



Caregiving

AMONG OLDER LESBIAN, GAY, BISEXUAL,
AND TRANSGENDER NEW YORKERS

by Marjorie H. Cantor,
Mark Brennan,
and R. Andrew Shippy

National Gay and Lesbian Task Force Policy Institute
Pride Senior Network
Fordham University Graduate School of Social Service



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This research was conducted by Pride Senior Network,
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with research underwritten by the New York Community Trust's Sam Wilner Fund.

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When referencing this document, we recommend the following citation:

Cantor, M. H., Brennan, M., & Shippy, R. A. (2004). *Caregiving among older lesbian, gay, bisexual, and transgender New Yorkers*. New York: National Gay and Lesbian Task Force Policy Institute.

The **National Gay and Lesbian Task Force Policy Institute** is a think tank dedicated to research, policy analysis and strategy development to advance greater understanding and equality for lesbian, gay, bisexual, and transgender people.

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Preface

BY MATT FOREMAN

EXECUTIVE DIRECTOR, NATIONAL GAY & LESBIAN TASK FORCE

As baby boomers head into their fifties and sixties, the US population grows slightly older with each passing day—and America’s gay population grows older right along with it. In this way, the release of *Caregiving Among Older Lesbian, Gay, Bisexual, and Transgender New Yorkers* could not be more timely.

Caregiving was made possible by a unique collaboration among the National Gay and Lesbian Task Force, Pride Senior Network, and the Fordham University Graduate School of Social Service. The Task Force is honored to be a part of such a prestigious assemblage of academics, social workers, and activists in the field of gerontology and health care, and is especially proud of this report.

The largest survey of its kind ever produced, *Caregiving* was funded by a grant from the Sam Wilner Fund of the New York Community Trust. It is the result of several years of research conducted by some of the leading thinkers on elder care issues. Researchers began by holding focus groups with older lesbian, gay, bisexual, and transgender (LGBT) New Yorkers all across the city. They then developed a survey that was ultimately completed by 341 LGBT New Yorkers 50 and older. The results of this study are a window into the social networks and caregiving experiences of LGBT elders in urban areas all over the country.

This study provides a comprehensive overview of the caregiving issues faced by older LGBT people in New York City, as well as detailed analyses of their caregiving experiences with blood relations, life partners, and friends. It concludes with policy recommendations, examining the impact of the National Family Caregiver Support Program, the Family Medical Leave Act, Social Security, Medicaid, and other laws and policies on LGBT elders.

Unfortunately, LGBT caregivers and care recipients still face discrimination at doctors’ offices, hospitals, nursing homes, and other places we entrust with the care of our loved ones. In identifying these issues, it is our hope to encourage lawmakers and policymak-

ers to incorporate the needs of our community into future public policy, to provide a foundation from which other researchers can further explore these issues, and to furnish health care providers who serve LGBT elders with information that will lead to more competent and sensitive care for their clients and patients.

Caregiving is the most recent in a long history of Task Force efforts on behalf of LGBT elders. *Outing Age*, published in 2000, was a direct examination of how public policy issues affect LGBT elders around the United States. For the past five years, the Aging Institute at the Task Force's annual Creating Change conference has provided a forum where issues of concern to LGBT elders are regularly explored and addressed. The Task Force Policy Institute is currently working with SAGE (Services and Advocacy for GLBT Elders) to prepare for the 2005 White House Conference on Aging, to insure that our community's issues and interests are addressed at this once-a-decade congress.

This study was released at the 2004 National Conference on Aging in the Lesbian, Gay, Bisexual, and Transgender Communities, a biennial event hosted by SAGE, the nation's oldest and largest social service and advocacy organization dedicated to LGBT seniors. The Task Force is especially grateful for the efforts of Pride Senior Network and the authors of this study, who took the ideas behind this report and made them a reality, conducting research, organizing focus groups, and collecting and analyzing data.

Today, the population of gay seniors in America is estimated at just under three million; by 2030, it could be nearly twice that. The caregiving by more than 25 million friends, family, and loved ones in America is valued at \$200 billion annually. Yet only three states—California, Hawaii, and Vermont—provide even unpaid leave to care for ill, same-sex partners.

Retirement communities aimed at gay men and lesbians have recently been popping up all across the Sunbelt: evidence of some success our community-based groups are having in making this segment of our community visible, both to other members of our own community and to the nation at large. It is the hope of the Task Force that this report will shed some light on the caregiving issues faced by this population, bringing us closer to the day when we can all have access to the health care services we need—regardless of the gender of our partners, or our sexual orientation.



Matt Foreman
Executive Director
National Gay and Lesbian Task Force

Executive Summary

INTRODUCTION

Like most Americans, as lesbian, gay, bisexual, and transgender (LGBT) people age, they begin to think about the caregiving needs they might face. The issue of caregiving has, in turn, become increasingly important to both younger and older members of the LGBT community. A broad definition of the term “caregiving” can include the day-to-day assistance we provide each other in our personal relationships. Caregiving in this study, however, refers to the definition usually used in gerontological and disability literature: specifically, the extensive, time-consuming aid needed by people who are so sick or frail that they require hands-on help with the tasks of daily living.

Caregiving is a universal experience, and most of us will provide caregiving assistance to others at some point in our lives. Individually, caregivers often provide support for parents with Alzheimer’s disease, partners with HIV/AIDS, and siblings with traumatic brain damage. In fact, more than 25 million Americans are currently providing caregiving assistance to a family member or close friend (United Hospital Fund and Visiting Nurses Service of New York [UHF], 2000)¹. Without such caregiving, society would incur enormous financial costs. For example, it is estimated that if informal caregiving assistance had to be purchased through formal providers, such as hospitals and nursing homes, its price tag would be approximately \$200 billion annually.² For this reason alone, public policy should provide for the maintenance and sustainability of informal caregivers.

Despite the anti-gay movement’s construction of “gay” and “family” as mutually exclusive categories, LGBT people are integral parts of the families they grew up in. As this study documents, LGBT people are very involved in caregiving with their *families of origin*, providing caregiving assistance for parents, chil-

Caregiving in this study refers to the extensive, time-consuming aid needed by people who are so sick or frail that they require hands-on help with the tasks of daily living.

Caregiving is a universal experience, and most of us will provide caregiving assistance to others at some point in our lives.

1. This report uses academic citation formatting. Full bibliographic citations for sources are available in the references section at the end of the report.
2. S. 538, The Lifetime Respite Care Act of 2003, Section 2901 (a) 8.

dren, aunts and uncles, and other relatives. LGBT people also often provide care to their *families of choice*, or same-sex partners and close friends who are sick, disabled, or frail with age. For example, there is extensive documentation of LGBT people providing care to friends and partners with HIV or AIDS.

To get a better understanding of the caregiving practices and needs of older LGBT people, researchers from Pride Senior Network, the National Gay and Lesbian Task Force Policy Institute, and the Graduate School of Social Service at Fordham University undertook the first large-scale study of caregiving among LGBT people. The survey, which targeted New York City residents, was based on information gathered at a series of focus groups with LGBT elders held in four of New York City's five boroughs. It utilized questions found in the most recent large-scale study of older New Yorkers, *Growing Older in New York in the 1990s: A Study of Changing Lifestyles, Quality of Life, and Quality of Care*, as well as other caregiving studies (Cantor & Brennan, 1993).

Participants, age 50 and older, were recruited from over 100 LGBT organizations in the New York City area. Groups that serve women and people of color were specifically targeted in order to gather as diverse a sample population as possible. Unlike most other demographic characteristics, sexual orientation can be difficult to assess because it is often concealed. To overcome this problem, several research methods were utilized to recruit study participants who were LGBT, including postering, advertising, one-to-one contacts, and snowballing techniques.

Despite the challenge in identifying a sample, 341 valid surveys were returned. Since the sample is not random and is also limited to New York City, the findings may not be generalizable to all LGBT people. The results do, however, represent an important first step in learning more about the social networks and caregiving experiences of LGBT elders. These data offer a compelling picture of LGBT caregivers, their assistance to members of their families of origin and families of choice, the variety and intensity of the tasks they perform, the impact of caregiving on their lives, as well as their unmet needs.

Despite the anti-gay movement's construction of "gay" and "family" as mutually exclusive categories, members of the LGBT community are integral parts of the families they grew up in.

Participants age 50 and older were recruited from over 100 LGBT organizations in the New York City area.

SIX MAJOR FINDINGS

1. LGBT PEOPLE PROVIDE EXTENSIVE CAREGIVING FOR THEIR FAMILIES OF ORIGIN AND FAMILIES OF CHOICE

- Nearly half of the respondents (46%) were providing caregiving assistance or had provided such assistance to a family of origin member or family of choice member within the past five years. Caregivers provided that care for an average of eight years.
- Differences between the caregiving experiences of family of origin and family of choice caregivers were not great, and were largely a reflection of the relationship between caregivers and care recipients, as well as their living arrangements.

- Family of choice caregivers were more likely to live with the person for whom they provided care, and were more involved in hands-on personal and household caregiving.
- Family of origin caregivers, who cared primarily for parents and other frail, elderly family members, tended to function as case managers rather than providing direct, hands-on care. For example, they arranged for services, played an advocacy role, and insured that needed services were available and in place.
- For caregivers of both family of origin and family of choice members, the most important assistance they provided was emotional support, visiting, and calling on the telephone.
 - Ninety-eight percent of caregivers reported visiting or telephoning a person in need from their family of origin, and 91% reported visiting or telephoning a person in need from their family of choice.
 - Caregivers felt that emotional support was the most important form of assistance they provided.
- Help with advice and decision-making were also important forms of assistance:
 - Over three-quarters of family of origin caregivers “always” or “often” provided advice and decision-making, and 54% of family of choice caregivers were involved in providing advice and decision-making assistance.
 - In over 75% of the caregiving situations, someone had authority for medical and legal decisions, and in a majority of those situations, the caregiver was the person with the authority regardless of whether the care recipient was a family of origin or family of choice member.
- LGBT caregivers in both groups were employed during the caregiving episode and had to negotiate the competing demands of caregiving and the workplace. Additionally, both groups of caregivers needed the same sort of support as heterosexual caregivers, including respite, information and referral, available backup services, and the opportunity to participate in support groups.
- Similarities in the amount of caregiving involvement, the reasons for providing care, and the stress and strain experienced were universal, and had more to do with the nature of the experience itself rather than whether the caregiving was being provided for a family of origin or a family of choice member.

Ninety-eight percent of caregivers reported visiting or telephoning a person in need from their family of origin.

LGBT caregivers needed the same sort of support as heterosexual caregivers, including respite, information and referral, available backup services, and the opportunity to participate in support groups.

2. LIKE HETEROSEXUALS, MANY LGBT RESPONDENTS WERE HIGHLY INVOLVED IN CAREGIVING FOR THEIR FAMILIES OF ORIGIN

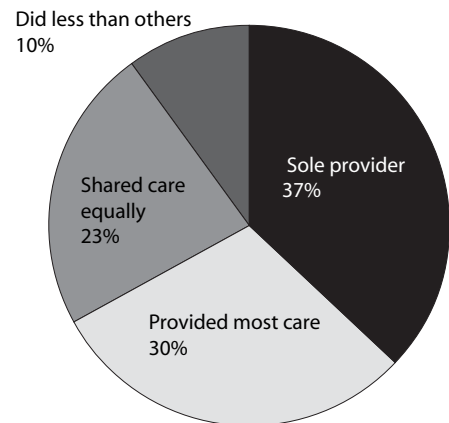
- Twenty-two percent of respondents were providing care for a member of their family of origin, or had provided such care within the past five years.
- Seventy percent of family of origin care recipients were women, 95% were heterosexual, 3% had an unknown sexual orientation, and 3% were lesbian or gay.³
- Over two-thirds of respondents were the primary caregivers for family of origin



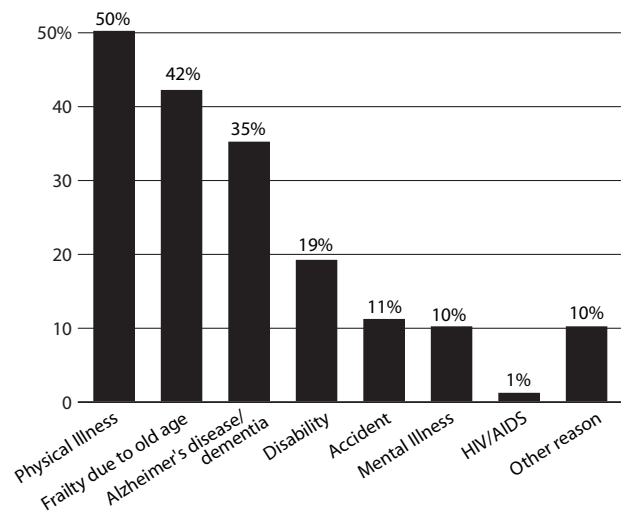
members. Thirty-seven percent were the sole care provider, 30% were providing most of the care, and 23% were sharing the care equally with others. Only 10% provided less care than others.

- Almost half of family of origin caregivers provided care on a daily basis, and another 24% provided care several times a week.
- Among family of origin caregivers, the care recipients were primarily parents (84%), with the remaining 16% comprised of siblings, children, and other relatives.
- The reasons family of origin members needed care included physical illness (50%), frailty due to old age (42%), Alzheimer’s disease/dementia (35%), disability (19%), accident (11%), mental illness (10%), other reason (10%), and HIV/AIDS (1%). (Respondents could choose more than one reason for needing care.)
- Sixty percent of caregivers of family of origin members provided financial help sometimes or often.
- Family of origin caregivers were significantly more likely to provide advice or decision-making support “often” or “sometimes” compared to family of choice caregivers, reflecting the age and frailty of the people for whom they were caring.
- The amount of help caregivers received from family and community providers was generally related to the level of stress that resulted from caregiving:
 - Among family of origin caregivers, 79% received assistance from others.
 - The majority of persons who regularly provided additional help were siblings, parents, other relatives, and friends.
 - Only a small group received regular assistance from visiting nurses or home health aides, underscoring the importance of the informal caregiving system in providing assistance to frail, elderly people.
- Difficulties with family and friends can be a further source of caregiving stress. The majority of family of origin caregivers experienced no difficulties. However, 33% reported difficulty with other family members, most frequently siblings.
- Although sexual orientation may have played a part in some difficulties with family members, almost two-thirds of LGBT caregivers reported that their sexual orientation made no difference in their family’s expecta-

Respondent’s Level of Care Involvement for Family of Origin Members



Reasons Family of Origin Members Needed Care



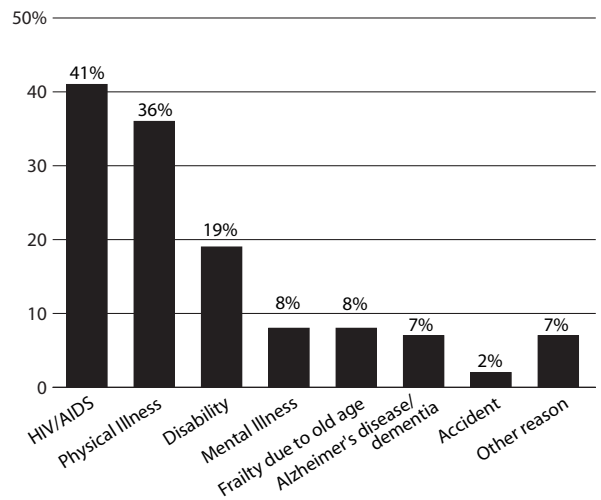
3. Percentages add up to more than 100 due to rounding.

tions regarding caregiving. However, one-third reported that family expected more of them because they were LGBT, and perceived to have fewer explicit family responsibilities. (This assumption was often false.)

