:**
- Would it be available and non-discriminatory?
- How do we address the “lack of any clearly recognizable effort to make elder care (including retirement communities, assisted living facilities and nursing homes) safer for LGBT elders”?
- Who will care for me— I have no partner or children?
- Abuse or neglect by caregivers in long-term facilities.
- Good care should I need any type of senior health care residency.
- Appropriate assisted living as lesbians’ age.
- Ability to access public at home care.

**Partner involvement:**
- Will partners be permitted to be involved in each other’s care?
- My partner’s statements of preference or concerns might not be honored.
- Discrimination/not being able to address my partner’s health needs.
- When will hospitals not continue to ask are you (partner) immediate family?
- Recognition of partner.
- Access to medical records, ability to be seen as legitimate legal rep for sick partner.
- Ability to be with my partner in the event that one or both of us need specialized care in a facility in the future.
- Need to have legalized marriage to protect partners’ rights in healthcare emergencies.
- Legal relationship with partner that allows full access to medical support/records; also isolation for single older lesbians.

**Healthcare providers & caregivers:**
- Will they be aware of and sensitive to lesbians, and partners?
- How do we know (or can we know) who are lesbian-friendly (lesbian affirmative) MDs (even though everyone should be treated equally)?
- Are healthcare providers knowledgeable about the specific needs, risks, and issues faced by lesbian elders? Can we receive quality care?
- Doctors aren’t familiar with the needs of a lesbian clientele.
- What can we do to address homophobia among providers?
- Access to QUALITY preventive medicine.
- Lack of knowledge, information on the part of providers regarding lesbians, cultural sensitivity, inquiry of patients regarding sexual orientation.
- To be able to feel safe from discrimination and mistreatment in health care settings - more visibility and positive regard for same-sex couples.
- Difficult to find out who lesbian-friendly providers are - and who is knowledgeable and sensitive about lesbian-specific issues. Want to know which hospitals to avoid (e.g. catholic) not sure which elder-care services are recommended or lesbian friendly.
- More sensitivity on the part of female physicians (strangely enough!).
Being “out” to providers:
- Access to care for women who don't feel comfortable being out.
- Willingness to be “out” to providers.
- Their [lesbian’s] own secrecy, which interferes with getting good health care.
- Ask sexual orientation on all forms (with option to decline) in order to get a better handle on disparities.

Insurance and legal coverage:
- Access to / availability of coverage by one partner for the other
- Inadequate health insurance
- General info about what to legally be prepared for and how

Equity in general:
- Equality for all. Sexual orientation should not be a factor.
- Getting the same fair and equitable treatment as any other group.
- Continued lack of education, homophobia, sexism and woman-hate in the society in which we live. Topped off by ageism.
- Good affordable healthcare.

Other:
- The concern is not for myself; although, I haven't thought about this much and may be missing something. When my partner has been hospitalized, I was able to stay overnight with her in her hospital room and was treated well. My concern for others is that lesbians, who are alone, will not have a health or mental health advocate, and will not have recognition of who they are, and may have financial worries when they need medical care.
- Same as for straight people: we should all have free, basic healthcare, which would include counseling for mental anguish due to being subject to discrimination.
- The rights conferred by marriage (i.e. insurance, being considered family.)
- Lack of information and messages targeted to lesbians regarding health care.
- Corvese Amendment to the RI CU [Civil Union] bill, which allows religious affiliated institutions and individuals to ignore our legal relationships.
- There needs to be more social outlets for older lesbians in order to prevent and avoid social isolation, depression. There also needs to be a service that provides transportation necessary for lesbians, who live by themselves and cannot get to necessary appointments.

Five individuals (10%) did not respond to this question. Five others (10%) indicated they had no problems or concerns. Two of the individuals with no concerns stated their reasons:

1. We have longstanding DPOA, Living Will, etc.
2. [I] am healthy and friends have received services needed.
Section 2: Health and Well-Being Part 1 – Specific Health Issues

In this section, respondents were asked about specific health issues to assess the awareness of specific health risks linked to the LGBT elder community. This section will inform education and outreach to this community.

Question 21: General Health

Of the women who responded to this assessment, 80% reported their general health in the range of good to excellent (see Figure 7).

Figure 7: Self-reported General Health Ranges

Question 22: Frequency of exams or screenings

National studies indicate LGBT people, and specifically elder lesbians, may not be seeking regular healthcare services. SAGE-RI asked the same question twice to determine if lesbian elders, in RI, seek age appropriate care: “How often do you receive these screenings now and prior to the age of 50”? We specifically asked about:

<table>
<thead>
<tr>
<th>Test</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Well Visit</td>
<td>EKG (Echocardiogram)</td>
</tr>
<tr>
<td>General Gynecological visit</td>
<td>Colonoscopy</td>
</tr>
<tr>
<td>Mammogram</td>
<td>Bone Density Test</td>
</tr>
<tr>
<td>Pap Smear</td>
<td>Vision Check</td>
</tr>
<tr>
<td>Blood Pressure</td>
<td>Hearing Check</td>
</tr>
<tr>
<td>Glucose Screening</td>
<td>Dental Check</td>
</tr>
<tr>
<td>Cholesterol Screening</td>
<td></td>
</tr>
</tbody>
</table>

The detailed data charts can be found in Appendix 1. From the data, it appears that lesbian elders in RI do, generally, receive age-appropriate screenings on a regular basis. Also, while they may not be visiting gynecologists, they are getting mammograms and pap smears, usually once a year, but sometimes within 2-4 years. Unfortunately, 6% of elder lesbians (over 50) never get mammograms while 10% never get pap smears. We did not ask why they do not get these screenings, so we do not know whether the lack of these screenings
should cause alarm for those 6-10%. Perhaps the screening most neglected is colonoscopy with 20% of those over 50 never getting them! This could signal that more education on this issue is needed. Interestingly, lesbian elders rarely (or never) get their hearing checked while most everyone of all ages, who responded have a dental check every six months (86%/71%) to a year (6%/20%)!

Question 24 and 25: Access to care and prescriptions

<table>
<thead>
<tr>
<th>Do you (or Are you able to):</th>
<th>Regularly</th>
<th>Usually</th>
<th>Infrequently</th>
<th>Never</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seek or get care when you need it</td>
<td>90%</td>
<td>10%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Get your prescribed medications in a timely matter</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Take prescribed medications in the correct/complete dosages at the correct times</td>
<td>98%</td>
<td>2%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Visit the emergency room rather than use a regular medical practitioner</td>
<td>4%</td>
<td>2%</td>
<td>45%</td>
<td>39%</td>
<td>10%</td>
</tr>
</tbody>
</table>

The respondents commented on their ability to seek care and get prescriptions; because, they generally have good healthcare coverage.

- As a veteran, I utilize VA Health care for almost all health matters.
- Good union health coverage.
- I am blessed with having had good health insurance in the past and also presently. Luckily...
- I am fortunate that I have excellent healthcare coverage provided by my employer.
- I get good health care because my job provides great health insurance. To me, that's the key issue for everyone I know, gay or straight.
- I have coverage from Medicare plus my secondary insurer, including prescription coverage.
- I get my medications from Canada, way cheaper. Outrageous the price difference, and only because the congress is in Big Farm's pocket.

As for the Emergency Room, most of those who answered the assessment mentioned they would prefer (and generally choose) to go to their primary physician for healthcare. Lesbians will use the Emergency Room or Urgent Care Facility for an emergency rather than as a first option for general health care purposes. One respondent commented:

- I can and will go to an emergency or urgent care facility, as needed, my doctor's office offers easily scheduled 'sick' visits, which I use as needed.

Question 26 and 27: Specific Health Matters & Relatedness to Lesbian Identity

The assessment question was: At any time in your life, have you been diagnosed with or experienced any of the following? Respondents could choose all the health conditions that applied to them.
Below are the responses in order of frequency.

<table>
<thead>
<tr>
<th>Experience / Diagnosis</th>
<th>Count</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis / Joint Pain</td>
<td>29</td>
<td>60%</td>
</tr>
<tr>
<td>Yeast / Bladder Infections</td>
<td>27</td>
<td>56%</td>
</tr>
<tr>
<td>Fibroids / Endometriosis</td>
<td>25</td>
<td>52%</td>
</tr>
<tr>
<td>Overweight / Obese</td>
<td>25</td>
<td>52%</td>
</tr>
<tr>
<td>High Cholesterol</td>
<td>24</td>
<td>50%</td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>21</td>
<td>44%</td>
</tr>
<tr>
<td>Depression</td>
<td>18</td>
<td>38%</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>16</td>
<td>33%</td>
</tr>
<tr>
<td>Vision Loss or Eye Disease</td>
<td>14</td>
<td>29%</td>
</tr>
<tr>
<td>TMJ (Jaw joint pain) or teeth grinding</td>
<td>13</td>
<td>27%</td>
</tr>
<tr>
<td>Anxiety (general)</td>
<td>12</td>
<td>25%</td>
</tr>
<tr>
<td>Asthma</td>
<td>12</td>
<td>25%</td>
</tr>
<tr>
<td>Skin Conditions (eczema, etc)</td>
<td>12</td>
<td>25%</td>
</tr>
<tr>
<td>Physical disability / loss of mobility</td>
<td>10</td>
<td>21%</td>
</tr>
<tr>
<td>Anemia</td>
<td>9</td>
<td>19%</td>
</tr>
<tr>
<td>Lyme Disease</td>
<td>9</td>
<td>19%</td>
</tr>
<tr>
<td>Sleep Disorders / Apnea</td>
<td>9</td>
<td>19%</td>
</tr>
<tr>
<td>Cancer / general (lung, liver, skin, etc)</td>
<td>8</td>
<td>17%</td>
</tr>
<tr>
<td>Alcohol / Drug Addiction</td>
<td>7</td>
<td>15%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7</td>
<td>15%</td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>6</td>
<td>12%</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>5</td>
<td>10%</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>5</td>
<td>10%</td>
</tr>
<tr>
<td>Cancer / women’s health related (such as breast, cervical, ovarian)</td>
<td>4</td>
<td>8%</td>
</tr>
<tr>
<td>Heart Disease / Cardiovascular Disease</td>
<td>4</td>
<td>8%</td>
</tr>
<tr>
<td>Stroke / Transient Ischemic Attack (TIA)</td>
<td>4</td>
<td>8%</td>
</tr>
<tr>
<td>Eating Disorders (Bulimia, Anorexia)</td>
<td>3</td>
<td>6%</td>
</tr>
<tr>
<td>ADD / ADHD</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Chronic Fatigue Syndrome / Epstein Barr</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Sexually Transmitted Diseases</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Anxiety related to fear of death, lack of healthcare, etc</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Multiple Sclerosis (MS)</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Pelvic Inflammatory Disease</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Crohn’s Disease</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Dementia / Alzheimer’s</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Learning Disability/Difference</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Mental Illness (Bipolar, Schizophrenia, OCD, etc)</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>

SAGE-RI also wondered if the respondents directly attributed any of these health issues or conditions to their lesbian identity/orientation. In this study, 82% of those who responded did not recognize a direct connection between their health conditions with being a lesbian. Of the 18% (9) who did, most of them (70%) described conditions such as anxiety, depression, or complex PTSD, alcohol abuse connected to fear of coming “out,” experiences of discrimination, and gay bashing. One respondent commented that even straight allies “are not aware [of] how pervasive discrimination is or the financial penalties we face.” Another understood her overeating (resulting in high cholesterol) as a coping mechanism...
for not recognizing her sexual orientation until later in her twenties. Additional responses included the aging process, and a sexually transmitted virus.

