

SAGE-RI / Healthcare for Lesbian Elders

Final Report, September 2012



Executive Summary

In 2012, with funding from the Women’s Fund of Rhode Island, SAGE-RI initiated a project to educate and empower lesbian elders in Rhode Island to seek quality, lesbian affirming health care. The first step in that process was to create two surveys, one for elder lesbians and the other for healthcare providers. Between May – July of 2012, both surveys were made available to the communities through a web-based survey (Zoomerang). Print copies were also provided on request and at various public events.

The following pages present an in-depth summary of the responses. From this data, the following key summary points can be made.

- ◆ 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 in these areas.
- ◆ Lesbian elders desire more information about specific healthcare providers to whom they can be open about their sexual identity and receive competent and non-discriminatory care.
- ◆ Lesbian elders in Rhode Island have higher than average percentages of certain health factors, specifically arthritis and joint pain, obesity/overweight, 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 perhaps can no longer care for themselves. They need better information about seeking services and support, especially from providers who understand their situation and needs as lesbians.
- ◆ While the majority of healthcare providers in RI claim themselves as “lesbian-friendly,” their knowledge, practices, and policies reflect limited (or no) competency in the areas of lesbian-specific health issues or cultural needs. Evidence for lack of good practice are embedded in statements from providers such as “we don’t ask” [about sexual orientation] or “we treat them like all others.” Most providers still offer only hetero-normative 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 (or include) LGBT clients. They also could benefit from more sensitivity awareness training.
- ◆ Providers generally have no way of knowing how many LGBTQ people they are serving. If they are tracking other demographics for the populations they serve (such as gender, age, race, language, healthcare issues, etc.) why do they not also include sexual orientation?

The following pages will provide more evidence and detail for these statements.

Table of Contents

Chapter 1: Survey Results — Responses from Lesbian Elders in RI	p. 3
Overview	
Section 1: Demographics	p. 4
Section 2: Health & Well-Being Part 1 (Specific Health Issues)	p. 13
Section 3: Health & Well-Being Part 2 (Experiences with Providers)	p. 19
Section 4: Healthcare Economics / Legal / Cultural Issues	p. 28
Section 5: Elder Care Services & Related Aging Concerns	p. 31
Chapter 2: Provider Survey - Healthcare for Elder Lesbians	p. 38
Overview	
Section 1: General Information	p. 38
Section 2: Policies & Practices	p. 39
Section 3: Demographics of Provider Respondents	p. 45
Section 4: Residential Services (Long Term Care, Nursing Homes, Assisted Living Etc.)	p. 47
Chapter 3: Critical Comparisons Between the Surveys	p. 53
Chapter 4: Concluding Remarks / Observations	p. 65
Index of Tables & Figures	p. 67-68
References	p. 69
Appendix 1: Frequency of Regular Health Screenings	p. 70-71

Chapter 1: Survey Results — Responses from Lesbian Elders in RI

This chapter of the report summarizes the responses to the survey completed by lesbian elders in Rhode Island. The survey was administered in the late spring / early summer of 2012.

WHO we asked to participate

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. We 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.

We advertised the survey in the following venues:

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

For the purposes of this survey:

Lesbian was used in this survey as an umbrella term to include all options of sexual identity as described above (also, see Section 1, Question 8).

Partner was used in this survey as an umbrella term to include life-time companion, girlfriend, lover or other descriptions for a sexual/intimate relationship.

Age group we asked to respond

At what age does one become a lesbian elder? There is no consensus among lesbians, or even those who sponsored this survey. We did, however, agree on these parameters.

- For the purposes of this survey, **the age of a lesbian elder is 65-years-of age** (born in or before 1947).
- We also requested responses from lesbians 55+ years of age (born in or before 1957); because we expect they are already considering the issues of elder healthcare.

The survey had 5 Sections:

1. General Demographics
2. Health & Well Being Part 1 (Specific Health Issues)
3. Health & Well-Being Part 2 (Experiences with Providers)
4. Healthcare Economics / Legal / Cultural
5. Elder Care Services & Related Aging Concerns

The survey report below is organized by section. For general ease of reading, we have combined responses thematically by the questions, though we have referenced each section and question numbers.

Lesbian Elder Survey Section 1 - Demographics

This section reflects WHO took the survey.

The survey to individual lesbians was administered via the Internet using Zoomerang. The data from that tool shows that we had 172 “looks” and received 43 complete responses. Additionally, we did offer printed surveys and received six (6) mailed responses. In order to use the Zoomerang data analyzing tools, those 6 responses were input into the Zoomerang web tool by the researcher in order to have more consistent and reliable information. **Therefore, we have a total of 49 responses.**

All responses are strictly confidential. The only required data were birth year and geographic location. Though we tried to prevent duplicate entries, we have no reliable way of knowing whether respondents answered more than one survey. There are only 3 surveys that appear to be duplicates, but the responses are different enough that we have counted all 49, so there may be some slight percentage of error.

We additionally had 14 partial responses in the Zoomerang. Of those, eight (8) had no data, 3 match those that were ultimately completed, and 3 were truly partials. Those three partials are NOT included in this data report.

Section 1 - Question 1

What Rhode Island town do you live in?

Table 1: Towns Represented

City & Zipcode	# of replies
Barrington, 02806	1
Bristol, 02809	1
Coventry, 02816	2
Cranston, 02905	3
Cranston, 02910	1
Cumberland, 02864	2
East Providence, 02914	1
Foster, 02825	1
Lincoln, 02865	2
Narragansett, 02882	5
No Kingstown, 02852	2
No Providence, 02904	2
Pawtucket, 02860	4
Providence, 02903	2
Providence, 02904	1
Providence, 02906	5
Richmond, 02892	1
Smithfield, 02917	1
So Kingstown, 02879	1
Wakefield, 02879	2
Warwick, 02886	3
Warwick, 02888	1
Warwick, 02889	2
W Warwick, 02893	1

Section 1 - Question 2

I do NOT live in Rhode Island, but I receive healthcare services in Rhode Island.

Table 2: States Represented

California, 91601 (Receiving healthcare in Providence)	1
Massachusetts, 02760 (Receiving healthcare in Providence)	1

Section 1 - Question 3 **** MANDATORY****

In what year were you born: 19_____

Of the 49 respondents, 55% (27) were 65-years of age or older (born in or before 1947). The oldest respondent was 84 (See Table 3).

Table 3: Ages over 65

Year	Age	# of respondents
1928	84	2
1932	80	1
1935	77	1

1939	73	2
1940	72	1
1941	71	1
1942	70	1
1943	69	4
1944	68	7
1945	67	1
1946	66	4
1947	65	2
TOTAL		27

Of the remaining 22, 91% (20) were aged between 64 – 57 (1948-1955), and 10% were younger than 55 (See Table 4).

Table 4: Ages 64 and Under

Year	Age	# of respondents
1948	64	4
1949	63	1
1950	62	2
1951	61	4
1952	60	2
1953	59	4
1954	58	1
1955	57	2
1960	52	1
1961	51	1
TOTAL		22

What is your primary race/ethnicity?

48 of the 49 respondents (98%) identified themselves as White (European) and one indicated she is Black / African.

Employment / Occupation / Income / Education

Of the respondents, 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 (5) of the nine (9) 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.

The respondent’s occupations were primarily located in three sectors: healthcare, education, and social services. Healthcare workers included nurses (5) [but NO doctors], and a range of positions including administration, research, CNA, psychotherapist, and an 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.

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

Those who responded to the survey 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

Figure 1: Currently Employed

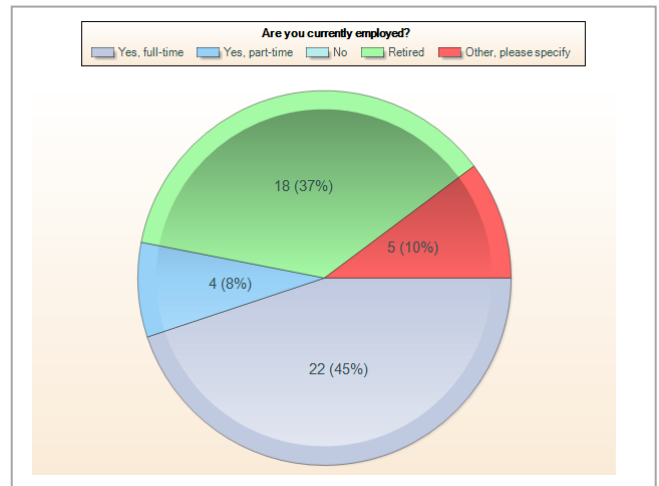
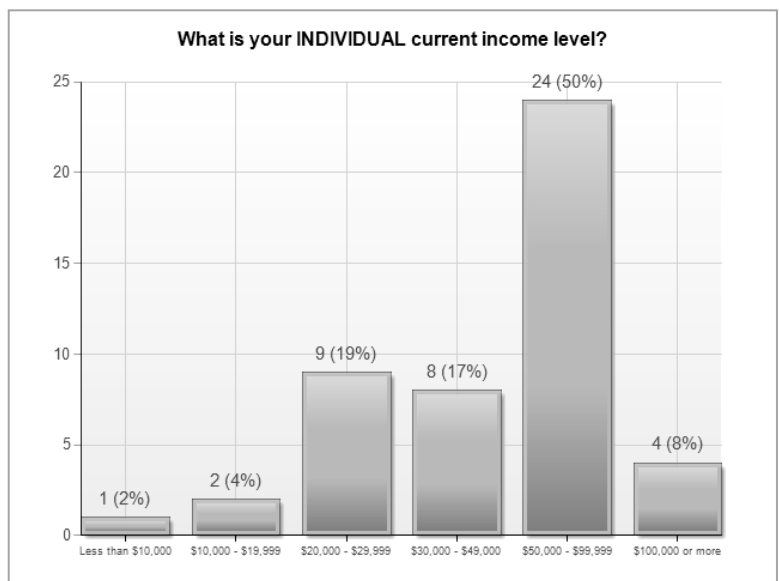


Figure 2: Income Level



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.

Section 1 - Question 8 - 9

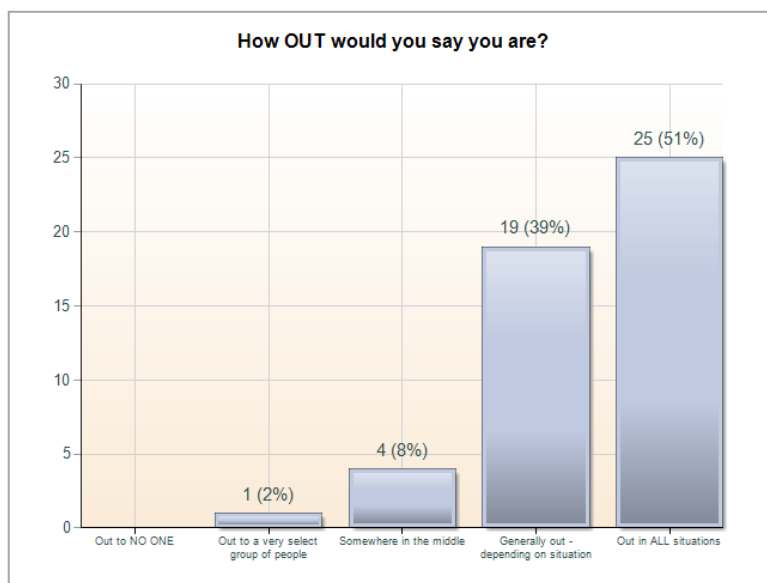
Sexual identity / orientation and willingness to be out

Of the 49 who responded to the survey, 46 (94%) identified themselves by using the term “lesbian.” Of those 46, 74% preferred to use ONLY lesbian. The remaining 12 also used multiple identifiers such as gay (6), bisexual (3), woman who prefers companionship with women (2), other labels—Dyke, Femme/Butch, Queer, or Homosexual— (7), and non-op trans (1).

Figure 3: Level of Being Out

The three (3) women who did NOT use the self-identifier lesbian at all preferred to identify themselves as gay (2) or bisexual (1).

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 we will see later, though, there is some discrepancy with being out in general and being out to healthcare providers.



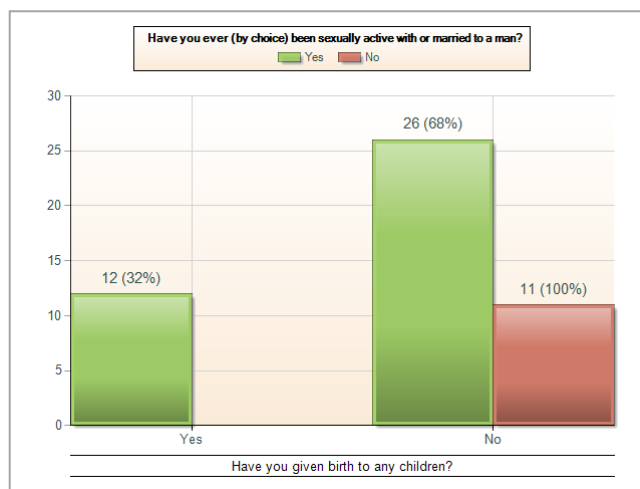
Section 1 - Question 10 - 15

Relational Situations

The women in this survey 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.

Figure 4: Sexually Active with Men

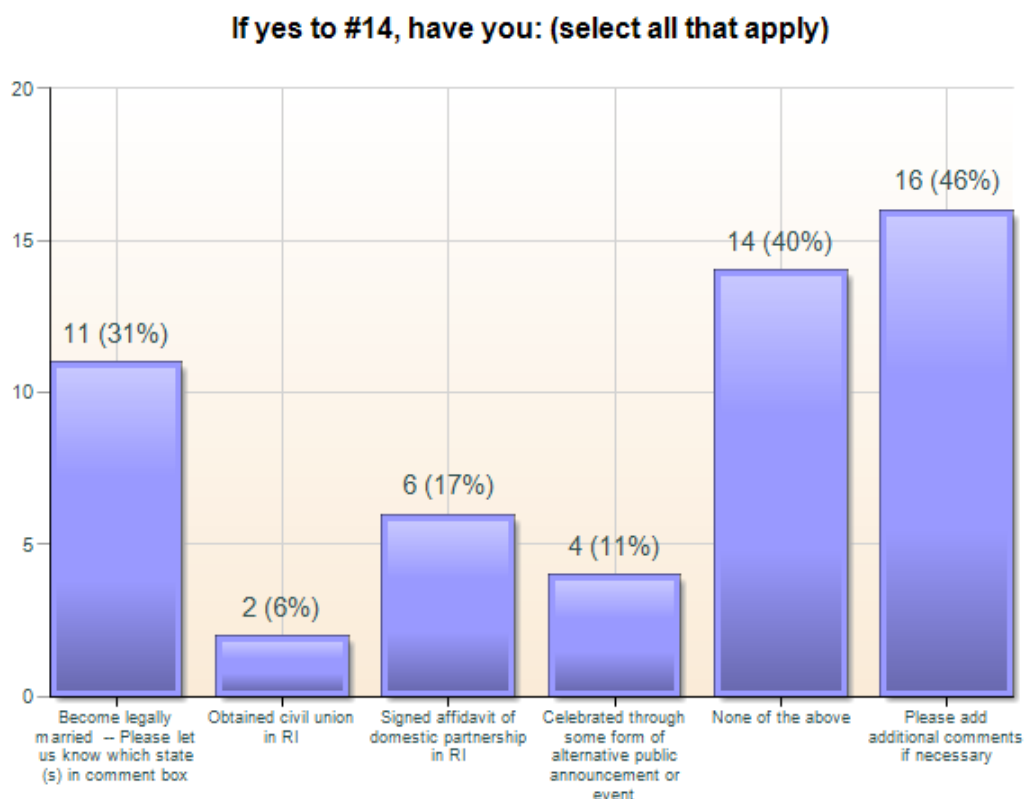
Of the 49 respondents, 12 (24%) reported themselves to be single, while one woman identified herself as celibate, and another chose non-monogamous/polyamorous. Two women also noted they are partnered (perhaps to each



other?) and monogamous in practice, but non-monogamous/polyamorous 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

Figure 5: Formalized Commitments



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.

Section 1 - Question 17

What is your religious/spiritual affiliation and does this affect your healthcare choices (if so, how)?

Generally, the predominant religious affiliation in Rhode Island is Roman Catholic. In our survey, there were 47 responses to the question of religious practices. Only 4 women (9%) claimed to be Catholic while at least 3 mentioned having been raised Catholic but moving on to other practices. Thirteen women (28%) stated they have no religions affiliation and there was even representation of Jewish, spiritual/pagan, and Unitarian

practices.