3. MANY LGBT ELDERS PROVIDE CARE TO PARTNERS AND FRIENDS—THEIR FAMILIES OF CHOICE

- Twenty-four percent of respondents reported having provided care to a person who was not related by blood in the previous five years, and 30% of those were actively providing that care when the survey was conducted.
- Fifty-four percent of family of choice members receiving care were either the partner or “significant other” of the LGBT caregiver. Male friends were the second most commonly reported relationship to the caregiver (30%), followed by female friends (5%), and men (7%) or women (3%) whose relationship to the caregiver was not specified.
- Within families of choice, 75% of care recipients were men; 25% were women; 89% were lesbian, gay, or bisexual; and 11% were heterosexual.
- While men and women were about as likely to care for a significant other or partner, male caregivers were more likely to be involved with male rather than female friends (35% and 2%, respectively). For women, the difference was not as large: 15% were caring for female friends, and 10% for male friends.
- Fifty-eight percent of family of choice caregivers provided care on a daily basis, with 23% providing care several times per week.
- More than four in five care recipients in this group (83%) had a serious illnesses requiring hospitalization. The reasons family of choice members needed cared were HIV/AIDS (41%) and other physical illness (36%), followed by disability (19%), mental illness (8%) and dementia (7%). An additional 8% reported that the care recipient was frail due to old age. Two percent needed care as the result of an accident, and 7% needed care for some other reason.
- Seventy-two percent of caregivers to family of choice members reported acting as a liaison to other family members on behalf of the care recipient “often” or “sometimes.”
- Fifty-one percent of caregivers to family of choice members provided financial help “sometimes” or “often.”
- Sixty-three percent of respondents indicated that they “always” or “often” dealt with medical providers, and 64% had been involved in making arrangements for medical care on behalf of the care recipient.

Reasons Family of Choice Members Needed Care



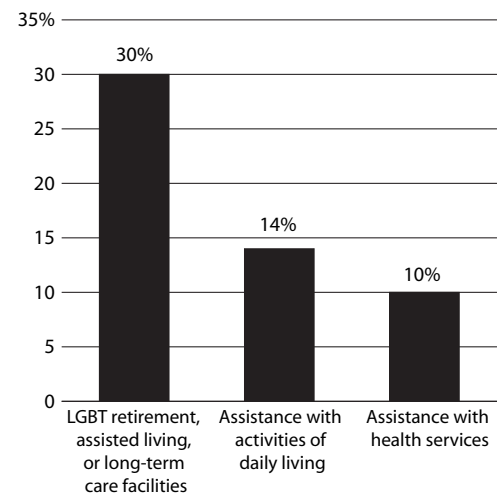
4. THE USE OF FORMAL COMMUNITY SERVICES WAS LIMITED AND SOMETIMES PROBLEMATIC

- The use of community services was low for both family of origin and family of choice LGBT caregivers. About 40% of both groups used visiting nurses and/or home health aides.
- Female caregivers were more likely to access community services than male caregivers.
- Many family of origin and family of choice caregivers accessed support groups and therapy for emotional and psychological support. One in five caregivers relied upon a clergy member for emotional and psychological support.
- Forty-one percent of family of origin and 26% of family of choice caregivers cited difficulties with formal service providers. The different types of assistance provided by the two groups (e.g., case management vs. hands-on assistance) may account for some of this difference. However, for both groups, fear of experiencing discrimination because of their sexual orientation may have been a factor in the caregivers' relations with medical personnel. This fear was less of an influence on relations with social workers.
- For both groups, most LGBT caregivers, whether caring for a member of their family of origin or choice, provided care largely alone and depended on other family members or friends to provide support and direct assistance. Formal community organizations, as is the case among caregivers in general, were only accessed as a last resort, after caregiving duties became overwhelming.

5. LGBT CAREGIVERS ENVISION A ROLE FOR THE LGBT COMMUNITY

- Although only a relatively small proportion of the sample (8%) indicated a need for caregiving themselves at the time of the survey, 19% reported that they had needed caregiving assistance in the past. Given the relatively young age of the sample, it is likely that the need for caregiving assistance will grow in the future, as the community continues to age.
- More than one in four respondents expressed a need for psychological and emotional support from the community, and about one-third noted that the LGBT community should provide a variety of social opportunities for its older members, including friendly visiting, age-inclusive social opportunities, and LGBT senior centers.
- Looking toward the future, almost 30% said they would like to have LGBT retirement, assisted living, or long-term care facilities, while 14% expressed a need for assistance with activities of daily living and 10% requested assistance with health services
- When asked why the LGBT community should help its older members, most said the community is best at caring for its own, reflecting the persistence of difficulties faced by LGBT people when they access caregiving

Types of Assistance Requested by LGBT Respondents



through mainstream health care and social services systems. This underscores the need for both mainstream and LGBT community agencies to outreach to older LGBT senior citizens in New York City and elsewhere.

6. INCLUSIVE AND SUPPORTIVE LAWS AND POLICIES ARE NEEDED TO HELP EASE THE BURDENS OF LGBT CAREGIVERS

- Nearly three quarters of LGBT caregivers surveyed in this study reported emotional stress related to caregiving that ranged from “moderate” to “a great deal.” Support services, like those outlined in the Life Span Respite Care Act (currently pending in Congress), are critical because they give the caregiver a temporary break from the stress and strain associated with caregiving.
- The National Family Caregiver Support Program (the Caregiver Support Program), enacted into law in 2000, includes a broad definition of caregiver that encompasses LGBT individuals caring for members of their families of origin and families of choice. Community-based LGBT organizations—particularly elder organizations, community centers, and health centers—should seek contracts to provide these services. It is important that LGBT people understand that they are eligible for the services of the Caregiver Support Program. Public education is a critical first step toward this goal.
- Forty percent of family of origin caregivers have used a visiting nurse service, and 43% have used a home care agency. While there is little research on homophobia in health care and home care, LGBT caregivers and care recipients may be particularly vulnerable to bias at the hands of caregiving assistants.⁴ Training of home care assistants in diversity and tolerance—including sexual orientation diversity—is critical if LGBT caregivers or LGBT elders in need of caregiving assistance are to access mainstream home health services.
- California’s Family and Medical Leave Law, enacted in 2002, allows employees to take six weeks of paid leave to care for an ill relative—including a domestic partner—or after the birth, adoption or foster placement of a child.⁵ Although nearly two dozen other states have family leave plans that provide unpaid leave, same-sex domestic partners are not eligible for most of these plans.⁶ Same-sex partners are also ineligible under the federal Family and Medical Leave Act. California’s law is unique in that it not only provides paid leave, but also includes same-sex domestic partners as a matter of course, rather than adding them to a pre-existing law. In order to provide equal treatment of same-sex couples under family and medical leave policy, more inclusive definitions of family should be written into state and federal law. This would not only benefit LGBT people, but all individuals taking care of a loved one.

The LGBT community should provide a variety of social opportunities for its older members, including friendly visiting, age-inclusive social opportunities, and LGBT senior centers.

Training of home care assistants in diversity and tolerance—including sexual orientation diversity—is critical if LGBT elders are to access mainstream home health services.

4. A 1994 study by the Gay & Lesbian Medical Association found that two-thirds of doctors and medical students reported knowing of biased caregiving by medical professionals; half reported witnessing it; and nearly 90 percent reported hearing disparaging remarks about gay, lesbian, or bisexual patients (Schatz & O’Hanlan, 1994).

5. Most workers are paid at a rate of about 55% of their salary. The program, which begins in 2004, will be completely employee-funded, with average annual payments of \$26 per worker.

6. The exceptions are Hawaii and Vermont, where reciprocal beneficiary and civil union laws added same-sex partners as family members eligible to take such leave.

Demographics of the Respondents

- Slightly more than half of respondents (52%) reported that they were single, while 40% were partnered. Women were more likely to be partnered than men (51% vs. 36%).
- One in five respondents (20%) had children, and 7% had grandchildren. Women were twice as likely as men to have children (30% vs. 15%).
- Most respondents (62%) lived alone, while 30% lived with their same-sex partner. Women were more likely than men to live with their partner (41% vs. 25%), while men were more likely than women to live alone (66% vs. 52%).⁷

Social Support Networks

- Nearly all respondents had family members or close friends as part of their support network. Approximately 33% had parents still living, 75% had siblings, 90% had other relatives, and 93% had friends.
 - Ninety percent of all respondents reported that they were “very close” or “somewhat close” with parents who were still living.
 - Eighty-four percent of the respondents with children reported being “very close” or “somewhat close” with their children.
 - Eighty-three percent of respondents who were grandparents said that they were “very close” or “somewhat close” to their grandchildren.
 - Fifty-nine percent of respondents with siblings said they were very close or somewhat close with their siblings.
- Although there is substantial interaction between LGBT people and members of their families of origin, respondents also relied heavily upon partners and friends as part of their social support networks: 40% of respondents were partnered, over 90% had an average of six friends in their networks, and 96% percent reported being somewhat close or very close to their friends.

Sociodemographic Characteristics of Respondents (Percent)

Age	Total	Women	Men
50 to 59	46	52	43
60 to 69	35	30	37
70 +	19	18	20
Race/Ethnicity*			
White	75	66	80
Black	10	10	9
Hispanic/Latino	12	20	9
Asian/Native American/Other	3	4	2
Relationship Status**			
Single	52	46	54
Partnered	40	51	36
Divorced/separated	7	4	9
Widowed	1	0	1
Living Arrangement*			
Alone	62	52	66
With partner	30	41	25
With others	8	7	9
Self-rated Health			
Excellent, good	44	38	46
Fair 45	52	42	
Poor	11	10	11
Very poor	1	0	1

Note: Apparent disparities between row totals and the number of individuals in the male and female categories are accounted for by the inclusion of data from the four transgender persons who are not included in the male or female analyses.

Age N=341, Race/Ethnicity N=335, Relationship Status N=337, Living Arrangement N=334, Self-rated Health N=338

*p < .05, **p < .01 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix, page 95.)

7. New York City living patterns are different than in most of the rest of the country. Many New Yorkers live alone in small apartments that they keep for economic reasons, but spend a lot of time with their partners.

CONCLUSION

The results of the study confirm that LGBT caregivers are an integral component of the larger caregiving community. These caregivers are dedicated to both their families of origin and their families of choice. Despite the fact that they are taking care of parents, children, partners, and siblings in need, LGBT caregivers are not provided with the same social, emotional, or financial support afforded to other caregivers. Policies that embrace wide definitions of family and caregiving and recognize same-sex relationships would help to ease the burdens and strains of caregiving. LGBT caregivers, like all caregivers, are doing extraordinary work. Activists and policymakers can enhance their work through supporting better, more inclusive public policies that foster support and equal recognition for LGBT people under the law.

Despite the fact that they are taking care of parents, children, partners, and siblings in need, LGBT caregivers are not provided with the same social, emotional, or financial support afforded to other caregivers.



1. Literature Review and Study Methodology

INTRODUCTION

Caregiving is a universal experience. All of us, at one time or another, have provided assistance to others, and every society places great value on lending a helping hand to those in need. Just like everyone else, members of the lesbian, gay, bisexual, and transgender (LGBT) community are involved with caring for parents, children, other relations, partners, and friends who are sick, disabled, or frail with age. And of course, LGBT people have had much experience providing care to friends and partners with HIV or AIDS.

As members of the LGBT community age, they, like most Americans, begin to think about the caregiving needs they might face. The issue of caregiving has, in turn, become increasingly important to both younger and older members of the LGBT community. It often involves both *families of origin*—the families into which people are born or adopted—and *families of choice*: one’s same-sex partner and closest friends. Most caregiving in the United States is provided by a spouse and/or the biological children of the care recipient (Horowitz, 1985; Neal, Ingersoll-Dayton & Starrels, 1997). Because it appears that LGBT people are less likely to have children than heterosexuals, the issue of caregiving is of particular importance to the LGBT community.

The term “caregiving” can include the day-to-day assistance we provide to one another in our personal relationships. But it is the extensive, time-consuming aid needed by those so sick or frail that they require assistance with the tasks of daily living that is usually referred to as “caregiving” in the gerontological and disability literature (Cantor & Brennan, 2000). It is this kind of caregiving that is the subject of this study.

To get a better understanding of these issues, researchers from Pride Senior Network, the National Gay and Lesbian Task Force Policy Institute, and the Graduate School of Social Service at Fordham University undertook the first large-scale study of caregiving in New York City’s LGBT community, surveying 341 New York City residents age

Most caregiving in the U.S. is provided by a spouse and/or the biological children of the care recipient. Because it appears that LGBT people are less likely to have children than heterosexuals, the issue of caregiving is of particular importance to the LGBT community.

50 or older. To ensure that the full extent of caregiving involving older LGBT people was included, the same questions were asked of those caring for parents and other relatives, and of those providing care for partners or friends. To better understand the impact of policies and programs on older LGBT people, questions about the use of formal health and social services and the projected need for assistance from the LGBT community were also included.

The current research falls into three main areas: the nature and extent of caregiving provided to families of origin and families of choice; attitudes about the caregiving experience; and needs for assistance with caregiving, and how such needs might best be met. This report addresses all three of these topics. To better understand the respondents' caregiving experiences, we collected background on the nature and extent of their informal social networks; their experiences with formal, community-based health and social service providers; their feelings about themselves; and their abilities to master their environment.

This report addresses the following questions:

1. Who are the respondents, and to what extent are they currently involved in providing care?
2. To whom is such caregiving provided?
3. What are the caregiving experiences of those assisting parents and other family of origin members?
4. What are the caregiving experiences of those assisting partners and/or friends?
5. What are the similarities and differences between these two types of caregiving experiences?
6. What is the current state of psychological well-being of the older LGBT adults in the study, including their sense of control over their lives?
7. What role do these older LGBT people envision for the LGBT community as a source of formal social support?
8. What are the policy and practice implications of these findings?