**Question 28 and 29: Delayed health-related testing or screening**

Respondents rated why they had delayed health-related testing or screenings. Only 88% (43) women answered the question. Of those between 25-30% had not delayed screenings. For those who did respond, the items with the most prevalent concerns were lack of finances (7% high; 14% moderate; and 16% some) and lack of insurance (12% high level of concern; 9% moderate level; and 7% some level). One response noted that without her current insurance, she would delay many tests and screenings.

Thirty eight percent (38%) indicated this as a moderate concern compared to those who just didn’t want to know (26%). One comment, “I have never delayed regular screenings, but have tolerated allergy symptoms and pain related to TJM partly for fear they were evidence of more serious illness.”

Only 10% reported fear of sexual orientation disclosure as some concern, while 62% claimed this was not at all a concern. Individual responses for delay of screenings included:

- Multiple sexual assaults by doctors.
- Insensitivity of physicians.
- Lack of transportation.
- Too many health issues going on at the same time.

There were two comments about colonoscopy with one response noting allergy to many of the preparations and another making a choice due to the risk factors outweighing benefit.

**Question 30 – 32: Physical or Emotional Impact**

Of those who responded to this question, 23% indicated they had been threatened within a romantic relationship with another woman, while another 24% noted they had been threatened because they are a lesbian. Fewer than 5% noted they were not sure or that the question was not applicable.

One woman did not seek support because, “I was in denial about the extent of the behavior - did not see it as stalking.” Only one person indicated that her fear of being “outed” prevented her from seeking healthcare or legal support. That experience, which involved abuse and various organizational power dynamics, also created long-term health issues for her.

**Question 33 -35: Alternative healthcare preferences**

In considering whether or not elder lesbians use or would care to use alternative and naturopathic care, the assessment specifically inquired about chiropractic, massage therapy, homeopathy/naturopathy, acupuncture, herbal supplements, and meditation/relaxation techniques. The most popular alternative care is massage therapy, followed by the use of herbal supplements and Meditation/relaxation techniques.
If they did not use those alternatives, it was important to know if those choices were connected to a fear of being “out” or for systemic reasons such as lack of insurance coverage for those practices. Across the board, in all the listed forms of alternative healthcare practices, no one indicated a fear of disclosure of sexual orientation as a reason for not using those methods. The most common stopping point seemed to be lack of insurance coverage or affordability. This was especially true for acupuncture (24%), massage (20%), use of herbal supplements (19%) and meditation (12%). Both chiropractic and homeopathy were noted evenly at 7% for lack of insurance/affordability.

<table>
<thead>
<tr>
<th></th>
<th>Regularly</th>
<th>Often</th>
<th>Infrequently</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Massage Therapist</td>
<td>26%</td>
<td>15%</td>
<td>26%</td>
<td>33%</td>
</tr>
<tr>
<td>Herbal Supplements</td>
<td>21%</td>
<td>8%</td>
<td>33%</td>
<td>38%</td>
</tr>
<tr>
<td>Meditation / relaxation techniques</td>
<td>17%</td>
<td>31%</td>
<td>23%</td>
<td>29%</td>
</tr>
<tr>
<td>Chiropractor</td>
<td>9%</td>
<td>17%</td>
<td>37%</td>
<td>37%</td>
</tr>
<tr>
<td>Homeopathy / Naturopathy</td>
<td>9%</td>
<td>5%</td>
<td>18%</td>
<td>68%</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>4%</td>
<td>6%</td>
<td>32%</td>
<td>57%</td>
</tr>
</tbody>
</table>

As might be expected, these questions raised some contention and comment. On average, nearly half of respondents indicated no particular reason for not using alternative practices. However, this question was not without its problems. As one person noted: “I do use some of these options, but not as often as I would because of financial choices ... not that I totally "can't afford" it. For some I do not use them because generally I prefer mainstream medicine. I might want to use them at times and would if insurance covered them. This question needs more clarity for me to answer fully and appropriately. Basically I don't ever avoid them because of my sexual orientation.”

However, some of the individuals who indicated no reason or “not applicable” also added these comments:

- Do not personally believe in alternative methods of healthcare.
- Do not really believe that alternative options are in the slightest bit effective.
- I prefer not to use alternative healthcare. I would consider it if my primary-care doctor recommended it.
- Describe homeopathy.
- It is not that I have "no reason," but that I have more faith in the scientific method than other practices.

One respondent wrote, “For #34, what about, ‘I think homeopathy is bogus’ as a reason? I must say, I think this questionnaire shows some stunning biases.” It could be noted, though, that typical in our society, there are biases against alternative medicine as well, as can be seen in this comment, “I have not found it necessary to pursue alternative medicine, and have more confidence in traditional medicine and trained health care providers.”

On the other hand, several respondents did indicate additional alternative measures they use, including a naturopath, who also has an MD, ear coning, hot-stone massage, special meditation and expressive arts therapy for cancer patients, physical therapy, and yoga.

Additional comments:

- I prefer integrative medicine, so I use what I consider helpful for whatever condition.
- I would prefer to use naturopathic/homeopathic rather than allopathic -- but in the U.S. that’s nearly impossible as it’s generally not covered by insurance.
Section 3: Health and Well-Being Part 2 - Experiences with Providers

In this section, respondents were asked about specific experiences with providers in order to create a directory and to advocate for better healthcare for aging lesbians in Rhode Island.

One of the goals of this assessment was to develop a directory of physicians and providers who positively and effectively provide quality healthcare and support for lesbian elders. Question 36 asked for recommendations of providers and Question 37 allowed for providers to be avoided. These questions generated a good starting point to assist lesbian elders, who are seeking such resources. These included 18 general physicians, 23 specialists, and 9 provider agencies. The list also included one geriatric physician, five physical and massage therapists, one chiropractor, one acupuncturist, and two naturopaths. The complete list can be found in the directory.

Question 38 and 40: Gender and sexuality of providers

SAGE-RI wondered if the concern of having a male physician or nurse would keep lesbians from seeking healthcare services. Only 7% indicated concern of having a male provider keeping them from seeking care, while 22% said that sometimes this is a concern. For 72% of the respondents, the concern of having a male provider was not a stopping factor.

However, when asked if they would PREFER to have a female healthcare provider, the responses corresponded to the type of care being sought. Those areas that might be considered most personal or vulnerable (such as general care, gynecology, and home care) showed the largest percentages of preference for female providers. However, for some of the medical specialties (proctologist, oncologist, etc.), about half of the respondents said gender of provider didn’t matter.

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>Always</th>
<th>Usually</th>
<th>Doesn't Matter</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gynecologist</td>
<td>71%</td>
<td>15%</td>
<td>15%</td>
<td>0%</td>
</tr>
<tr>
<td>Home care provider</td>
<td>60%</td>
<td>30%</td>
<td>11%</td>
<td>0%</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>57%</td>
<td>27%</td>
<td>16%</td>
<td>0%</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>41%</td>
<td>39%</td>
<td>20%</td>
<td>0%</td>
</tr>
<tr>
<td>Proctologist</td>
<td>41%</td>
<td>13%</td>
<td>39%</td>
<td>7%</td>
</tr>
<tr>
<td>Other Specialists</td>
<td>33%</td>
<td>15%</td>
<td>52%</td>
<td>0%</td>
</tr>
<tr>
<td>Oncologist</td>
<td>31%</td>
<td>16%</td>
<td>53%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Similarly, we wanted to know what expectations healthcare seekers might have if their healthcare provider was lesbian or gay. We also requested additional comments in this area and received some additional insight.

<table>
<thead>
<tr>
<th>Expectations of LGBT Providers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like to know</td>
<td>61%</td>
</tr>
<tr>
<td>I would have an ally</td>
<td>51%</td>
</tr>
<tr>
<td>I'd be more inclined to share my own lesbian orientation/identity</td>
<td>35%</td>
</tr>
<tr>
<td>I would expect that I'd be treated with greater respect</td>
<td>37%</td>
</tr>
<tr>
<td>I'd expect more knowledgeable care related to being a lesbian</td>
<td>57%</td>
</tr>
<tr>
<td>I'd expect more knowledgeable care related to being a AGING lesbian</td>
<td>53%</td>
</tr>
</tbody>
</table>
Respondents’ comments included:

- I would expect/hope all of the above from any physician and have had experiences of all from both lesbian & straight docs/providers.
- I would HOPE all of the above would be true -- in non-medical situations, I’ve known some lesbian practitioners, who aren't always so enlightened. Often are, but not always.
- I would share more.
- I would think that a lesbian would be more comfortable with me and with physical exams especially.
- My biggest concern is the competency of the provider not his/her sexual orientation.
- My health care provider IS a lesbian.

Seventeen responses (35%) indicated they would be more inclined to share their own sexual orientation if their provider was “out” also. Of those, though, only three noted they were not already “out” to their primary physician. There does not seem to be a statistically significant correlation between knowing the sexual identity of a provider as encouraging the actual coming “out” to one’s physicians; as so many are already “out” to their care providers.

**Question 41 and 42: Sexual identity/orientation disclosure**

When considering disclosure to providers, it is helpful to consider whether these women are “out” in general. When cross referenced with Question #9, 25 women reported being “out” in all situations; all, but one, noted they were “out” to their primary physicians. These same women were also “out” to most of the other physicians they used, except for some specialists.

<table>
<thead>
<tr>
<th>Identity Disclose to Providers</th>
<th>Yes</th>
<th>No</th>
<th>Some</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Physician</td>
<td>90%</td>
<td>8%</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>60%</td>
<td>9%</td>
<td>4%</td>
<td>28%</td>
</tr>
<tr>
<td>Gynecologist</td>
<td>66%</td>
<td>4%</td>
<td>2%</td>
<td>28%</td>
</tr>
<tr>
<td>Proctologist</td>
<td>24%</td>
<td>11%</td>
<td>2%</td>
<td>63%</td>
</tr>
<tr>
<td>Oncologist</td>
<td>20%</td>
<td>4%</td>
<td>0%</td>
<td>76%</td>
</tr>
<tr>
<td>Alternative health care provider (chiropractor, acupuncture etc.)</td>
<td>60%</td>
<td>7%</td>
<td>13%</td>
<td>20%</td>
</tr>
<tr>
<td>Other Specialists</td>
<td>51%</td>
<td>12%</td>
<td>28%</td>
<td>9%</td>
</tr>
</tbody>
</table>

For the 19 women, who reported being generally “out” depending on situation, 90% noted they were “out” to their primary physicians (10% not “out”). They were also less likely to be out to alternative care providers or specialists. Regardless of how “out” they generally are, women did report being “out” to their gynecologist. The one response, which was “out” only to a select few, also identified as bisexual and was not “out” to any of her healthcare providers.
It was also important to learn what guides a woman’s decision to reveal her sexual orientation to a physician. According to responses, not being “out” with the healthcare provider was relevant to the type of care being sought rather than fear of discloser.