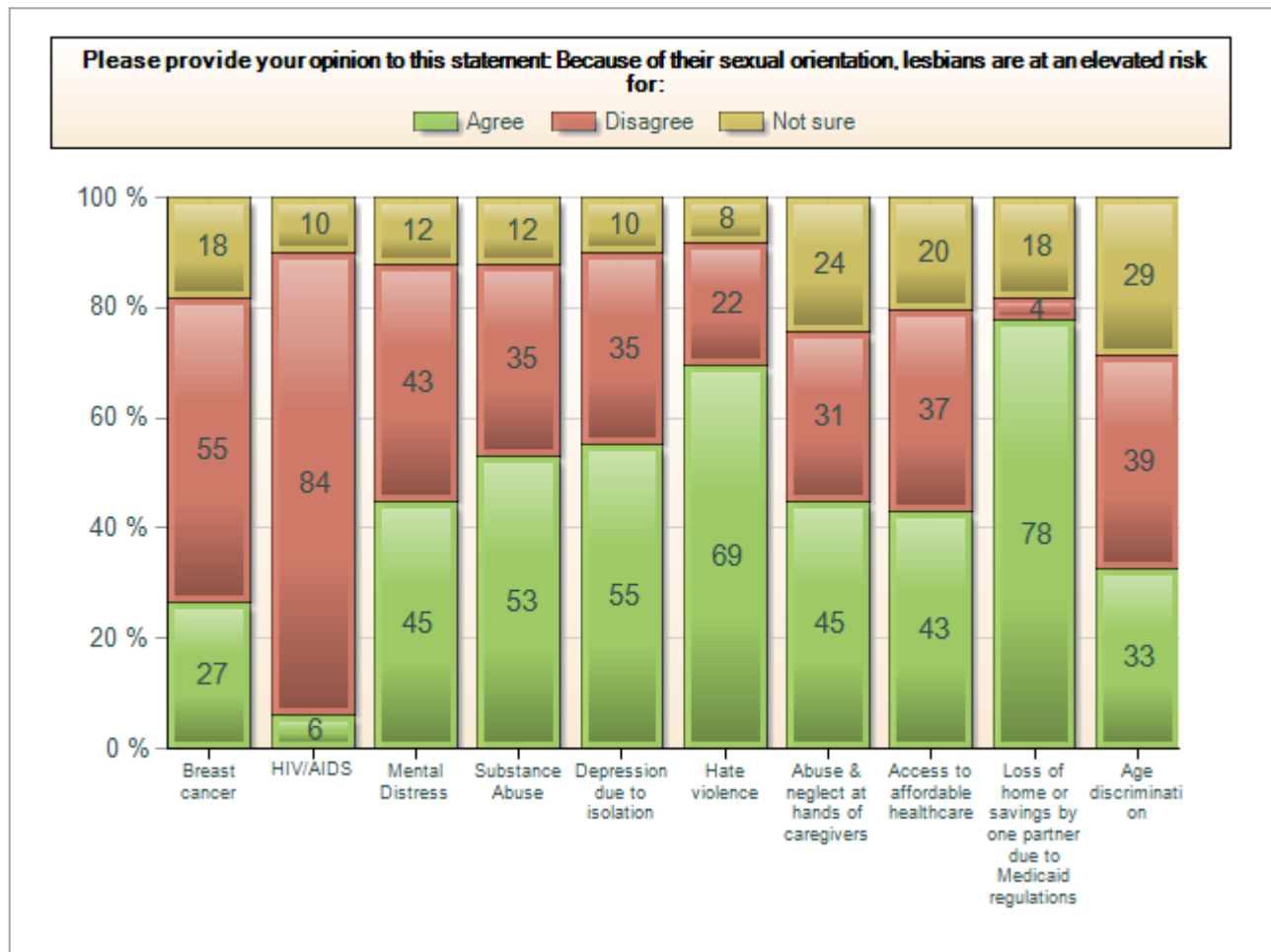
ALL of the responses indicated that individual’s religious affiliation has no impact on healthcare choices. However, here, and in a later question, two different respondents did mention that they specifically avoid religion-based healthcare facilities due to the RI Corvese amendment and attitudes towards homosexuality. Corvese amends H6103 (RI Civil Union bill) to allow any religiously connected entity to ignore the legal import of a civil union for any purpose.

Section 1 - Question 18 **** MANDATORY ****

Please provide your opinion to this statement: Because of their sexual orientation, lesbians are at an elevated risk for:

The chapter on health and wellness in the report *Aging in Equity: LGBT Elders in America* by the Funders for Lesbian and Gay Issues (2004) makes two important points. First of all, 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” (p.10). This reality, however, is changing. In recent years, calls for proposals

Figure 6: Agree or Disagree to Statement—Lesbians at Elevated Risk for Certain Health Issues



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.

The *Aging in Equity* report (Funders for Lesbian and Gay Issues, 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. Question 18 in Section 1 was derived from those indicators. We wondered whether lesbians in RI are aware these issues. The risks we 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, age discrimination (see Figure 6). This was one of the only 3 mandatory questions on the survey. We also asked this mandatory question of providers. In Section 4 of this report, we will compare the findings from both surveys.

We also asked—“What would you say is your biggest concern or need related to healthcare issues and services for lesbians in RI”(Section 1 - Question 19). The opinions of the respondents have been organized thematically below.

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? (2 mentions)
- “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? (2 responses)
- How do we know (or can we know) who are lesbian-friendly (lesbian affirmative) MDs (even though everyone should be treated equally)? (5 mentions)

- Are healthcare providers knowledgeable about the specific needs, risks, and issues faced by lesbian elders? Can we receive quality care? (3 mentions)
- 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.
- We should ask sexual orientation on all forms (with option to decline) in order to get a better handle on disparities.

Insurance / 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 concerns included:

- The concern is not for myself ... tho 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 info and messages targeted to lesbians regarding health care.
- Coresve 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., and 2) [I] am healthy and friends have gotten services needed.

Lesbian Elder Survey Section 2 – Health and Well-Being

The questions in this section specifically addressed healthcare issues.

Section 2 - Question 21

In general, my health is:

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

Section 2 - Question 22

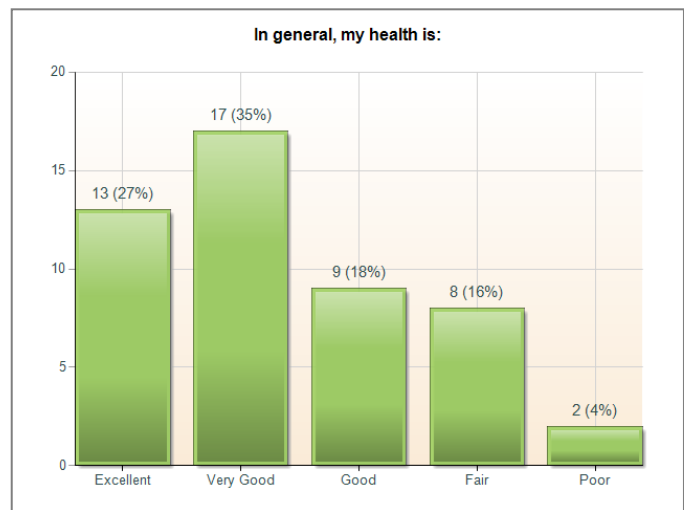
Frequency of exams or screenings

At SAGE-RI, we have been aware of national studies that indicate LGBT people, and specifically elder lesbians, may not be seeking regular healthcare services. We 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:

- Primary Care Well Visit
- General gynecological visit
- Mammogram
- Pap Smear
- Blood Pressure
- Glucose Screening
- Cholesterol Screening
- EKG (Echocardiogram)
- Colonoscopy
- Bone Density Test
- Vision Check
- Hearing Check
- Dental Check

The detailed data charts can be found in Appendix 1.

Figure 12: Self-reported General Health Ranges



From the data, it appears that lesbian elders in Rhode Island 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) and 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 should be needed. Interestingly, lesbian elders rarely (or never) get their hearing checked while most everyone of all ages who responded have a dental check every 6 months (86%/71%) to a year (6%/20%)!

Access to care and prescriptions

Table 5: Access to Care & Prescriptions

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

The respondents to the question of accessible care also made some interesting observations. The women commented on their ability to seek care and get their 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.

Another woman also mentioned, "I get my meds 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 survey 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.

- 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.

Specific Health Matters & Relatedness to Lesbian Identity
--

On the survey, we asked this question: 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. These are their responses, in order of frequency (See Table 6).

Table 6: Specific Health Issues for Respondents

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

We 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 saw no direct connection between their health conditions with being a lesbian. Of the 9 (18%) who did, most of them (70%) described conditions such as anxiety, depression, or complex PTSD and alcohol abuse connected to fear of coming out and experiences of discrimination and gay bashing. One woman commented that even straight allies “are not aware [of] how pervasive discrimination is or the financial penalties we face.” Another woman understood her overeating (resulting in high cholesterol) as a coping mechanism for not recognizing her sexual orientation until later in her twenties. Additional single responses included the aging process, and a sexually transmitted virus.

Section 2 - Question 28 & 29

Delayed health-related testing or screening

We asked women to rate why they had delayed health-related testing or screenings. Only 43 women answered (88%) 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 woman noted that if she didn't have her current insurance, she would delay many tests and screenings.

Those who didn't want to take the time (38%) saw this as only some or moderate concern while those who just didn't want to know was a low 26%. One respondent did have this to say, “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 woman noting she's allergic to many of the preparations and another making a choice not to because, for her, the risk factors outweigh the benefit.

Have you ever been (physically or emotionally) threatened or abused, harassed, stalked, or targeted at any time in your life...?

Of those who responded to this question, 23% checked that 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 said 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.

Preference for alternative (naturopathic) health solutions or care

We wanted to know if elder lesbians use or would care to use alternative and naturopathic care. We specifically asked 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 (See Table 7).

Table 7: Alternative Care Choices

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

If they did not use those alternatives, we wanted 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.

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 person also added this comment: “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. These women noted:

- 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 here in the U.S. that's nearly impossible as it's generally not covered by insurance.

Lesbian Elder Survey Section 3 – Health and Well-Being (Experiences with Providers)

In this section, we 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 survey was to develop a directory of physicians and providers who positively and effectively provide quality healthcare and support for lesbian elders. In question 36, we asked for recommendations of providers and question 37 allowed for providers to be avoided. With these questions, we 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.

Section 3 - Question 38 -40

Gender and sexuality of providers

We 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 would keep 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 (See Table 8).

Table 8: Preference For a Female Healthcare Provider

	Always	Usually	Doesn't Matter	Never
Gynecologist	71%	15%	15%	0%
Home care provider	60%	30%	11%	0%
General Practitioner	57%	27%	16%	0%
Nurse Practitioner	41%	39%	20%	0%
Proctologist	41%	13%	39%	7%
Other Specialists	33%	15%	52%	0%
Oncologist	31%	16%	53%	0%

Similarly, we wanted to know what expectations healthcare seekers might have if their healthcare provider was lesbian or gay (See Table 9). We also requested additional comments in this area and received some additional insight.

- 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.

Table 9: Expectations of LGBT Providers

I would like to know	61%
I would have an ally	51%
I'd be more inclined to share my own lesbian orientation/identity	35%
I would expect that I'd be treated with greater respect	37%
I'd expect more knowledgeable care related to being a lesbian	57%
I'd expect more knowledgeable care related to being a AGING lesbian	53%
I'd expect more suitable questions related to sexual orientation and activity or marital status at intake or on forms	55%
None of the Above	14%

It should be noted that 17 respondents (35%) indicated they would be more inclined to share their own sexual orientation if their provider was out. Of those 17, though, only 3 noted they were NOT out 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 (see next question).

Section 3 - Question 41 & 2

Sexual identity/orientation disclose to healthcare providers and why.

Table 10: Identity Disclose to Providers

	Yes	No	Some	N/A
Primary Physician	90%	8%	2%	0%
Nurse Practitioner	60%	9%	4%	28%
Gynecologist	66%	4%	2%	28%
Proctologist	24%	11%	2%	63%
Oncologist	20%	4%	0%	76%
Alternative health care provider (chiropractor, acupuncture etc.)	60%	7%	13%	20%
Other Specialists	51%	12%	28%	9%

As we look at disclosure to providers, it's also helpful to consider whether these women are out in general, or not. When cross referenced with question #9 in section 1, we found that of the 25 women who reported being **out in all situations**, all but one noted they were out to their primary physicians. These same women also were out to most of the

other physicians they used, except for some specialists.

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. Women using gynecologists, regardless of how out they generally are, DID report being out to the gynecologist. The one woman who was out only to a select few, (who also identified as bisexual), was NOT out to any of her healthcare providers.

We also wanted to know what guides a woman’s decision to reveal her sexual orientation to a physician. We first asked, “...if you’re NOT out, please indicate why.” The highest-ranking responses had more to do with relevance to the type of care being sought rather than fear of disclosure.

Table 11: What Guides Willingness Whether to Be Out to a Physician

Depends on what kind of care I'm seeking	57%
Doesn't matter for that kind of care	52%
Healthcare admittance forms at the office or hospital don't provide appropriate ways to do so	22%
Don't want to discuss it with my physician	9%
Just afraid to AND None of their business AND Past negative experiences with healthcare providers	4% EACH
Afraid others will find out AND Don't want to “out” my partner	0% EACH

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.

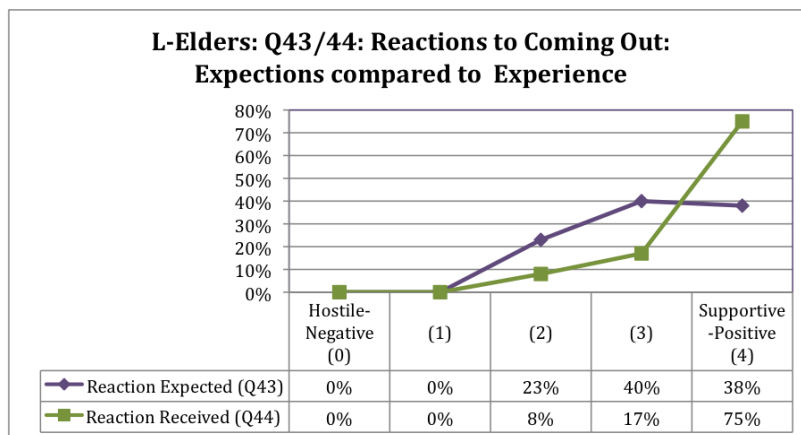
Section 3 - Question 43-51

Disclosures: Expectations & Reactions & Levels of Care

We wanted to know, when coming out, what kind of reactions lesbians *expect* to receive from their healthcare providers as compared to what kind of reactions they did receive (see Figure 8). For the most part, lesbians did not expect negative treatment, nor did they receive it. But, in general, their experiences were more positive than they’re expectations.

- We also asked:
- 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

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

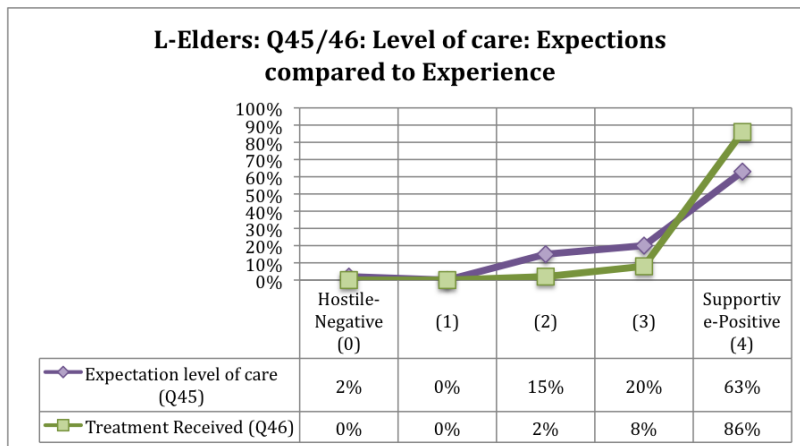


- healthcare you receive? And
- If [they] already DO know about your sexual identity/orientation, are you generally treated with dignity and respect?

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 woman added 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."

Figure 9: Levels of Care - Expectation Compared to Experience



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.