Chapter 1 of this report includes a review of the literature on caregiving with respect to LGBT adults, and a description of the study's methodology. Chapter 2 is devoted to a thorough examination of the characteristics of the respondents, including the nature and extent of their informal social networks. A discussion of caregiving for family of origin members (Chapter 3) and family of choice members (Chapter 4) follows. Chapter 5 compares the caregiving experiences of family of origin and family of choice caregivers. This is followed in Chapter 6 by a discussion of contextual issues in the lives of lesbian, gay, bisexual, and transgender older adults, and, in Chapter 7, the role of the LGBT community in providing caregiving assistance to its members is discussed. The study's conclusions can be found in Chapter 8, while Chapter 9 is devoted to policy implications and ideas for future research.

Caregiving is broadly defined as instrumental, informational, or emotional support provided by others to support those individuals challenged in their efforts to remain independent in the community.



LITERATURE REVIEW

In the field of gerontology, the last three decades have seen growing and continued interest in the informal social support systems of older adults. In general, these studies have found that older people are endowed with active and supportive social networks consisting of kin, and friends and neighbors who are engaged in considerable exchanges of instrumental assistance and emotional support (Cantor, 1989; Chappel, 1990; National Alliance for Caregiving, 1997; Cantor & Brennan, 2000). In many cases, formal, community-based service providers may supplement, and in some cases substitute for, these informal supports when assistance is either unavailable or beyond the capabilities of family and friends (Cantor, 1989).

For older adults experiencing declining health and increased frailty, caregiving assistance from both informal and formal sources can make the difference between remaining in one's home or facing institutionalization. For our purposes, caregiving is broadly defined as instrumental, informational, or emotional support provided by others to support those individuals challenged in their efforts to remain independent in the community. While the existing literature on caregiving has provided a wealth of information on the experiences of caring for older adults, few if any studies have considered the sexual orientation of either caregivers or the care recipients during the caregiving episode. Therefore, what we know about caregiving from the gerontological literature may not necessarily be generalizable to lesbian, gay, bisexual, and transgender caregivers and their families.

Although it is beyond the scope of this study to provide an exhaustive review of the caregiving literature, we will briefly review research on the demographics of LGBT elders, as well as the limited literature on social support and caregiving among older LGBT adults, before turning to the results of the present study.

While the existing literature on caregiving has provided a wealth of information on the experiences of caring for older adults, few if any studies have considered the sexual orientation of either caregivers or the care recipients.

RESEARCH ON OLDER LGBT PEOPLE

Although older LGBT individuals comprise a sizeable part of the elderly population of New York City, there is a dearth of research about their social lives, the character and organization of their social networks, and the extent to which their social care needs are being met. Additionally, there are few national surveys that ask about sexual orientation, and even fewer that ask about gender identity, making it difficult to accurately estimate the total LGBT population. The few surveys that do capture data usually ask about sexual behavior, not orientation or identity. Whether or not surveys ask about sexual behavior or orientation, these surveys likely undercount LGBT populations if respondents are wary of "coming out" to a researcher.

Exact figures on the prevalence of older LGBT adults are not available. Early estimates were based on estimates of the overall homosexual population projected by Alfred Kinsey et al. at roughly 8 to 10% of the overall population (Kinsey, Pomeroy, & Martin, 1948; Kinsey, Pomeroy, & Martin, 1953). In the early 1980s, two researchers estimated that there were approximately 1.75 million lesbians and gay men age 65 and older and 3.5 million age 60 and older (Berger, 1982; Dawson, 1982). A rough average of estimates from more recent studies indicates that the lesbian, gay, and bisexual (LGB)

share of the population is likely to range from 3 to 8% of the US population (Sell, Wells, & Wypij, 1995; Laumann, Gagnon, Michael, & Michaels, 1994; Lukenbill, 1995). This would mean that currently there are anywhere from one million to 2.8 million LGB seniors (age 65 and older) in the United States (Cahill, South, & Spade, 2000). And by 2030, that estimate would grow to between two and six million LGB seniors. (This estimate is based on the Administration on Aging's projection of an elder population of 69.4 million in 2030).⁸

Another source of data is voter exit polls. From 1990 to 2000, the Voter News Service (VNS) asked about sexual orientation in voter exit polls during national elections (Bailey, 2000).⁹ From 1996 to 2000, the openly LGB vote emerged as a sizeable, discrete voting block of four to five percent of the vote in national congressional and presidential elections (Ibid.).¹⁰ Exit poll data demonstrate striking age differences: in 1996, 4.3% of voters over 40 said they were gay, lesbian, or bisexual, versus 6.0% of voters under 40. In 1998 these figures further diverged: 3.3% of older voters self-identified as gay, lesbian, or bisexual, while 6.4% of younger voters did (Ibid.). It is unclear whether this means that older voters are less likely to consider themselves gay, lesbian, or bisexual, or that older voters are less willing to "come out" to a stranger outside a polling place.

There are no national data available on transgender people in the US, so we are unable to estimate a population range for transgender seniors (Goldberg, 1996; Cloud, 1998). However, it is important to note that transgender people exhibit the full range of sexual orientations, from homosexual to bisexual and heterosexual (Green, 2000).

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CAREGIVING BY NONTRADITIONAL CAREGIVERS

Given the well-documented findings that, after one's spouse, adult daughters are overwhelmingly the primary caregivers to older adults (e.g., Horowitz, 1985; Neal et al., 1997; Chappel, 1990), many researchers have turned their attention to "nontraditional" caregivers, such as male friends and relatives, and nonkin members of the social support system. In a large-scale study of New York's elderly, Cantor (1977) found that friends play a crucial role in providing care, and in situations where there were no kin, or no available kin, older people turned to friends and neighbors as their source of informal support. Further, both genders are involved in such caregiving. Stoller (1990) reported that while women accounted for the majority of nonspousal caregivers to her elderly sample, approximately 41% of nonspousal caregivers were men. Male caregivers were less likely than women to provide hands-on types of instrumental assistance, and there was evidence of a shift to female caregivers over time as the care recipient's health worsened and frailty increased. Similarly, Neal and colleagues (1997) reported that there was no gender difference in the provision of seven of 13 caregiving tasks (i.e., personal and health care types of assistance) among employed caregivers. However, female caregivers were more

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8. Available at <http://agingstats.gov>

9. In 1990 VNS started asking, if respondents were gay or lesbian. In 1992 VNS switched the wording of this question to "gay, lesbian, or bisexual." VNS does not ask about gender identity.

10. Openly gay, lesbian, and bisexual voters (Voter News Service does not ask about gender identity) were 5.0% of all voters in the 1996 congressional/presidential election, 4.2% in 1998, and 4.1% in 2000. This is equivalent in size to the Latino vote, and about half the size of the African American vote. (Unpublished analysis of 2000 VNS data.)



likely to provide transportation, shopping, housekeeping, meal preparation, and to check on the older person by phone compared with men.

RACIAL DIVERSITY AND CAREGIVING

Researchers have also begun to expand the study of caregiving to ethnic minority populations (e.g., Chatters, Taylor, & Jackson, 1989; Cantor & Brennan, 2000; Delgado & Tennstedt, 1997; Mui, 1992). For example, McCann and colleagues examined differences between African American and white older caregivers, finding that older African Americans were significantly more likely to be providing care, provided a greater number of hours of care per week, and were more likely to provide assistance to friends compared with their white counterparts (McCann et al., 2000).

CAREGIVING IN THE LGBT COMMUNITY

What, then, is the situation for older LGBT adults? The conventional wisdom holds that many individuals in the current cohort of older LGBT individuals are estranged from their families of origin because of the strains associated with revealing their sexual orientation. If true, this would affect the availability of these individuals to provide care to parents and other relatives. The literature on the social networks of older LGBT persons is unfortunately as limited as that on caregiving in this community. However, studies that have been conducted suggest that LGBT adults are not estranged from their families of origin. In a study of social networks among older (i.e., 60 years or more) LGBT adults, Grossman and colleagues reported that approximately one-third of respondents reported siblings in their social support networks and 40% noted the presence of other relatives. Only 4% listed a parent as a source of support, which may be due in part to the age of the sample (Grossman, D'Augelli, & Hershberger, 2000).

In terms of caregiving, what research exists demonstrates that LGBT older adults are involved in providing this type of assistance to members of their family of origin. Kimmel (1995) suggested that LGBT caregivers might provide certain advantages over heterosexual siblings in that they may be more available to provide help and even move in with the care recipient because they are not involved in traditional social roles (e.g., heterosexual marriage with children). In a study of lesbian and gay adults of all ages, Fredriksen (1999) reported that 32% of respondents were providing caregiving assistance. In Fredriksen's study, lesbians were more likely to be caring for an older person or a child (i.e., kin), while gay men were more likely to be caring for another working-age adult (i.e., nonkin). Overall, caring for a member of the family of origin accounted for over one-quarter of caregiving situations reported.

As noted by Barker (2002), many dependent older people receive help from nonrelated persons even when family is involved in caregiving. To counteract limited financial and familial resources, some people have developed nontraditional households comprised of unrelated individuals. The presence of such "fictive kin" in the informal support networks of African Americans has resulted from the resource limitations noted by Barker (Cantor & Brennan, 2000). Furthermore, given that the presence of similar others can bolster self-esteem among stigmatized populations such as homo-

LGBT caregivers might provide certain advantages over heterosexual siblings in that they may be more available to provide help and even move in with the care recipient because they are not involved in traditional social roles.

sexuals, one would expect that such fictive kin would also be evident in the social networks of LGBT adults, and indeed that is the case (Grossman et al., 2000). Grossman and colleagues reported that close friends were the most frequently mentioned source of social support among older LGBT adults (90%), followed next by their partners (44%).

There have been extensive studies of caregiving to this family of choice by LGBT adults, but the majority has focused on care for persons with HIV/AIDS (e.g., Pearlin, Aneshensel, & LeBlanc, 1997; Turner, Pearlin, & Mullan, 1998). Although these studies have described another type of caregiving experience, there is an inherent danger in extrapolating this HIV/AIDS-specific experience of caregiving to the global caregiving needs and experiences of the LGBT older adults. The issue of caregiving to partners and friends suffering from illnesses other than HIV/AIDS by LGBT adults has remained largely unexplored.

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Despite the growing interest in the LGBT population, relatively little is known about the caregiving experiences of midlife and older LGBT people, both in terms of caring for biological families (i.e., families of origin) and their partners and friends (i.e., families of choice) outside of the context of HIV/AIDS. This study was designed to examine the extent of caregiving provided to members of both the family of origin and family of choice in the past five years, and to compare the caregiving experiences of LGBT older adults in these different types of families.

BARRIERS TO UTILIZATION OF FORMAL COMMUNITY SERVICES

As care recipients become frailer and more dependent, the role of formal community services becomes more important. Unfortunately, use of such services as adult home care may pose particular difficulties for LGBT caregivers. Lack of recognition of same-sex couples under most health care policies, Social Security, and the Family and Medical Leave Act leaves LGBT families with fewer resources with which to access formal care providers. Unlike surviving partners in legally married couples, for example, same-sex partners' beneficiaries must pay taxes on retirement savings plans, and are not usually eligible for pensions that help support widows and widowers (Cahill, Ellen, & Tobias, 2000). Such discriminatory policies likely lead informal caregivers to play an even greater role in the lives of LGBT seniors.

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Even for those who can afford formal care providers, fear of discrimination may lead LGBT caregivers to avoid such services. A 1994 study of New York State Area Agencies on Aging (AAA) found that of 63 lesbians and 58 gay men surveyed, 72% were tentative about using AAA services due to lack of trust and perceived lack of understanding on the part of AAA personnel. Only 19% reported involvement with a senior center (Lesbian and Gay Aging Issues Network of the American Society on Aging [ASA], 1994).

Such fears of discrimination are well founded. The same study found that 46% of the AAAs reported that openly gay men and women would not be welcome at the senior centers in their areas (ASA, 1994). Homophobic attitudes in nursing homes have been well documented (Cook-Daniels, 1997). As of May 2004, it is still legal to discriminate



against gay, lesbian, and bisexual people in 36 states. Discrimination against transgender people is legal in 46 states. Reports of bias are common. One researcher describe a lesbian nursing home resident whom staff members refused to bathe because they did not want to touch her (Raphael, 1997). In another case, a home health care assistant threatened to out an elderly gay male client if he reported her negligent care (Cook-Daniels, 1997).

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PREFERENCE FOR ASSISTANCE

The importance of informal care in the lives of older LGBT people is further underscored by looking at preferences for assistance in time of need. The hierarchical compensatory theory of social support (Cantor, 1979) posits that, among older people, the choice of whom to turn to at times of need is ordered according to the primacy of the relationship of the helper to the elder, rather than by the nature of the task. When the initial preferred group is absent, other groups act as replacements in a compensatory manner. Thus, in the two large-scale previous studies of older New Yorkers (Cantor & Brennan, 1993), kin were preferred as the primary source of support, regardless of the kind of caregiving required. Only to the extent that family members were not available did friends, neighbors and, as a last resort, formal organizations become important in the provision of social support. Furthermore, when the samples were divided between those with functional biological kin and those without such kin, respondents without functional family support tended to rely more frequently on friends, neighbors and themselves.

Previous studies of gay men and lesbians have found that most have several gay or lesbian friends who function as a chosen family and form important components of their social support networks (Beeler, Rawls, Herdt, & Cohler, 1999; Grossman, et. al., 2000). The importance of friends in the informal social networks of gay men, lesbians, and bisexuals was further underscored in a study by Dorfman et. al. (1995) that compared the social networks of older heterosexual and homosexual adults. Although the levels of social support were different, heterosexual elders received most of their support from family members, while gay men and lesbians received more support from friends.

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STUDY SAMPLE AND METHODOLOGY

SAMPLE AND DATA COLLECTION PROCEDURES

The main purpose of this study was to obtain as broad a picture possible of the caregiving experiences, social support networks, and needs for assistance of older LGBT individuals in New York City. Because it was not possible to obtain a random sample of such adults, several different approaches were utilized to obtain as valid a sample as possible. From September 2000 through December 2001, participants were recruited from over 100 LGBT organizations in the New York City area. Groups that serve women and people of color were specifically targeted in order to gather as diverse a sample population as possible. Six methods were utilized to recruit study participants. The most important

was flyers, which were mailed to LGBT organizations for distribution to their membership. The flyers asked people interested in the study to contact the research team for a survey. Some organizations had their members complete surveys at one of their regular meetings. Advertisements were also placed in newspapers and through listservs of professionals working with the target population. One-to-one contact with potential respondents was made by tabling at various meetings and community events. Unlike other demographic characteristics, sexual orientation can be difficult to assess because it is often concealed. Employing a snowball sampling approach, the researchers encouraged respondents to recruit friends unaffiliated with any LGBT organizations in order to reach individuals who are not as open about their sexual orientation.

Surveys were completed anonymously and returned to the researchers in a postage-paid envelope included with the survey. Participants were notified that by returning the completed survey, they were giving their consent to participate in the study.

Participants age 50 and older were sought, in part because people often begin to provide care for their parents at that age. Other eligibility criteria included being lesbian, gay, bisexual, or transgender, and a resident of New York City. Although 348 surveys were returned, seven did not meet the age criterion, resulting in a net sample of 341. Because of difficulties in obtaining a random and representative sample, the findings cannot be generalized to all LGBT people, but do represent an important first step in learning more about the social networks and caregiving experiences of this social minority group in the aging population.