<table>
<thead>
<tr>
<th>What Guides Willingness Whether to Be Out to a Physician</th>
<th>57%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depends on what kind of care I’m seeking</td>
<td>57%</td>
</tr>
<tr>
<td>Doesn’t matter for that kind of care</td>
<td>52%</td>
</tr>
<tr>
<td>Healthcare admittance forms at the office or hospital don’t provide appropriate ways to do so</td>
<td>22%</td>
</tr>
<tr>
<td>Don’t want to discuss it with my physician</td>
<td>9%</td>
</tr>
<tr>
<td>Just afraid to</td>
<td>AND</td>
</tr>
<tr>
<td>Afraid others will find out</td>
<td>AND</td>
</tr>
</tbody>
</table>

In most cases, women who chose “other” as a response explained they had not come “out” because they had not used a specific care service (e.g., oncologist). One woman indicated that being lesbian is in her record; so, she feels no need to come “out” with additional providers.

**Question 43 – 51: Expectations, Reactions, and Levels of Care**

When asked what kind of reactions lesbians expect to receive from their healthcare when coming “out” to providers in comparison to what kind of reactions they actually received, lesbians neither expected negative treatment, nor received it (see Figure 8). In general, their experiences were more positive than they’re expectations.

*Figure 8: Reactions to Coming Out: Expectations as Compared to Experiences*

<table>
<thead>
<tr>
<th>L-Elders: Q43/44: Reactions to Coming Out: Expectations compared to Experience</th>
<th>0%</th>
<th>0%</th>
<th>23%</th>
<th>40%</th>
<th>38%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reaction Expected (Q43)</td>
<td>Hostile-Negative (0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reaction Received (Q44)</td>
<td>[1]</td>
<td>[2]</td>
<td>[3]</td>
<td>[4]</td>
<td></td>
</tr>
</tbody>
</table>

Responses to the following questions were also collected and analyzed: 1) Would revealing your sexual identity/orientation to your healthcare provider affect the level of healthcare received, and 2) For providers that already know your sexual identity/orientation, are you generally treated with dignity and respect. Again, those who responded reported better treatment than they expected (see Figure 9).
Only 73% of respondents indicated they had not experienced discrimination, hostility, or poor care from a healthcare provider that they suspected had to do with their sexual identity/orientation; but, one response included this comment: “...sometimes I’ve wondered how support staff (i.e., nursing assistants) would react, and as a young woman I felt less valued for being single.”

Twelve percent (12%) reported they had experienced some form of discrimination. Those who offered explanation recognized discrimination in attitude or behavior, for example:

- She kept mentioning her husband. She isn't my current MD.
- I get this more because of my weight issues, but have occasionally experienced what feels like a pulling away or lack of interest in whatever I say next.
- I had a doctor 25 years ago in Iowa who was hostile and a primary care doctor in CT 10 years ago who didn't seem as supportive as I would have liked.
- Many years ago I had a number of bad experiences but none recently.

Another 15% said they were not sure if they had experienced discrimination. Those who offered explanation wonder whether the treatment they received had to do with sexual orientation or just unprofessional behavior by the physician.

- I can't tell if their "disinterest" in regular bad bedside manner, or because I'm fat.
- I had a neurologist who made a comment to my partner when she came with me to an appointment for a diagnosis that bothered us. It could have been an attempt at a joke (of a sexual nature) or possibly it was a comment he often made to patients that was not sexual at all. I'll always wonder.
- One primary care physician wouldn't accept my partner as a patient, whereas she'd accepted married heterosexual partners I knew.

Additionally, respondents do feel confident that their primary healthcare providers are knowledgeable about the specific health needs of lesbians, especially elders, as compared to healthcare providers in general (see Figure 10).
Only one respondent (2%) noted that her physician directly attributed her health conditions to her lifestyle or identity as a lesbian, while 8% noted their physicians suggested there may be some relevant health factors related to lesbian identity. The only detailed comment/explanation stated had to do with mental health concerns when the respondent experienced hostility when she first came “out.” According to the responses (81%), most felt their providers did not make correlations between specific health concerns and lesbian orientation.

Equally important is the confidence lesbian elders have that their providers maintain confidentiality in connection to sexual identity. Nearly 31% of respondents indicated a range of uncertainty about whether or not the healthcare provider would maintain confidentiality about patient, sexual orientation (see Figure 11).

Figure 11: Confidence in Confidentiality
Question 52: Additional comments (concerns/issues)

Two themes emerged from responses when asked for comments about the healthcare lesbian elders receive:

1. The intake forms and other questionnaires used by physicians and healthcare facilities need to be more inclusive. They should at least signal that they understand their patients/clients might be lesbian or gay. Questions related to sexual activity and marital status generally assume heterosexuality, thus forcing the patient to decide how to approach the practitioner. While the staff might not seem biased, their intake procedures signal otherwise. For example:

   - Only one of my providers had a health questionnaire asking about sexual orientation. None of the others have or have directly asked when forms ask "marital status" I now write in domestic partner hoping they'll change the form if it's noted. Sometimes I write "none of the above." But I don't write lesbian partner because I want them to have to ask. Somehow I feel it's their responsibility rather than having a heterosexual assumption. The only provider who asked who I live with was a young medical resident. Perhaps there is hope for future providers.
   - I observe more heterosexism, in questions, forms, etc, from office and insurance staff than from providers.

2. Lesbians, themselves, are not necessarily aware of healthcare risks and issues of importance to them due to their sexual orientation. Some feel their providers—though supportive—may not know these concerns either. More education is needed in this area for both providers and users of healthcare services. For example:

   - I don't think healthcare providers in general have any idea about health needs of lesbians. The doctors to whom I am out never mention my sexual preference.
   - What are the specific health issues I face because I am a lesbian?
   - Please educate us about the particular health risks and needs of lesbian patients, especially elders.

3. Other concerns:
   - Visitation rights.
   - Nursing home staff and bias towards gay people.
   - Sexual orientation is not confidential information and more visibility would be better.
   - Lesbians who are unhappy with their providers should take the time to seek new providers.
   - Lack of confidence in new electronic records management systems to maintain confidentiality.
   - Need for lesbian cancer patient group at Women & Infants.
   - Sometimes I think that someone who is fat receives worse and more prejudicial treatment for being fat rather than for being lesbian!
Question 53: Experiences in Facilities

In addition to coming “out” to individual physicians, lesbian elders also face potential discrimination in healthcare facilities. When asked this question: In a medical care facility or situation (such as hospital, emergency room, rehabilitative care) -- if your sexual identity/orientation has been known to staff or caregivers -- have you ever ...

- Experienced discrimination, hostility, harassment, or poor care that you suspected might have to do with being a lesbian?
- Been denied visitation by or access to a partner or family-member-of choice?
- Experienced isolation or inappropriate placement in a ward or on a floor?

Several concerns can be pulled from this information; the first related to the experiences of discrimination, hospitality, harassment, or poor treatment. Perhaps the numbers most telling are the percentages of women who could not clearly respond yes or no, but rather that they suspected or were not sure whether they are being treated poorly (see Figure 12).

Figure 12: Treatment in Medical Care Facility if Sexual Orientation Is Known

<table>
<thead>
<tr>
<th>Experience</th>
<th>Yes</th>
<th>Suspected</th>
<th>Not Sure</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced discrimination, hostility, harassment,</td>
<td>4%</td>
<td>11%</td>
<td>15%</td>
<td>55%</td>
<td>15%</td>
</tr>
<tr>
<td>or poor care that you suspected might have to do</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>with being a lesbian?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Been denied visitation by or access to a partner</td>
<td>9%</td>
<td>2%</td>
<td>0%</td>
<td>70%</td>
<td>19%</td>
</tr>
<tr>
<td>or family-member-of choice?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experienced isolation or inappropriate placement</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>74%</td>
<td>22%</td>
</tr>
<tr>
<td>in a ward or on a floor?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Only a few offered any explanation, but one woman suggested that, because of her butch appearance, a nurse was “rough and clipped.” Someone else mentioned the issues were more related to “cluelessness” on the part of staff, a situation experienced as insensitive. Another woman had an experience of doubt, “I was in a hospital recovering from surgery and a female nurse was giving me a bed bath and was a bit ‘too attentive’ to my private parts. I always thought – Nah - that was my own perception.”

One of the individuals, who directly answered no to the question of discrimination, offered a descriptive example that also points to the education needed by providers relevant to lesbians and healthcare:

*My partner was hospitalized for meningitis -- when we asked the treating physician re: risk of my getting it (after telling him we were life partners) he dismissed our*
concern, "only risk is from close bodily contact." When I pointed out that as lesbian partners, we indeed had "close bodily contact" he seemed annoyed and still did not answer the question. (The nurses, however, were brilliant and got us/me the info we needed.)

There were, however, a few positive respondents about being treated respectfully (as lesbians) by staff at healthcare facilities.

The second important piece of information from this chart relates to the real concern mentioned by lesbians at various points in this assessment, specifically in relation to visitation rights. As one woman stated, “In the Emergency Room, I responded that I was not a family member. I complained and she was reprimanded.” Another couple travels prepared, “…my partner and I always carried our health care powers of attorney with us and offer to provide them from the outset.”

Questions 54 – 60: Mental Health Concerns

Lesbian and gay people have a long history of experience with the mental health profession. Many lesbian elders are of the generation who came out or came of age during the time when the American Psychological Association still listed homosexuality as an illness. Therefore, when asked, “Have you ever gone to a therapist or counselor BECAUSE you are a lesbian (to explore your sexual identity/orientation)?” Only 38% responded yes, while 62% responded no.

Of those who responded yes, though, several indicated they had gone when they were young and first came out, many years ago. For some that was 40-45 years ago. One woman mentioned going to a support group. Two women mentioned specific issues related to difficult relationships. One woman offered this story:

_I think I went because everyone did -- and we all happened to be lesbians going to other lesbians -- seemed the "popular/expected" thing to do -- I was having trouble with relationships - immaturity - and was emotionally abused by the power relationship in therapy -- it was all kind of twisted and I felt much better and more empowered when I stopped going!_

Additionally, only one person responded that she experienced unwanted or unwarranted psychiatric “treatment” to change or “realign” her sexual identity/orientation. And no one said that the fear of unwanted psychiatric “treatment” to change or “realign” prevented them from seeking the help of mental health counseling or a therapist for more general issues. One woman did offer, though, that she had been to therapy for reasons NOT related to being a lesbian. Nearly 40% of women did attribute some level of depression or chronic stress to a lifetime of experiences or stigma related to their lesbian identity/orientation (see Figure 13).

In this assessment, seven women (15%) responded that they had experienced the death of life/long term woman partner or companion. Only one of those women, though, expressed that the concern or reluctance about revealing her sexual identity/orientation prevented her from seeking services for grieving or other related issues. She did offer this statement, though, “This occurred 25 years ago and acceptance was not as forthcoming or understood by many.” One other woman mentioned that before she went to anyone, she did some research to find a supportive counselor. All seven responded that they had been able to find
the services they needed to address this loss. For some, it was a therapist but for others it was a circle of friends and other supportive people.

**Question 61: Additional comments on Health and Well Being**

We received a few open-ended statements at the end of this section of the assessment. These are some that were unique and not repeated from other areas of the assessment.

- As lesbians age, many who do not have children or have little involvement with family members may find themselves without an advocate for their care, which is a frightening thing when navigating the health care system and support systems. A lot can happen to people who do not have someone advocating for them—negatively.
- Being single, I don’t need to come out in all circumstances. I’d probably not come out to care providers in hospitals, rehab centers, nursing home, since there are so many people touching & controlling aspects of my care & comfort. If I had a partner, that would change, as her involvement would be important, AND she could run any interference if I got any antigay behavior.
- I did have the experience of losing child of a partner.
Section 4: Healthcare Economics, Legalities, Culture

Socioeconomic and legal factors do affect the healthcare of lesbians. This section requested information about what factors specifically affect assessment respondents.