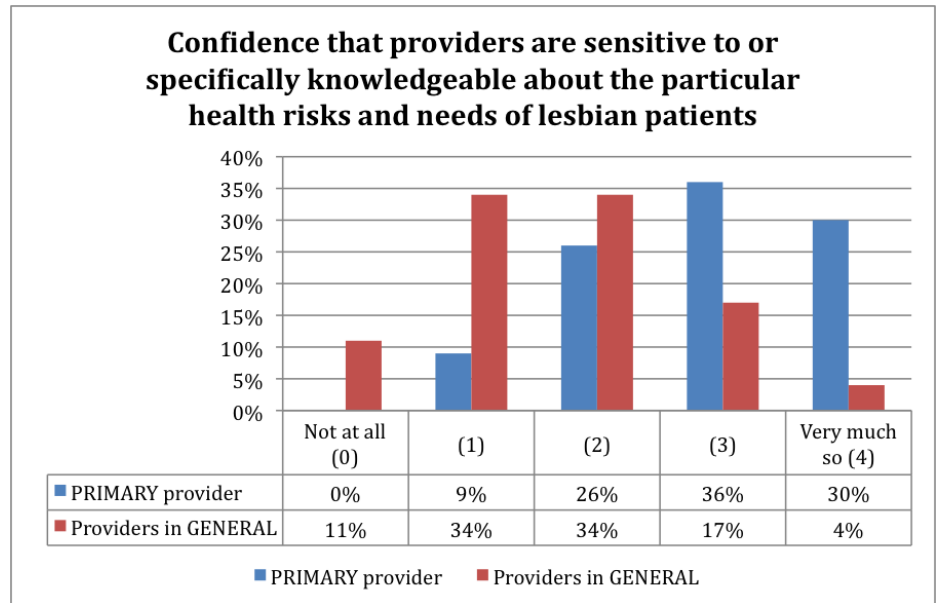
Another 15% said they were not sure if they had experienced discrimination. Those who offered explanation wonder whether the treatment they received had to do with sexual orientation, or just unprofessional behavior by the physician.

- 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 PCP [primary care physician] wouldn't accept my partner as a patient, whereas she'd accepted married heterosexual partners I knew.

Additionally, the women who took this survey 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).

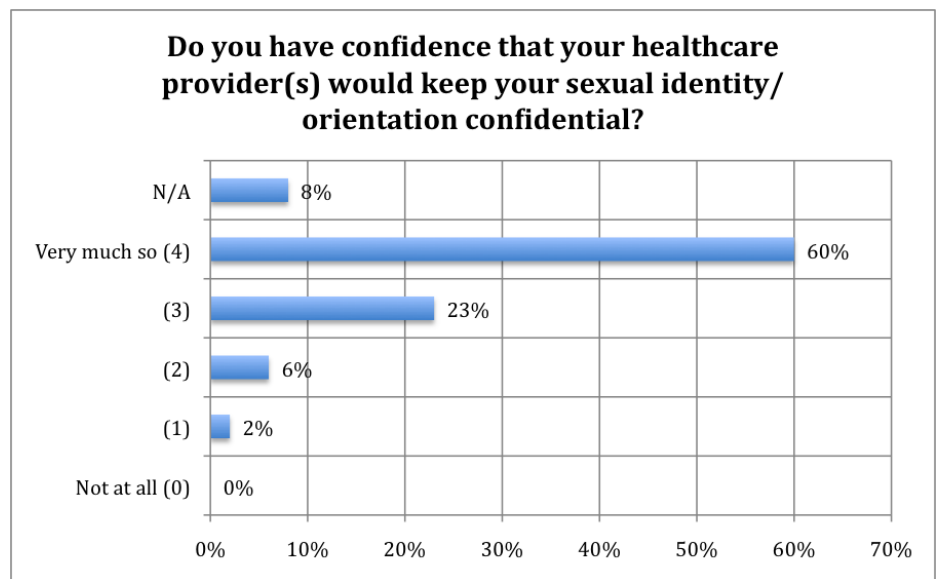
Only one respondent (2%) noted that her physician **directly attributed her health conditions to her lifestyle or identity as a lesbian**, while 8% noted their physicians suggested there may be some relevant health factors related to lesbian identity. The only detailed comment/explanation stated this had to do with mental health concerns when the respondent experienced hostility when she first came out. Most physicians (81%), though, did not make correlations between specific health concerns and lesbian orientation.

Figure 10: Confidence in the Knowledge of Providers about Lesbian Healthcare



We also wondered if lesbian elders have confidence that their providers maintain confidentiality in connection to sexual identity. It seems to be some uncertainty about whether the healthcare provider would maintain confidentiality about patient sexual orientation, with nearly 31% indicating a range of uncertainty (see Figure 11).

Figure 11: Confidence in Confidentiality



Section 3 - Question 52

Related to being a lesbian, please add additional comments about the healthcare you receive or concerns/issues you have.

We also asked an open-ended question asking for comments about the healthcare lesbian elders receive and other concerns. Two themes emerged from the responses:

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 per se
2. Lesbians themselves are not necessarily aware of healthcare risks and issues specifically 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 drs 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 (direct quotes) expressed in these responses included:
- 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!

Section 3 - Question 53

Experiences in Facilities

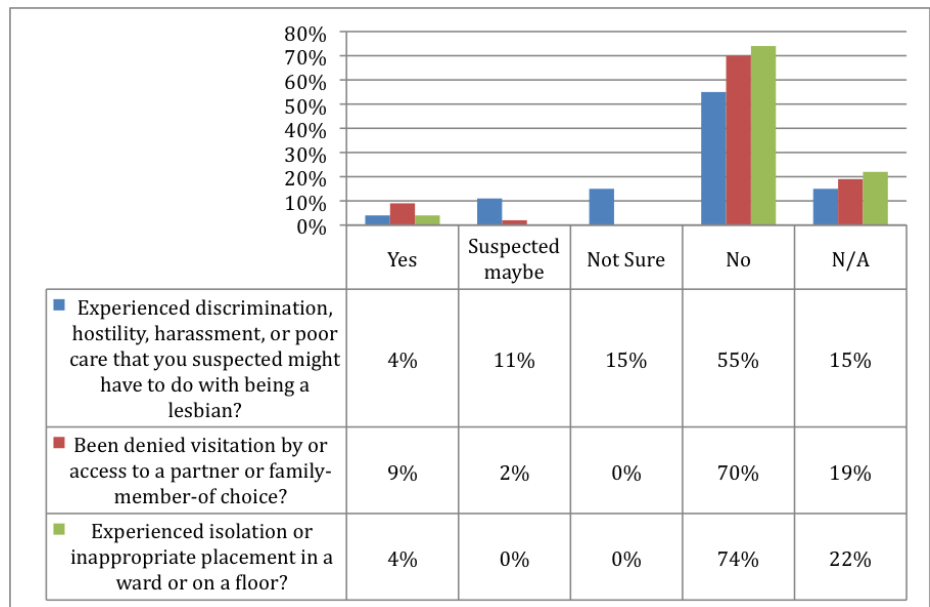
In addition to coming out to individual physicians, lesbian elders also face potential discrimination in healthcare facilities. We asked this question: In a medical care facility or situation (such as hospital, emergency room, rehabilitative care) -- if your sexual identity/orientation has been known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

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



One of the individuals who directly answered NO to the question of discrimination descriptively offered an 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 respondents who spoke quite positively about how they have been treated quite 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 survey, specifically in relation to visitation rights. As one woman stated: “Told in emergency room at RI hospital that partner 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.”

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, we 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.

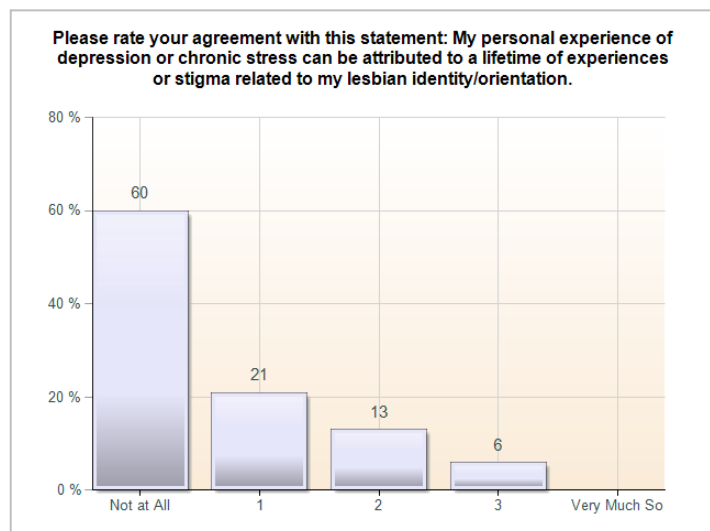
One woman offered this story as well:

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 survey, 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.

Figure 13: Depression & Sexual Identity



We invite you to make additional comments on anything in Sections 2 & 3: (Health & Well-Being) of the questionnaire.

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

- 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

Lesbian Elder Survey Section 4 – Healthcare Economics / Legal / Culture

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

Section 4 - Question 62 - 66

Health Insurance

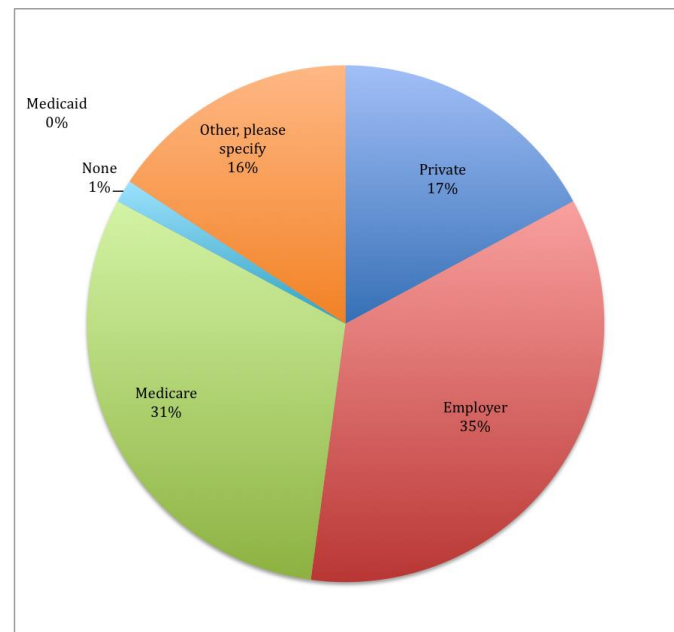
In our survey, 83% of respondents indicated they had some form of coverage from private, employer, or Medicare sources (see Figure 14). In this survey, only 1 person (2%) revealed she had no health insurance coverage. No one is currently on Medicaid. Those who selected “other” indicated a range of services including military/veteran’s, 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 survey, 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 women realized her employer had NOT counted this a taxable income and was surprised to learn about this issue.

Figure 14: Type of Insurance Coverage



Legal Documentation for Medical Decisions

We wondered if lesbian elders in Rhode Island are prepared with many of the legal documentations recommended to protect their healthcare interests. Such documents include:

- a Will
- 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

In general (see Figure 15), a good 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).

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.

Figure 15: What Legal Documents Do You Have?

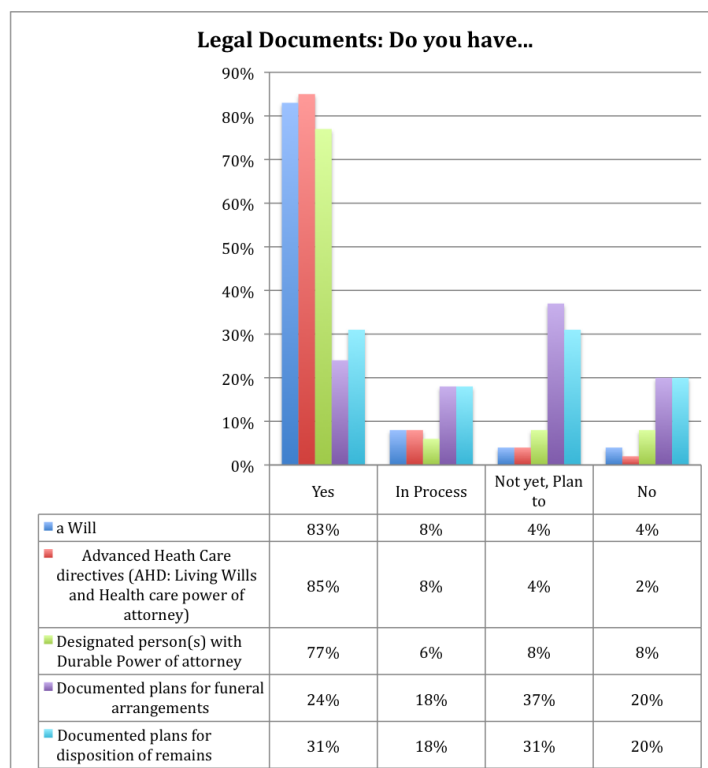
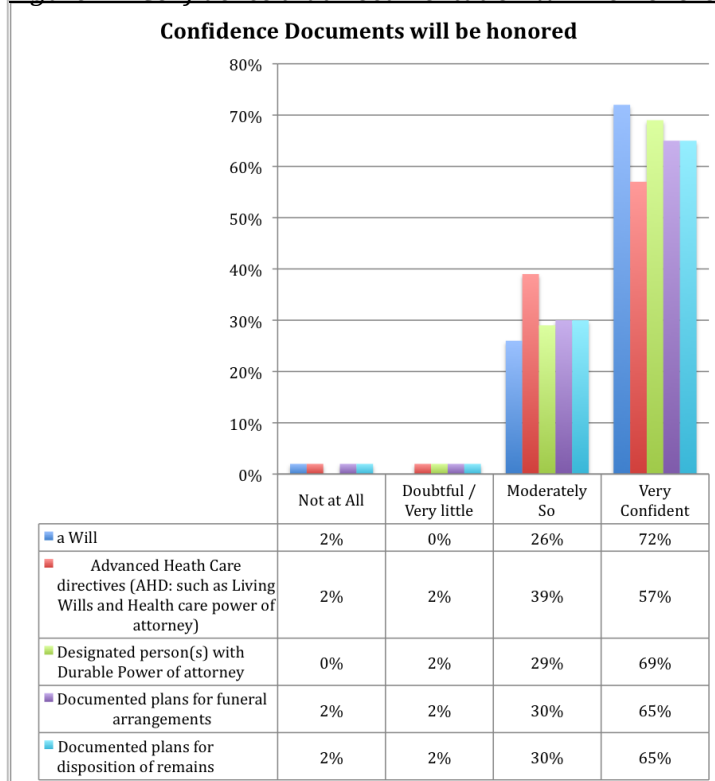


Figure 16: Confidence that Documentation Will Be Honored



We invite you to make additional comments on anything in this section (Section 4: Healthcare Economics / Legal / Culture) of the questionnaire.

We received a few open-ended statements at the end of this section of the survey. Two themes emerged from the responses.

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 makes 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.

Lesbian Elder Survey 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.

Section 5 - Question 72 -73

Programs or organizations in Rhode Island or nationally that provide support services or advocacy for LGBT elders

For the most part, older lesbians in Rhode Island 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.

We did receive 21 responses specifically naming 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 Massachusetts also added some MA based services such as: Seashore Point Assisted Living in Provincetown, Meal Sites sponsored by Massachusetts Division on Aging & an effort to develop home care by Massachusetts based advocacy agencies.

We also asked, "What more do you need or want to know more about?" We received two specific requests:

- 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.

...and these comments:

- 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.

Aging Support Services

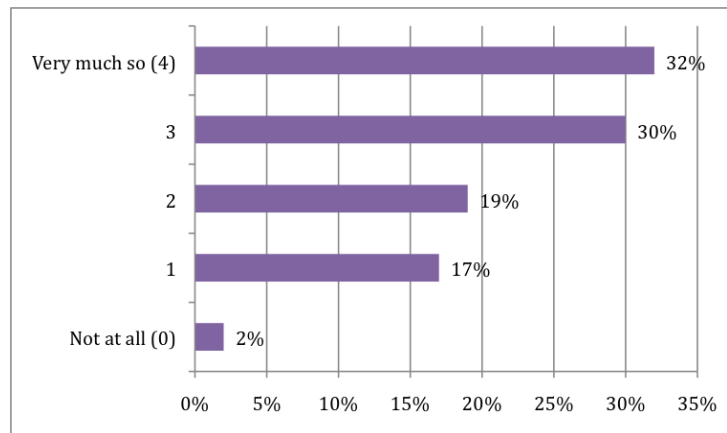
Questions 74-80 applied to a future time...If or when women might get to a situation when they would need additional assistance or could not adequately care for themselves...

