

# **CAMP Rehoboth Community Center**

Health and Wellness Needs of the  
Senior LGBTQ Community in  
Sussex County, Delaware:  
A Needs Assessment



**CAMP Rehoboth  
Community Center**

**2016**

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**Executive Summary**

With the support of a Grant-In-Aid from the State of Delaware General Assembly, CAMP Rehoboth, a 501 (c) (3) nonprofit, LGBTQ community service organization, undertook a study to gather information about the health and wellness needs of the growing senior (50 years and above) population living in Sussex County, Delaware. This report focuses on the findings uncovered through a Survey Monkey questionnaire returned by 288 people, a focus group of 16 individuals, and a report from the Peer Leader of the Trans-Talk and TransParent discussion and support groups. A consultant analyzed the survey data and prepared tables showing numbers of responses to questions and percentages across age groups (50-59, 60-69, 70 and above). Members of the Health Committee considered the data from the three sources, determined major findings, and authored the report. Findings from the report will be used as discussion tools through three community forums to take place in the fall of 2016 and winter of 2017. The goal is to work together with other organizations and community members to make important changes that will increase the health and wellness benefits of the senior LGBTQ population in Sussex County, Delaware. Data analysis tables are available upon request from the Director of Health and Wellness Programs at CAMP Rehoboth.

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This study was funded by an appropriation from a Grant-In-Aid from the Delaware State Legislature to support the activities of non-profit organizations providing services to the citizens of Delaware. The purpose of the funding is to provide supplemental funding to service agencies.

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**Major Findings**

*"In the past it was not safe to go to doctors. It's better now."* Respondents desire high-quality health care in Sussex County more than they want a physician who is LGBTQ. This applies to both general practice physicians and specialists. However, they want their physicians and specialists to be LGBTQ-friendly.

*"There's a big lack of doctors overall, primary care physicians, specialists. I can't find one taking new patients. It is impossible to get a referral for a psychiatrist."* Respondents will and do travel out of state to find high-quality health care. A significant percentage report the lack of high-quality health care locally (both general practice physicians and specialists).

*"We need more social groups outside of bars."* While tobacco use among senior respondents is low, alcohol consumption is above the national average.

*"We need a list of gay-friendly doctors."* Many respondents are unaware of local health care resources or how to locate them. A "health broker" resource was identified as a need.

*"We need psychological services that are lacking now, ones that specialize in LGBTQ elder issues. As one ages, one is cut from the herd. There are a lot of grief support services out there, but it would help if it was LGBTQ oriented."* Almost half of the respondents reported that they struggled with mental health issues. As respondents age, their concerns include the stress they encounter, depression, loneliness, and lack of sufficient finances to see them through their retirement years.

*"One thing CAMP Rehoboth can work on: a sort of 'Gay Google,' a resource clearing house, a lead person with staff/volunteers to compile resources and manage a dedicated web page for senior services (including home repair)."* Senior LGBTQ individuals still look to LGBTQ organizations to provide support, social activities, referrals, and to take care of their needs, rather than seeking resources in the general community.

*"We need LGBTQ training for school personnel, and LGBTQ Cheer, Health fairs, training for physicians and medical personnel, marketing to attract LGBTQ doctors and specialists to Sussex County, sensitivity training for health care providers in Sussex County."* All three data sources urged CAMP Rehoboth to continue outreach efforts to community partners and to engage with other organizations to meet the needs of senior LGBTQ persons.

**Background of the Study**

Understanding the needs and challenges of all seniors is critically important because that population is growing rapidly. This is especially true in Sussex County, Delaware. According to the Delaware Population Consortium Annual Population Projection of November 2015, the number of senior citizens age 60+ living in Sussex County, Delaware, is expected to increase 16% between 2015 and 2020. People age 65+ are projected to increase by 18.3% and age 75+ by a whopping 31.4% in those five years. State and local government and institutions serving seniors are highly interested in ascertaining the needs of the seniors, especially those, such as the LGBTQ population, who have historically been underserved.

CAMP Rehoboth conducted a study to better understand the concerns and needs of aging lesbian, gay, bisexual, transgender, and questioning (LGBTQ) seniors aged 50 and above living in Sussex County, Delaware. This report summarizes the study findings and relates the hopes, fears and challenges told by a sample of over 300 aging LGBTQ people living in Sussex County. Findings from this study and other research will be used to suggest strategies that CAMP Rehoboth can implement to address the needs and concerns identified.

The study was comprised of two data-gathering instruments and a report from the CAMP Rehoboth Trans-Talk and TransParent support groups. The primary data source was an electronic Survey Monkey questionnaire.

The questionnaire was followed by a small, face-to-face focus group to allow responses to questions not easily answered by yes/no or check-the-box answers.