Questions 62 – 66: Health Insurance

In our assessment, 83% of respondents indicated they had some form of coverage from private, employer, or Medicare sources (see Figure 14). In this assessment, only one person (2%) revealed she had no health insurance coverage. No one is currently on Medicaid. Those who selected “other” indicated a range of services including military/veteran, AARP supplemental, COBRA (Blue Cross, Blue Shield), employer covered Medigap, Union-sponsored coverage, and Medicare supplemental.

For those in with a spouse or partner, 68% reported that their employer offers health care insurance benefits to same-sex couples. However, only 21 of the 30 (70%) opted to use that coverage. Another 23% opted to no use the employers offer to same-sex couples because they had adequate or better coverage through another means. Another 3% reported they did not want to come out. There was no one who opted to NOT use the offered coverage because they did not want to pay the additional income cost tax penalty.

For those whose employers do NOT offer same-sex health insurance benefits, we asked, “... you know if that was due to restrictions by the insurance company they use?” In most cases, the respondents (54%) had no idea why. Based on the responses, the restrictions seemed to be employer-based rather than the insurance company restriction, but this is not definitive. In one case, the woman responded said she works for the federal government so coverage is not allowed. One woman did mention that her employer is discriminatory.

From this assessment, we also learned that only 65% ARE aware that when an employee opts to pay for same-sex health insurance benefits, the amount counts as taxable income to the employee. One person commented that has financially hit her and her partner very hard; another woman realized her employer had NOT counted this a taxable income and was surprised to learn about this issue.
Questions 67 and 68: Legal Documentation for Medical Decisions

SAGE-RI wondered if lesbian elders in RI are informed about the many the legal documentations recommended to protect their healthcare interests. Such documents include:

- Last Will In Testament
- Advanced Heath Care directives (AHD: such as Living Wills and Health care power of attorney)
- Designated person(s) with Durable Power of attorney
- Documented plans for funeral arrangements
- Documented plans for disposition of remains

A majority of respondents are prepared with Wills (83%), Advanced Health Care Directives (85%), and Durable Powers of Attorney (77%). There seems to be less preparedness, though, for funeral arrangements and disposition of remains - less than 35% for both (see Figure 15).

It is interesting to note, though, that even though women may have or be in the process of preparing these various legal documents, they are not as confident that these will be ultimately be honored (see Figure 16). Unfortunately, we did not ask for the reasons this skepticism exists, so we do not know if these reactions are familial, societal, or legal.
Respondents indicated that a designated partner or family-member-of-choice has not been denied the right to decide medical care (51%). This situation was not applicable to many (47%), however. Only one respondent reported having been denied decision-making rights.

**Question 71: Additional Comments – Healthcare Economics / Legal / Culture**

Two themes emerged from responses to the open-ended statements at the end of this section:

1. Being out with family, children, and other influential persons in your life will reduce some of the legal concerns met by lesbians.
   - “All the problems you have asked about are non issues once you are out. There are so many allies waiting to help but you can't get help with out asking.”
   - “My wife and I have been together for 25 yrs. We choose our health care providers after checking with them about their willingness to treat us as a couple. Being out avoids a lot of problems.”

2. Having different laws state-to-state creates confusion and uncertainty.
• “California RDP (Registered Domestic Partners) laws make my RDP my legal spouse so theoretically we don’t need to designate funeral arrangements of disposition of remains because a surviving spouse can do so. In RI, I am not so sure of the CU law. I do know that St. Anne’s Cemetery in Cranston will not let my RDP be listed as “beloved partner of” on her tombstone.”
• “Since marrying in MA, these things are murkier.”
• “Since my sister would be my designated person for questions above, and she lives out of state, being distant and not a lesbian is my issue.”
• “My Will specifically disinherits anyone who would challenge it. My attorney is a well-respected probate court judge; but, I know of similar situations where family of origin was given priority consideration.”

Section 5 – Elder Care Services & Related Aging Concerns

The health and well-being of aging lesbians (as with any aging adult) depends on additional support systems. This section elicited thoughts on such areas.

Questions 72 and 73: Supportive Programs in RI or Nationally

For the most part, older lesbians in RI have a limited sense of services that could provide support services of advocacy specifically for LGBT elders. Only 29% of older lesbians reported having knowledge of agencies that could provide support services or advocacy for LGBT elders. Approximately a third (31%) reported that they had some knowledge with 29% having no knowledge of support services.

Twenty-one responses specifically named services they did know. Of those, 19 listed SAGE and/or SAGE-RI; and, of those, 75% listed only SAGE. Additional single responses included: GLAD (Gay & Lesbian Advocates & Defenders), the LGBT Task force of the American Society on Aging and NASW (National Association of Social Workers), OLOC (Old Lesbians Organizing for Change), Coalition Against Domestic Violence, HRC (Human Rights Campaign), and Kathys’ Group. A respondent from MA also added some MA-based services such as: Seashore Point Assisted Living in Provincetown, Meal Sites sponsored by MA Division on Aging and an effort to develop home care by MA-based advocacy agencies.

When asked, “What more do you need or want to know about?” The following responses were received:

• “Are there assisted living facilities, home health care agencies that are welcoming?”
• “What lawyers can help with these legal issues related to healthcare & advocacy?”
• “I would like to know more about retirement living for elderly lesbians/gays.”
• “Social activities and outlets for older lesbians.”
• “If there are more [in addition to SAGE] I’d like to know ... plus we should have services that are closer to home.”
• “If I needed help, I probably would speak directly to the problem person(s), and if that didn’t work, have my lawyer write.”
• “I know very little about SAGE.”

Questions 74-80: Aging Support Services

This section of questions applies to a future time. Referring to a time when women would
Questions 74 and 75: Concern for Aging

Elders in the US and RI are generally concerned about who will care for them or how they will receive support or care as they age, especially if they are not able to care for themselves. This concern could potentially be magnified for LGBT people, especially if they are single, distanced from relatives, or have no children of their own. Therefore, respondents were asked, “How concerned are you about who will provide or how you will receive support or care?” The overwhelming majority (98%) of our respondents expressed concern about the care they will receive as they age (see Figure 17).

While their concerns were high, when asked who will care for them, most respondents could identify at least one or a few groups of people they might be able to rely on (see Figure 18). While many elders did indicate relatives and/or children, these caregivers ranked lower than partners, friends, and even elder-service agencies. It is significant to note that 10% of respondents have no idea who will care for them. We might also wonder about the care for the 78% relying on a partner should they outlive that partner.

When analyzing the responses, those who ranked themselves high (between 2 to 4) on the concern scale had fewer expectations of who would care for them. The percentage relying on partners, friends, and families of choice were quite similar. However, those with highest concerns for their care seemed more inclined to expect they would depend on elder-service agencies (58%) rather than on children (34%). It appears that lesbians, who have children, feel less concern for their elder care than those who do not have children.

Questions 76 and 79: Use of Social Services

From the data above, at least half of the lesbians responding to the assessment expected they might use some form of elder services or agencies as they age. Anticipating
this, respondents were then asked which services they might use such as adult day care, in-home health aides, transportation services, elder visitors, Meals-on-Wheels, recreational groups, and senior centers (see Figure 19). It is interesting to learn which services elder lesbians in RI are inclined to use, as well as what they will use as compared to what they hope to avoid. In general, most lesbians responding indicated they might use services for elders if necessary. Unfortunately, though, the options for Senior and Community Housing, Assisted Living Facilities, or Nursing Homes were inadvertently omitted in Question 77. The responses may be in the same ranges, but in this case, it is unknown.

Expecting that some elder lesbians would be using a diversity of services or agencies, we wanted to know whether respondents would be comfortable coming “out” and if coming “out” might compromise the care they receive. We asked if they would feel comfortable letting agency staff know they are lesbian or gay if social-service healthcare supports in RI. While the majority (69%) said they would let agency staff know their orientation, and 18% stated it would depend. For those who explained the response, “it depends,” three themes emerged:

1. Level of trust related to quality of care -
   - “I would insist on it to be sure I get quality care - would want to know about them first to see if I can trust them.”
   - “I expect professional service”

2. Type of agency or service and relevance to care -
   - “Depends on what services are used”
   - “If I were living alone, I probably wouldn't feel a need to tell them.”

3. General Assessment of the agency (related to #1) -
   - “I’d have to know their philosophy. If they are connected to a religious group, it would be a concern.”
   - “I would want them to know so that I can judge their suitability for me.”

Figure 19: What Elder Services Might Be Used?
Respondents were asked whether or not the fear of exposure of sexual identity/orientation might prevent the use of these services. Additionally, if sexual identity was known, do lesbians feel this would compromise the level of care or respect they would receive from those services? In general, fear of disclosure about one’s sexual orientation will not necessarily prevent lesbians from using many of the available elder services or agencies (see Figures 20 and 21). These same respondents, however, are not as confident about the quality of care or respect they would receive if their sexual orientation were known. Perhaps they will choose to use them, and then simply not come out.

It’s also interesting to explore, service-by-service, how the fear of sexual-orientation exposure might prevent use as compared to the concern for compromising quality of care (see Figure 22). In looking at the data this way, conclusions may not be drawn; but, comparisons may be interesting especially as it relates to housing.

Figure 20: Fear of Disclosure Preventing Use of Services

Figure 21: Care Compromised if Sexual Identity Known?
Figure 22: Elder Services — Fear of Disclosure Preventing Use Compared to Concern for Compromised Care
Question 80: Additional Comments (related to Questions 77-79)

The following comments are about the use of elder services:

- “Again, I'd probably not come out if seeking housing, in home care, etc., as I'd be at the mercy of others.”
- “Although I know it happens, I just can't tolerate the idea of going back into the closet. So, as my partner and I age, we both are committed to staying true to ourselves and hoping/trusting that we will find the care/resources we need.”
- “I am hoping that I die quickly and cheaply.”
- “I can't wait to torture the conservative old people in the nursing home, if I have to go there. My style is pretty much, "Hi I'm Carol and I'm a dyke" It should wilt a few old homophobes.”
- “I wish there were nursing homes supportive of LGBT elders.”
- “I've read about people who were discriminated or felt discriminated in these situations. I don't know if this is in RI.”
- “MOW [Meals on Wheels] and DEA Elder Care agencies have an affirming LGBT policy. There is many LGBT staff in these settings.”
- “My wife and I have been together for 25 yrs. We choose our health care providers after checking with them about their willingness to treat us as a couple. Being out avoids a lot of problems.”
- “The other participants or residents in these programs are as much of an unknown worry as the staff -- perhaps more so, actually.”
- “There is always a chance to meet someone who is a problem but in general I think society is quite accepting of lesbians/gay men. I find people in health care are kind to those they attend to.”
- “Things are changing for the better (I hope)-- so maybe by the time I need these services my answers would be different -- but if right wing Christians take over, I'm less likely to trust everything government based!”
- “Would like list of asst. living/ nursing homes in area that are Lesbian friendly”
- “Yeah, in RI religious based services can legally discriminate against and ignore our legal relationship. What's with that?”
- “At times I felt at risk - when I was DELIVERING services in a senior center, assisted living. I felt I would not be respected as a provider if folks knew I was a lesbian and when seeking accommodations for my in-laws, my partner and I felt the need to disclose we were lesbians prior to taking the place, to see their radiant feelings. That should not have to be -- but it is.”
- “Finding appropriate, compatible, and affordable living arrangements in a community of diverse aging lesbians is very important. I am interested in discovering this with those who have similar concerns.”