Section 5 - Question 74 - 75

Concern for aging — who will provide or how to receive support or care

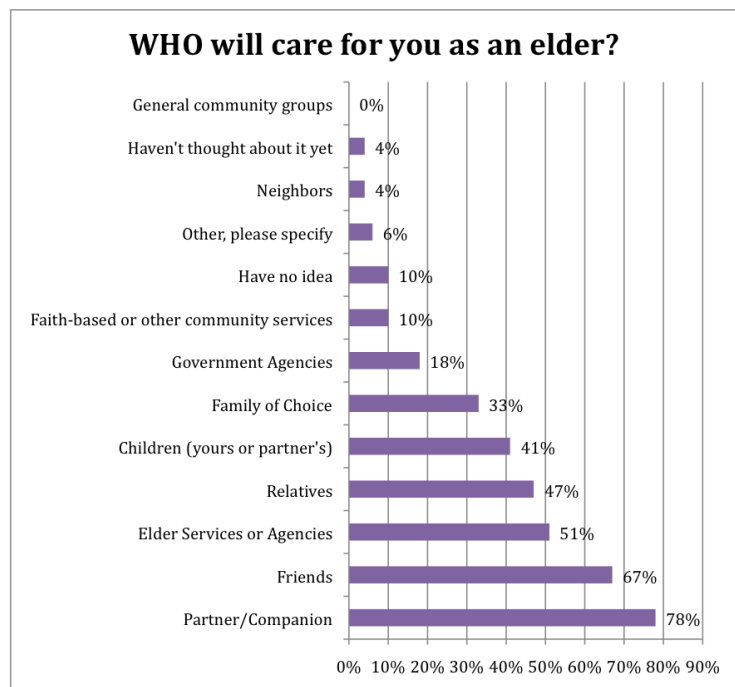
Elders in the U.S. and Rhode Island are generally concerned about who will care for them or how they will receive support or care as they age, especially if they are not able to care for themselves. This concern could potentially be magnified for LGBT people, especially if they are single, distanced from relatives, or have no children of their own. So we 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).

Figure 17: Levels of Concern for Provision of Care or Support



While their concerns were high, when asked WHO will care for you, most respondents could indicate 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. We do think it is significant to note that 10% 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.

Figure 18: WHO Do You Expect Might Care for You?



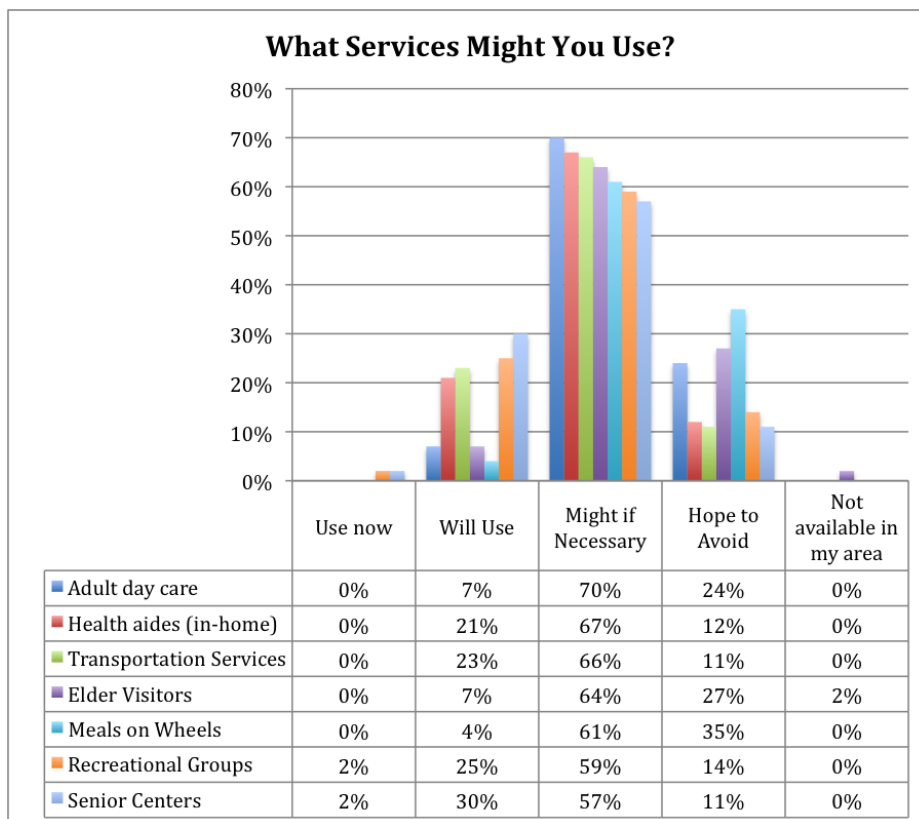
We also did a quick crosscheck to see if those who ranged themselves high (between 2 to 4) on the concern scale had fewer expectations of WHO would care for them. The differences were not significant. The percentage relying on partners, friends, and families of choice were quite similar. However, those 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.

The Use of Social Services for Elders in RI

As we can see from the data above, at least half of the lesbians responding to the survey expected they might use some form of elder services or agencies as they age. Anticipating this, we specifically asked, then, what 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 see what services elder lesbians in RI may be inclined to use, as well as what they WILL use as compared to what they hope to avoid. In general, most lesbians responding to the survey indicated they MIGHT use services for elders if necessary.

Figure 19: What Elder Services Might Be Used



Unfortunately, though, the options for Senior/Community Housing, Assisted Living, or Nursing Home were inadvertently omitted in question #77. The responses may be in the same ranges, but in this case, we do not know.

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 you were to need social service healthcare supports in RI, would you feel comfortable letting agency staff know you are a lesbian/gay?” While the majority (69%) said they would let agency staff know their orientation, 0% responded “no,” 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.”

We also wanted to know whether the fear of exposure of sexual identity/orientation might prevent the use of these services. Also, if sexual identity was known, do lesbians feel this would that compromise the level of care or respect they would receive from those services? As we can see from the grids (see Figures 20 and 21), 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. 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

Figure 20: Fear of Disclosure Preventing Use of Services

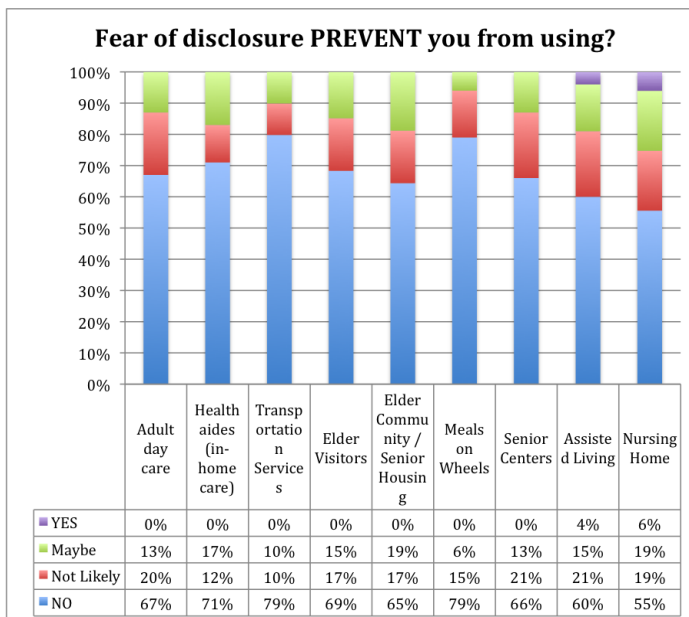
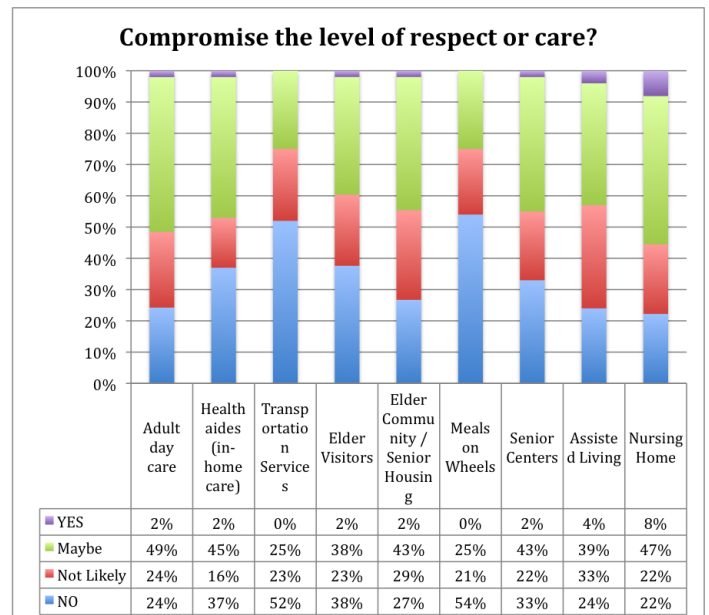


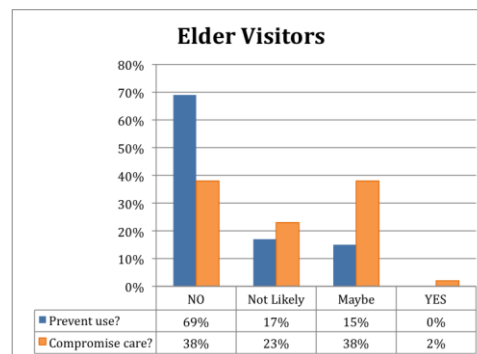
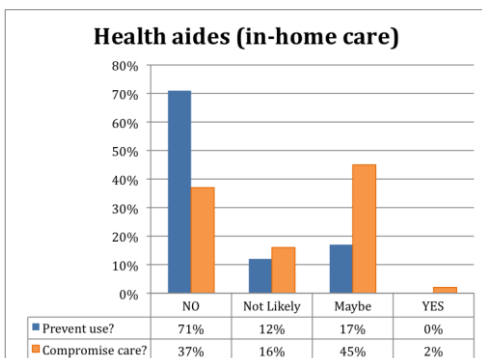
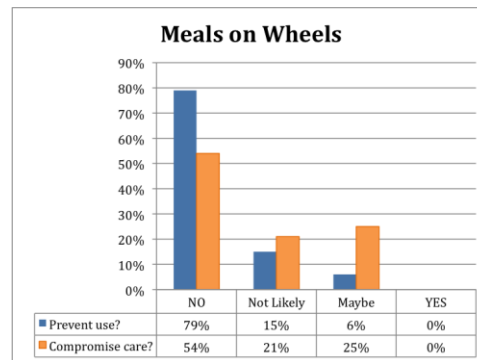
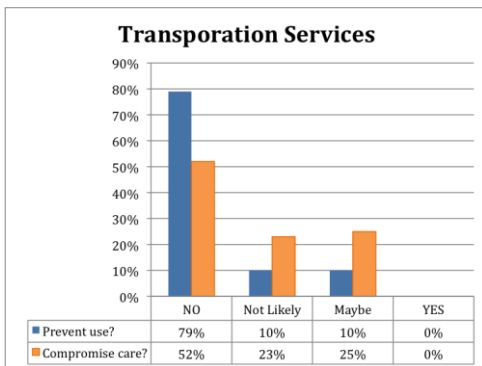
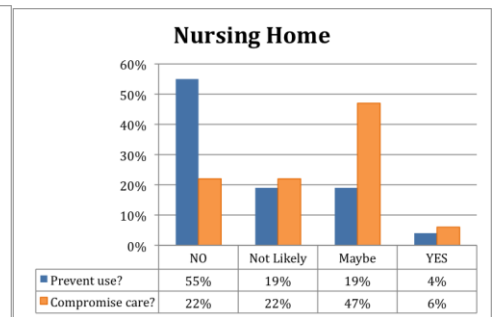
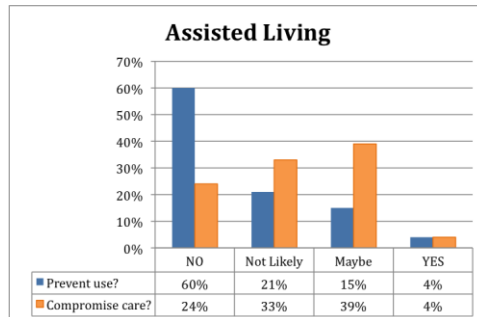
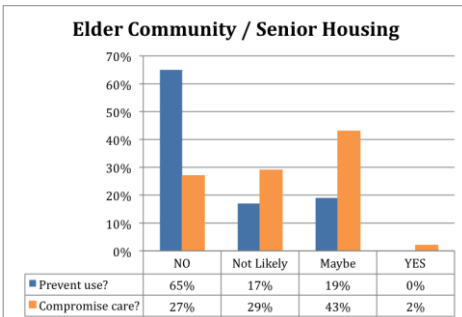
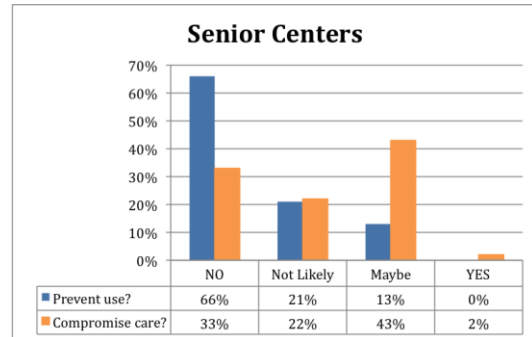
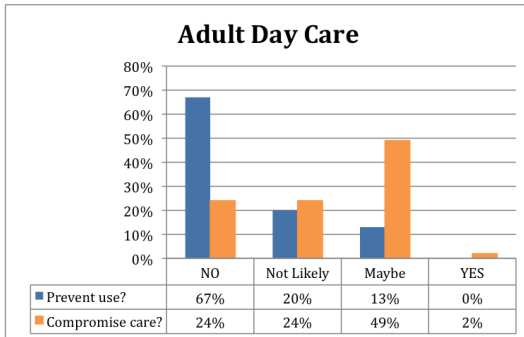
Figure 21: Care Compromised if Sexual Identity Known?



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 we may not be able to draw any conclusions, but it is curious to see the comparisons, especially when it comes to housing situations.

Figure 22: Elder Services — Fear of Disclosure Preventing Use Compared to Concern for Compromised Care



Do you have additional comments about #77 - 79?
--

We requested additional comments related to questions #77-79 about the use of elder services. These are the comments we received.

- 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 are 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?
- A 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 & 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 & 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.

Current Residents Living in Senior Housing, Assisted Living, or Nursing Home

Questions 81 - 86 pertained ONLY to those who currently receive in-home care -- OR -- live in Senior Housing, Assisted Living, Nursing Home, or similar facility.

We had 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."

Section 5 - Question 88

We invite you to make any additional comments about this survey in general.

- Very thorough, informative that makes me think about my aging as a lesbian.
- This survey 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 a survey.
- 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 survey that encompasses all aspects of lesbian/elder lesbian healthcare issues. I commend you for this survey!
- Too Long (2 comments like this)

Section 2: Provider Survey - Healthcare for Elder Lesbians

The survey 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 partial responses in the Zoomerang; those are NOT included in this data report. Additionally, we did offer printed surveys and received 53 mailed responses. The state’s Quality Improvement Organization for healthcare had made the hard copies of those surveys 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.**

Provider Survey Section 1: General Information

These questions, intended for ALL providers, built a profile about general care for elder lesbian patients / clients.

Question 1 & 2

Percentage of patients / clients served

We started the Provider Survey by asking them:

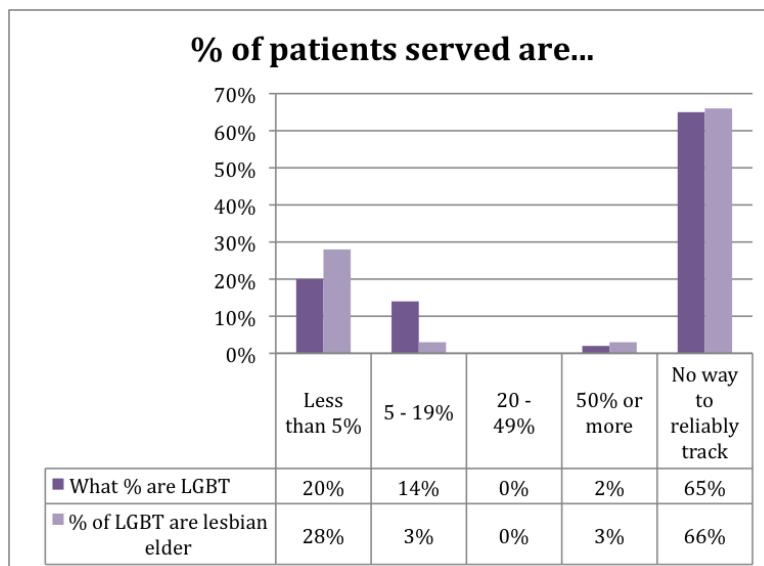
- What percentage of provider’s patients/clients is LGBT

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).

Figure 23: Percentage of LGBT Patients & Subset of Lesbian Elders



Question 3 - 6

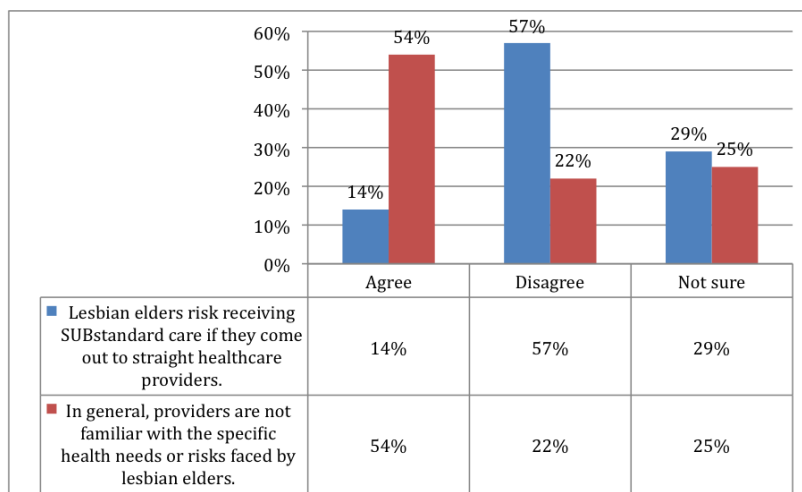
Levels of Care

From the perspective of providers, we wanted to know about the level of care available to elder lesbians. We asked these them to agree or disagree with these two statements:

- Lesbian elders risk receiving SUBstandard care if they come out to straight healthcare providers.
- In general, providers are not familiar with the specific health needs or risks faced by lesbian elders.