A third source of data was sought to understand the needs of the Transgender population. The small (1%) of Transgender individuals responding to the survey did not allow for valid data analysis. However, the very real health concerns of this group of respondents could not be overlooked. Fortunately, CAMP Rehoboth has sponsored a Trans-Talk and a TransParent group for over a year. The Health Director and Peer Facilitator of the groups shared comments and concerns from participants attending the groups for inclusion in this report.

### **National Studies**

Several national organizations and the U.S. Government have published studies looking at the needs of 50+ LGBTQ seniors, reports that can be very useful in understanding the need. The reports emphasize that LGBTQ people in their 50's and older continue to face health disparities when compared with the general population. They are likely to have experienced past discrimination in jobs, family and personal situations, laws and governmental regulations, and religious institutions. Many have become estranged from their families, have not married nor had children, and now face the aging process with less support than the heterosexual community. In spite of recent rapid progress towards equal rights, LGBTQ individuals continue to face health disparities linked to societal stigma, discrimination, and denial of their civil and human rights.

National studies agree that the LGBTQ senior population is growing. The National Resource Center on LGBTQ Aging reports that the LGBTQ older adult population is expected to grow from the estimated 1.6 to 2.4 million in 2010 to as many as 7 million by 2030. Understanding the needs of this significant community, therefore, is critical.

### **A Little Bit about CAMP Rehoboth, A Vibrant Sussex County LGBTQ Organization**

CAMP Rehoboth, the organization that conducted the survey, is a 501 (c) (3) nonprofit, LGBTQ community service organization, founded in 1991 to "create a more positive" (CAMP) relationship among all the people and diverse communities in Sussex County, Delaware. The geographical area primarily served by CAMP Rehoboth includes Rehoboth Beach, Lewes, Dewey Beach, Milton, Georgetown, Bethany, and surrounding communities.

CAMP Rehoboth promotes the arts, develops health programs, fights discrimination, hosts sensitivity training, and develops good relationships with local media, police, government and community. The organization provides community training and advocacy programs for LGBTQ issues, counseling and health services, support groups, information services for residents and tourists, gallery and performance space for artists, and many activities that feature education, and entertainment.

### **CAMP Rehoboth Health and Wellness Programs**

Health and Wellness programs have served over 10,000 individuals by/engaged in health and well-being programs offered free of charge at CAMP's Community Center.

Groups that promote community well-being regularly use the CAMP Rehoboth Community Center for meetings, including Alcoholics Anonymous, Narcotics Anonymous, National Alliance on Mental Illness, Delaware Breast Cancer Coalition, Aging in Place, as well as a partnership with Beebe Healthcare that provides essential health screenings and flu shots several times a year at the Community Center.

Since 2015 several new health and wellness programs were initiated at CAMP Rehoboth: Young Adult Discussion Group; Alzheimer's Caregiver Support Group; Trans-Talk; TransParent; Grief Group; Women's Enrichment Group; and Silver Pride, a discussion and social group for the over-50 LGBTQ population.

## **A Survey of LGBTQ Seniors in Sussex County: A Needs Assessment**

### **Purpose of the Survey**

CAMP Rehoboth designed the study with the goal of gaining better understanding of the health and social needs of the LGBTQ Sussex County residents who are 50 years of age or older. The survey asked participants to share their experiences with healthcare providers, the quality of care received in healthcare settings, and their concerns regarding future wellness and health care needs as they grow older. Responses identified vital resources needed by the Sussex County LGBTQ community.

### **Methodology**

#### **Survey Development**

Questions were formulated in five main areas: demographic (age, gender, zip code, etc.); aging and mental and physical health needs, concerns, and access to services; financial situation and concerns; social and activity needs; and support systems. The survey was advertised through Constant Contact and in ads placed in the CAMP Rehoboth magazine, *Letters from CAMP Rehoboth* and was available for response for three months.

#### **Sample**

Responses from individuals living outside Sussex County or younger than 50 years of age were eliminated. The final sample consisted of 288 people who met the criteria, completed the questionnaire, and sent it in electronically, along with a handful of people who chose to submit a paper copy of the survey. The number was a little over 20% of the group to whom the survey was sent.

#### **Results**

A consultant was hired to analyze the data. Data tables showing responses for each question are available from CAMP Rehoboth.

The following report summarizes key findings revealed in the survey. Percentages were rounded up to the nearest 0.5%. Camp Rehoboth also conducted an in-person focus group receiving input from approximately 12 people. Where information from the focus group was added, a notation to that effect will be made in the text.