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SURVEY INSTRUMENT

To better understand the issues involving LGBT caregivers, focus groups on caregiving practices and needs were held with several dozen LGBT people age 50 and older in four of the five boroughs of New York City—Queens, Brooklyn, Manhattan, and Staten Island. Based upon the issues raised in the focus groups, and the existing body of knowledge on informal caregiving and research on older New Yorkers (Cantor, 1993; Cantor & Brennan, 1993; Cantor & Brennan, 2000), a survey instrument was developed and pre-tested. This questionnaire was 18 pages in length and consisted of the following four sections:

1. **Section One** requested demographic information about the respondent, including age, employment status, living arrangement, level of education, and measures of health status and life satisfaction.
2. **Section Two** was completed by respondents who were providing care to a family of origin member or had done so in the past five years. It contained questions about the person being cared for, including their place of residence, sexual orientation, and the nature of their care needs. It also asked about the caregiver's experience, including the type of assistance the respondent provided, the amount of time he or she spent caregiving, the extent to which other family members were involved and the level of the respondent's responsibility, the kinds of difficulties he or she encountered, and the reasons why the respondent had

Researchers encouraged respondents to recruit friends unaffiliated with any LGBT organizations in order to reach individuals who are not as open about their sexual orientation.



assumed caregiving responsibilities. It also included measures of the stress and strain experienced by the caregiver. The section concluded with questions on the use of community-based services, including those offered by the LGBT community.

3. **Section Three** was completed only by those respondents who were caring for a member of their family of choice, or had done so within the past five years. It contained a set of questions identical to those in Section Two, but focused on a member of the respondent's family of choice, providing for a comparison with the data from the previous section.
4. **Section Four** was completed by all respondents, and solicited information about their social networks. It included several self-diagnostic indicators of well-being, and also assessed the degree to which respondents had disclosed their sexual orientation to various social groups, and the level of support they had from family and friends regarding their sexual orientation. It also asked about how they wanted LGBT community organizations to help older members in need of assistance. The final set of questions targeted sensitive demographic information, like race and income, which are more likely to be completed after respondents have had a chance to become comfortable with the questionnaire.

2. Sample Characteristics

SOCIODEMOGRAPHIC CHARACTERISTICS

The sample for the study consisted of 223 males, 103 females, 4 transgender individuals, and 1 person who did not indicate gender (see Table 2.1). Three-quarters were non-Hispanic white, 12% were Hispanic, and 10% were African American. Asian/Pacific Islanders and American Indians/Alaska Natives each made up less than 1% of the sample group. Two percent of respondents did not fall into any of these categories.

Sixty-two percent of respondents lived alone; 30% lived with a partner or significant other, and the remaining 8% lived with family or friends. Forty percent indicated they were in a committed relationship, although not all of these lived with their partners. In general, participants were highly educated, and the majority were still working, mainly in professional, white-collar occupations (see Table 2.2). Reported income varied: one-third reported annual incomes ranging from \$25,000 to \$50,000; one-third earned \$50,000 to \$100,000; and 11% had incomes over \$100,000 (see Table 2.2a). However, a small but substantial group of respondents (20%) reported incomes of less than \$25,000 per year. The vast majority (78%) indicated they had “enough money with a little extra,” or that money was not a problem. Given the high proportion of respondents in their fifties (46%), self-reported health status was surprisingly low: only 44% rated their health as excellent or good, with 45% indicating their health was only fair. Eleven percent said their health was poor or very poor (see Table 2.1).

Efforts to increase the representation of people of color in the sample above 25% were not successful, and it was impossible to make statistically significant comparisons between their survey answers and those of people who identified as “white.” Differences in the responses of male and female survey participants were analyzed and are noted throughout.

Forty percent of respondents were in a committed relationship, although not all of these lived with their partners.



2.1: Sociodemographic Characteristics of Respondents (Percent)

Age	Total	Women	Men
50 to 59	46	52	43
60 to 69	35	30	37
70 +	19	18	20
Race/Ethnicity*			
White	75	66	80
Black	10	10	9
Hispanic/Latino	12	20	9
Asian/Native American/Other	3	4	2
Relationship Status**			
Single	52	46	54
Partnered	40	51	36
Divorced/separated	7	4	9
Widowed	1	0	1
Living Arrangement*			
Alone	62	52	66
With partner	30	41	25
With others	8	7	9
Self-rated Health			
Excellent, good	44	38	46
Fair 45	52	42	
Poor	11	10	11
Very poor	1	0	1

Note: Apparent disparities between row totals and the number of individuals in the male and female categories are accounted for by the inclusion of data from the four transgender persons who are not included in the male or female analyses.

Age N=341, Race/Ethnicity N=335, Relationship Status N=337, Living Arrangement N=334, Self-rated Health N=338

*p < .05, **p < .01 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

2.2: Sociodemographic Characteristics of Respondents (Percent)

Education*	Total	Women	Men
Less than high school	7	10	5
High school graduate	7	13	5
Some college	15	12	16
College graduate	22	14	25
Graduate/professional degree	50	52	49
Employment			
Working full-time	37	41	35
Working part-time	8	11	6
Self-employed	10	10	10
Self-employed full-time	1	1	0
Self-employed part-time	2	3	1
Homemaker	0	0	0
Retired	37	28	40
Unemployed	3	2	4
Other	3	5	3
Type of Work			
Executives/professionals	17	18	17
Administrators	38	46	35
Small business owners	2	3	1
Clerical and sales workers	21	14	24
Skilled workers	17	13	18
Semi-skilled/operatives	4	6	4
Unskilled workers/domestics	1	1	0
Other	1	0	1

Note: N indicates the total number of individuals who answered each question.

Education N=340, Employment N=336, Type of Work N=331

*p < .05 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

COMPONENTS OF INFORMAL SOCIAL SUPPORT NETWORKS

Respondents had relatively extensive informal social networks, with virtually all reporting one or more friends or relatives in their network (see Tables 2.3 & 2.3a). Contradicting the belief that LGBT adults are estranged from their biological families, 40% reported a parent in their informal networks, three-quarters were in frequent contact with one or more siblings, and 70% had at least one other relative to whom they felt close. The vast majority of those with a living parent reported being in contact with them at least weekly. In addition, 20% reported having one or more children, and 8% were grandparents.

The level of interaction and closeness among family members was highest between parents and children. Although somewhat lower among siblings, over half of the

respondents said they were very or somewhat close to one or more brother or sister. Although there was substantial interaction between LGBT persons and members of their biological families, it was partners and friends who formed the bedrock of the social support networks. Forty percent of respondents were partnered, but over 90% had an average of six friends in their networks. The frequency of contact and degree of closeness was decidedly highest between friends. There were few significant gender-based differences in social support and interactions.

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2.2a: Sociodemographic Characteristics of Respondents (Percent)

Income Level*	Total	Women	Men
<\$10,000	5	0	7
\$10,000–\$25,000	16	19	15
\$25,001–\$50,000	35	33	36
\$50,001–\$100,000	32	39	29
\$100,001–\$150,000	8	8	7
\$150,000 +	4	1	5

Note: N indicates the total number of individuals who answered each question.

Income Level N=320, Income Adequacy N=337

*p < .05 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

2.3a: The Average Number of Social Network Components of Study Respondents (Percent)

Components	Total		Women		Men	
	M	SD	M	SD	M	SD
Parent	1.3	0.5	1.3	0.5	1.2	0.4
Child*	2.0	1.2	1.9	1.0	2.2	1.3
Grandchild**	3.0	1.6	3.9	1.4	2.2	1.4
Sibling	2.1	1.6	1.3	0.5	2.0	1.5
Relative	3.0	2.7	2.7	2.3	3.2	2.9
Friend	5.9	5.2	6.5	6.2	5.7	4.7

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

*p < .05, **p < .01 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

2.3: The Extent and Number of Social Network Components of Study Respondents (Percent)

Have Component (y)	Total	Women	Men
Partner	40	51	36
Parent	32	35	32
Child**	20	30	15
Grandchild	7	11	5
Sibling	74	73	75
Other Relative	90	89	91
Friend	93	93	93

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Partner N(y)=135, Parent N(y)=110, Child N(y)=66, Grandchild N(y)=23, Sibling N(y)=250, Other Relative N(y)=300, Friend N(y)=311

**p < .01 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)



2.4: Contact and Closeness with Parents (Percent)

Face-To-Face Contact	Total	Women	Men
Daily	6	8	4
Weekly	13	3	18
Monthly	14	22	10
Several times per year	36	42	34
Once a year or less	32	25	34
Telephone Contact			
Daily	19	19	19
Weekly	50	44	53
Monthly	15	17	14
Several times per year	9	6	11
Once a year or less	7	14	3
Degree of Closeness			
Very close	51	44	54
Somewhat close	32	28	35
Not too close	10	14	8
Not close at all	7	14	3

Note: N indicates the total number of individuals who answered each question.

Face-To-Face Contact N=110, Telephone Contact N=110, Degree of Closeness N=109

2.5: Contact and Closeness with Children (Percent)

Face-To-Face Contact	Total	Women	Men
Daily	9	13	6
Weekly	25	26	22
Monthly	17	19	16
Several times per year	37	36	41
Once a year or less	12	7	16
Telephone Contact			
Daily	13	21	6
Weekly	50	52	49
Monthly	17	14	21
Several times per year	8	7	9
Once a year or less	11	7	12
Degree of Closeness			
Very close	64	65	65
Somewhat close	20	23	19
Not too close	5	7	3
Not close at all	11	7	13

Note: N indicates the total number of individuals who answered each question.

Face-To-Face Contact N=65, Telephone Contact N=63, Degree of Closeness N=64

2.6: Contact and Closeness with Grandchildren (Percent)

Face-To-Face Contact	Total	Women	Men
Daily	4	9	0
Weekly	26	36	9
Monthly	4	0	9
Several times per year	44	36	55
Once a year or less	22	9	36
Telephone Contact*			
Daily	5	9	0
Weekly	19	36	0
Monthly	19	27	10
Several times per year	48	27	70
Once a year or less	10	0	20
Degree of Closeness			
Very close	44	46	36
Somewhat close	39	46	36
Not too close	9	9	9
Not close at all	9	0	18

Note: N indicates the total number of individuals who answered each question.

Face-To-Face Contact N=23, Telephone Contact N=21, Degree of Closeness N=23

*p < .05 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

Women were more likely to report having partners, children, and grandchildren in their social networks. There were no significant gender differences in terms of closeness to network members, but women were more likely to maintain face-to-face contact with siblings compared with men (see Tables 2.4–2.7).

AVAILABILITY AND ADEQUACY OF SOCIAL SUPPORT

Respondents were asked about the availability and adequacy of help with the tasks of day-to-day living (instrumental support), and if they had someone to talk to and with whom to share confidences (emotional support). Sixty-four percent reported that they had all the instrumental support they needed, although another 19% felt they could have used a little more. However, the responses about emotional support disclosed a much greater level of deprivation. Over one-third reported inadequate emotional support, suggesting a need for more opportunities for closeness with social network members (see Table 2.8).

2.7: Contact and Closeness with Siblings (Percent)

Face-To-Face Contact**	Total	Women	Men
Daily	4	8	2
Weekly	7	14	4
Monthly	11	12	11
Several times per year	37	42	35
Once a year or less	42	24	49
Telephone Contact			
Daily	3	7	2
Weekly	27	34	24
Monthly	28	24	29
Several times per year	28	20	32
Once a year or less	14	15	13
Degree of Closeness			
Very close	30	33	28
Somewhat close	30	29	30
Not too close	26	21	29
Not close at all	15	18	13

Note: N indicates the total number of individuals who answered each question.

Face-To-Face Contact N=249, Telephone Contact N=248, Degree of Closeness N=247

**p < .01 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

2.8: Availability and Adequacy of Social Support (Percent)

Availability of Instrumental Support	Total	Women	Men
Most of the time	44	49	42
Some of the time	24	26	24
Only occasionally	22	17	24
Not at all	10	8	10
Adequacy of Instrumental Support			
I got all I needed	64	60	67
A little more	19	20	19
Some more	13	17	12
A lot more	3	3	2
Availability of Emotional Support			
Most of the time	55	61	53
Some of the time	25	23	26
Only occasionally	14	10	15
Not at all	6	6	6
Adequacy of Emotional Support			
I got all I needed	40	43	40
A little more	24	24	25
Some more	23	22	23
A lot more	12	10	12

Note: N indicates the total number of individuals who answered each question.

Availability of Instrumental Support N=331, Adequacy of Instrumental Support N=317, Availability of Emotional Support N=333, Adequacy of Emotional Support N=327



EXTENT OF CAREGIVING

Nearly half of the respondents were currently providing care, or had been caregivers in the past five years, to members of their biological families (families of origin) or to same-sex partners or friends (families of choice). At the time of the interview, slightly more than one-third of those providing care to a member of their family of origin were still involved in caregiving. Among respondents caring for a member of their family of choice, slightly less than one-third were still providing that care. In both groups, caregiving usually continued until the death of the person being cared for, or, in the case of older parents, until their institutionalization.

3. Caregiving for Family of Origin Members

Of the 341 respondents in the study, nearly one-quarter indicated that they were involved in the care of a family of origin member, or had been at some time during the past five years. Of this group, 39% were still caring for a member of their family of origin at the time of the survey, and another 61% had been involved in caregiving within the previous five years (see Tables 3.1 and 3.1a). Caregiving episodes were protracted in many cases: the average number of years of care provision was 8.4. The main reasons given for no longer being involved in caregiving was the death or institutionalization of the care recipient (89%). Only a small percentage indicated that someone else was providing care or that the person no longer needed care. No one indicated that they had stopped providing care because it had become too difficult to do so.

CHARACTERISTICS OF CARE RECIPIENTS

As is typical in studies of caregiving for older people, the largest proportion of family of origin care recipients were parents (84%); in keeping with statistics on the greater longevity of women, 63% were mothers and 21% were fathers (see Tables 3.2–3.2b). Respondents also provided care for other family of origin members: 4% for children, 7% for siblings, and 5% for other relatives.

Overall, 70% of family of origin care recipients were women and 30% were men. Most were elderly: their average age at the onset of the caregiving episode was 74. The vast majority of family of origin care recipients were heterosexual (95%). However, a small proportion of care recipients (3%) were LGBT, and another three percent (3%) of responses indicated that the recipient's sexual orientation was unknown.

The vast majority of family of origin care recipients were heterosexual (95%).



3.1: Caregiving Experience with Family of Origin Members in Past Five Years (Percent)

	Total	Women	Men
Provided Care in the Past Five Years (y)^a	22	36	16
Currently Providing Care (y)	39	41	35
Reason Caregiving Had Ended			
Death or institutionalized	89	91	88
Person no longer needed care	4	0	8
Someone else responsible for care	7	9	4
Caregiving became too difficult	0	0	0
Other reason	2	0	4

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Family of origin caregivers N=75; women N=37; men N=37. Some totals do not equal 100% due to multiple response categories and the exclusion of transgender individuals from gender comparisons because of the small number of them in the study (N=4).