Figure 24: Substandard Care Compared to Knowledge of Lesbian Health Issues

While the majority (57%) disagreed that lesbian elders risk of receiving SUB standard care, it also seems that the majority (54%) agree 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 2 providers (3%) who do have 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.

Provider Survey Section 2: Policies & Practices

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

Question 6 - 9

Lesbian-friendly providers

Of the 65 responses we 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 they:

- Are 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 (1) – response from a Home Health Provider
- Unknown (1)
- This is never addressed (1)

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:
 - Patients treated with dignity and respect
 - Staff are trained
 - “I believe it is all in the way they are treated - JUST LIKE EVERYONE ELSE!”
 - “Our open, friendly, accepting, and caring attitude.”
 - “Discrimination is not tolerated”
- Providers ask open-ended, non-assuming questions about sexual orientation and practices
 - “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
 - Providers who are out and list LGBT as a specialty and/or talk about healthcare challenges (2 mentions)
- Materials are posted or provided
 - Stated in literature and admission policy/packets and posters in units
 - Language used on forms
 - LGBTQQ friendly materials on display (SAGE Posters, Options Magazine)
 - 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 7 responses (18%) indicated they have no idea or are unsure how their clients would know that.

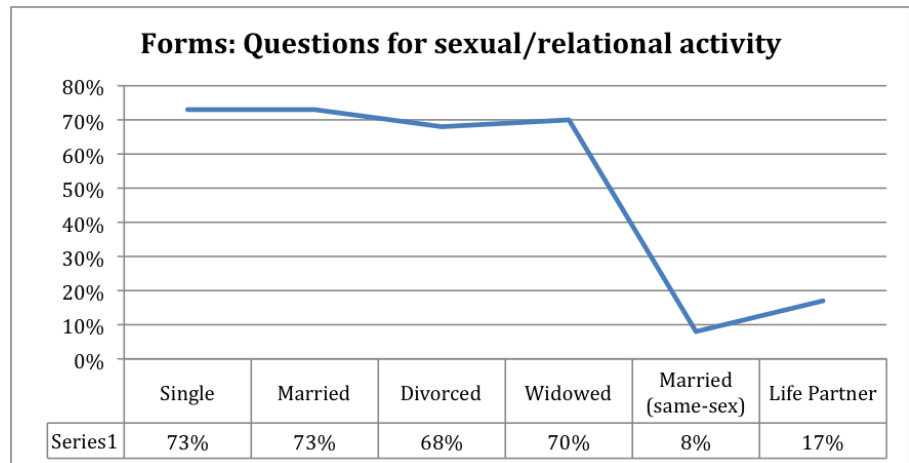
- They would not necessarily know that. Our mission statement says we serve the entire community, and that is meant to be inclusive of everyone. We expect all staff to deliver culturally competent care. That said, most lesbian patients have probably encountered

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/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.

Figure 25: Intake Forms—Indicators of Sexual/Relational Activity



Nearly 92% of the providers completed this question in some way (see Figure 25). Most providers (nearly three-quarters) indicated the use of traditional hetero-normative indicators for sexual/relational activity.

Those who used the option “Married same-sex” used this along with Married. This was also true (except in one case) for those who offered the option “Life Partnership / Long-term relationship.” Additionally, of those who use these terms, five (5) 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 the offer the option for “transgender.”

There were thirteen providers (22%) who did not select any of the options we offered to the question of intake forms, but they did provide their own options/comments. We’ve organized them here 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 # and what the relationship is to my client.
- No intake forms (2), one asks in context
- Blank or Not Sure (2)

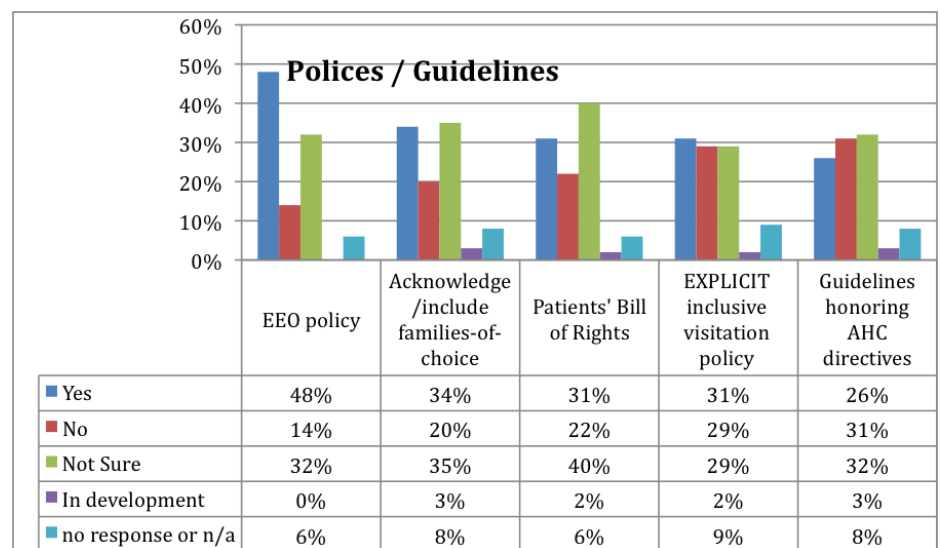
Another way to determine the support or attitude about LGBT patients/clients it to find out if providers have specific policies and practices in place and what the consequences might be for not following those stated guidelines. So, we directly asked:

Question # 9: Does your office / practice / facility have:

- a Patients' Bill of Rights and/or non-discrimination policy that EXPLICITLY includes sexual orientation?
- a 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?
- an EXPLICIT 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 all 65 (100%) of respondents. As we consider WHO filled in the surveys, predominately nurses and support staff (see below), 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.

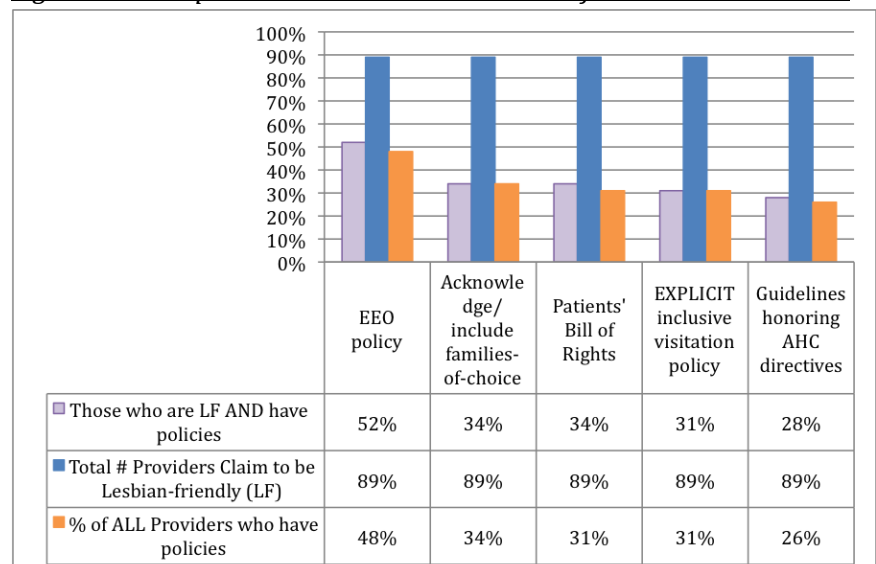
Figure 26: Providers with Stated Policies Pertaining to LGBT Clients



Earlier we noted that 89% of providers who responded to our survey claim to be lesbian-friendly, and 40% of those indicated they follow non-discrimination policies and treat all patients the same.

But the actual numbers reveal discrepancies. We compared the actual numbers of those who claim to be lesbian-friendly with the policies they DO 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 who claim they have actual policies in place (i.e. "Yes" to Question #9). The orange bars to the right indicate ALL

Figure 27: Compare Policies in Place to Claim of Lesbian-Friendliness



providers who claim they have actual policies in place (i.e., the “Yes” columns in Figure 26).

We asked for additional comments to the question of policies. Emergent themes include:

- Providers are willing to look into policies now that this survey made the point.
 - Points out things that I should check into for the agency where I work.
 - Would consider these items now that it is broached
 - I'm not extremely familiar with my employer's policies / guidelines with respect to LGBT specifically.
- 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 who 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 (r.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
- 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 Health Care directives
 - I am a one person psychotherapy office so don't have much of this in writing or it is n/a
- Miscellaneous Responses included:
 - Sexual orientation not asked/talked about at employment
 - Same sex partners are not allowed benefit coverage for 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.

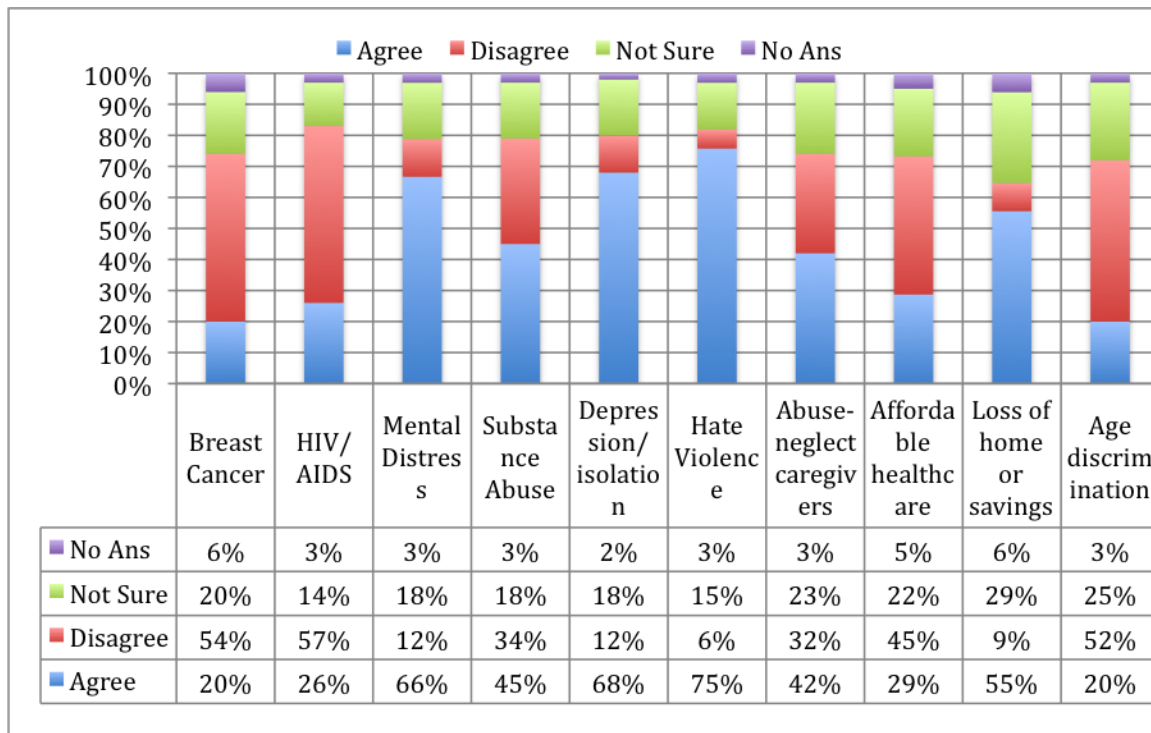
We also asked what the consequences are for “medical personnel, administrators, or staff who do not adhere to or honor the policies as outlined by your office, practice, or facility.” We received 28 written responses to this open-ended question. Of those who responded, seven (25%) were not sure what 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.

In a few responses (14%), the 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.

RISK Factors

As we mentioned in the Lesbian Elder Survey (Section 2, Question #18, p.9), 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. We wondered whether healthcare providers in RI are aware these issues. The risks we 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, age discrimination (see Figure 28). These are the responses given by the providers who responded to the survey. In Section 4 of this report, we will compare the findings from both surveys.

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



Provider Survey Section 3: Demographics – Provider Respondents

These questions helped us to understand responses within a context of WHO answered them.

**** Indicates MANDATORY response required**

Questions 13 and 14 on the Provider Survey sought the primary location and professional roles of providers completing the survey (See Tables 12 and 13).

Table 12: Locations of Provider Respondents

ZIP CODE	City	Count
	All 1 responses unless otherwise noted	
02804	Ashaway	
02806	Barrington	3
02809	Bristol	
02814	Chepatchet	
02817	W. Greenwich	
02818	E. Greenwich	2
02828	Smithfield	
02840	Newport	3
02842	Middletown	3
02852	N. Kingstown	
02859	Pascoag	3
02860	Pawtucket	5
02863	Central Falls	
02874	Saunderstown	
02879	Wakefield	2
02882	Narragansett	
02886	Warwick	3
02891	Westerly	
02893	W. Warwick	3
02903, 02904, 02905, 02906, 02907, 02908, 02911	Providence	15
02914	E. Providence	
02916	Rumford	
02919	Johnston	
02920	Cranston	
	NO RESPONSE	9

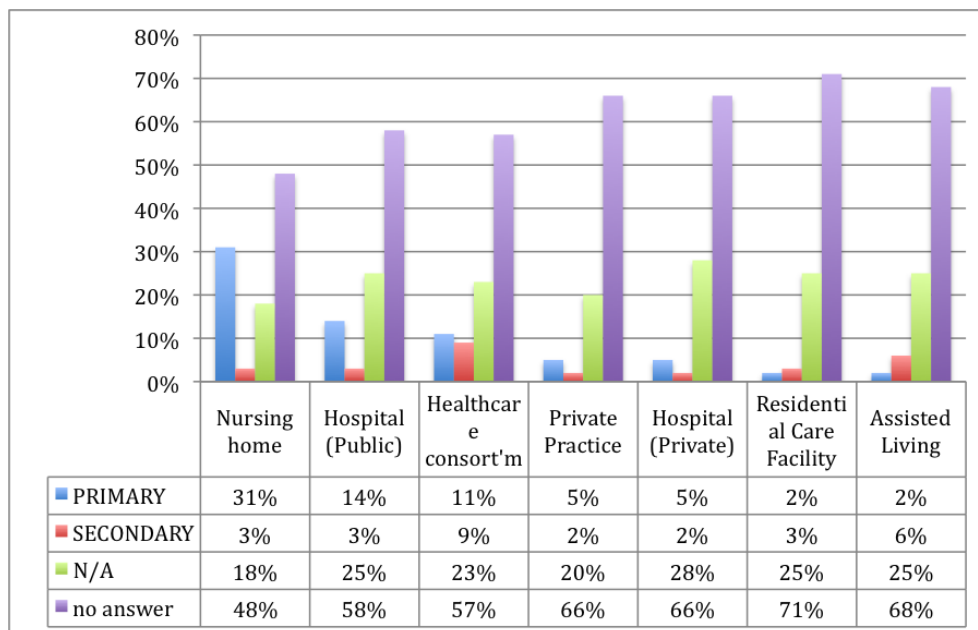
Table 13: Provider or Agency Staff Completing the Survey

Physician (Primary Care)	4
Physician (Geriatrician)	1
Physician (Other Specialist)	1
Nurse or Nurse Practitioner	40 (Nurses also included these comments, 1 each: Administrator, Owner of Facility, Care Manager, Clinical Nurse, Specialist, CAN)
Administrator	5
Support Staff / general care provider	2
Other, please specify	Intern, Director of Clerical (?) Service Home Care, Psychotherapist, Clinical Social Worker, Pharmacist (3), Acupuncturist, Quality & Compliance
Blank / No response	2

Additional Demographics: Types of Healthcare Services, Professional Roles, and LGB Staff

We also wanted to know what type of healthcare service these providers offer. We asked them to indicate both primary and secondary services (see Figure 29) and to list other forms of services they provide if not indicated in our choices.