### **SECTION I & II – Screening and Demographics**

Camp Rehoboth received 288 completed surveys that met the established criteria of age, status, and residency in Sussex County, DE. The majority of responders were white, non-Hispanic, retired, married or partnered LGBT people aged 60-69 years living in Rehoboth Beach and Lewes. The 50-59 and 70-79 age ranges had about 1/4 each of survey responders. The sample was equally divided between men (48%) and women (47%). Only 1% indicated transgender or gender fluid status, and 4% did not provide an answer. When describing their sexual orientation, 50% indicated they were gay, 43 % lesbian, 3% bisexual, 1% heterosexual and 3% did not provide an answer. More than 1/3 had an income of over \$100,000 a year; 15% lived on less than \$50,000 a year.

For each question the percentage of people not responding ranged from 3-12%. A demographics table on the next page provides additional information.

Demographics of Survey Responders							
Age	50-59	60-69	70-79	80+			No response
	25%	51%	21%				3%
Zip Code	Rehoboth	Lewes	Millsboro	Milton	Other Sussex Co.		No response
	54%	21%	6%	6%	10%		3%
Race	Caucasian	African American	Multi-racial	European			No response
	95%	1%	1%	1%			2%
Ethnicity	Hispanic	Non-Hispanic	Middle Eastern				No response
	1%	95%					3%
Employment Status	Retired	Part-to-Full Time Work	Unemployed	Disabled-Unable to work	Employed to Supplement Retirement		
	54%	36%	1%	1%	5%		4%
Sources of Income	Investments Or savings	Social Security	Employment	Pension	Social Security Disability	Other	
	55%	48%	43%	43%	1%	6%	
Living Situation	Live with partner or spouse	Live with others	Live alone	Live with family or in other situation			No response
	67%	5%	22%	3%			3%
Relationship Status	Married or partnered	Single	Widowed	Living with someone	Dating	Divorced	No response
	64%	20%	4%	4%	3%	2%	3%
Gender	Male	Female	Transgender				No response
	48%	47%	1%				4%
Gender ID	Not Transgender		Transgender or gender fluid				No response
	94%		2%				4%
Sexual Orientation	Gay	Lesbian	Bisexual	Hetero-sexual or sexual being			No response
	50%	43%	3%	2%			3%

TABLE 1

## SECTION III – Healthy Behaviors

### Current Overall Health and Exercise

The great majority (81%) of respondents considered their health to be good or very good, although they appeared to exercise less than what health sources recommend. Over half (54%) reported moderate exercise at least three times per week. The next highest group exercised 1-2 days a week (29%), but 15% did not exercise at all.

### Tobacco & Alcohol

Most respondents said that they do not smoke (90%) at the present time. However, reported alcohol use appeared higher than for the general population. The *Washington Post* of September 25, 2014, published a report showing 60% of Americans consume less than one drink per week, compared with 34% of survey responders who said they drink once a week or on weekends and special occasions. Almost half (44%) of respondents reported drinking one or more alcoholic beverages three to seven days a week. Only 18% reported no alcohol use at all.

## SECTION IV – Healthcare Issues & Aging

### Mental Health

Almost half of the respondents reported that they struggled with mental health issues. 46% of respondents have not seen a doctor or other professional within the past two years for the listed mental health issues. 21% of them ranked depression as their Number One mental health concern. Anxiety was a close second (15%).

Respondents took the time to write in many mental health conditions that they struggled with, including substance abuse, bipolar disorder, grief and loss issues, stress, ADHD, insomnia, relationship and caretaker concerns, and a variety of other emotional issues.

Several people who did seek treatment wrote in that “I just wanted to talk to someone about it.” Another person wrote, “I sought professional help because I was unhappy with my life.” One person reported that they are “fortunate to have excellent supplementary insurance which covers all.” Of those who did seek treatment for mental health issues, 23% utilized their primary care physician for assistance, and 13% sought secondary care from specialists.