^a: Proportions based on total sample (N=341), and total women (N=103) and men (N=233).

Provided Care in the Past Five Years N(y)=75, Currently Providing Care N(y)=29, Reason Caregiving Had Ended N=47

3.1a: Caregiving Experience with Family of Origin Members in Past Five Years (Percent)

Length of Episode Among Current Caregivers (Years)

Total		Women		Men	
M	SD	M	SD	M	SD
8.4	10	9.8	11.9	6.8	7.7

Note: N indicates the total number of individuals who answered each question.

Current Caregivers N=29

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

Table 3.2: Characteristics of Family of Origin Care Recipients (Percent)

Relationship to Caregiver	Total	Women	Men
Mother	63	62	62
Father	21	19	24
Son	4	5	3
Sister	3	3	3
Brother	4	3	5
Aunt	1	3	0
Female relative (unspecified)	1	3	0
Other relative (unspecified)	3	3	3
Gender of Care Recipient			
Male	30	28	32
Female	70	72	68

Sexual Orientation of Care Recipient*

	Total	Women	Men
Lesbian or gay	3	3	3
Heterosexual	95	92	97
Bisexual	0	0	0
Transgender	0	0	0
Do not know	3	5	0

Note: N indicates the total number of individuals who answered each question.

Relationship to Caregiver N=75, Gender of Care Recipient N=74, Sexual Orientation of Care Recipient N=74

*p < .05 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

LIVING ARRANGEMENTS

In many situations reported in the literature on caregiving, the person receiving care and the caregiver live together. This household arrangement reflects the important role spouses play in caregiving, but is also found among children who move in with an elderly parent, or, more commonly, invite a parent to move in with them. However, families are increasingly providing care for an elderly member who desires to continue to live in

his or her own home and maintain a large measure of independence. This trend was reflected in this survey. Only 27% of the family of origin care recipients lived in the same residence as their LGBT caregivers. Of the remainder, 30% were currently living alone and another 49% had lived alone but moved in with the caregiving recipient during the course of the caregiving episode. Of these later older persons 24% moved in with other family members, 16% with a nonrelated person, and 35% were in institutions or other long term care facilities.

Thus family of origin care recipients not living with caregivers either lived alone (35%), in nursing homes or other institutions (25%), or with other family members (24%). An additional group (16%) lived with people to whom they were not related (see Table 3.2a). These statistics are striking. A substantial number of care recipients still lived alone, or had lived by themselves at one time during the caregiving episode. And a large number who transitioned from living alone to living with other family members did not move in with their caregiver. One key difference between the family of origin caregivers in this sample and many other samples of caregivers is that relatively few of those providing care lived with those receiving care (Neal et al., 1997). Such living arrangements do not imply that the caregivers in this study were not close to their care recipients, or that they were not deeply involved in caregiving. But they do have implications for the types of care being provided, as well as the amount of time spent providing care.

3.2a: Characteristics of Family of Origin Care Recipients (Percent)

Recipient Living with Caregiver	Total	Women	Men
Yes	27	35	17
No	73	65	83
If no, currently living with:			
Partner/significant other	2	0	4
Husband	2	5	0
Mother	2	5	0
Sister	4	9	0
Neighbor	2	0	4
Other nonrelative	4	5	4
Alone	35	18	50
Alone, then with other family	14	18	7
Alone, then with other nonkin	10	5	14
Alone, then institutionalized	26	36	18

Note: N indicates the total number of individuals who answered each question.

Recipient Living with Caregiver N=74

Table 3.2b: Characteristics of Family of Origin Care Recipients

Age of Care Recipient at Start of Episode (Years)

Total		Women		Men	
M	SD	M	SD	M	SD
73.9	17.9	73.0	18.4	74.7	17.6

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)



REASONS FOR REQUIRING CARE

Respondents were presented with a list of common reasons that people require care. They were asked to indicate all of those applicable to the family of origin care recipient for whom they were responsible (see Table 3.3). The two main causes that emerged were physical illness (50%) and frailty due to age (42%). Nineteen percent of respondents reported that their care recipients required care due to disabilities like vision loss or stroke. Thirty-five percent mentioned Alzheimer’s disease or dementia as a major reason for providing care, while 10% indicated their care recipients suffered from mental illness. A smaller group (11%) were providing care in response to a specific accident. These responses were very much in line with the principal reasons older people generally require care. Eighty-one percent of those being cared for were hospitalized during the course of the caregiving episode, a further indication of the level of frailty and disability of the care recipients.

3.3: Reasons Family of Origin Members Needed Care (Percent)

Reasons Recipient Needed Care	Total	Women	Men
HIV/AIDS	1	0	3
Physical illness	50	49	53
Disability	19	27	11
Mental illness	10	16	3
Alzheimer’s disease/dementia	35	35	36
Frailty due to old age	42	38	44
Accident	11	11	11
Other reason	10	5	14
Care recipient was hospitalized (y)	81	85	79

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question.

TYPES OF ASSISTANCE

In order to determine what kind of caregiving survey respondents provided, and with what frequency, they were presented with a list of 15 types of assistance commonly provided by caregivers, and asked to rate their level of participation in each. Although the majority of the respondents did not live with the care recipient, the level of involvement was extremely high. The types of assistance provided can be grouped into the following five categories (see Tables 3.4–3.4c):

- *Emotional support.* Between 84% and 90% of the family of origin caregivers indicated they always provided emotional support, including visiting and telephoning, and very few respondents said they did not provide such help at all. As is the case for most caregivers, LGBT caregivers play a crucial role in providing emotional support and companionship to family members for whom they provide care.

- *Advice and decision-making.* After emotional support, providing advice and assistance in making decisions, whether financial or with respect to medical care, is the most frequently mentioned form of assistance. Seventy-seven percent of respondents always provided such assistance, and another 15% sometimes gave decision-making advice; only 6% were not involved in decision-making at all.
- *Acting as a liaison with other family members.* Another important role assumed by the family of origin caregivers was keeping in touch with other family members regarding such things as prognosis, level of morbidity, and the level of morale of the care recipient. Seventy-two percent of the respondents said they always played this role, and another 27% indicated that they were sometimes or occasionally involved in this way. Only 10% acted as liaisons with other family members only occasionally, and nearly no one indicated that they did not perform this function at all.
- *Case management.* Insuring that the care recipient is getting help from medical and social service professionals, as well as dealing with those professionals, are tasks that often fall to a caregiver. Sixty-nine percent of family of origin caregivers indicated that they always or often dealt with medical providers, and 63% had been involved in making arrangements for medical care, relatively large numbers that make sense given the relatively high educational level of this sample and their likely ability to deal with bureaucracies in their own lives. In their capacity as case managers, 60% were always involved in money management for the care recipient, although only

3.4: Types of Assistance and Level of Involvement in Caregiving to Family of Origin Members (Percent)

Personal Care and Mobility	Total	Women	Men
Personal care			
Not provided	38	28	47
Only occasionally	29	36	22
Sometimes	11	6	17
Always or often	22	31	14
Mobility			
Not provided	15	16	14
Only occasionally	29	24	31
Sometimes	23	22	26
Always or often	33	38	29
Transportation			
Not provided	17	19	16
Only occasionally	19	19	16
Sometimes	25	25	26
Always or often	39	38	42

Note: N indicates the total number of individuals who answered each question.

Personal care N=73, Mobility N=73, Transportation N=64

3.4a: Types of Assistance and Level of Involvement in Caregiving to Family of Origin Members (Percent)

Household Management	Total	Women	Men
Shopping/laundry			
Not provided	20	24	17
Only occasionally	20	16	22
Sometimes	16	14	19
Always or often	43	46	42
Cooking			
Not provided	34	32	33
Only occasionally	19	8	31
Sometimes	20	24	17
Always or often	27	35	19
Cleaning house			
Not provided	37	35	39
Only occasionally	14	19	8
Sometimes	14	5	22
Always or often	37	41	31

Note: N indicates the total number of individuals who answered each question.

Shopping/laundry N=74, Cooking N=74, Cleaning house N=74



3.4b: Types of Assistance and Level of Involvement in Caregiving to Family of Origin Members (Percent)

Case Management Assistance	Total	Women	Men
Assist with health care providers			
Not provided	1	3	0
Only occasionally	12	5	19
Sometimes	18	11	22
Always or often	69	81	58
Arrange for medical care			
Not provided	10	3	15
Only occasionally	10	5	15
Sometimes	17	19	15
Always or often	63	73	55
Contact family and friends			
Not provided	1	0	3
Only occasionally	10	8	9
Sometimes	17	16	18
Always or often	72	76	70
Medical Care			
Provide medical care			
Not provided	59	51	66
Only occasionally	22	29	16
Sometimes	9	6	13
Always or often	10	14	6
Received training for medical/personal care (y)			
	25	25	24
Who trained medical/personal care?			
Partner/significant other	0	0	0
Physician/specialist	8	0	25
Nurse	67	75	50
Home health aid	25	25	25

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Assist with health care providers N=74, Arrange for medical care N=71, Contact family and friends N=71, Provide medical care N=68, Received training for medical/personal care N(y)=12, Who trained medical/personal care? N=12

3.4c: Types of Assistance and Level of Involvement in Caregiving to Family of Origin Members (Percent)

Emotional Support and Advice	Total	Women	Men
Emotional support			
Not provided	1	3	0
Only occasionally	1	3	0
Sometimes	13	8	16
Always or often	84	87	84
Visiting or telephoning			
Not provided	1	3	0
Only occasionally	0	0	0
Sometimes	8	12	5
Always or often	90	85	95
Advice or decision making			
Not provided	4	5	3
Only occasionally	4	0	8
Sometimes	15	8	19
Always or often	77	87	69
Financial Help and Management			
Financial help			
Not provided	31	28	34
Only occasionally	10	6	14
Sometimes	19	17	20
Always or often	40	50	31
Managing money			
Not provided	18	14	22
Only occasionally	11	11	11
Sometimes	11	14	6
Always or often	60	60	61

Note: N indicates the total number of individuals who answered each question.

Emotional support N=75, Visiting or telephoning N=72, Advice or decision making N=74, Financial help N=72, Managing money N=72

40% always provided financial assistance. Another 20% were sometimes involved in providing financial help, but 40% did not provide, or only occasionally provided, monetary assistance.

- *Household management and hands-on assistance.* The final group of items in the list involved hands-on assistance, including meal preparation, housework, personal care, and assistance with transportation. Respondents were significantly less involved in these ways. The proportion either always or sometimes performing such tasks ranged from a low of 19% (assistance with medical care) to a high of 64% (providing transportation). The tasks most frequently performed were shopping and laundry, followed by housework and preparing meals. But the number of respondents performing each task always, often, or sometimes was not high—usually less than half of the sample.

The lower proportion of respondents involved in personal care and housekeeping is not surprising, since most caregivers did not live with those family of origin members for whom they provided care. These caregivers were, however, clearly involved in making sure that the care recipient received the appropriate level of care, and they played an important role in insuring that the appropriate care was provided.

There were few significant differences in the proportion of men and women undertaking the variety of tasks discussed above. However, there are three trends worth noting. Women indicated that they prepared meals, provided personal care, and dealt with nurses or other health care providers at higher levels than those reported by male caregivers. This trend is borne out by other caregiving studies, and is in keeping with rather traditional ideas about caregiving gender roles.

MOST IMPORTANT TYPE OF ASSISTANCE

Survey respondents were asked what kinds of assistance they provided (see Tables 3.4–3.4c) Among LGBT elders caring for members of their family of origin, providing emotional support and insuring that their family members received the care they need were of paramount importance, and encompassed a large proportion of the care provided. A plurality (40%) felt that providing emotional support and companionship was the most important way in which they helped. Thirty-nine percent of the family of origin caregivers listed case management as most important. A smaller proportion of caregivers believed that household or personal care assistance was the most important way they helped, in line with the lower number of respondents providing such assistance at all.

Given that most family of origin caregivers did not live with the care recipient, it is not surprising that others cleaned and provided personal assistance with greater frequency. Although there was no difference between men and women in their appraisal of the ways in which they provided help, women were more likely to participate in caregiving tasks involving traditional female roles than men.

Among LGBT elders caring for members of their family of origin, providing emotional support and insuring that their family members received the care they need were of paramount importance.



CAREGIVER TRAINING

Providing personal and medical care for frail and disabled elderly people can require a high level of skill and expertise. As previously noted, the provision of such care was not common among caregivers for family of origin members. Among those providing such care, only 26% indicated receiving any training for medical or personal care tasks (see Table 3.4b). Such training was overwhelmingly provided by visiting nurses (68%) or home health care aides (25%). Only 8% involved in providing such training were physicians.

CAREGIVER STRESS

The literature on caregiving is replete with evidence that providing care on a regular basis can both induce stress and feelings of burden, and can interfere with other aspects of the caregiver's life. Accordingly, this survey contained questions designed to shed light on how caregiving affected the LGBT respondents in the study.

TIME SPENT PROVIDING CARE

The amount of time spent providing care is clearly a key factor in the stress and burden experienced by caregivers. Respondents indicated that they spent considerable time caregiving, underscoring the degree of responsibility and involvement in caring for their family of origin members (see Tables 3.5 and 3.5a). Almost half of all family of origin caregivers were involved in caregiving on a daily basis, while nearly another quarter of respondents were involved several times a week. Thus, almost three quarters of family of origin caregivers were involved in providing care at least once per week. Another 25% indicated that they were involved several times per month, and a small minority (4%) were involved only once per month or less.

Not only were the vast majority of family of origin caregivers frequently involved in caregiving, but also the typical number of hours per week spent on caregiving was considerable. Ranging from 1 to 168 hours, family of origin caregivers provided an average of 29 hours of care weekly. There were no significant differences between men and women with regard to the amount of time spent caregiving.