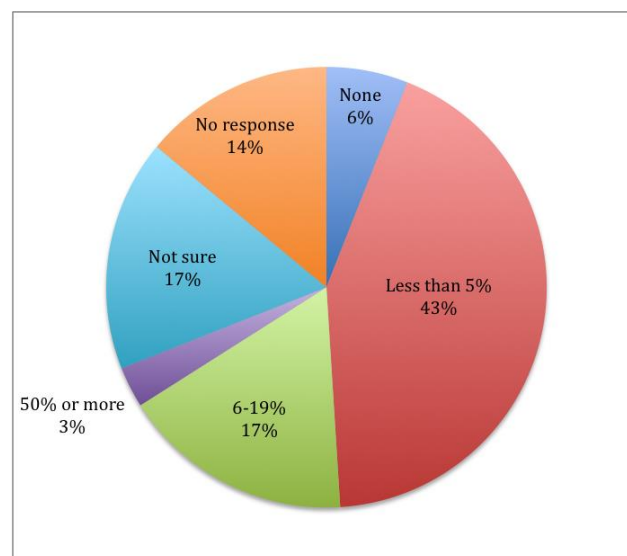
Figure 29: Primary and Secondary Types of Healthcare Services



The additional services of the respondents include:

- 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 (4)
- PACE
- Pharmacy
- Private Home Care
- Social Services Agency
- Sub acute (Nursing Home)

Figure 30: Percentage of Professionals in Agency/Facility Known to be LGB



We also wondered if the providers had a sense of who among their colleagues are known to be lesbian, gay, or bisexual (see Figure 30). Nearly half indicated having fewer than 5% or no LGB colleagues. None of the responses indicated the answer range of 20-49% LGB colleagues. One-third, though, either did not answer the question or said they just didn't know.

Provider Survey Section 4: Residential Services (Long-Term Care, Nursing Homes, Assisted-Living, etc.)

These specific questions were intended ONLY for those responding on behalf of nursing home, assisted living, or other long-term/residential and similar facilities.

Section 4 was designed only for those providers offering some form of extended stay in residential services. Thirty-eight of the 65 providers who responded to the survey (58%) completed this section. Of those who answered this section, 20 (53%) indicated their primary service as nursing home. One indicated it is an Assisted Living Facility while two others stated they are Home Health Care agencies.

Table 14 Types of Services that Completed Section 4

Services	Number	Percent
Nursing Home	20	53%
Assisted Living	1	3%
PACE RI	1	3%
Home Health Care Agencies	2	5%
Hospitals, Clinics, Healthcare consortium, etc. offering residential as additional care option	9	24%
No response to type of service but answered questions in this section	5	13%
TOTAL RESPONSES	38	

The full range of answers from all facilities to the questions is featured below. Because the majority of response came from nursing home facilities, we will specifically highlight their responses. 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.

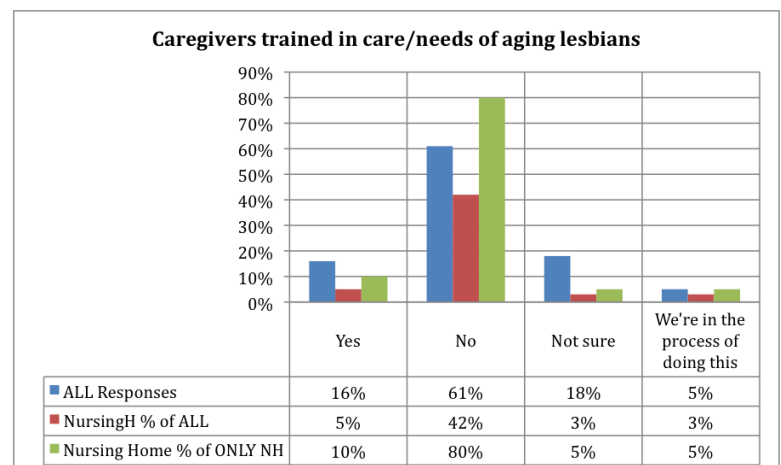
Question 18

Are caregivers / staff at your facility trained or experienced in the specific healthcare and aging needs of lesbians?

We wondered if residential staff received any kind or specific healthcare or cultural awareness 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 nursing home staff reported they receive no specific training in lesbian elder healthcare. One of the responses from a Nursing Home that offers NO training offered this comment:

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

Figure 31: Caregivers Trained in the Needs of Lesbians



One general care facility that DOES offer training stated this happens within the context of annual in-service training.

Question 19 - 22

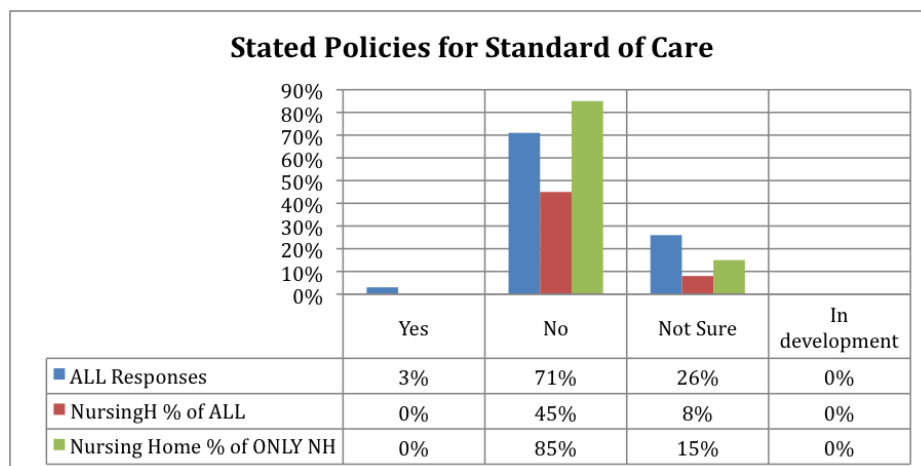
Clear and Stated Policies for Care and Resident Rights

In addition to training, we also wondered whether residential facilities had stated specific policies to guide them in standards of care specifically for LGBT clients as well as protect their clients, and to what extent staff knows about them. We asked two specific questions:

1. (Q19) Do you have stated policies or standards for caring for lesbian (LGBT) clients / residents? and
2. (Q 20) Does your facility provide written policy statements (such as a "Bill of Rights") to your residents / clients?

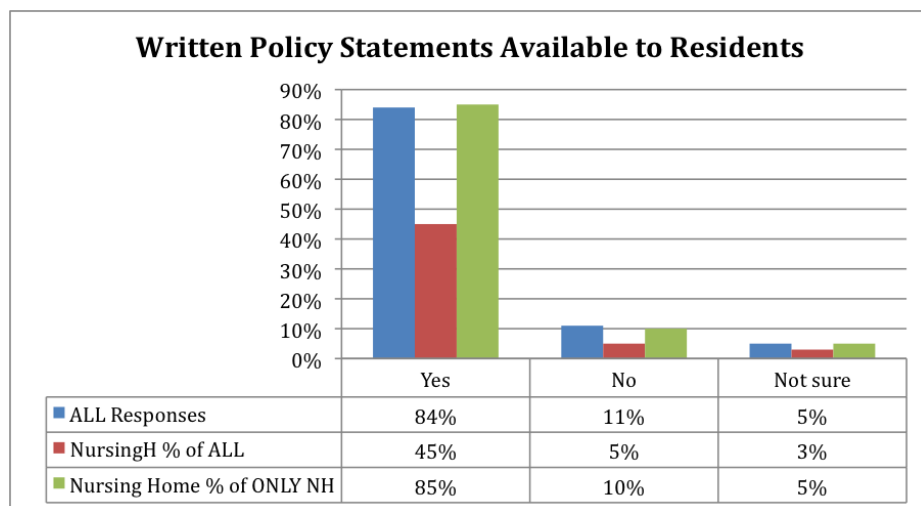
In addition to not receiving training the majority of staff in these facilities claims to NOT have policies or standards to specifically guide them in the care of LGBT patients (see Figure 32). Two of the responses from Nursing Homes that answered NO to this question offer explained that they feel their policies cover ALL patients and are not specific to age, race, religious beliefs or sexual orientation.

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



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). We received a number of responses to the open-ended explanation space related to this question. Curiously, most of these statements came from the

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



same Nursing Home facilities that responded they have no training for staff and no stated policies! These 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 are also posted throughout the facility.
- All residents families/staff receive education 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 pt on POA
- All residents treated with respect and dignity regardless of sexual orientation. This includes resident's rights of privacy with visits, etc
- Bill of rights are reviewed on admission with 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 facilities 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 [persons] are educated to these regulations. A violation by law may result in termination."

Question 22

How does your facility handle hostile or prejudicial treatment by staff towards lesbian (LGBT) clients/residents?

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 (2 responses)
- 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

Several responses (18%) indicated respondents have not yet 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

How does your facility handle hostile or prejudicial treatment between residents, especially hate or bias against lesbian (LGBT) residents?

In general, of the 63% who responded to this question, most places do not tolerate resident-to-resident 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. Expectation r.e. 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 more proactive stance 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 & screened.”

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

Question 24 & 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:

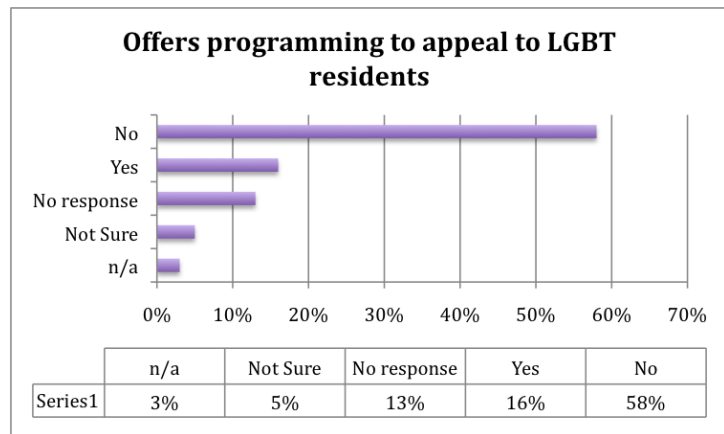
- Reside together in the same dwelling or room;

- Share the same bed if they choose; and
- Participate in each other’s care or decision-making

Of those who responded to the Residential Questions section of the survey, 53% allow for 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).

[Reminder: 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.]

Figure 34: Options for Same-Sex Couples in Residential Facilities

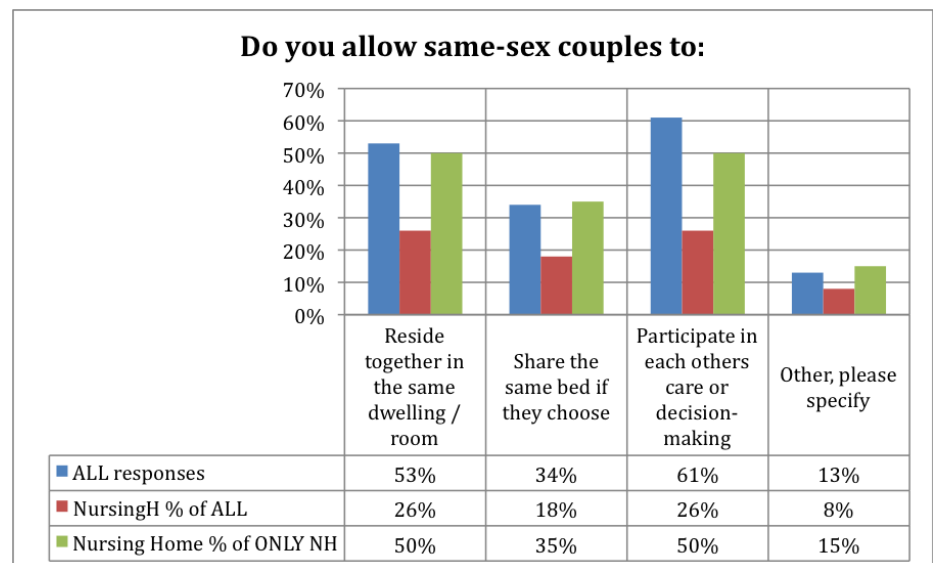


One of the facilities that responded positively to these questions also added, “They are afforded the same rights as heterosexual couples. It would be discriminatory to do otherwise.” One respondent, who works in a Catholic hospital, answered that she herself as a worker would permit lesbian-couples 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 the hospital.

One respondent did NOT select the share room/dwelling or bed options, but noted they have private rooms. It’s unclear, though, what would be available in those private rooms! Three of the nursing home respondents did NOT select any of these options, but also noted that they have not yet 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 facilities indicate they do not, though one facility said they would if it was requested.

Figure 35: LGBT Programming at Residential Facilities



Question 26

If your facility openly supports lesbian (LGBT) residents/clients, have you (as an institutional provider) experienced harassment, limited financial support, or other bias?

Due to the responses we received, it may be safe to assume that 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.

Section 3: Critical Comparisons between the Surveys

While the responses on each survey are interesting in themselves, we also thought it would be important to cross-reference some of the data. The key question (among many) is this: How do the perspectives of lesbian elders compare to the perceptions, knowledge, or attitudes of healthcare providers? Throughout this next section, we will refer to the surveys in this way:

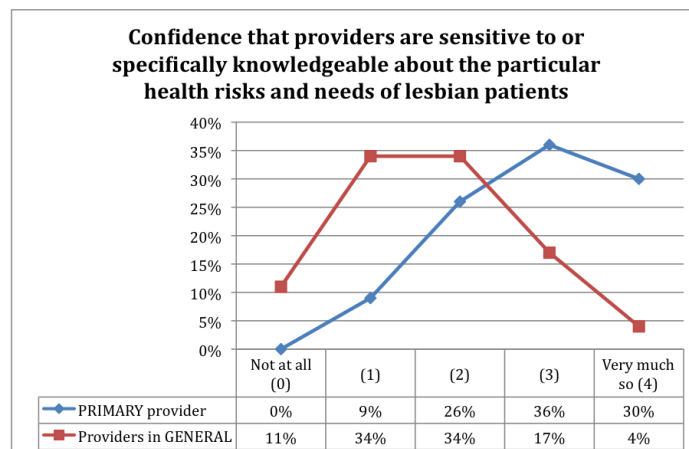
- Survey of Healthcare for Lesbians completed by Individuals as: “L-Elders”
- Provider Survey on Healthcare for Lesbian elders as: “Providers”

Knowledge about Lesbian Healthcare Needs

In the L-Elders survey, 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? And
- **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?

Figure 36: L-Elders Confidence in Providers



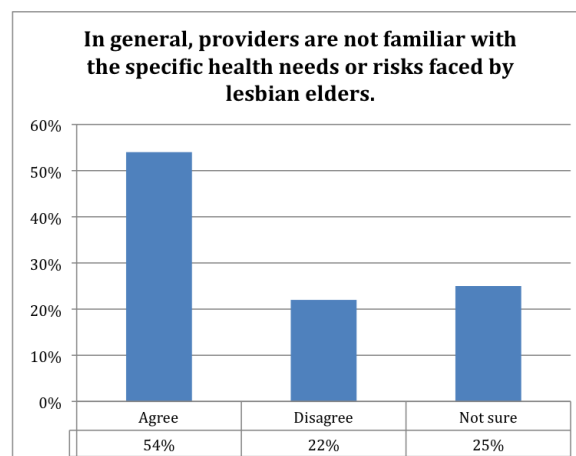
Similarly, we asked Providers:

- **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). If we look at the lower end of the range from 0-2, we see that 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).

Figure 37: Provider Familiarity with Lesbian Elder Healthcare Issues



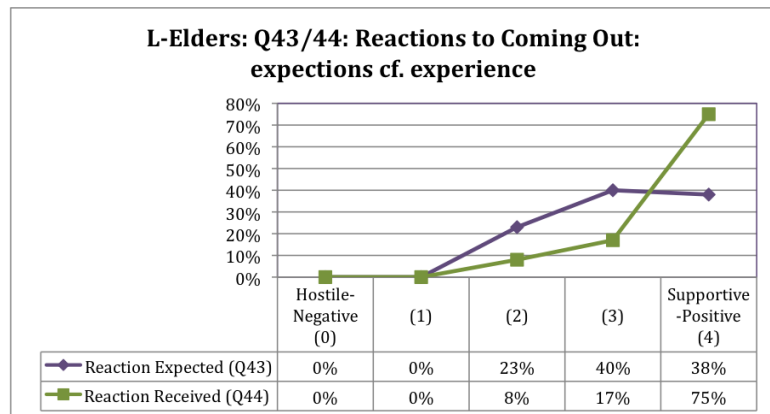
From this, we can conclude that both patients and providers AGREE that more information, education, and knowledge about the particular health risks and needs of lesbian patients, especially elders, needs to be made available. Awareness training and education would benefit everyone.