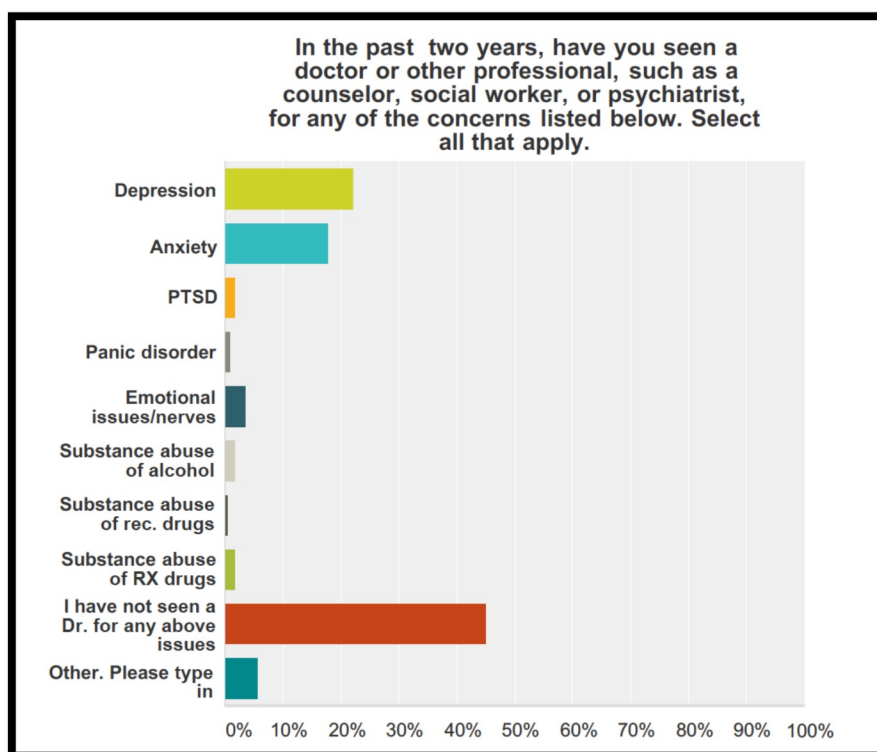


Table 2

**Mental Health Treatment Hurdles**

When asked why they did not seek professional services for mental health issues, some stated a lack of professional help available locally, lack of appropriate professional help that accepted their insurance, and difficulty getting a “timely appointment.” One person wrote, “I have not had a recommended psychiatrist since moving to this area.” Some reported that they did not want to take drugs. Others said the problem was not “that bad.” Several people indicated that they could not afford treatment, and one person wrote, “I no longer seek help in Sussex County because help costs money out of pocket, and I cannot afford it.” Another wrote, “There is pathetically little aid, either financially or medically, to treat severe depression.”

**Physical Health Treatment Hurdles & Locale**

65% of respondents have had one or more of the physical health concerns listed in the survey as shown in Table 3. Most (81%) of respondents indicated that they have seen a doctor or other health professional in the past two years for one or more of the health concerns listed: high blood pressure (40%), orthopedic impairments (25%), heart disease (21%), and obesity and diabetes (14% each). Other conditions written in included macular degeneration or glaucoma, kidney dysfunction, cognitive dysfunction, Parkinson’s, and multiple sclerosis.

Almost one fifth (19%) of respondents had not seen a doctor or health professional for the past two years for any of the physical health concerns listed in the survey. The most frequent reasons cited were difficulty finding competent local health professionals and the scarcity of doctors and specialists in the local area (15%). 10% reported not having encountered any hurdles in receiving care.