HELP FROM OTHERS

The amount of help a caregiver receives from family and community-based providers is generally related to the level of stress that comes with caregiving, and persons receiving little or no help are most at risk for stress-related problems. Among the family of origin caregivers, 77% received assistance from others, while 23% received no help (see Table 3.5). Respondents were asked about who else helped to provide care on a regular basis. The responses ranged from relatives, neighbors, friends, and partners, to nurses, home health care aides, and community-based organizations that are part of the formal

3.5: Frequency of Caregiving and Contextual Issues for Family of Origin Members (Percent)

Frequency of Care Provision	Total	Women	Men
Every day	47	58	34
Several times per week	24	17	31
Several times per month	25	19	31
Once a month or less	4	6	3
Someone Else Helped with Caregiving (y)	77	73	81
Level of Care Involvement			
Respondent was sole provider	37	40	35
Respondent provided most care	30	26	32
Respondent shared caring equally	23	23	24
Respondent did less than others	10	11	8
Difficulty with Family/Friends (y)	33	40	27
Different Family Expectations of Caregiver Due to Sexual Orientation			
They expect more	34	34	35
They expect less	4	3	6
Makes no difference	61	63	59

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Frequency of Care Provision N=72, Someone Else Helped with Caregiving N(y)=58, Level of Care Involvement N=73, Difficulty with Family/Friends N(y)=24, Different Family Expectations of Caregiver Due to Sexual Orientation N=70

3.5a: Frequency of Caregiving and Contextual Issues for Family of Origin Members

Number of Caregiving Hours Per Week					
Total		Women		Men	
M	SD	M	SD	M	SD
29.0	35.2	34.3	37.4	23.6	32.6

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

health care service system. The majority of persons who regularly provided additional help were siblings, parents, and other relatives. A sizable group was identified as friends, neighbors, other unrelated people, and partners, suggesting that the family of origin caregivers received support and assistance from other members of their social networks. Only a small group received regular assistance from visiting nurses or home health care aides, underscoring the importance of the informal caregiving system in providing assistance to frail, elderly people.

Having sole responsibility for caregiving can be a serious source of stress for caregivers. Over one-third of family of origin caregivers (37%) indicated that they were the sole person providing care, while another 30% said they were providing most of the care. Thus, over two-thirds were the primary caregiver—a further indication of the risk for stress to which these caregivers were exposed. Another 23% were sharing the care equally with others. Only 10% indicated that they did less than others, which may be an indication of situations in which formal, long-term care agencies were involved in providing assistance.



RELATIONSHIPS WITH OTHERS

Another potential source of stress for caregivers is found in their relationships with other family members, and with medical and social service providers. A caregiver's stress level can be exacerbated if such relationships are strained, or if the caregiver is not accepted as the person responsible for managing care. Respondents were therefore asked a series of questions about their relationships with family members and health care providers aimed at eliciting the extent and nature of such conflicts where they existed. Respondents were also asked if their own sexual orientation was a factor in such conflicts.

A significant minority (34%) indicated that their families expected more of them because they were LGBT.

A significant minority of family of origin caregivers (33%) reported experiencing difficulties with some of the care recipient's friends or relatives (see Table 3.5). When asked with whom, siblings were mentioned most frequently, followed by friends and other people to whom the care receiver was not related. In one case, a care recipient's partner was specifically mentioned, although it is likely that other friends and unrelated people may have been the partners of caregivers as well. In only one case was another relative (an aunt) listed as the person with whom the caregiver experienced conflict.

Having difficulties with siblings over caregiving responsibilities is not uncommon in families involved in the care of a frail or elderly person. But it was possible that in the case of LGBT caregivers, sexual orientation might become an additional source of friction. In focus groups held prior to the study, some participants suggested that because many LGBT people are childless and therefore have fewer explicit family responsibilities, more is expected of them when it comes to caregiving than of their heterosexual siblings. Sixty-one percent of family of origin caregivers felt their sexual orientation had no bearing on expectations of their caregiving responsibilities. A significant minority (34%), however, indicated that their families expected more of them because they were LGBT, while 4% felt that less was expected of them because they were LGBT.

LEGAL ISSUES

Caregivers sometimes face problems with the formal health and social services systems because they do not have legal authority to make important medical or financial decisions. The respondents caring for members of their family of origin overwhelmingly indicated that there was someone with legal authority to make medical decisions involving care (81%). Of these, 57% said it was they who had that authority. Another 15% said they shared responsibility with another person, and just over a quarter (28%) said that someone else was responsible (see Table 3.6). If someone else had legal authority in health matters, that other person was almost always another family of origin member, usually a sibling (68%) or the spouse of the care recipient (16%). In three cases, an unrelated person was the designated person; and in one case a physician had legal authority to make them.

Given the amount of time and effort being spent by the family of origin caregivers, and the fact that many carried the majority of caregiving responsibilities, it was heartening

3.6: Medical Authority and Legal Issues for Family of Origin Members (Percent)

	Total	Women	Men
Someone Had Authority for Medical Decisions (y)	81	78	83
Who Had Medical Authority?			
Respondent	57	59	57
Someone else	28	28	30
Shared with family	15	14	13
Someone Had Authority for Legal Decisions (y)	74	64	83
Who Had Legal Authority?			
Respondent	59	65	55
Someone else	26	22	31
Shared with someone unrelated	15	13	14

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Someone Had Authority for Medical Decisions N(y)=60, Who Had Medical Authority? N=60, Someone Had Authority for Legal Decisions N(y)=53, Who Had Legal Authority? N=53

to find that so many had been designated to make health care-related decisions for their care recipient. Only 19% of family of origin caregivers said there was no one with such legal authority over medical decisions.

Most of the family of origin care recipients had also designated someone to make legal decisions for them. Fifty-nine percent of the family of origin caregivers said that they were that person, and another 15% indicated that they shared the authority with their family. About one-quarter indicated that legal decisions were in someone else’s hands, usually a sibling. These findings regarding legal authority mirror those on health care decision making, suggesting that most LGBT family of origin caregivers had both caregiving responsibilities and legal authority for the family members for whom they provided care.

Most LGBT family of origin caregivers had both caregiving responsibilities and legal authority for the family members for whom they provided care.

CAREGIVERS’ PERSONAL LIVES

The stress and feelings of burden experienced by caregivers are directly related to the impact caregiving has on their personal lives. To determine how they were most affected by caregiving, respondents were presented with a series of statements about their lives and asked to indicate which they had experienced (see Table 3.7). One group of statements involved the impact of caregiving on social relationships and personal time. Another concerned its impact on work, health, family relationships, and finances. The final group involved disclosures about sexual orientation.



3.7: Burden and Strain Experienced by Family of Origin Caregivers (Percent, in rank order)

Caregiving Burdens (y)	Total	Women	Men
1. Places limits on social life	65	70	60
2. Had to take time off work*	56	70	43
3. Don't have enough time for myself	51	57	46
4. Difficulty with other care providers	44	51	38
5. Worry about cost of care	39	38	41
6. Problems with family members	36	38	35
7. Lack of privacy	35	38	30
8. Health suffers	29	30	30
9. Requires my constant attention	23	27	19
10. Strained relationship with my partner**	23	38	8
11. Forced me to conceal sexual orientation**	13	24	3
12. Forced me to come out	3	5	0

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question.

*p < .05, **p < .01 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

Caregiving most heavily affected the family of origin caregivers' personal lives and their freedom to do what they desired. Sixty-five percent indicated that caregiving limited their social lives, and 55% that they did not have enough time for themselves. Thirty-five percent felt caregiving interfered with their privacy. These findings are very much in line with the other research on caregivers, and underscore the need for intermittent respites from caregiving responsibilities.

Most respondents had not yet reached retirement age, and were still employed. As a result, many experienced conflicts between work and caregiving to their family of origin members. Fifty-six percent had to take time off from work because of caregiving responsibilities. Women were more significantly affected in this way (70%) than men (43%).

Their role as case managers was also an important source of stress. Forty-four percent of respondents reported conflicts with medical or social service providers, including the unavailability of doctors, difficulty getting medical prognosis or guidance on providing care, and problems obtaining home health care or domestic help. Respondents were asked to identify the people with whom they had such difficulties; they cited physicians and specialists most frequently, followed closely by home health care aides and the staff of health care facilities. Nurses, social workers and insurance providers were cited to a lesser extent.

From the data collected, it is impossible to infer to what extent difficulties with medical personnel involved homophobia or a refusal to accept the LGBT caregiver as the spokesperson for the patient. Problems with home health care aides, including tardiness and refusing to do certain tasks, often come up in studies of caregiving for the frail elderly, and in this study, home health care aides were cited almost as often as physicians as a source of conflict and stress. Social workers were less frequently mentioned as sources of difficulty than medical professionals or health care facility staffers. They

may have been, as a group, more sensitive to needs of the care recipients and their caregivers, although it is possible the caregivers did not have as much contact with social workers as with other health care providers.

One-third of the family of origin caregivers indicated they had problems with family members during the course of providing care. Given that nearly all of them acted as a liaison with family members, that number seems to be disproportionately high.

Caregivers of the disabled or frail elderly often indicate that the rigors of providing assistance affects their health, but only 30% of the family of choice caregivers indicated that their health had suffered due to caregiving. Because these caregivers were less involved in household or personal care than with providing emotional support and case management, the stress associated with caregiving may not have manifested in physical health problems as often, particularly given the relatively young age of many of the caregivers in the study.

Women were significantly more likely than men to report that caregiving strained their relationship with a partner (38% and 8%, respectively) and that caregiving forced them to conceal their sexual orientation (24% and 3%, respectively). It is not clear why gender differences emerged in these areas. While only 3% of respondents reported that being a caregiver forced them to come out of the closet, 13% of both male and female family of origin caregivers said that being a caregiver forced them to conceal their sexual orientation. Though not a major problem for the LGBT care-

While only 3% of respondents reported that being a caregiver forced them to come out of the closet, 13% said that being a caregiver forced them to *conceal* their sexual orientation.

Table 3.7a: Burden and Strain Experienced by Family of Origin Caregivers (Percent)

How Much Spent on Caregiving Per Week?	Total	Women	Men
Less than \$50	53	49	57
\$50 to \$100	31	37	24
\$100 to \$500	17	14	19
\$500 or more	0	0	0

Note: N indicates the total number of individuals who answered each question.

How Much Spent on Caregiving Per Week? N=72

3.7b: Burden and Strain Experienced by Family of Origin Caregivers (Percent)

Extent of Overall Strain in Caregiving Role	Total	Women	Men
Emotional			
Little or none	4	5	3
Some strain	14	8	19
Moderate strain	22	27	17
A lot/a great deal	61	59	61
Physical			
Little or none	36	33	36
Some strain	18	19	17
Moderate strain	27	19	36
A lot/a great deal	19	28	12
Financial			
Little or none	43	34	49
Some strain	16	20	14
Moderate strain	26	26	27
A lot/a great deal	16	20	11

Note: N indicates the total number of individuals who answered each question.

Emotional N=74, Physical N=73, Financial N=73



givers in this sample, this issue may have resonance in other LGBT communities, and should be examined further with other LGBT populations.

MONEY SPENT ON CAREGIVING

Concerns about the costs of providing care were cited by 39% of the caregivers, a statistic related to how much the caregivers spent on caregiving each week (See Table 3.7a). About half (52%) of the caregivers spent less than \$50 per week. Thirty-two percent spent between \$50 and \$100 per week, while 16% spent between \$100 and \$500. (These expenses may not have been solely medical, and could include household help and other incidentals.)

STRESS LEVEL

To verify the level of strain and burden caregivers experienced, family of origin caregivers were asked indicate its impact on them in three areas: emotional, physical, and financial (see Table 3.7b). Although most indicated that they spent money each week on caregiving, and a small proportion spent considerable amounts, 43% indicated feeling little or no financial strain. Another 42% noted feeling some or moderate financial strain, while only a small proportion (16%) felt considerable financial strain. This distribution is not surprising given the relatively high income of many of the respondents, and that over half spent less than \$50 per week on caregiving.

A somewhat smaller proportion (36%) indicated experiencing little or no physical strain. A more substantial group (45%) experienced moderate physical strain, while only 19% indicated feeling considerable physical strain. It would appear that respondents felt somewhat more physical strain than financial strain in their caregiver roles.

It is in the arena of emotional strain, however, that the real toll for the family of origin caregivers is greatest. Only 4% said they experienced little or no strain. Thirty-five percent reported some or moderate emotional strain. But over half of the family of origin caregivers, the largest group by far (61%), indicated that they felt considerable levels of emotional strain. This finding is not inconsistent with other research on caregivers. Among the family of origin caregivers in this study, there were, however, somewhat lower levels of physical strain than what is often reported.

Over half of the family of origin caregivers (61%) indicated that they felt considerable levels of emotional strain.

REASONS FOR PROVIDING CARE

Despite the stress and burdens experienced by caregivers, taking care of a frail family member is widespread in most cultures. In a national study on caregiving, the Kaiser Family Foundation found that one in four adults is an informal caregiver and that as the American population ages, it is likely that families will take on an even greater caregiving responsibility in order to keep loved ones in the community. People provide

care for many reasons. The family of origin caregivers in this study were given a list of common reasons and asked to indicate which of them explained why they had become a caregiver (see Table 3.8).

The most commonly cited reasons were that the care recipient deserved to be cared for (89%), that caregiving allowed the person to remain at home (64%), and that being a caregiver was part of the individual's nature (64%). These responses suggest that nurturing was an important component of caregiving for the caregivers, as was recognition that they had a responsibility to make it possible for someone close to them to remain at home, a nearly universal desire among older people, including those who are ill or frail. Fulfilling family obligations and using the opportunity to become closer to their families of origin were also major incentives for providing care. Forty-four percent indicated that their family expected them to be the caregiver, 35% felt there was no one else to provide the care, and 18% indicated that providing care enabled them to become closer to their family.

Providing care to a family of origin member enhanced personal feelings of purpose, self-worth, and social responsibility.

3.8: Reasons for Providing Care Among Family of Origin Caregivers (Percent)

Sense of Responsibility (y)	Total	Women	Men
Care recipient deserved care	89	92	87
It was respondent's responsibility	79	76	81
Family expected me to provide care	44	46	43
To avoid feelings of guilt/regret	25	22	27
Avoidance of Institutionalization (y)			
Care recipient able to stay home	64	70	60
No one else was available	35	27	43
Personal Reasons (y)			
Part of respondent's nature	64	70	57
Emotionally/spiritually nurturing	31	30	30
Provided respondent sense of purpose	28	27	30
Made respondent a better person	23	16	30
Became closer to respondent's family	19	16	22

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Sense of Responsibility N(y)=178, Avoidance of Institutionalization N(y)=99, Personal Reasons N(y)=165

3.9: Formal Organizations Used by Family of Origin Caregivers (Percent)

Long-Term Care (y)	Total	Women	Men
Visiting nurse service*	40	54	27
Home health care agency	43	46	41
Emotional/Psychological Support (y)			
Support groups*	17	27	8
Therapy	21	22	22
Clergy	23	30	16
Community-Based Services (y)			
Senior LGBT organization	1	3	0
Other LGBT organization	1	3	0
Senior center	16	11	22
Informational Assistance (y)			
Phone information line*	11	19	3
Internet	21	22	19
Other (y)	24	19	30
Difficulties with Formal Service Providers (y)			
	41	44	38

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Long-Term Care N(y)=62, Emotional/Psychological Support N(y)=46, Community-Based Services N(y)=14, Informational Assistance N(y)=41, Other N(y)=18, Difficulties with Formal Service Providers N(y)=30

*p < .05 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)



A smaller proportion responded in terms of fulfilling their personal needs. Thirty-one percent agreed that being a caregiver nurtured them spiritually or emotionally; 28% said being a caregiver provided them with a sense of purpose; 25% became a caregiver to avoid feelings of guilt or regret; and 23% agreed that caregiving makes them a better person. Taken in combination with the fact that almost three-quarters of the family of origin caregivers felt that caregiving was part of their nature, these responses suggest that providing care to a family of origin member enhanced personal feelings of purpose, self-worth, and social responsibility.