Knowledge about Lesbian Healthcare Needs

In the L-Elders survey, we asked a series of related questions:

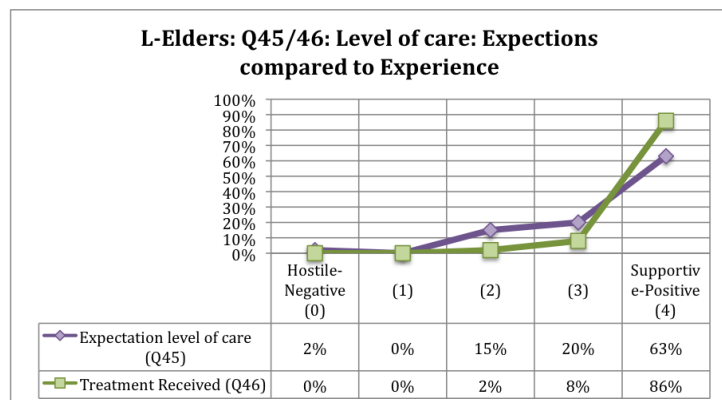
- **Q43:** If / when you were to disclose your sexual identity/orientation, what kind of reaction did you EXPECT? And
- **Q44:** If / when you HAVE disclosed your sexual identity/orientation (or our provider figured it out), what kind of reaction did you receive?
- **Q45:** If your physician(s) or healthcare 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?

Figure 38: Reactions to Coming Out - Expectations as Compared to Experiences



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 we asked L-Elders, the Provider responses do give us some insight into their general openness towards lesbian patients.

Figure 39: Levels of Care - Expectation Compared to Experience



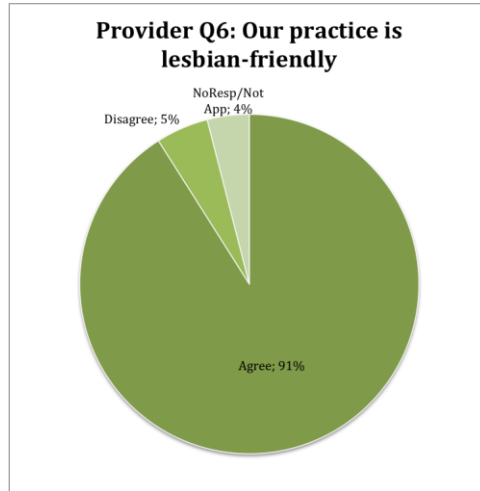
Figures 38 and 39 illustrate that while lesbians may be skeptical and expect negative reactions or

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. (GLMA, 2006, p. 24-25).

Figure 40: Providers as Lesbian-Friendly



Policies to Follow Legal Directives

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

- a Will
- 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:

- a Patients' Bill of Rights and/or non-discrimination policy that EXPLICITLY includes sexual orientation;
- a 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; and/or
- an 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, we will focus on the AHCD and the Durable Power of Attorney (DoPA) as these are the ones most likely directly affecting interactions with healthcare providers. We saw that many L-Elders do have some legal safeguards in place, especially AHCD.

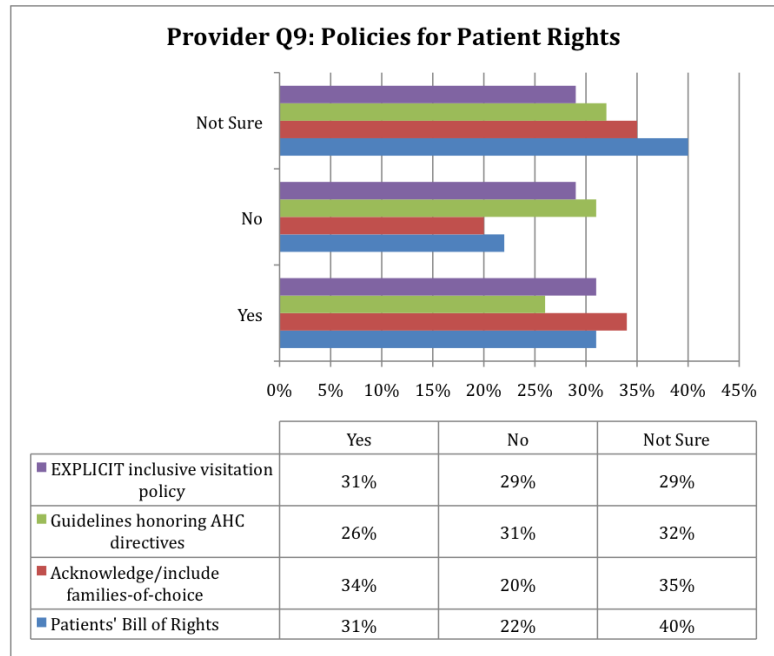
Table 15: Legal Documentation & Confidence

L-Elders Q 68 & 69	Yes	In Process	Not yet, Plan to	No	Confidence will be followed: Moderately So	Confidence will be followed: Confident
Advanced Health Care directives (AHCD: Living Wills and Health care power of attorney)	85%	8%	4%	2%	39%	57%
Designated person(s) with Durable Power of Attorney	77%	6%	8%	8%	29%	69%

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

L-Elders skepticism on this issue may be well founded. Less than 35% of the providers who responded indicated that they definitely have policies and practices in place that will ultimately safeguard lesbian-rights 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 we exactly asked both L-Elders and Providers had to do with specific risks to lesbian health (see Section 2, L-Elders Q18 and Section 3, Providers Q 12). As we mentioned, the chapter on health and wellness in the report *Aging in Equity: LGBT Elders in America* by the Funders for Lesbian and Gay Issues (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 lesbian elders. This question was derived from those indicators.

The risks we 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 below (using the sources cited above) shows a factor-by-factor comparison between L-Elders' and Providers' knowledge about each risk factor for aging lesbians. As you can see from the responses we received, this information is significant and shows that neither providers nor lesbians know much about healthcare risks for lesbian elders.

Breast Cancer (Figure 42)

Research suggests that lesbians are at an elevated risk for breast cancer NOT because they are lesbians. Lesbian lifestyle (or behavior) corresponds to the factors correlated with higher cancer rates exist:

- Cigarette smoking
- Alcohol Use
- Obesity
- Lack of childbirth (especially prior to the age of 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. – GLMA, 2006, p. 26

Figure 42: COMPARE - Breast Cancer

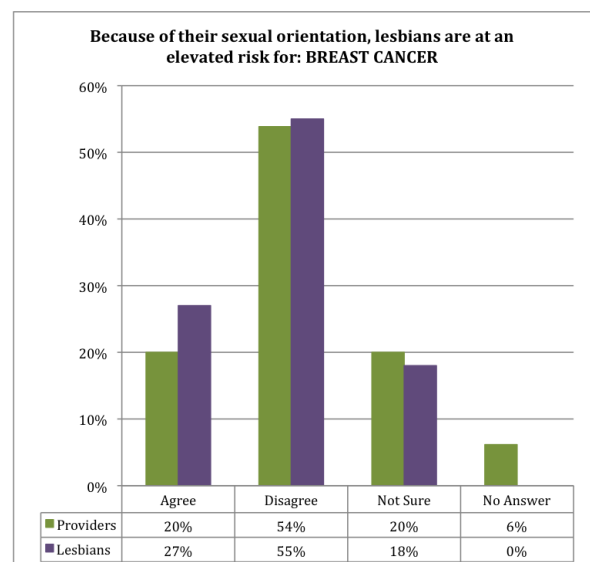
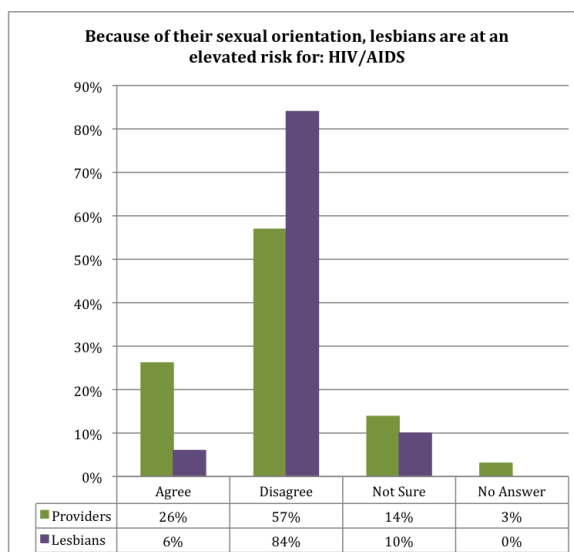


Figure 43: COMPARE - HIV/AIDS

HIV / AIDS (Figure 43)

“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” (GLMA, 2006, p. 28). 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.



Mental Distress (Figure 44) & Depression (Figure 45)

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”(GLMA, 2006, p. 26). Those additional stressors include:

- Estrangement from families
- Challenges adjusting to minority sexual orientation
- Hiding aspect’s of one’s identity over a lifetime
- Hostility and abuse faced throughout ones 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 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. 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

Figure 44: COMPARE - Mental Distress

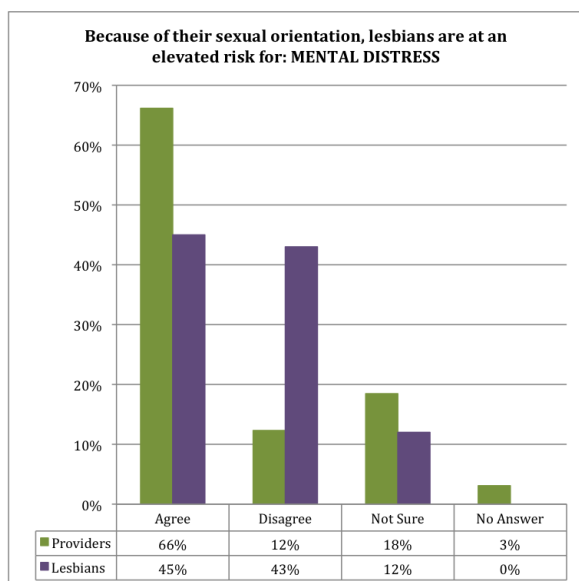
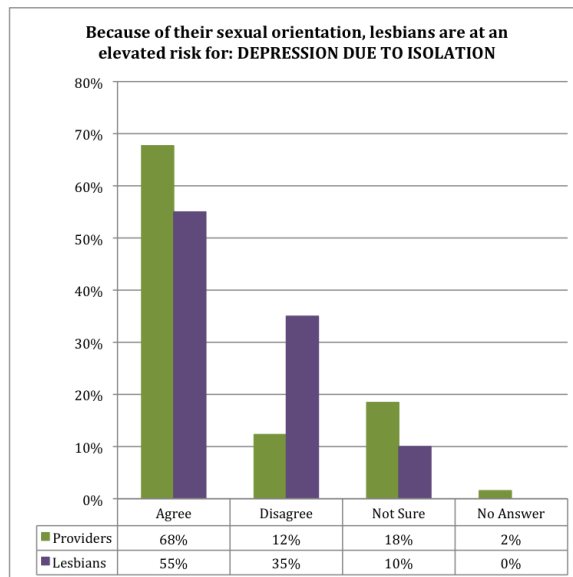


Figure 45: COMPARE - Depression

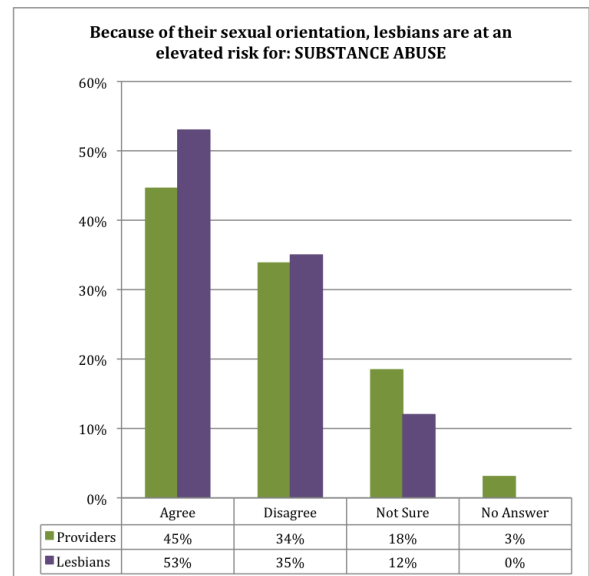


establishment (Funders, 2004). “Lesbians and bisexual women of color face a ‘double jeopardy’ due to the added stress of racial or ethnic discrimination that may place them at even higher risk”(GLMA, 2006, p. 26).

Substance Abuse (Figure 46)

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. 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 (GLMA, 2006, p. 26).

Figure 46: COMPARE - Substance Abuse



Hate Violence (Figure 47) & Elder Abuse (Figure 48)

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.

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. Fear of

Figure 47: COMPARE - Hate Violence

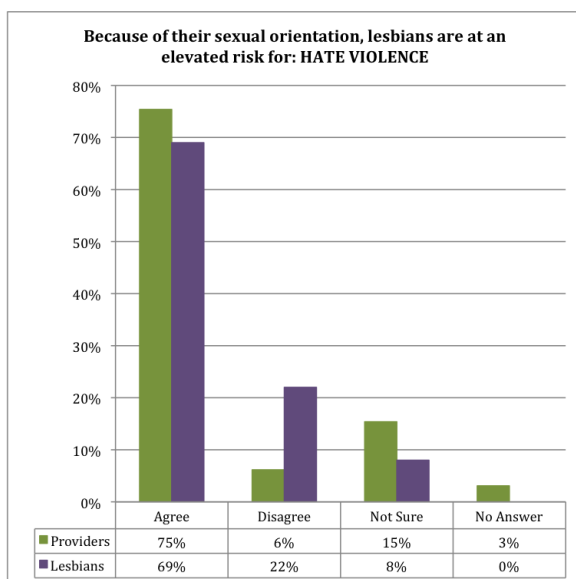
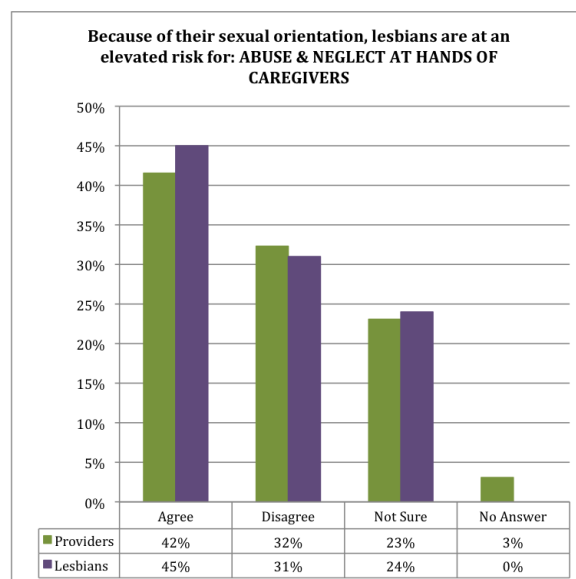


Figure 48: COMPARE - Abuse & Neglect from Caregivers



institutionalization and general distrust of law enforcement authorities often discourages LGBT elders from reporting abuse and neglect (Funders, 2004).

Economics of Healthcare (Figures 49-50)

The following quotes are taken from several publications.

Because legally sanctioned marriage is one of the primary routes to health insurance in the U.S. (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. (GLMA, 2006, p. 25)

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. (MAP & SAGE, 2010, p. 20)

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)s, pensions, veterans benefits, and employee benefits such as spousal health care coverage for retired workers, partnered LGBT elders face major disparities that have real and lasting impacts on their financial security and health and well-being, when compared to heterosexual married couples (MAP & SAGE, 2010, p. 9).

NOTE: Even if Rhode Island did allow for the legal marriage of lesbian couples, federal law (Defense of Marriage Act – DOMA) 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

Figure 49: COMPARE - Affordable Healthcare

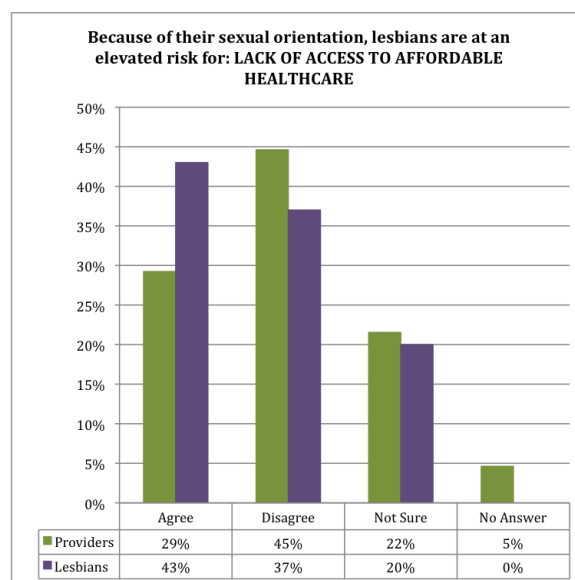
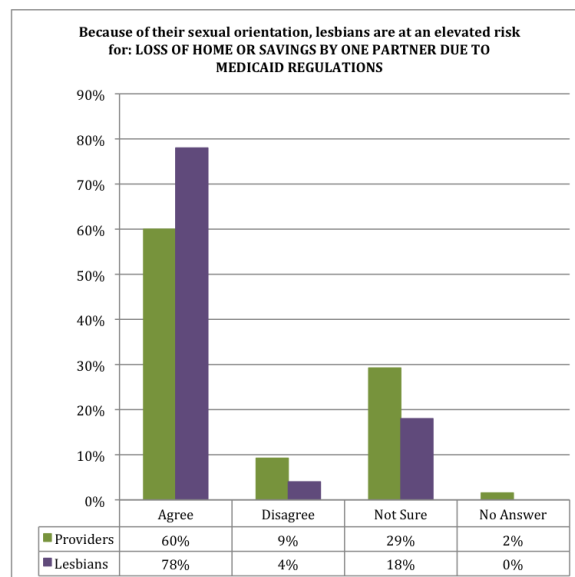


Figure 50: COMPARE - Loss of Home, etc.