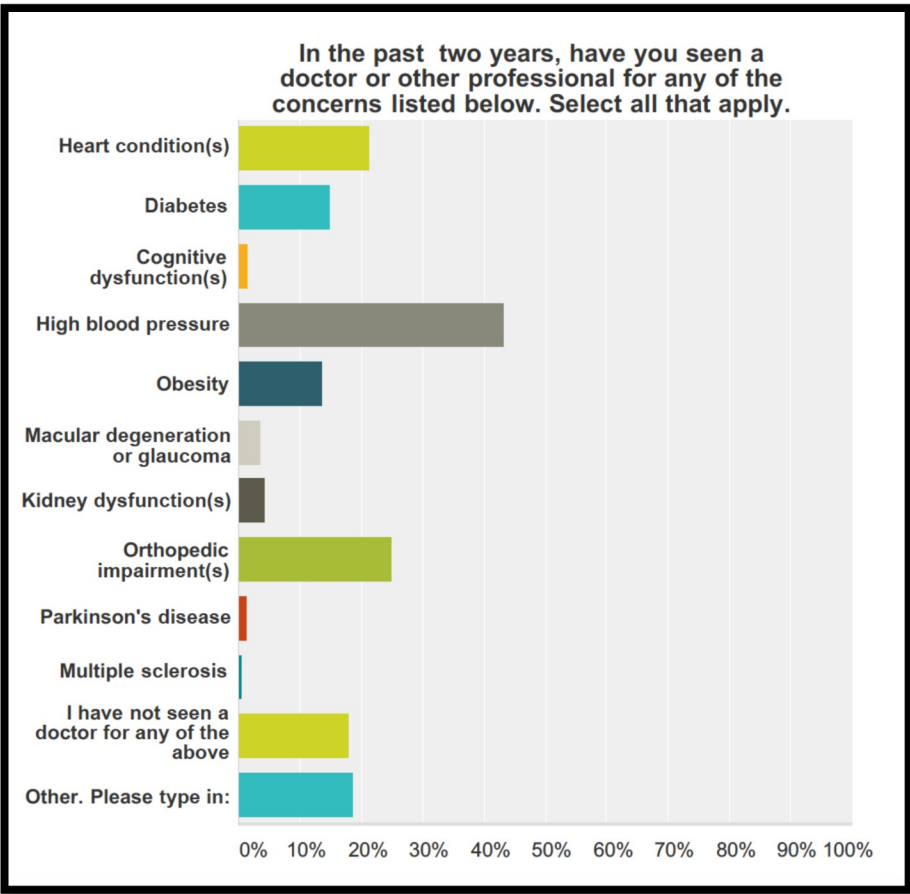


Table 3

## **Sussex County vs. Out of State Services**

69% of respondents reported seeing a primary care physician in Sussex County three or less times a year. About one-fifth (41%) of respondents used out-of-state medical providers, citing the lack of specialists or good specialists locally who dealt with their particular health issue as their reason for going out of state for treatment.

## **Health Provider Sexual Orientation Disclosure**

70% of respondents are “out” to their health care providers about their sexual orientation. Less than 10% stated that they were not out to any healthcare providers. The majority of respondents (64% and higher) found their dentists, primary care doctors, nurses, nurse practitioners, pharmacists, specialty doctors, technicians and office staff to be accepting of their sexual orientation. 67% of respondents had not experienced discrimination nor been uncomfortable in a health care setting. However, 15% disclosed that they hesitated to discuss certain aspects of their life with healthcare providers.

## **Hurdles to Healthcare**

The inability to easily or conveniently get an appointment (32%), the overall poor quality of healthcare providers in Sussex County (24%), and the inability to easily or conveniently see specialty physicians (23%) were the top three hindrances reported that negatively affect the respondents’ access to quality health care in Sussex County. 18% of respondents cited the inability to easily or conveniently identify LGBTQ-friendly healthcare providers who themselves are LGBTQ as a hindrance to accessing quality healthcare in Sussex County.

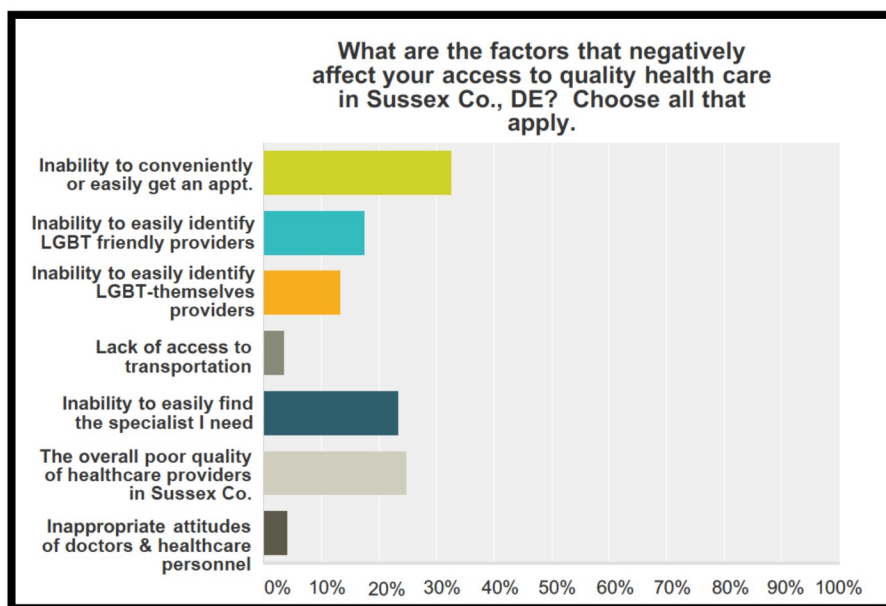


Table 4

## **Fears of Aging**

13% of respondents ranked declining physical health as they age to be their most important aging concern, followed by losing independence, loneliness/isolation (13%), losing independence and losing a partner (12%). Respondents wrote in that they would like home care that would enable them to age in place, they worried about a declining quality of life, and were concerned about not being able to care for oneself and being a burden to others, and they feared growing old alone. 14% of respondents cited loneliness/isolation as their Number One fear of growing old.