Questions 81 – 86: Current Residents of Senior Housing, Assisted Living, or Nursing Home

These questions pertained only to those, who currently receive in-home care or live in senior housing, Assisted Living Facility, or a nursing home, or similar facility.

There were no responses from women currently in this situation. Question 86 asked, “If you ever experienced any kind of discrimination or poor treatment, would you feel willing and/or able to make a complaint?” Three of the four women who responded (75%) indicated they would make a complaint and the 4th responded as “maybe.”
Question 88: General Comments about the Assessment

- “Very thorough, informative that makes me think about my aging as a lesbian.”
- “This assessment doesn't appear to be useful because so many of the questions seem to be asking for specific answers. It's more an invitation to gripe than an assessment.”
- “Good Job!”
- “I'd love to be a medical advocate for someone who needs it. We need advocacy training to take place at senior centers. I volunteer to drive other seniors to medical appointments and I see the need for advocacy for seniors in general. I imagine that lesbians who have financial problems, health problems, and have no lesbian community would love to have someone like me as an advocate.”
- “It is disquieting to realize that there are too many sisters out there that still are hiding and are nervous and scared. Women who are not getting good health care because they can't come out to their providers. And are there really providers who would change the level of care they gave me if I came out?”
- “A wonderful, thoughtful assessment that encompasses all aspects of lesbian/elder lesbian healthcare issues. I commend you for this assessment!”
- “Too long.”
Chapter 2: Provider Assessment - Healthcare for Elder Lesbians

The assessment to providers was administered via the Internet using Zoomerang. The data from that tool shows that we had 46 “visits” and received 12 complete responses. We received 11 partially completed responses in the Zoomerang; those are not included in this data report. Additionally, we did offer printed assessments and received 53 mailed responses. The state’s Quality Improvement Organization for healthcare had made the hard copies of those assessments available at learning sessions they conducted. Present at those sessions were professional staff including RNs, administrators, directors of nursing, pharmacists, and CEOs representing long term care, hospitals, home health, pharmacies, insurers, government representatives and adult day care directors from around the state. As a result, we have a total of 65 responses from providers.

Section 1: General Information

These questions, intended for all providers, built a profile about the general care for elder, lesbian patients and clients.

Questions 1 and 2: Percentage of Patients/ Clients Served

The Provider Assessment opened by asking what percentage of providers’ patients/clients is LGBT; and, of the LGBT patients/clients served, how many are lesbian elders? For both questions, roughly 65% of providers reported no way of reliably tracking this information (see Figure 23).

Questions 3 – 6: Levels of Care

From the perspective of providers, SAGE-RI wanted to know about the level of care available to elder lesbians. Respondents were asked to agree or disagree with the following two statements:

• Lesbian elders risk receiving substandard care if they come “out” to heterosexual healthcare providers.
• In general, providers are not familiar with the specific health needs or risks faced by lesbian elders.

While the majority (57%) disagreed that lesbian elders are at risk of receiving substandard care, it also seems that the majority (54%) agreed that providers are not familiar with the specific healthcare needs or risks faced by those same clients/patients (see Figure 24).
Also significant, one-fourth of providers were not sure of how to respond to these statements.

In a related question, 85% of providers have not encountered elder lesbian patients or clients who have received substandard care or been denied care because of their sexual orientation. One of those providers, a therapist who primarily works with youth, stated s/he does not have any elder clients. There were two providers (3%) with patients who have received substandard care. Several comments came from the 12%, who were not sure about these experiences among their clients. Those comments included:

- Because they may have and been afraid to divulge
- Not sure if care concerns are related to medical population in general or sexual orientation
- We have no mechanism in place or reliable way to identify these points

Nearly 9% of providers indicated they had observed colleagues making disparaging remarks against or providing reduced care to lesbian elders. One commented s/he knew this because of the jokes being told. Only 2% were not sure if they had observed the detrimental behavior while 89% said they had not made these observations of their colleagues.

**Section 2: Policies & Practices**

These questions, for all providers, provided specific insight into the understanding of policies and practices for serving lesbian patients / clients.

**Questions 6 – 9: Lesbian-Friendly Providers**

Of the 65 responses received, 89% (58) of providers claim to be lesbian-friendly. Most, however, did not explain why they thought this to be true. The explanations we did receive include:

- “Our workplace has benefits for employees that support partners.”
- “We treat everyone equally with respect.”
- “We do not ask.”
- “We embrace the resident’s right that states everyone is treated equally, regardless of race, religion, sexual orientation, etc.”
- “Our office is because [_____name of SAGE member____] is the brains behind the operation (sorry, couldn't resist).”

Three respondents (5%) indicated they are not lesbian-friendly. One offered no explanation while the others mentioned the following:

- A Catholic hospital with religious conflict
• [Have] no formal policy

Those who did not select as lesbian-friendly, but who also did not disagree, included these responses:

• Not applicable – response from a Home Health Provider
• Unknown
• This is never addressed

Though the majority of providers claimed to be lesbian friendly, we wanted to know how their patient/clients would actually know that. This question not only provides some support to women who might disclose their sexual orientation, but also gives insight into provider descriptions of what constitutes “lesbian-friendly.” We received 40 written responses (69% of the 58). These themes emerged from the responses:

• Providers (40% of responses) follow non-discrimination policies and treat all patients the same:
  o “Patients are treated with dignity and respect.”
  o “Staff is trained.”
  o “I believe it is all in the way they are treated – just like everyone else!”
  o “Our open, friendly, accepting, and caring attitude.”
  o “Discrimination is not tolerated.”

• Providers ask open-ended, non-assuming questions about sexual orientation and practices:
  o “We show them that they are valued by welcoming, listening and attending to their needs. We treat everybody with dignity and respect.”

• Agency has staff that are lesbian/gay and who may also be out:
  o Providers who are out and list LGBT as a specialty and/or talk about healthcare challenges.

• Materials are posted or provided:
  o Stated in literature and admission policy/packets and posters in units.
  o Language used on forms.
  o LGBTQQ friendly materials on display (SAGE Posters, Options Magazine)
  o Website

Only one agency claimed to offer programming directly focused for their LGBT clients, an Alzheimer’s support group. Also, some providers take the lack of complaint or overt discrimination as an indication of being lesbian-friendly.

• No patients have been discriminated against due to sexual orientation.
• There never has been a complaint.
• Though they claim to be lesbian-friendly, at least 18% indicated they have no idea or are unsure how their clients would know that.
• “Our mission statement says we serve the entire community, and that is meant to be inclusive of everyone. We expect all staff to deliver culturally competent care. That said, most lesbian patients have probably encountered insensitivity at one time or another, and may be understandably wary in absence of a specific message affirming sensitivity to their culture.”

One of the key indicators lesbians may use to gauge the awareness or support of a provider or the providers’ knowledge of lesbian-elder healthcare issues often has to do with the sexual and relational questions asked on intake forms or other questionnaires. Therefore,
we asked providers what choices they provide on their forms to indicate sexual/relational activity.

Nearly 92% of the providers completed this question in some way (see Figure 25). Most providers indicated the use of traditional hetero-normative indicators for sexual and relational activity. Those who used the option “married same-sex” used this along with married. This was also true for those who offered the option “Life Partnership / Long-term relationship.” Additionally, of those who use these terms, five also provide the option of “Significant Other” and one uses “Partnered with female/male partner.” One respondent mentioned this issue has come up in their staff meetings, though nothing has been done, and another says they offer the option for “transgender.”

Thirteen providers (22%), who did not select any of the options we offered to the question of intake forms, responded in other ways. Two providers indicated they don’t include information on the intake forms, but ask the information in person. Other commented and those responses have been organized, below, by theme:

Open-ended options:
- Marital status with ________________ [open ended lines].
- There is a line to fill out, no specific box to check. The patient can put whatever their status is.
- Our form has an open-ended question.
- Our forms are free text, [i.e.] the providers document patients' caregivers, support persons in whatever language the patient uses.
- The choice of partner in addition to spouse, friend, other family member
- Partnered with female/male partner.

Question not asked:
- We do not ask residents their sexual identity/activity.
- On paperwork, I don't ask about relationship status. I only ask for an emergency contact number and what the relationship is to my client.

Another way to determine the support or attitude about LGBT patients/clients it to find out if providers have specific policies and practices in place and what the consequences might be for not following those stated guidelines. Question 9 directly inquired about whether or not their office, practice, or facility has the following supportive elements in place:

- Patients' Bill of Rights and/or non-discrimination policy that explicitly includes sexual orientation?
• Policy or practice to acknowledge and include families-of-choice (same-sex life partners, designated friends, etc.) in making medical decisions if your patient/client is unable to do so.
• Clear guidelines for honoring Advanced Health Care directives (and other similar documents) for LGBT patients/clients.
• Inclusive visitation policy that grants same-sex couples equal visitation access similar to those offered heterosexual couples and next of kin.
• Equal employment opportunity policy that specifically states sexual orientation.

Figure 26 represents the answers from 100% of respondents. As we consider who completed the assessments, predominately nurses and support staff, it is important to note the large percentage of policies or guidelines they are not familiar with related to patient care, specifically Patients’ Bill of Rights and inclusion of families of choice.

Earlier, it was noted that 89% of providers, who responded to our assessment, claim to be lesbian-friendly, and 40% of those indicated they follow non-discrimination policies and treat all patients the same. The actual numbers, however, reveal discrepancies. We compared the actual numbers of those who claim to be lesbian-friendly with the policies they have in place. In Figure 27, the centered-blue bar indicates the 89% claim of lesbian-friendliness. The lavender bars to left are those providers, who claim to be lesbian-friendly and have actual policies in place. The orange bar to the right indicates all providers, who claim they have actual policies in place.

Additional comments were shared and organized into the following emergent themes:

1. Providers are willing to look into policies now that they are aware.
2. Durable Powers’ of Attorney and other written directives make a difference to providers (therefore, lesbians would do well to have them).
   - We definitely practice this; Policy or practice to acknowledge and include families-of-choice (same-sex life partners, designated friends, etc.)
   - The resident advanced-directive states that makes decisions for the person. We do not care who that relationship person is. If there is no DPOA, we go to family.
   - Our policies do not specify that anyone with a specific relationship or role (i.e. the patient) will be guaranteed access. Policies support access by the individuals identified by the specific patient, regardless of the person’s relationship to the patient.
   - A specific DPOA for healthcare if on file covers above concerns.

3. A one-person practice may not have written policies in place; but, that does not mean they will not follow certain practices. Also, not all policies may pertain to them.
   - Since I am an Acupuncturist, I do not discuss nor have policies regarding advanced directives.
   - I am a one-person psychotherapy office; so, I don’t have much of this in writing or it is not applicable.

4. Additional responses included:
   - Sexual orientation is not asked/talked about at employment.
   - Same-sex partners are not allowed benefit coverage for their partner.
   - Our patient rights states to be treated with respect regardless of race, religion, gender, age, marital status, national origin, sexual preference, financial means or cognitive, mental or physical disabilities.

The assessment also addressed the consequences for “medical personnel, administrators, or staff, who do not adhere to or honor the policies as outlined by your office, practice, or facility.” We received 28 written responses to this open-ended question. Of those who responded, 25% were not sure what the consequences would be. In most cases, but not all, these tended to be the same individuals, who were not sure what policies were in place. Just more than half (57%) claimed a range of action that included formal reprimand, discussion and corrective action plan, re-training, or termination. From the responses, it seemed the corrective action might be progressive as incidents increased or dependent on the situation; while in other cases, termination might be immediate.