COMMUNITY RESOURCES

Although older people are mainly cared for by family, partners, close friends and neighbors, formal community-based agencies can often make a difference in the level of stress experienced by the caregiver, and even make it possible for frail elders to remain in their homes. LGBT people have sometimes resisted turning to formal providers that are not part of the LGBT community. Would having to care for a sick or frail family of origin member mitigate such hesitancy? To find out, survey respondents were asked whether they had sought assistance from support groups, individual or group therapy, information phone lines for caregivers, the Internet, a religious or spiritual leader, LGBT organizations, home health care agencies, or senior centers. As Table 3.9 indicates, respondents' reliance on community services or organizations was minimal. Less than half of the 75 family of origin caregivers had turned to even one of the organizations on the list. Only visiting nurse services and home health care agencies were accessed in a significant number of cases (40% and 43%, respectively). Since most of the caregivers did not reside with care recipients and sizeable proportions of the care recipients had lived at home for some time during the caregiving episode, reliance on such agencies is not surprising.

The caregivers' need for personal support was evident by their involvement in support groups (18%), individual therapy (22%), and counseling with a religious or spiritual leader (23%), suggesting a need for personal support among caregivers. Yet, few people accessed any other service or organization during the caregiving experience, even those based in the LGBT community. Only 1% of respondents reported using the services of an agency serving LGBT seniors, or the LGBT community in general, a trend that is somewhat disturbing. This contrasts with 21% who turned to the Internet for information on caregiving, and 11% who used a phone information line for caregivers.

These findings suggest that most LGBT people caring for a member of their family of origin go it alone, and depend on other family members, partners and friends to provide support and assistance when needed. Only when the pressures of caregiving become more than their informal systems can accommodate do they turn to formal community organizations, primarily for nursing and home care assistance.

Only 1% of respondents reported using the services of an agency serving LGBT seniors, or the LGBT community in general, a trend that is somewhat disturbing.

4. Caregiving for Families of Choice

Of the 341 respondents in the study, 24% reported having provided care to a person who was not related by blood in the previous five years. Most of these care recipients were same-sex partners or close friends. In the caregiving literature, such care recipients are known as members of one's "family of choice." Men were somewhat more likely to report being a caregiver for a family of choice member (27%) than women (20%). Thirty percent of these caregivers were providing care to this unrelated individual at the time of the survey, comprising 8% of the total sample (see Table 4.1). Of those contemporaneously providing care, the caregiving episode ranged from six months to 34 years; on average, its duration was 8.3 years (see Table 4.1a).

Of the 69% who reported that the caregiving episode had ended, the vast majority (85%) said it was because the care recipient had died. Nine percent had stopped because the person no longer needed care, and 5% reported that someone else had assumed caregiving responsibilities. No family of choice caregiver stopped caregiving because it had become too difficult. (Three percent stopped providing care for some other reason.)

CHARACTERISTICS OF CARE RECIPIENTS

In 54% of the reported caregiving episodes, the person receiving care was the partner or "significant other" of the LGBT caregiver. Male friends were the second most commonly reported relationship to the caregiver (30%), followed by female friends (5%), and men (7%) or women (3%) whose relationship to the caregiver was not specified (see Table 4.2). Significant gender differences emerged regarding the relationships between caregivers and care recipients. While men and women were about as likely to care for a significant other or partner, male caregivers were more likely to be involved with male rather than female friends (35% and 2%, respectively). For women, the difference was not as sharp: 15% were car-

In 54% of the reported caregiving episodes, the person receiving care was the partner or "significant other" of the LGBT caregiver.



4.1: Caregiving Experience with Family of Choice Members in Past Five Years (Percent)

	Total	Women	Men
Provided Care in Past Five Years (y)^a	24	19	27
Currently Providing Care (y)	31	24	33
Reason Caregiving had Ended			
Death or institutionalized	85	88	83
Person no longer needed care	9	6	10
Someone else responsible for care	5	6	5
Caregiving became too difficult	0	0	0
Other reason	3	6	2

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Family of choice caregivers N=83; women N=21; men N=62. Some totals do not equal 100% due to multiple response categories and the exclusion of transgender individuals from gender comparisons because of the small number of them in the study (N=4).

^a Proportions based on total sample (N=341), and total women (N=103) and men (N=233).

Provided Care in Past Five Years N(y)=83, Currently Providing Care N(y)=25, Reason Caregiving had Ended N=60

4.1a: Caregiving Experience with Family of Choice Members in Past Five Years

Length of Episode Among Current Caregivers (years)

Total		Women		Men	
M	SD	M	SD	M	SD
8.3	8.4	7.8	5.0	8.4	9.0

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

4.2: Characteristics of Family of Choice Care Recipients (Percent)

Relationship to Caregiver*	Total	Women	Men
Partners/significant other	54	60	53
Female friend	5	15	2
Male friend	30	10	35
Female unspecified relationship	3	5	2
Male unspecified relationship	7	5	8
Other unrelated person	1	5	0

Gender of Care Recipient***

Male	75	15	94
Female	25	85	7

Sexual Orientation of Care Recipient*

Lesbian or gay	84	65	90
Heterosexual	11	25	7
Bisexual	5	10	3
Transgender	0	0	0

Recipient Living with Caregiver

Yes	45	70	51
No	37	30	49

If no, with:

Partner/significant other	6	0	8
Male friend	3	0	4
Female friend	0	0	0
Neighbor	3	0	4
Alone	78	100	72

Alone, then with other family member	3	0	4
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Alone, then with other unrelated person	6	0	8
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Note: N indicates the total number of individuals who answered each question.

Relationship to Caregiver N=81, Gender of Care Recipient N=83, Sexual Orientation of Care Recipient N=83, Recipient Living with Caregiver N=82

*p < .05, ***p < .001 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

4.2a: Characteristics of Family of Choice Care Recipients

Age of Care Recipient at Start of Episode

Total		Women		Men	
M	SD	M	SD	M	SD
55.0	15.7	58.1	14.9	54.1	16.0

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

ing for female friends, and 10% for male friends. Nearly half of all caregivers (46%) provided care to someone in addition to the individual they reported on in the survey. Usually this person was a partner, significant other, or friend.

Given the greater proportion of male to female respondents and the relationship of caregivers to care recipients described above, it is not surprising that 75% of care recipients were men, while only 25% were women. None of the family of choice caregivers in the sample reported providing care to a transgender person. Older LGBT caregivers were significantly more likely to provide care to someone of the same gender. Among women, 85% provided care to another woman, while 94% of men provided care to another man.

On average, male and female care recipients were 55 at the beginning of the caregiving episode. Although family of choice caregivers tended to care for their peers, there was a significant difference in the age of the care recipient as a factor of the age of the caregiver. The average age of the care recipients of caregivers 70 years and older was 70. But the average care recipient of caregivers 60 to 69 years of age was 53 years old. The average care recipient of 50 to 59 year-old caregivers was 52 years of age (see Table 4.2a).

Eighty-four percent of the care recipients were lesbian or gay, and 5% were bisexual. A small but sizable minority of family of choice care recipients were heterosexual (11%). Women were more likely to provide care to a heterosexual or bisexual, and less likely to provide care to a person who was gay or lesbian, than men. Women's care recipients were 25% heterosexual, 10% bisexual, and 65% gay or lesbian. Men's care recipients were 7% heterosexual, 3% bisexual, and 90% gay or lesbian.

Eighty-four percent of the care recipients were lesbian or gay, and 5% were bisexual. A small but sizable minority were heterosexual (11%).

LIVING ARRANGEMENTS

In 55% of cases, the caregiver and care recipient lived in the same household. Of the remaining 45%, more than three-quarters (78%) lived alone. Others had lived alone and then moved in with someone unrelated to them during the course of their illness. At the time of the interview, 85% of family of choice care recipients had died or been institutionalized.

REASONS FOR REQUIRING CARE

More than four in five care recipients in this group (83%) had serious illnesses requiring hospitalization. The most frequently cited reasons for needing care were HIV/AIDS (41%) and other physical illness (36%), followed by disability (19%), mental illness (8%) and dementia (7%). An additional 8% reported that the care recipient was frail due to old age, and 2% needed care as the result of an accident. Seven-percent reported other reasons (see Table 4.3).

There were significant associations between the reason a care recipient required care and the gender of the family of choice caregiver.

Women were twice as likely to report providing care because of general physical illness, while men were five times as likely to report providing care because of HIV/AIDS.



4.3: Hospitalization, Reasons Family of Choice Members Needed Care (Percent)

	Total	Women	Men
Care Recipient was Hospitalized *	83	85	82
Reasons Recipient Needed Care *			
HIV/AIDS***	41	10	50
Physical illness**	36	60	29
Disability	19	30	16
Mental illness	8	5	10
Alzheimer's disease/dementia	7	0	10
Frailty due to old age	8	5	10
Accident	2	5	2
Other reason	7	5	8

Note: N indicates the total number of individuals who answered each question.

Care Recipient was Hospitalized N=66

*p < .05, **p < .01, ***p < .001 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix A)

4.4: Types of Assistance and Level of Involvement in Caregiving to Family of Choice Members (Percent)

	Total	Women	Men
Personal Care and Mobility			
Personal care**			
Not provided	31	5	40
Only occasionally	27	27	28
Sometimes	13	32	7
Always or often	29	37	25
Mobility			
Not provided	20	5	26
Only occasionally	14	5	17
Sometimes	28	35	26
Always or often	38	55	31
Transportation*			
Not provided	15	24	25
Only occasionally	16	0	16
Sometimes	20	6	28
Always or often	48	71	32

Note: N indicates the total number of individuals who answered each question.

Personal Care N=77, Mobility N=79, Transportation N=75

*p < .05, **p < .01, (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix A)

Female caregivers were twice as likely to report providing care because of general physical illness than males (60% and 29%, respectively), while men were five times as likely as women to report providing care because of HIV/AIDS (50% and 10%, respectively). Caregivers 60 to 69 years of age and 70 years or more were two and three times more likely to report caring for someone because of a disability (31% and 19%, respectively), than caregivers 50 to 59 years of age (8%).

TYPES OF ASSISTANCE

Family of choice caregiving was assessed in the same manner as family of origin caregivers. In order to determine what kind of caregiving survey respondents provided, and with what frequency, they were presented with a list of 15 types of assistance commonly provided by caregivers, and asked to rate their level of participation in each as “always or often,” “sometimes,” “only occasionally,” or “not provided”. The types of assistance can be grouped into the following four categories (see Tables 4.4–4.4b):

- *Emotional support.* Nearly all family of choice caregivers (93%) said they provided emotional support to the care recipient always or often. The remainder provided this type of support at least some of the time. Eighty-three percent always or often visited or telephoned, and another 9% did so sometimes.

4.4a: Types of Assistance and Level of Involvement in Caregiving to Family of Choice Members (Percent)

Household Management	Total	Women	Men
Shopping/laundry*			
Not provided	12	0	16
Only occasionally	10	0	14
Sometimes	21	21	21
Always or often	57	79	50
Cooking*			
Not provided	23	5	29
Only occasionally	9	0	12
Sometimes	14	16	14
Always or often	53	79	45
Cleaning house**			
Not provided	20	0	27
Only occasionally	11	5	14
Sometimes	24	21	24
Always or often	44	74	36
Case Management Assistance			
Assist with health care providers			
Not provided	17	6	19
Only occasionally	18	6	22
Sometimes	22	24	22
Always or often	43	65	37
Arrange for medical care**			
Not provided	24	10	17
Only occasionally	12	10	14
Sometimes	24	20	33
Always or often	40	60	36
Contact family and friends			
Not provided	15	10	17
Only occasionally	13	5	22
Sometimes	30	25	17
Always or often	42	60	44

Note: N indicates the total number of individuals who answered each question.

Shopping/laundry N=77, Cooking N=77, Cleaning house N=79, Assist with health care providers N=77, Arrange for medical care N=75, Contact family and friends N=79

*p < .05, **p < .01, (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

4.4b: Types of Assistance and Level of Involvement in Caregiving to Family of Choice Members (Percent)

Medical Care	Total	Women	Men
Provide medical care***			
Not provided	44	12	55
Only occasionally	22	47	15
Sometimes	11	0	15
Always or often	22	41	16
Received training for medical/personal care (y)			
	34	24	39
Who Trained Medical/Personal Care?			
Partner/significant other	5	0	7
Physician/specialist	10	20	13
Nurse	35	40	27
Home health care aid	50	40	53
Emotional Support and Advice			
Emotional support			
Not provided	0	0	0
Only occasionally	0	0	0
Sometimes	7	5	8
Always or often	93	95	92
Visiting or telephoning			
Not provided	4	0	5
Only occasionally	4	8	4
Sometimes	9	15	7
Always or often	83	77	84
Advice or decision-making			
Not provided	4	5	3
Only occasionally	10	11	10
Sometimes	32	11	39
Always or often	54	74	48

Note: N indicates the total number of individuals who answered each question.

Provide medical care N=72, Received training for medical/personal care N(y)=22, Who trained medical/personal care? N=20, Emotional support N=82, Visiting or telephoning N=69, Advice or decision-making N=79

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

***p < .001 (Chi-Square Tests of Significance, For a definition of statistical significance see Appendix)



4.4c: Types of Assistance and Level of Involvement in Caregiving to Family of Choice Members (Percent)

Financial Help and Management	Total	Women	Men
Financial help			
Not provided	36	24	39
Only occasionally	13	29	9
Sometimes	7	0	9
Always or often	44	47	44
Managing money*			
Not provided	25	12	28
Only occasionally	8	6	9
Sometimes	20	6	25
Always or often	47	77	39

Note: N indicates the total number of individuals who answered each question.

Financial help N=75, Managing money N=75

*p < .05 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

- *Advice and decision-making.* More than half (54%) the family of choice caregivers provided advice or assisted with decision making always or often, and 32% helped at least some of the time. Only 4% did not provide advice or help with decisions.
- *Case management.* Family of choice caregivers provided high levels of assistance with case management tasks. Two-thirds (66%) provided case management help with health care providers (43% always or often and 22% sometimes). Similarly high proportions were involved in making arrangements for medical care (40% always or often and 24% sometimes). Women were much more likely than men to provide this type of assistance on a consistent basis (always or often: 60% and 36%, respectively), while men were more likely to do so intermittently compared with women (sometimes: 33% and 20%, respectively).

This heavy involvement with case management duties also extended to contacting family and friends: 42% provided help in this way always or often and 30% did so sometimes. Nearly three-quarters (73%) of caregivers 70 and older reported providing case management help with medical care at least sometimes, as compared with 63% of caregivers in their sixties, and 58% of those in their fifties. This finding is likely related to the relationship between the average age of the care recipient and provider in each age group, with the oldest caregivers being less likely to provide hands-on care.