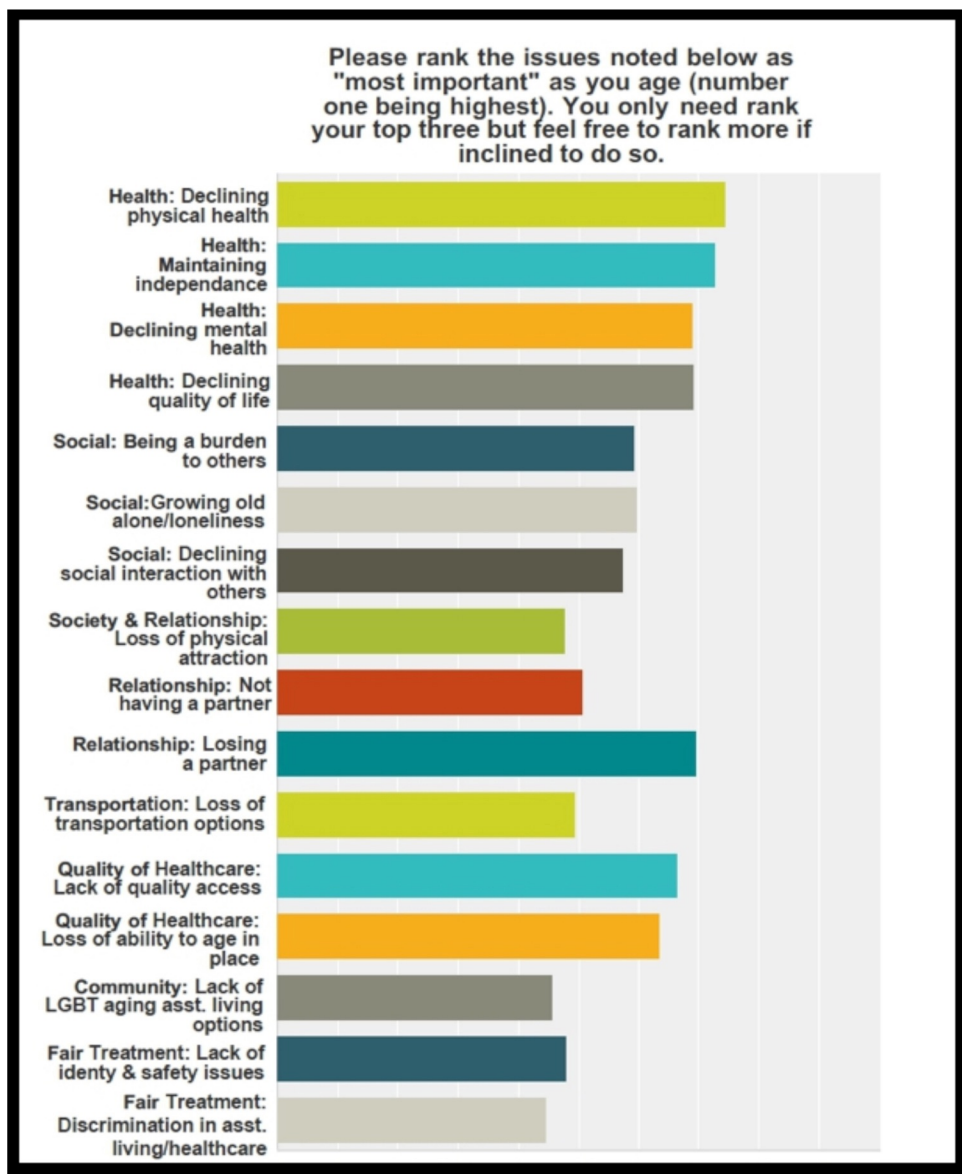


Table 5

## SECTION V – Cultural Competence and Support Systems Q40-42

Most (82%) respondents stated that they are more concerned about the quality of care that is available than discrimination. However, 61% of people taking the survey ranked a welcoming and nondiscriminatory attitude on the part of providers and facilities to be extremely important. Although 67% of respondents sought treatment for health concerns immediately, without fear of discrimination, 14% reported delay in seeking treatment due to fear of discrimination based on their sexual identity or gender identity/expression.

When asked if sufficient support systems exist in Sussex County, DE, for LGBTQ senior and aging people that treat LGBTQ people with respect, most respondents (47%) said "no." A few stated that they may not be aware of existing support systems. Some indicated that, regardless of one's sexual orientation, there is an overall lack of services in Sussex County.

**SECTION VI -- Independent Housing and Assisted Living/Nursing Homes Q43-45**

30% of respondents were somewhat concerned that they would face discrimination in an assisted living or nursing home facility.

**SECTION VII – Activities & Support Systems in Retirement Q46-50**

72% of respondents felt accepted without discrimination when participating in social situations such as dining groups, social clubs, veteran associations, etc., in Sussex County. They found the YMCA, faith-based, and sports groups (e.g., pickle ball, softball) in eastern Sussex County to be particularly supportive.