Fourteen percent of respondents reiterated discriminatory behavior was not tolerated or that such actions were illegal; but, they also did not offer what specific consequences might take place.

**Question 12: Risk Factors**

As in the Lesbian Elder Assessment (Section 2, Question #18), the report *Aging in Equity: LGBT Elders in America* (2004) and *Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients* (Gay and Lesbian Medical Association—GLMA, 2006) suggest some primary healthcare issues for LGBT elders. This question was derived from those indicators. SAGE-RI wondered whether healthcare providers in RI are aware these issues. The risks included were: breast cancer, HIV/AIDS, mental distress, substance abuse, depression due to isolation, hate violence, abuse and neglect at hands of caregivers, access to affordable healthcare, loss of home or savings by one partner due to Medicaid.
restrictions, and age discrimination (see Figure 28). These are the responses given by the providers, who responded to the assessment. In Section 4 of this report, we will compare the findings from both assessments.

Figure 28: Agree or Disagree—Lesbians at Elevated Risk for Certain Health Issues

![Figure 28: Agree or Disagree—Lesbians at Elevated Risk for Certain Health Issues](image)

Section 3: Demographics – Provider Respondents

The questions in this section helped the researchers understand the responses within a context of who completed the assessment. Some questions required a response.

Questions 13 and 14: Primary Location and Professional Role

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<tbody>
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<tr>
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</tr>
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<tr>
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<td>E. Providence</td>
<td>1</td>
</tr>
<tr>
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<tr>
<td>02919</td>
<td>Johnston</td>
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</tr>
<tr>
<td>02920</td>
<td>Cranston</td>
<td>1</td>
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<tr>
<td></td>
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## Provider or Agency Staff Completing the Assessment

<table>
<thead>
<tr>
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</thead>
<tbody>
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<td>Physician (Primary Care)</td>
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</tr>
<tr>
<td>Physician (Geriatrician)</td>
<td>1</td>
</tr>
<tr>
<td>Physician (Other Specialist)</td>
<td>1</td>
</tr>
<tr>
<td>Nurse or Nurse Practitioner</td>
<td>40 (Nurses also included these comments, 1 each: Administrator, Owner of Facility, Care Manager, Clinical Nurse, Specialist, CNA)</td>
</tr>
<tr>
<td>Administrator</td>
<td>5</td>
</tr>
<tr>
<td>Support Staff / general care provider</td>
<td>2</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>Intern, Director of Clerical (?) Service Home Care, Psychotherapist, Clinical Social Worker, Pharmacist (3), Acupuncturist, Quality &amp; Compliance</td>
</tr>
<tr>
<td>Blank / No response</td>
<td>2</td>
</tr>
</tbody>
</table>

## Questions 15 – 17: Additional Demographics

### Types of Healthcare Services:

SAGE-RI wanted to know what type of healthcare service the providers offer. They were asked to indicate both primary and secondary services (see Figure 29) and to list other forms of services they provide if not indicated in the choices.
The additional services of the respondents included:

- Private, n-p, institution provides myriad of services in extended community for families, children, elders, etc.
- Audiologist
- Clinic based
- Clinical dementia research
- Community Healthcare center
- Free Clinic
- Health Education Center
- Home Health Care
- PACE
- Pharmacy
- Private Home Care
- Social Services Agency
- Sub-acute (Nursing Home)

**LGBT Employees:**

It was important to know if the providers had a sense of who, among their colleagues, are lesbian, gay, or bisexual (see Figure 30). Nearly half indicated having fewer than 5% or no LGBT colleagues. None of the responses indicated the answer range of 20-49% LGBT colleagues. One-third, though, either did not answer the question or said they just didn’t know.
Section 4: Residential Services

These specific questions were intended only for providers responding, who provide care in nursing homes, assisted living facilities, or other long-term/residential and similar facilities.

Fifty-eight percent of the providers, who responded to the assessment, completed this section. Of those, 53% indicated their primary service as nursing home (and one Assisted Living Facility and two Home Health Care agencies.)

<table>
<thead>
<tr>
<th>Types of Services</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Home</td>
<td>20</td>
<td>53%</td>
</tr>
<tr>
<td>Assisted Living</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>PACE RI</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>Home Health Care Agencies</td>
<td>2</td>
<td>5%</td>
</tr>
<tr>
<td>Hospitals, Clinics, Healthcare consortium, etc. offering</td>
<td>9</td>
<td>24%</td>
</tr>
<tr>
<td>residential as additional care option</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No response (but answered questions in this section)</td>
<td>5</td>
<td>13%</td>
</tr>
<tr>
<td><strong>TOTAL RESPONSES</strong></td>
<td><strong>38</strong></td>
<td></td>
</tr>
</tbody>
</table>

The majority of responses came from nursing home facilities; and they are highlighted below. In the next few figures, “NursingH % of All” refers to what percentage of all the responses to these questions are from nursing home staff. The percentages listed as “Nursing Home % of ONLY NH” compares Nursing Home to Nursing Home responses.

Question 18: Training in the Healthcare and Aging Needs of Lesbians

SAGE-RI wanted to know if residential staff received healthcare or cultural awareness training with regard to the specific needs of aging lesbians. Figure 31 illustrates the lack of training available to caregivers, who work in residential facilities, specifically on the healthcare and aging needs of elder lesbians. This is especially true for nursing homes where 80% of staff reported they receive no specific training in lesbian, elder healthcare.

A provider, working in a nursing home without training, offered this comment:

“Don’t believe there is a different need. Aging people are aging people regardless of their sexual orientation.”

One care facility that does offer training stated that it happens in the context of the annual, in-service training.
Questions 19 – 22: Clear and Stated Policies for Care and Resident Rights

In addition to training, the researchers wanted to learn whether or not residential facilities used specific policies to guide them in standards of care for LGBT clients, as well as to protect their clients; and if so, to what extent the staff was aware of them. We asked two specific questions:

- Do you have stated policies or standards for caring for lesbian (LGBT) clients / residents?
- Does your facility provide written policy statements (such as a "Bill of Rights") to your residents / clients?

In addition to not receiving training, the majority of staff in these facilities claims not to have policies or standards to specifically guide them in the care of LGBT patients (see Figure 32). Two of the responses, from nursing home providers that answered, “no” to this question, explained that their policies cover “all” patients and are not specific to age, race, religious beliefs, or sexual orientation.

Though it seems that staff may not be trained or aware of policies or standards for care, it does seem that residents are provided with some form of “Bill of Rights” or other clear policy statements (see Figure 33). A number of providers responded to this question in the comment section. Interestingly, most of the statements came from the same nursing home providers that indicated having no training for staff and no stated policies. The comments included:

- Actively. We spend considerable time with residents, families and staff to educate them on the rights and their meaning.
- All residents are provided with a copy upon admission. The Bill of Rights is posted throughout the facility.
- All residents’ families/staff receive education.

Figure 32: Facilities with Stated Policies or Standards of Caring for LGBT Clients/Patients

![Stated Policies for Standard of Care](image)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
<th>In development</th>
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<tbody>
<tr>
<td>ALL Responses</td>
<td>3%</td>
<td>71%</td>
<td>26%</td>
<td>0%</td>
</tr>
<tr>
<td>NursingH % of ALL</td>
<td>9%</td>
<td>45%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Nursing Home % of ONLY NH</td>
<td>9%</td>
<td>85%</td>
<td>15%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Figure 33: Written Policy Statements (such as Bill of Rights) for Residents/ Clients

![Written Policy Statements Available to Residents](image)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALL Responses</td>
<td>84%</td>
<td>11%</td>
<td>5%</td>
</tr>
<tr>
<td>NursingH % of ALL</td>
<td>45%</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Nursing Home % of ONLY NH</td>
<td>85%</td>
<td>10%</td>
<td>5%</td>
</tr>
</tbody>
</table>
in basic human rights, which are part of the residents’ bill of rights.

- Provided on admission/Posted throughout facility. Education for staff.
- Signed on admission by patient on POA.
- All residents treated with respect and dignity regardless of sexual orientation. This includes resident’s rights of privacy with visits, etc.
- The Bill of Rights is reviewed on admission with the patient and family.
- Everyone is everyone - we aren’t interested in sexual orientation.
- It is the starting point of many of our policies and procedures.

Additional responses from the remainder of the providers echoed the statements above, including inclusion in a patient handbook.

- All residents have the right to be treated with dignity and respect regardless of gender, cultural beliefs, ethnic background, medical diagnosis, marital status, or sexual orientation.
- Staff that does not follow these regulations risks termination. “There is a regulatory Resident Bill of Rights. This is giving to all residents, so they are aware of their rights. Staff is educated to these regulations. A violation by law may result in termination.”

**Question 22: Hostile or Prejudicial Treatment by Staff Towards Clients**

We also asked how the facility would handle hostile or prejudicial treatment by staff towards lesbian clients. Regardless of the responses in questions #18 & 19 above, most responses indicated such behavior is not tolerated and would receive a range of corrective actions. Responses included:

- Counseling with manager.
- This is abuse and would be reported to our regulatory agencies and the person would be removed pending an investigation. If confirmed they would be dismissed.
- Just as we would any hostile or prejudicial treatment towards any other resident. It isn't tolerated.
- Warning process and dismissal.
- If this happened, they would be disciplined (perhaps terminated) as they would be for any prejudicial behavior.
- Staff would be terminated - prejudice treatment would be viewed as abuse.
- Disciplinary action - it is called abuse - all staff must respect residents’ rights.
- We would handle the same way work place violence, sexual harassment.
- We would handle with employee counseling / write up if necessary and education/re-education.
- Dismissal.
- It is treated as an individual performance issue where appropriate. Cultural competency training for individuals or groups may be utilized as appropriate.

Eighteen percent of respondents have not had to deal with situations of prejudicial treatment, and appeared to have no clear policies in place to handle them should there be a need.

**Question 23: Hostile or Prejudicial Treatment between Clients**

In general, of the 63% who responded to this question, most places do not tolerate client-to-client hostile or prejudicial behavior. Responses included a range of actions:
- Intervention by varied staff, social worker, nurses, including DNS and administrator. Room changes and floor changes initially would be in the mix beyond counseling the individual or individuals involved.
- Just as we would any hostile or prejudicial treatment towards any other resident. It isn't tolerated.
- Social worker involvement.
- We would handle with employee [sic] counseling / write up if necessary and education/re-education.
- Would handle like we do all other patient to patient situations.
- The patient/residents would be separated & education would be provided. If the behavior continued, the abuser would be transferred to another facility.
- Involve social services & education - respect rights of all.
- Policies support safety for all patients. Expectations regarding patient conduct are stated in the patient handbook. Inappropriate behavior is dealt with on an individual basis when needed.
- Depending on the severity of the circumstances, outcomes range from resident education to unit changes, to discharge from facility.

One facility took a proactive approach of screening residents before admittance: “Residents … are assessed for admission it is a process of admission that residents respect each other. Residents who are unable to abide by this are given notice to leave.” Another facility responded: “It does not happen here - staff is trained and screened.”

About 16% of responses indicated they have not had to deal with the situation of tensions between residents, though no additional explanation of what might happen was mentioned. One might ask, then, do they have a policy that prevents such mistreatment, or if mistreatment happens will they then create a policy? One response did indicate that such an incident has not yet happened; and, they do not have a policy if it does.