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” (Funders, 2004, p. 13).

Also note:

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 5-year financial look back policy [<http://www.caregiverlist.com/Rhode-Island/medicaid.aspx>] making an immediate transfer of property a liability.

For more detail on Medicare & Medicaid from an LGBT perspective, see MAP & SAGE (2010) pages 15-16.

For Rhode Island information about Medical assistance for seniors, go to:

<http://www.dhs.ri.gov/Elders/HealthMedicalServices/tabid/285/Default.aspx>

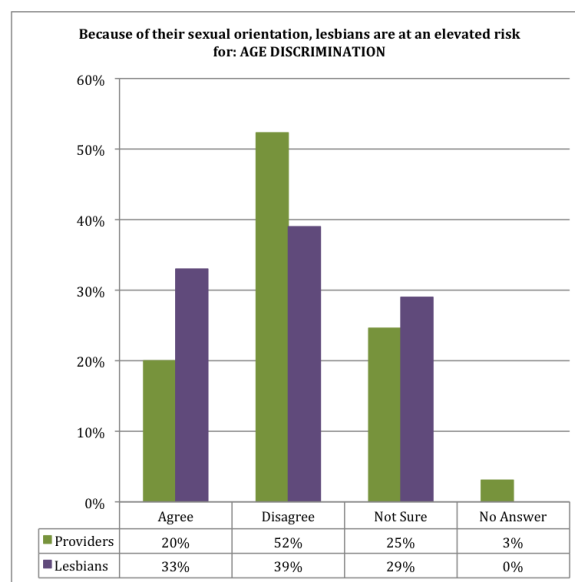
Age Discrimination (Figure 51)

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. 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.

(MAP & SAGE, 2010, p. 4)

Figure 51: COMPARE - Age Discrimination



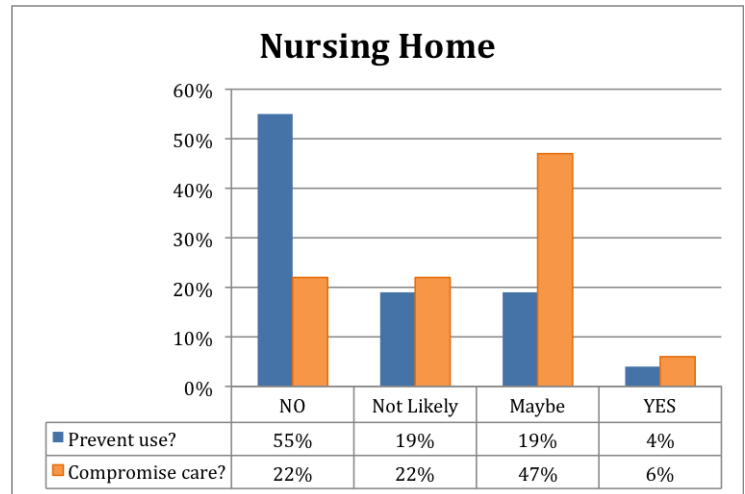
Conundrum: Nursing Homes

We added this comparison on Nursing Homes 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 DID ask them:

- **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].

Figure 52: L-Elders Concerns for Coming Out to Nursing Home Staff



As we can see from the responses (see Figure 52), L-Elders are concerned their disclosure might compromise their care. 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 (MAP & SAGE, 2010, pp. 35-36).

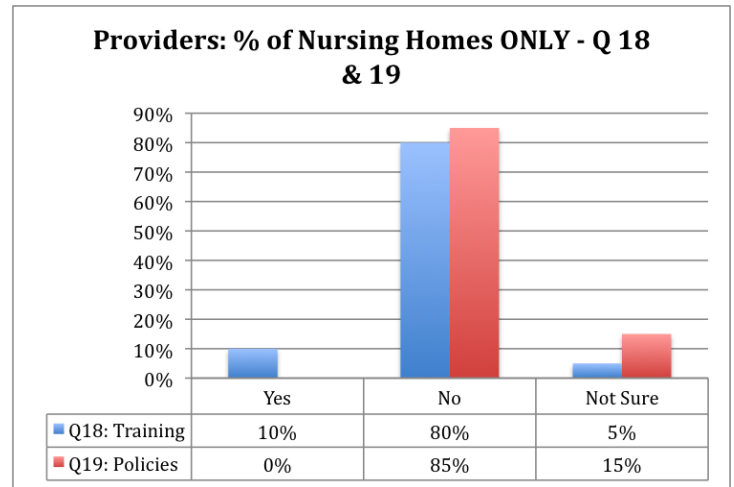
We asked Providers, specifically those offering residential services such as nursing homes, these questions:

- **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 survey 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 in *Improving the Lives of LGBT Older Adults* (MAP & SAGE, 2010). “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” (37).

Figure 53: Providers in Nursing Homes Experienced n Lesbian Elder Care



Section 4: Concluding Remarks / Observations / Guides to Next Steps

In Section 1 and 2 of this survey report, we have generally recorded the responses we received from lesbian elders and healthcare providers in Rhode Island. Section 3 offers some comparisons between the two surveys as well as connections to national research studies. Since our data pool is relatively small and reached only a limited population of lesbian elders and providers, we may not be able to draw any definitive conclusions. We do think, however, we can offer some observations to point us towards future discussions, additional research, and advocacy for lesbian elders in Rhode Island. We offer these suggestions in order as they appear in the report, rather than by developing priorities.

L-Elders Survey – 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 survey (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 (etc): 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 (etc.): Question: Do lesbians know why / how / when they SHOULD be out in order not to compromise their health and care?
- Q45-46 (etc): 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 familiarity 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 Survey – Observations:

- Q1: So many providers (65%+) – DON'T track the sexuality of their patients – why? Do they track gender, age, race, etc? Or 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, etc)

As mentioned in comparatives in Section 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)

Index of Tables & Figures

Table 1: Towns Represented.....	5
Table 2: States Represented	5
Table 3: Ages over 65.....	5
Table 4: Ages 64 and Under.....	6
Table 5: Access to Care & Prescriptions.....	15
Table 6: Specific Health Issues for Respondents.....	16
Table 7: Alternative Care Choices	18
Table 8: Preference For a Female Healthcare Provider	20
Table 9: Expectations of LGBT Providers	21
Table 10: Identity Disclose to Providers.....	21
Table 11: What Guides Willingness Whether to Be Out to a Physician.....	22
Table 12: Locations of Provider Respondents	46
Table 13; Provider or Agency Staff Completing the Survey.....	46
Table 14: Legal Documentation & Confidence	57
Figure 1: Currently Employed	6
Figure 2: Income Level	6
Figure 3: Level of Being Out.....	7
Figure 4: Sexually Active with Men.....	7
Figure 5: Formalized Commitments.....	8
Figure 6: Agree or Disagree to Statement—Lesbians at Elevated Risk for Certain Health Issues	9
Figure 7: Self-reported General Health Ranges	13
Figure 8: Reactions to Coming Out: Expectations as Compared to Experiences.....	21
Figure 9: Levels of Care - Expectation Compared to Experience	22
Figure 10: Confidence in the Knowledge of Providers about Lesbian Healthcare	23
Figure 11: confidence in Confidentiality	23
Figure 12: Treatment in Medical Care Facility if Sexual Orientation Is Known	25
Figure 13: Depression & Sexual Identity.....	26
Figure 14: Type of Insurance Coverage.....	28
Figure 15: What Legal Documents Do You Have?	29
Figure 16: Confidence that Documentation Will Be Honored	29
Figure 17: Levels of Concern for Provision of Care or Support.....	32
Figure 18: WHO Do You Expect Might Care for You?	32
Figure 19: What Elder Services Might Be Used.....	33
Figure 20: Fear of Disclosure Preventing Use of Services.....	34
Figure 21: Care Compromised if Sexual Identity Known?.....	34
Figure 22: Elder Services — Fear of Disclosure Preventing Use Compared to Concern for Compromised Care	35
Figure 23: Percentage of LGBT Patients & Subset of Lesbian Elders	38
Figure 24: Substandard Care Compared to Knowledge of Lesbian Health Issues	39
Figure 25: Intake Forms—Indicators of Sexual/Relational Activity	41
Figure 26: Providers with Stated Policies Pertaining to LGBT Clients.....	42
Figure 27: Compare Policies in Place to Claim of Lesbian-Friendliness	42
Figure 28: Agree or Disagree—Lesbians at Elevated Risk for Certain Health Issues	45
Figure 29: Primary and Secondary Types of Healthcare Services.....	47
Figure 30:Percentage of Professionals in Agency/Facility Known to be LGB	46
Figure 31: Caregivers Trained in the Needs of Lesbians	47
Figure 32 Facilities with Stated Policies or Standards of Caring for LGBT Clients/Patients.....	48

Figure 33: Written Policy Statements (such as Bill of Rights) for Residents/Clients	48
Figure 34: Options for Same-Sex Couples in Residential Facilities	51
Figure 35: LGBT Programming at Residential Facilities	51
Figure 36: L-Elders Confidence in Providers	53
Figure 37: Provider Familiarity with Lesbian Elder Healthcare Issues	53
Figure 38: Reactions to Coming Out - Expectations as Compared to Experiences.....	54
Figure 39: Levels of Care - Expectation Compared to Experience	54
Figure 40: Providers as Lesbian-Friendly	55
Figure 41: Provider Policies for Patient Rights.....	57
Figure 42: COMPARE - Breast Cancer	58
Figure 43: COMPARE - HIV/AIDS.....	59
Figure 44: COMPARE - Depression.....	59
Figure 45: COMPARE - Mental Distress	59
Figure 46: COMPARE - Substance Abuse	60
Figure 47: COMPARE - Hate Violence	60
Figure 48: COMPARE - Abuse & Neglect from Caregivers	60
Figure 49: COMPARE - Affordable Healthcare	61
Figure 50: COMPARE - Loss of Home, etc.	61
Figure 51: COMPARE - Age Discrimination	62
Figure 52: L-Elders Concerns for Coming Out to Nursing Home Staff	63
Figure 53: Providers in Nursing Homes Experienced n Lesbian Elder Care	64

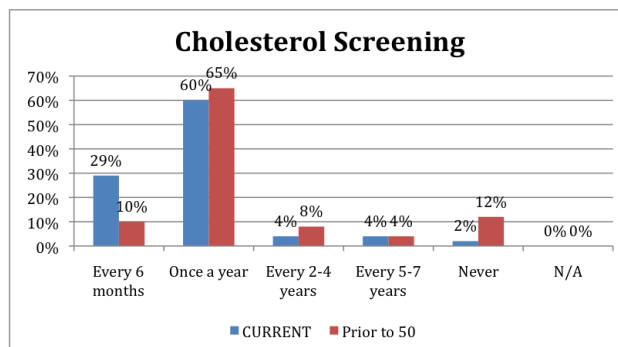
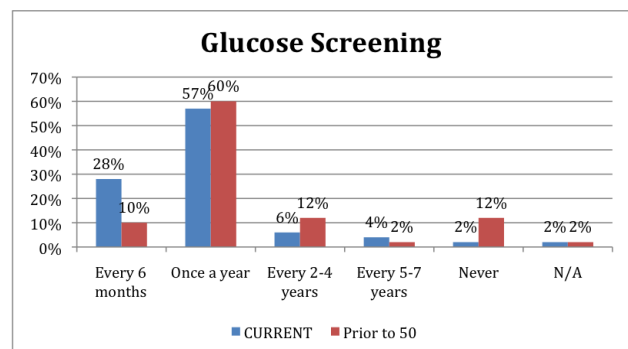
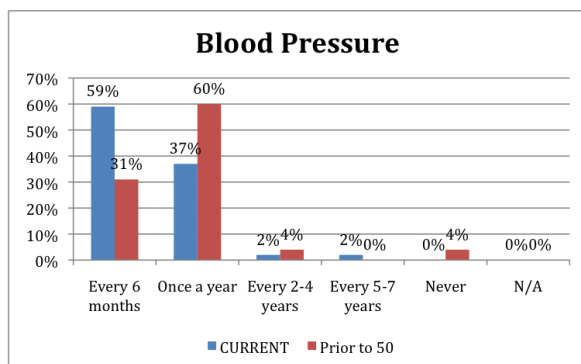
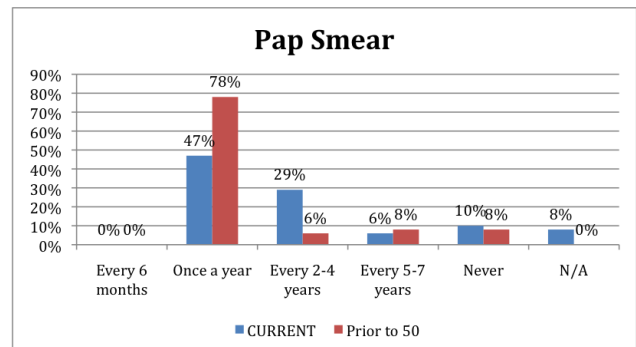
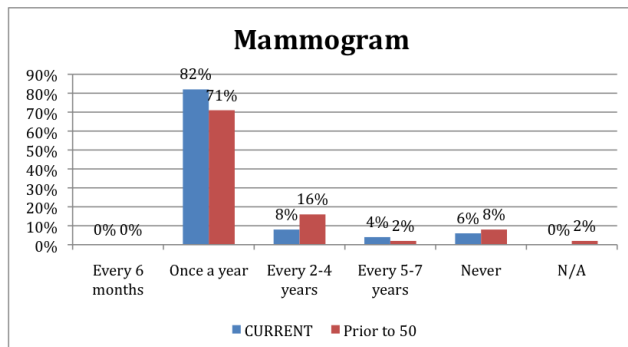
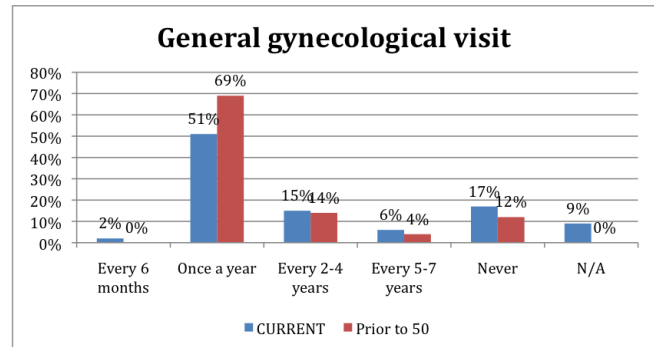
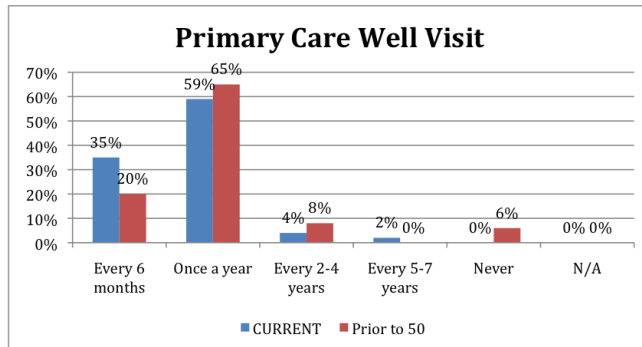
References

- Funders for Lesbian and Gay Issues. (2004). *Aging in equity: LGBT elders in America*. Retrieved August 2012 from: www.lgbtfunders.org/files/AgingInEquity.pdf
- Gay and Lesbian Medical Association (GLMA). (2006). Guidelines for care of lesbian, gay, bisexual, and transgender patients. (23-34). Retrieved August 2012 from: http://www.glma.org/data/n_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf
- LGBT Movement Advancement Project (MAP) and Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE). (March 2010). *Improving the lives of LGBT older adults*. Retrieved August 2012 from: <http://sageusa.org/uploads/Advancing%20Equality%20for%20LGBT%20Elders%20%5BFINAL%20COMPRESSED%5D.pdf>

Appendix 1: Frequency of Regular Health Screenings

These are the detailed graphs for Lesbian Elder Survey, Section 2 -23, 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 (cont.)