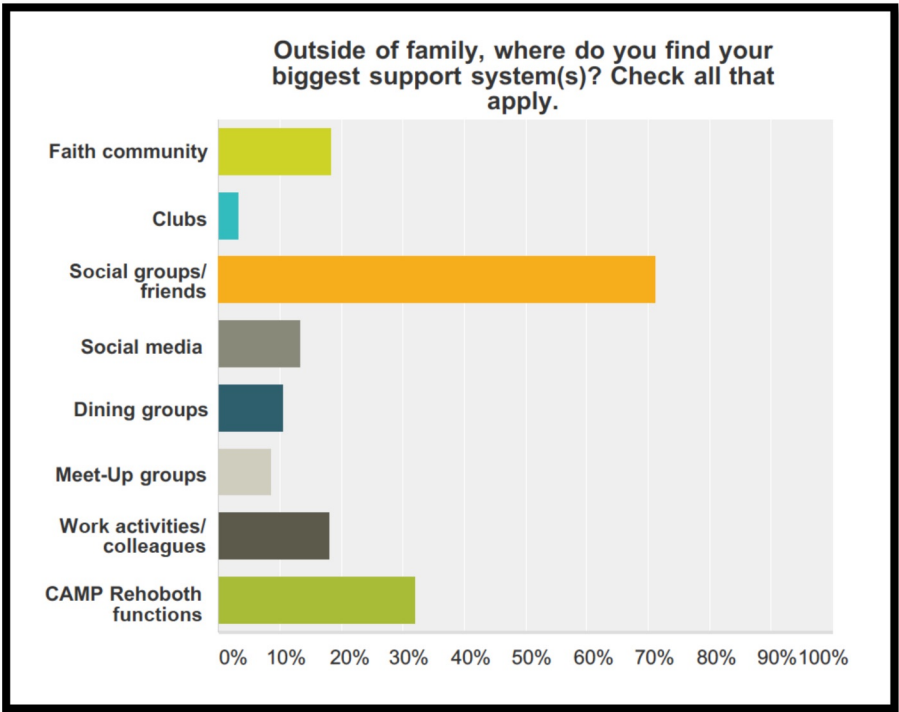


Table 6

56% of respondents cited that there are activities for seniors in Sussex County, Delaware, where they are comfortable being “out” about their sexual orientation. 83% of respondents did not regularly access local services for seniors such as Cheer and Elder Centers but planned to do so in the future.

**SECTION VIII – Other Opportunities with CAMP Rehoboth Q51-53**

An underlying unspoken question of the survey was whether LGBTQ members of CAMP Rehoboth were more trusting about support and acceptance from the community at large because, for a quarter of a century, CAMP Rehoboth has been an advocate and support to them. The more positive responses of the sample, compared with the national studies, seemed to indicate that LGBTQ seniors in Sussex County, Delaware, have been able to live out their senior years in a less-discriminating environment because of CAMP Rehoboth’s advocacy and support for the past 26 years. Indeed, several made the point that a “CAMP Rehoboth bubble” exists that has resulted in better treatment of the LGBTQ population in the survey geographic area.

**FOCUS GROUP FEEDBACK**

**Purpose of the Focus Group**

When the Health Committee was developing the electronic survey, they noticed that some questions required more than a “yes/no” or a “check the box” response. The team decided to hold a small focus group to discuss open-ended questions that could explore in depth the needs of the target group. Focus group input would be compared with results of the electronic survey. Details on the methodology of the Focus group ate available from CAMP Rehoboth

## **Summary of Responses**

Responses have been combined across individuals and table discussion groups and are summarized here. As much as possible, actual words of the respondents are used. One of the overarching themes below is a desire for separate but equal services and facilities for LGBTQ seniors. It may be that these seniors, based on possible discrimination they experienced in their lifetime, feel more comfortable in LGBTQ settings than in settings for the general public. Many seem to consider these to be “straight” settings.

**Q1.** *Over a lifetime, has your sexual orientation and/or gender identity/expression negatively impacted your health/access to health services? If so, how? Moving to today, do you believe that your sexual orientation and/or gender identity/expression currently has an impact on your health and/or access to appropriate and supportive health services? Give examples of when you have had bad experiences or been uncomfortable.*

In the past it was not safe to go to doctors. Some doctors might not treat you because of your sexuality. I was denied services many years ago due to sexual orientation and told to see “another doctor.” It is better now but still needs improvement. People say that it’s easier to talk to a doctor about a partner now. Gay marriage made it better. Regarding the forms at the doctor’s, does checking “single” at our age predispose a doctor to believe I am LGBTQ? If I am out as a gay man, the doctor assumes I have had multiple partners and always wants to test for HIV. I still go by “don’t ask, don’t tell” when it comes to doctors.