Questions 24 and 25: Services & Programming for LGBT Residents

We also wanted to know—as a statement of support for lesbian elders—whether residential services offer/allow same-sex couples to: reside together in the same dwelling or room, share the same bed if they choose, and participate in each other’s care or decision-making.

Fifty-three percent of respondents allow couples to reside together while only 34% allow them to share a bed if they choose. A higher percentage (61%) allows for participation in each other’s care (see Figure 34). In the next few figures, “NursingH % of All” refers to what percentage of all the responses to these questions are from nursing home staff. The percentages listed as “Nursing Home % of ONLY NH” compares nursing home to nursing home responses.
One provider responded positively to these questions and added, “They are afforded the same rights as heterosexual couples. It would be discriminatory to do otherwise.” One respondent, who works in a Catholic hospital, answered that she, as a worker, would permit lesbian-couples to share a room or bed and participate in each other’s care. She noted, however, this is her personal decision and certainly does not reflect the policies of her employer.

One respondent did not select the share room/dwelling or bed options, but noted they have private rooms. It’s unclear, what would be available in those private rooms. Three of the nursing home respondents did not select any of these options, but noted that they have not encountered these situations; therefore, it is unclear whether they have a policy in place or would allow for them. Only one general respondent mentioned s/he was not sure if any of these services were allowable.

We also asked if these facilities offer any specific programming (educational, entertainment, etc.) that would appeal to LGBT residents (see Figure 35). More than half (58%) of the respondents indicate they do not; though one facility, indicated they would if it was requested.

**Question 26: Harassment or Bias’ as a Result of Supporting LGBT Elders**

Due to the responses we received, it may be safe to assume that health facilities have not been denied financial support if they openly support lesbian elders. Only 24% responded “no” to this question while nearly half of the responses (47%) indicated they were not sure and 26% did not respond at all.
Chapter 3: Critical Comparisons of the Assessments

While the responses on each assessment are interesting in themselves, a cross-reference or comparison of the data is important. The key question for the comparison was how the perspectives of lesbian elders compare to the perceptions, knowledge, or attitudes of healthcare providers. References to the two groups of respondents are throughout this section; and, each group is referenced in the following manner:

**L-Elders** - Assessment of Healthcare for Lesbians completed by Individuals  
**Providers** - Provider Assessment on Healthcare for Lesbian elders

**Knowledge about Lesbian Healthcare Needs**

In the L-Elders assessment, we asked two related questions:

- **Q48:** Do you have confidence that your primary healthcare provider is sensitive to or especially knowledgeable about the particular health risks and needs of lesbian patients, especially elders?
- **Q49:** Do you have confidence that healthcare providers, in general, are sensitive to or especially knowledgeable about the particular health risks and needs of lesbian patients, especially elders?

Similarly, Providers were asked:

- **Q3:** Indicate if you agree/disagree with this statement: In general, providers are not familiar with the specific health needs or risks faced by lesbians.

In general, L-Elders were far more confident in the care and knowledge of their primary care providers than of healthcare providers in general (see Figure 36). When considering the lower end of the range (from 0-2), nearly 79% of L-Elders have little-to-moderate confidence in the knowledge that general healthcare providers have of lesbian-specific healthcare issues.

While the providers rated themselves slightly better, it should be noted that more than half (54%) agree that providers are not knowledgeable about lesbian healthcare issues. Additionally, another 25% are not certain (see Figure 37).

Both patients and providers agree that more information, education, and knowledge about the particular health
risks and needs of lesbian patients, especially elders, needs to be made available. Awareness training and education would benefit everyone.

In the L-Elders assessment, we asked a series of questions related to disclosure and experiences:

- **Q43**: If / when you were to disclose your sexual identity/orientation, what kind of reaction did you EXPECT?
- **Q44**: If / when you HAVE disclosed your sexual identity/orientation (or our provider figured it out), what kind of reaction did you receive?
- **Q45**: If your physician(s) or healthcare providers were to know of your sexual identity/orientation, how do you think this would affect the level of healthcare you receive?
- **Q46**: If your physician(s) or healthcare providers already DO know about your sexual identity/orientation, are you generally treated with dignity and respect?

Similarly, we asked Providers (**Q6**) to indicate if they believe their practice or facility is lesbian-friendly. Though this question is not exactly the same as those asked of L-Elders, the Provider responses do give insight into their general openness towards lesbian patients.

Figures 38 and 39 illustrate that while lesbians may be skeptical and expect negative reactions or compromised care, in fact, they actually receive better treatment than they anticipated. Some of this expectation may have to do with how healthcare facilities represent themselves. While 91% of providers responded that they are indeed lesbian friendly (see Figure 41), they had a much harder time describing how they actually relay that information to their patients. Hetero-normative intake forms, dodging questions of same-sex sexual activity, lack of LGBT health literature or posters mixed in among other waiting room literature, and other forms of avoidance or invisibility do not signal openness to lesbian healthcare concerns. These will contribute to lack of openness of lesbian patients. As one of the lesbian respondents put it, “Somehow I feel it's their responsibility rather than having a heterosexual assumption.”

In addition to the direct health impacts of societal homophobia, perceived or real
homophobia from health care providers may discourage lesbians and bisexual women from seeking care. Without evidence to the contrary, lesbian and bisexual patients may expect discrimination in the health care environment. Therefore, it is important to take the steps ... to make your practice environment visibly welcoming.

![Figure 40: Providers as Lesbian-Friendly](image)

**Policies to Follow Legal Directives**

The lesbian elders were asked if they are prepared with many of the legal documentations recommended to protect their healthcare interests (Q68 & 69). Such documents include:

- Last Will & Testament
- Advanced Health Care Directives (AHCD: such as Living Wills and Health care power of attorney)
- Designated person(s) with Durable Power of Attorney
- Documented plans for funeral arrangements
- Documented plans for disposition of remains

Similarly, we asked Providers (Q9) if they have specific types of policies in place such as:

- Patients' Bill of Rights and/or non-discrimination policy that EXPLICITLY includes sexual orientation
- Policy or practice to acknowledge and include families-of-choice (same-sex life partners, designated friends, etc.) in making medical decisions if your patient/client is unable to do so
- Clear guidelines for honoring Advanced Health Care directives (and other similar documents) for LGBT patients / clients
- EXPLICIT, inclusive visitation policy that grants same-sex couples equal visitation access similar to those offered heterosexual couples and next of kin.

For the purposes of the comparison, the researchers focused on the AHCD and the Durable Power of Attorney (DoPA) since they are the documents most likely directly affects
interactions with healthcare providers. According to assessment responses, many L-Elders have some legal safeguards in place, the AHCD in particular.

In spite of their preparation, though, L-Elders’ confidence levels that directives will be followed are not as strong. For example, of the 85% of respondents, who have an AHCD, only 57% are confident they will be followed (See Table 14).

<table>
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<tr>
<th>Legal Documentation &amp; Confidence</th>
<th>L-Elders Q 68 &amp; 69</th>
<th>Yes</th>
<th>In Process</th>
<th>Not yet, Plan to</th>
<th>No</th>
<th>Confidence will be followed: Moderately So</th>
<th>Confidence will be followed: Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced Heath Care directives (AHCD: Living Wills and Health care power of attorney)</td>
<td>85%</td>
<td>8%</td>
<td>4%</td>
<td>2%</td>
<td>39%</td>
<td>57%</td>
<td></td>
</tr>
<tr>
<td>Designated person(s) with Durable Power of Attorney</td>
<td>77%</td>
<td>6%</td>
<td>8%</td>
<td>8%</td>
<td>29%</td>
<td>69%</td>
<td></td>
</tr>
</tbody>
</table>

L-Elders skepticism on this issue may be well founded. Less than 35% of the providers indicated they have policies and practices in place that will ultimately safeguard lesbian-righs in their own healthcare (see Figure 41). A similar percentage of providers responded they are not sure of any such policies while nearly a quarter (on average) stated they have no such policies. This should cause LGBT activists and advocates to not only encourage lesbian elders to get such legal safeguards, and to carry them at all times, but also to push for more cohesive measures and proactive policies among healthcare providers to have such documents honored and followed!

Figure 41: Provider Policies for Patient Rights
Lesbian Health Risk Factors

One of the few questions that both L-Elders and Providers were asked focused on some primary healthcare issues for lesbian elders (Section 2, L-Elders Q18 and Section 3, Providers Q12). The risks included were: breast cancer, HIV/AIDS, mental distress, substance abuse, depression due to isolation, hate violence, abuse and neglect at hands of caregivers, access to affordable healthcare, loss of home or savings by one partner due to Medicaid restrictions, and age discrimination. The discussion is a factor-by-factor comparison between L-Elders’ and Providers’ knowledge about each risk factor for aging lesbians. This information reveals a lack of knowledge for both healthcare providers and lesbian elders about healthcare risks for lesbian elders.

Breast Cancer

Research suggests that lesbians are at an elevated risk for breast cancer, but not because they are lesbians. A lesbian lifestyle (or behavior) corresponds to the factors correlated with higher cancer rates exist including:

- Cigarette smoking
- Alcohol Use
- Obesity
- Lack of childbirth (especially prior to Age 30)

In some cases, these risk behaviors result from the stress and stigma of living with homophobia and discrimination. For reasons stated above, lesbians often avoid routine screenings, specifically pap smears and mammography. Additionally, in some communities, lesbians may not have access to lesbian health support groups and may be wary of coming out to oncologists.

Lesbians, as a group, have fewer pregnancies, and when they do bear children, it tends to be at older ages than heterosexual women. Because of this absence of or delayed childbearing, lesbians and bisexual women may be at greater risk for some cancers, such as breast cancer (see Figure 42).

HIV / AIDS

While documentation of female-to-female, HIV transmission has been controversial and not definitive, lesbians can become infected through other risk behaviors, such as intravenous drug use, accidental needle sticks, and sex with men. Elder lesbians, especially if they have been in a trusted and monogamous long-term relationship, will not likely be at an elevated risk for sexually transmitted HIV/AIDS. Their vulnerability will more likely be related to other risk activities (see Figure 43).

---

Figure 42: COMPARE - Breast Cancer

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Disagree</th>
<th>Not Sure</th>
<th>No Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providers</td>
<td>20%</td>
<td>54%</td>
<td>20%</td>
<td>4%</td>
</tr>
<tr>
<td>Lesbian</td>
<td>77%</td>
<td>55%</td>
<td>10%</td>
<td>0%</td>
</tr>
</tbody>
</table>

---

4 GLMA, 2006, p. 28
Mental Distress & Depression

Aging lesbians may face parallel mental health issues faced by aging women in general, but research has shown lesbians and bisexual women to have higher rates of depression than heterosexual women, often due to stigma related stress. Those additional stressors include:

- Estrangement from families
- Challenges adjusting to minority sexual orientation
- Hiding aspects of one’s identity over a lifetime
- Hostility and abuse faced throughout one’s life due to being a lesbian
- Ongoing-lack of support for same-sex relationship and family structures

These experiences are further compounded by increased isolation due to reduced mobility, and death of a long-term partner and peers, and lack of age-appropriate socializing opportunities. All these factors may foster depression. This depression often goes unrecognized due to heterosexual bias of caregivers and health professionals (see Figure 45). Due to age and cultural history, lesbian elders may also be more reticent to seek mental health care services due to remembrances of repressive treatment of LGBT people by the psychiatric establishment.  