**Q2.** *What would you like us to know about health and access to services in Sussex County? Who do you call, and where do you get information on resources? What barriers have you experienced?*

There’s a big lack of doctors overall, primary care physicians, specialists. I can’t find one taking new patients. It is impossible to get a referral for a psychiatrist. There are only three in the county, and they don’t take new patients, so I got to the Emergency Room at the hospital. The wait is too long for an appointment once a doctor is located, weeks to months to wait. Health care in Sussex County has improved the last 15 years, but population growth has outpaced doctor growth. I am forced to travel elsewhere for health services.

Best resources are people at CAMP Rehoboth and the Cheer Center, your own research, friends, Beebe Hospital and doctor referrals. You must find your own resources and do the legwork. We need advocacy for medical issues, insurance, and Medicare. We need a list of gay friendly doctors.

**Q3.** *Some sources indicate depression, loneliness, and suicide rates are higher for older and LGBTQ people. When we look at LGBTQ seniors, impacts of increasing disability, isolation, and grieving for friends, partners, and family who have passed away may be multiplied. What services and support do you think are needed for LGBTQ seniors suffering from depression, isolation and loneliness?*

We need social connections and daytime activities. Everything seems geared toward evening activities and food. It is hard to meet other LGBTQ seniors. Activities are not enough, not publicized enough, and too limited. They should be geared toward our age group and educational, such as trips to see shows and museums. We need more social groups outside of bars.”

We need mental health services that are lacking now, particularly ones that specialize in LGBTQ elder issues. We need to get the word out to people, establish networks of support, with transportation, doctors, and groceries. We need advocacy.

### ***Q4 and the Final Question.***

*Given the discussion from the preceding questions, what would a satisfactory support system of LGBTQ aging people in Sussex County look like?*

CAMP Rehoboth can be an advocate, community partner, have a hot line, and provide transportation.

We need CAMP Rehoboth to outreach to other organizations and a network of LGBT settings. We need an electronic comprehensive resource directory to help us navigate healthcare and community resources.

We need LGBTQ training for school personnel, and LGBTQ Cheer, Health fairs, training for physicians and medical personnel, marketing to attract LGBTQ doctors and specialists to Sussex County, sensitivity training for health care providers in Sussex County.

### **TRANSGENDER FEEDBACK**

The Transgender group of respondents to the survey was about 1% of the total respondent population. This was too small a sample to include in the statistical analysis of responses.

In order to include the very real health concerns of the LGBTQ Transgender group in this report, the CAMP Rehoboth Health Program Director shared feedback from the Trans-Talk group sponsored by CAMP Rehoboth. Group concerns include:

- The CAMP Rehoboth Trans-Talk group says that insurance companies have been finding gender conforming surgeries to be elective surgeries, and thus denying coverage in spite of what the law provides. Some people have appealed to the Insurance Commissioner, who is helpful, but the insurance companies are so big and powerful that progress is slow.
- Trans-Talk group members talk about the same issues as the survey respondents, such as the lack of doctors, especially high-quality medical service providers, in Delaware. However, they have more specific needs than their lesbian and gay cohorts. Gender conforming surgery is incredibly expensive. Finding an endocrinologist friendly to transgender individuals, one who knows the needs of the Trans community, in rural areas such as Sussex County, Delaware, is almost impossible.
- Those who are mobile and more affluent go to providers in larger, urban areas such as the Mazzoni Center in Philadelphia, the Whitman Walker clinic in the District of Columbia, or Chase Brexton Health Services in Baltimore. Transgender people who are lower income do not have resources to leave the state for services and may not have access to health services they desperately need.
- Increasingly, transgender individuals are “coming out of the closet,” similar to what their lesbian and gay associates did not that many years ago. Some of these major health concerns include:
  - Mental health challenges, including gender dysphoria, or the feeling that one’s identity as male or female differs from one’s biological sex;
  - The struggle of navigating the gender change process, including change of name, birth certificate, dealing with insurances, family and friends, work;
  - Finding and working with a health provider who understands that the individual will need lifetime medication to transition to and remain the gender congruent with their emotional and mental belief.

### **NEXT STEPS – MOVING THE REPORT OUT INTO THE COMMUNITY**

Report findings will be shared through three community forums held at CAMP Rehoboth in 2016 and 2017. The expected outcome of the forums is that other community members and organizations will plan collaboratively with CAMP Rehoboth to bring about some of the needed changes identified in the study. CAMP Rehoboth also will use the study findings to develop additional social and health groups and to determine other ways to support LGBTQ seniors living in Sussex County.

Sources reported include Healthy People 2020 (U.S. Department of Health and Human Services, 2010), Human Rights Campaign (2013), National LGBTQ Health Education Center (2016), and Services; National LGBTQ Health Education Center (2016); and SAGE (Advocacy for Gay, Lesbian, Bisexual and Transgender Elders, 2016).





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