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5 GLMA, 2006, p. 26
6 Funders, 2004
SAGE-RI Assessment Results
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Lesbians and bisexual, women-of-color, face double jeopardy due to the added stress of racial or ethnic discrimination that may place them at even higher risk.\(^7\)

**Substance Abuse**

Lesbians and bisexual women, especially young women, may drink alcohol and use other drugs, and smoke at higher rates than heterosexual women, again increasing the risk of heart disease, chronic obstructive pulmonary disease (COPD), and other health problems (see Figure 46). Reasons for the increased prevalence of these risk factors among lesbians and bisexual women include the chronic stress and other mental health challenges of discrimination and homophobia, as well as the prominent role that bars and clubs have played in lesbian subcultures and as women-only spaces.\(^8\)

**Hate Violence & Elder Abuse**

Hate violence continues to rise against LGBT peoples (despite decreases in violent crimes) and presents a major public health issue. According to the *Aging in Equity* study (Funders, 2004), quality data on how hate violence specifically affects LGBT seniors is lacking. But lesbian seniors in this current generation have lived during the time when homosexual behavior was both heavily stigmatized and illegal. Hate violence is “normalized” thus contributing to a lifelong expectations of stigma, harassment, discrimination and experiences of violent hate-based acts against them and/or their peers (see Figure 47).

Violence includes abuse or neglect at the hands of caregivers. Elder abuse and neglect can happen to anyone, but isolated seniors are at most risk (see Figure 48). Fear of institutionalization and general distrust of law enforcement authorities often discourages LGBT elders from reporting abuse and neglect.\(^9\)

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7 GLMA, 2006, p. 26
9 Funders, 2004
SAGE-RI Assessment Results
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Economics of Healthcare

Because legally sanctioned marriage is one of the primary routes to health insurance in the US (along with employment), lesbians experience lower health insurance rates than heterosexual women. Studies have estimated that between 20% and 30% of lesbians do not have health insurance compared to 15% of the general population.10 See Figure 49.

Federal tax law currently allows an employer to provide health insurance to the heterosexual spouse of an employee or retired employee as a tax-free benefit. However, when employers offer the same benefit to same-sex couples, federal law treats the value of the partner’s insurance as taxable income and the LGBT retiree then pays income taxes on this benefit.11

Many of the programs and laws designed to protect older Americans are founded on the presumption of marriage. Social Security provides extra benefits to spouses, for example, while estate tax law provides tax exemptions for estates passed between spouses. From Social Security and Medicaid to 401(k), pensions, veterans’ benefits, and employee benefits such as spousal health care coverage for retired workers, partnered LGBT elders face

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10 GLMA, 2006, p. 25
11 MAP & SAGE, 2010, p.20
SAGE-RI Assessment Results
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major disparities that have real and lasting impacts on their financial security and health and well-being, when compared to heterosexual married couples. Even if Rhode Island did allow for the legal marriage of lesbian couples, federal law still prohibits the benefits of these federal benefits.

...economic realities are shared by all senior citizens, but for LGBT elders, the burden is worsened by unequal treatment of same-sex couples under Medicaid regulations, which allow one member of a married heterosexual couple to retain a jointly owned house without jeopardizing his or her spouse’s right to Medicaid coverage. LGBT elders in committed, long-term relationships are not afforded these same protections, even though they, like heterosexual married couples, have supported the Medicaid infrastructure as taxpayers throughout their lives. As observed in a policy report by the National Gay and Lesbian Task Force in 2000, “[t]his unequal treatment can force same-sex couples into a Hobson’s choice of getting the medical coverage to meet a partner’s health care needs versus giving up a couple’s home and life savings.”

Additionally, Medicare and Medicaid have restrictive policies and complicated rules that can be complicated and area applied differently in each state. For example, in Rhode Island, there also exists a five-year financial look back policy making an immediate transfer of property a liability.

For Rhode Island information about Medical assistance for seniors, go to: http://www.dhs.ri.gov/Elders/HealthMedicalServices/tabid/285/Default.aspx

Age Discrimination

All older people face considerable challenges as they age, including the frustrations of coping with an aging body and, often, a prolonged period of frailty and dependency at the end of life. Older people also face the challenge of maintaining a valued place in society while aging. ..As members of a legally and socially disfavored minority, LGBT elders face significant additional obstacles to successful aging that heterosexual older adults do not. See Figure 51.

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12 MAP & SAGE, 2010, p. 9
13 Defense of Marriage Act – DOMA
14 Funders, 2004, p. 13
16 MAP & SAGE, 2010, p. 4
SAGE-RI Assessment Results
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Broadly speaking, three unique circumstances make successful aging more difficult for LGBT people:

- The effects of social stigma and prejudice, past and present.
- Reliance on informal families of choice for social connections, care and support – at a time when government and other institutions largely define family based on marriage and biological kin.
- Inequitable laws and programs that fail to address, or create extra barriers to, social acceptance, financial security, and better health and well-being for LGBT elders.

Figure 51: COMPARE - Age Discrimination

Conundrum: Nursing Homes

This comparison on Nursing Homes was added because so many of the Provider respondents (58%) are based there. One of the pressing concerns expressed by L-Elders is who will care for them in their aging years, especially if they are unable to care for themselves. Regrettably, we inadvertently omitted asking L-Elders whether they anticipate using or might use Nursing Homes if necessary. We asked:

- **Q78:** Would the fear of disclosure about your lesbian identity/orientation PREVENT you from considering the use of [Nursing Homes].
- **Q79:** If your lesbian orientation/identity were known, do you think this would compromise the level of respect or care you would receive from [Nursing Homes].
L-Elders are concerned their disclosure might compromise their care (see Figure 52). These are legitimate concerns. LGBT elders in nursing homes and assisted living facilities are at particular risk of neglect and abuse, despite the fact that this treatment is in violation of federal law. Not only do LGBT elders face potentially hostile staff members, but there are other considerable challenges, including hostile fellow patients; denial of visits from families of choice or from friends the staff does not approve of; refusal to allow same-sex partners to room together; and refusal to involve families of choice in medical decision making, even when there are legal directives in place.17 Providers, specifically those offering residential services such as nursing homes, were asked:

- **Q18:** Are caregivers/staff at your facility trained or experienced in the specific healthcare and aging needs of lesbians?
- **Q19:** Do you have stated policies or standards for caring for lesbian (LGBT) clients/residents?

Again, those 53% of L-Elders, who wonder if coming “out” might or would compromise their care in a nursing home, may have some legitimate concern. Respondents to the provider assessment claimed to receive no training (80%) or did not have or were unsure if they had stated policies (100%) for caring for LGBT residents (see Figure 53). The lack of knowledge on this second point is startling because under the Nursing Home Reform Act, Nursing Homes are required to make written policies available to residents describing a specific list of clients’ rights.

Though these statements cover ALL residents, they can provide some support for LGBT residents. Our findings reflect the research, “Improving the Lives of LGBT Older Adults.”18 While these rights, theoretically, provide some protections, many LGBT elders still hide their identities, feel uncomfortable launching complaints, or are not well enough to self-advocate. Additionally, many patients, families of choice, and facility staff are unaware of these federal protections.

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17 MAP & SAGE, 2010, pp. 35-36
18 MAP & SAGE, 2010
SAGE-RI Assessment Results
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Chapter 4: Concluding Remarks, Observations, Next Steps

In Chapters 1 and 2 of this report, we have generally recorded the responses received from lesbian elders and healthcare providers in RI. Chapter 3 offers comparisons between the two assessments, as well as connections to national research studies. Since the data pool is relatively small and reached only a limited population of lesbian elders and providers, SAGE-RI may not be able to draw any definitive conclusions. It is possible, however, to offer observations to inform future discussions, additional research, and advocacy for lesbian elders in RI. The following suggestions are organized in the order in which they appear in the report, rather than by developing priorities:

L-Elders Assessment – Observations

- Our lesbian elders’ respondents were predominately white, highly educated, generally out, and most with relatively decent income. Population GAPS: Lesbian elders of color & of limited means/income & careers. We’re not clear if the reasons for this have to do with the reach of SAGE-RI, our own limited visibility and advertising, the mechanism of the assessment (mostly web-based with few printed copies), or general unwillingness of more closeted lesbians to participate. The explanation could be some combination of all of the above!
- For the most part, L-elders in RI DO tend to have regular visits and screenings and recommended by the healthcare guidelines. (Q#22).
- The predominance of health diagnosis responses (Q26) reflects consistency with national studies of lesbian health (MAP & SAGE, 2010).
- For Alternative/Naturopathic care (Q33-35), the report writer was personally surprised these were not more embraced than it seemed to be as her own experience has seen higher interest in these practices among her circle of friends.
- Q42: It’s clear lesbian elders need better forms, questions, and other ways to be invited to discuss sexuality and relationships with healthcare providers in order to receive overall better care.
- Q42: Question: Do lesbians know why / how / when they SHOULD be out in order not to compromise their health and care?
- Q45-46: Competing identities: How do lesbians know why they receive the treatment they do from providers? What can be attributed to gender, sexuality, race, age, and language/culture? And in some cases, is it (like one woman suggested) she gets treated worse/dismissed more because she is fat rather than because of her lesbianism? And what about providers that just have deplorable bedside manner? And when is that well-intentioned providers act (or not) from lack of knowledge or accurate information as compared to willful prejudice? Do providers “know” when they’re being insensitive – or think they are being supportive when they actually are not?
- Q#49: Surprise and need for concern that 31% of respondents seem unsure about whether their providers will keep sexual identity/orientation confidential?
- Q#52: CLEAR observation: In general, there is a significant need for more education about lesbian healthcare issues for both providers AND lesbians themselves!
• Q53: What can be done to support or address the issue of conflict between an individual provider’s behavior and policies of facilities (e.g., an individual who may be more open than the facility allows or shows her/him to be)? What happens when personal willingness to be supportive contradicts the policies of a hospital, especially in a situation such as a Catholic hospital? What can individuals control with their agencies?

• Q66: Lesbian elders in RI need a lot more familiarly with the penalty of taxable income related to having a same-sex partner on a health insurance policy.

• Q78-79: – Though lesbians may use (or decide to use) agencies and services for elders, do they then NOT come out & hope for the best?

**Providers Assessment – Observations:**

• Q1: So many providers (65 %+) – DON’T track the sexuality of their patients – why? Do they track gender, age, or race? Is this the assumptions of heterosexuality at work?

• Q3: If so many providers are NOT familiar with lesbian elder health care needs, how are they not offering substandard care?

• Q3 & Q9: Better education is needed for providers in terms of health AND policies/standards! Also, (Q5), while providers may not be observing disparaging remarks, based on responses to other questions, we might wonder about their sensitivity to or real capacity to understand or recognize offensive remarks or substandard care.

• Q6: There is a need for better understanding of “lesbian-friendly.” Just because providers treat “everyone the same” does not mean they understand how they operate out of hetero-normativity (same as white people who don’t have cultural sensitivity.)

As mentioned in Chapter 4, a need to understand the importance of legal documentation and better standards/policies for making sure patients are asked their wishes and – when these can be followed without documentation (e.g., I introduce my partner to my physician/surgeon prior to a non-emergency treatment and expect, then, that hospital staff will recognize her centrality to my care, visitation, and decision-making)
References


Appendix 1: Frequency of Regular Health Screenings

These are the detailed graphs for Lesbian Elder Assessment, Section 2-23, and p.13:

- Questions 22: Please indicate how often you currently have the following exams or screenings
- Questions 23: Please indicate how often you had the following exams or screenings—prior to age 50
Appendix 1 (continued)