More than half of family of choice caregivers provided monetary assistance: 44% often helped financially, while 7% did so at least some of the time. Two-thirds (67%) of caregivers helped with financial management tasks at least sometimes; 25% did not assist in this way at all.

- *Household help and hands-on assistance.* The proportion of family of choice caregivers involved in household management tasks was quite high, as might be expected.

ed from a sample in which more than half resided with the care recipient. Over three-quarters provided assistance by shopping or doing laundry on a regular basis. More than half (53%) always or often cooked, while another 14% did so sometimes. While a similar proportion of caregivers were involved with housecleaning for the care recipient, there were gender differences in providing this type of support. Women were more likely than men to report helping with housecleaning often (74% and 36%, respectively), while men were more likely than women never to provide such help (27% and 0%, respectively).

Only two in five family of choice caregivers were regularly involved in personal care tasks like bathing and grooming, with 29% reporting they provided this help always or often and 13% providing personal care sometimes. Men were much less likely to help in this area compared with women: 40% of male caregivers reported they did not provide this type of help, compared to only 5% of females. Nearly two-thirds of women (68%) provided this type of help at least some of the time, as compared with 32% of men. Two-thirds of respondents provided assistance with mobility (like getting around the house) at least some of the time. A similar proportions (68%) provided help with transportation (like providing a ride) at least some of the time. There were no gender differences in the involvement of caregivers with these tasks (see Table 4.4).

CAREGIVER STRESS

Providing care on a regular basis can induce stress and feelings of burden, as well as interfere with other aspects of the caregiver's life. Like family of choice caregivers, family of origin caregivers were asked questions designed to shed light on how caregiving affected them.

MOST IMPORTANT TYPE OF ASSISTANCE

When asked to name the most important way that they helped the care recipient, family of choice caregivers overwhelmingly said it was by providing emotional support (71%).

CAREGIVER TRAINING

Assisting with personal and medical care tasks often requires certain skills; about one-third of these caregivers (34%) reported receiving this type of training. As expected, one-third also reported providing medical care at least some of the time, and 42% helped with personal care. In most cases, either a home health care aid (50%) or nurse (35%) provided this training. Physicians provided training to family of choice caregivers only 10% of the time (see Table 4.4b).

Involvement with medical care tasks was relatively low. Only one-third (33%) provided this type of help on a regular basis (22% always or often, and 11% sometimes). Women were significantly more likely to provide this help always or often (41%) than



men (16%), and men were much more likely than women not to provide this type of help at all (55% and 12%, respectively).

TIME SPENT PROVIDING CARE

Over half of family of choice caregivers provided care every day (58%), and nearly one-quarter (23%) provided help at least several times per week. About one-fifth provided care several times per month (16%), while only 4% said they provided care once per month or less (see Table 4.5). On average, family of choice caregivers reported providing 46 hours of care in a typical week. Caregivers 70 and older reported the highest average hours of care per week (62 hours). The average weekly hours of care was 49 among those aged 60 to 69, and 37 among those age 50 to 59 (see Table 4.5a). This finding may reflect the fact that older people are more likely to be retired and have the time to devote to caregiving. It could also mean that the care recipients for whom this group was responsible were, on average, older, and in need of more care.

HELP FROM OTHERS

Thirty-seven percent of the family of choice caregivers reported being the sole provider of care; 63% reported assistance from others on a regular basis. In most of those cases, the assistance came from someone unrelated (43%), a friend (18%), or the partner or significant other of the care recipient (8%). Forty-three percent of caregivers were the only person who provided a substantial amount of care, while 25% said they provided most of the care. For another 25%, caregiving was shared equally with another person; 8% provided less care than others (see Table 4.5).

RELATIONSHIPS WITH OTHERS

Twenty-three percent of the family of choice caregivers reported problematic interactions with the care recipient's biological family. Approximately two-thirds (63%) did not feel their sexual orientation made a difference in terms of expectations of them as a caregiver; 30% felt more was expected of them because of their sexual orientation, and a small proportion (7%) reported they felt less was expected of them.

LEGAL ISSUES

In 67% of cases, family of choice caregivers reported that someone had the authority to make medical decisions for the care recipient, and in 60% of these cases, it was the caregiver who had sole (55%) or shared (5%) authority (see Table 4.6). Caregivers 70 and older were more likely to report that someone had this authority (88%) than caregivers in their sixties (52%) and in their fifties (64%).

A similar proportion of caregivers reported that someone had the authority to make legal decisions for the care recipient (67%), and in 58% of these cases, the caregiver had either sole (54%) or shared (4%) responsibility for legal decisions. There was no association between the age of the caregiver and the likelihood of someone having this authority. If someone else had responsibility for legal decisions, it was usually someone unrelated (22%) or a male friend of the care recipient (15%).

4.5: Frequency of Caregiving and Contextual Issues for Family of Choice Members (Percent)

Frequency of Care Provision	Total	Women	Men
Every day	58	75	53
Several times per week	23	15	24
Several times per month	16	10	18
Once a month or less	4	0	5
Someone Else Helped with Caregiving (y)	63	55	65
Level of Care Involvement			
Respondent was sole provider	43	67	36
Respondent provided most care	25	11	30
Respondent shared caring equally	25	17	26
Respondent did less than others	8	6	8
Difficulty with Family/Friends (y)	23	21	24
Different Family Expectations of Caregiver due to Sexual Orientation			
They expect more	30	33	28
They expect less	7	11	6
Makes no difference	63	56	67

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Frequency of Care Provision N=83, Someone Else Helped with Caregiving N(y)=52, Level of Care Involvement N=80, Difficulty with Family/Friends N(y)=19, Different Family Expectations of Caregiver due to Sexual Orientation N=73

4.5a: Frequency of Caregiving and Contextual Issues for Family of Choice Members

Number of Caregiving Hours Per Week					
Total		Women		Men	
M	SD	M	SD	M	SD
47.0	48.0	54.1	44.2	44.4	49.5

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

4.6: Medical Authority and Legal Issues for Family of Choice Members (Percent)

	Total	Women	Men
Someone Had Authority for Medical Decisions (y)*	67	70	66
Who Had Medical Authority?			
Respondent	55	69	52
Someone else	39	31	41
Shared with unrelated person	5	0	7
Someone Had Authority for Legal Decisions (y)**	67	65	67
Who Had Legal authority?			
Respondent	54	75	49
Someone else	41	25	44
Shared with unrelated person	4	0	5

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Someone Had Authority for Medical Decisions N(y)=55, Who Had Medical Authority? N=56, Someone Had Authority for Legal Decisions N(y)=55, Who Had Legal Authority? N=55

*p < .05, **p < .01 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)



CAREGIVER STRESS

Respondents were asked to report on how caregiving had impacted their lives. For 35%, being a caregiver reduced their sense of privacy; 52% said that it placed limits on their social lives; and 41% said they did not have enough time for themselves (see Table 4.7). Forty-three percent said they had had to take time off from work because of caregiving responsibilities, and women were more than twice as likely to report taking time off from work than men (70% and 33%, respectively). Forty-one percent reported difficulties with health or medical providers; 20% reported that their own health had suffered; and 28% said that being a caregiver caused them worry about the costs of providing care. Twenty-six percent of family of choice caregivers felt burdened because the care recipient needed their constant attention. Another 16% said that caregiving had caused problems with members of the care recipient's family.

Caregiving also had an impact on issues related to sexual orientation and relationships. Eleven percent reported that being a caregiver forced them to come out, while 15% reported that they were forced to conceal their sexual orientation. For another 14% of caregivers, problems with his or her partner or significant other were attributed to being a caregiver.

MONEY SPENT ON CAREGIVING

Among family of choice caregivers, money spent on caregiving per week tended to be minimal, with nearly two thirds (64%) spending less than \$50 per week. About one fifth spent from \$50 to \$100 per week, while 15% reported considerable caregiving expenses of \$100 or more per week (see Table 4.7a).

**Table 4.7: Burden and Strain for Family of Choice Caregivers
(Percent, in rank order)**

Caregiving Burdens (y)	Total	Women	Men
1. Limited my social life	52	70	45
2. Had to take time off work	43	70	33
3. Had difficulty with other care providers	41	55	37
4. Don't have enough time for myself	41	50	38
5. Lack of privacy	35	45	32
6. Worry about cost of care	28	30	28
7. Requires constant attention	26	20	28
8. Health suffers	20	20	20
9. Problems with family members	16	15	17
10. Forced me to conceal my sexual orientation	15	30	10
11. Strained my relationship with my partner	14	25	10
12. Forced me to come out	11	10	12

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question

4.7a: Burden and Strain for Family of Choice Caregivers (Percent)

How Much Spent on Caregiving Per Week?	Total	Women	Men
Less than \$50	64	67	64
\$50 to \$100	21	17	20
\$100 to \$500	14	11	15
\$500 or more	1	6	0

Note: N indicates the total number of individuals who answered each question.

How Much Spent on Caregiving Per Week? N=78

4.7b: Burden and Strain for Family of Choice Caregivers (Percent)

Caregiving Strain	Total	Women	Men
Emotional			
Little or none	13	11	14
Some strain	14	21	12
Moderate strain	27	42	22
A lot/A great deal	47	26	52
Physical			
Little or none	38	21	44
Some strain	20	21	18
Moderate strain	22	26	21
A lot/A great deal	21	32	18
Financial			
Little or none	52	39	55
Some strain	22	17	24
Moderate strain	18	39	12
A lot/A great deal	8	6	9

Note: N indicates the total number of individuals who answered each question.

Emotional N=79, Physical N=77, Financial N=77

STRESS LEVEL

Caregivers were asked to rate the degree of physical, emotional, and financial strain they experienced on a scale from one (little or no strain) to five (a great deal). About one-fifth of family of choice caregivers (21%) reported a lot or a great deal of physical strain. Nearly half (47%) reported that caregiving caused a lot or a great deal of emotional strain. Significant financial strain was reported by only 8% of family of choice caregivers (see Table 4.7b).

REASONS FOR PROVIDING CARE

Survey respondents were asked why they had assumed a caregiving role. Eighty-three percent said they became caregivers because the care recipient deserved to be taken care of (see Table 4.8). Fifty-eight percent did so because they felt it was their responsibility. The same percentage (58%) provided care so the care recipient could remain at home, and because it was part of their nature. Nearly half (49%) said they became a caregiver because no one else was available. Forty-one percent said that being a caregiver nurtured them spiritually or emotionally, 36% believed it had made them a better person, and 35% that it had given them a sense of purpose. One in 10 said they provided care to avoid feeling regret or guilt. Although only 8% said they became a caregiver due to “family expectations,” women were about four times more likely to report this reason than men (21% and 3%, respectively).



4.8: Reasons for Providing Care Among Family of Choice Caregivers (Percent)

Sense of Responsibility (y)	Total	Women	Men
Care recipient deserved care	83	79	83
It was respondent's responsibility	58	58	57
Family expected respondent to provide care**	8	21	3
To avoid feelings of guilt/regret	10	11	10
Avoidance of Institutionalization (y)			
Care recipient able to stay home	58	68	53
No one else was available	49	53	48
Personal Reasons (y)			
Part of respondent's nature	58	47	60
Emotionally/spiritually nurturing	41	42	40
Provided respondent sense of purpose	35	21	38
Made respondent a better person**	36	10	45
Became closer to respondent's family	1	0	2

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question

**p < .01 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

4.9: Formal Organizations Used by Family of Choice Caregivers (Percent)

Long-Term Care (y)	Total	Women	Men
Visiting nurse service	38	40	37
Home health care agency	31	40	28
Emotional/Psychological Support (y)			
Support groups	37	45	33
Therapy	32	25	35
Community-Based Services (y)			
Senior LGBT organization*	14	0	18
Other LGBT organization	16	15	17
Senior center	9	15	7
Informational Assistance (y)			
Phone information line	6	10	5
Internet	14	21	12
Other (y)	11	15	10
Difficulties with Formal Service Providers (y)			
	26	39	22

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Long-Term Care N(y)=56, Emotional/Psychological Support N(y)=56, Community-Based Services N(y)=31, Informational Assistance N(y)=16, Other N(y)=9, Difficulties with Formal Service Providers N(y)=20

*p < .05 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

COMMUNITY RESOURCES

Family of choice caregivers were presented with a list of community-based resources and asked to which, if any, they had turned during the caregiving episode. Thirty-eight percent had used a visiting nurse service, while 31% had used a home health care agency (see Table 4.9). Caregivers in their fifties were the least likely to report accessing this type of service (15%), compared with 44% of those in their sixties and 47% of those 70 and older. This finding is likely related to the greater average age of care recipients among the older caregiving groups.

Thirty-seven percent had turned to a support group while caregiving; 32% had been in individual or group therapy; and 17% had sought counsel from clergy or other spiritual figures. Fourteen-percent had used the Internet to obtain information relevant to their caregiving role. Fourteen-percent had also sought out a LGBT senior service orga-

nization like Pride Senior Network or Senior Action in a Gay Environment. Only 9% reported turning to a senior center, and only 6% had used a telephone information service. Eleven percent reported turning to types of community-based resources other than those discussed here. About one-quarter (26%) reported that they had had some kind of difficulty in dealing with one or more of these service providers.

As was true for the family of origin caregivers, these findings suggest that most LGBT people caring for a member of their family of choice do it largely alone, only occasionally relying on other family members or friends to provide support and direct assistance. Formal community organizations—primarily nursing and home health care assistance—tend to be used as a last resort, after caregiving duties becoming overwhelming.

Most LGBT people caring for a member of their family of choice do it largely alone, only occasionally relying on other family members or friends to provide support and direct assistance.



5. Comparing Caregivers' Experiences in Families of Origin and in Families of Choice

The focus of this study is the nature and extent of caregiving provided by older LGBT individuals to two groups: biological family members (families of origin), and same-sex partners, close friends, and other unrelated individuals (families of choice). The same questions were asked of respondents involved in caregiving with both types of families, permitting the separate examination of the caregiving experiences of both groups, as documented in the preceding two sections. This section compares the caregiving experiences of family of origin and family of choice caregivers, and draws a composite picture of the caregiving experiences of the older LGBT community in New York City. The most important finding is that the similarities in the amount of caregiving involvement, the reasons for providing care, and the nature of the stress and strain involved in caregiving have more to do with the nature of the experience itself than the specific familial relationship between caregiver and care recipient.

The similarities in the amount of caregiving involvement, the reasons for providing care, and the nature of the stress and strain have more to do with the nature of the experience itself than the specific familial relationship between caregiver and care recipient.

LEVEL OF CAREGIVING INVOLVEMENT

A similar proportion of the total sample had provided care during the previous five years to a member of their family of origin (22%) and a member of their family of choice (24%). A slightly higher proportion of those caring for members of their family of origin were still providing care at the time of the survey (39%) compared with family of choice caregivers (30%), but this difference is not statistically significant. The major reason caregivers in both groups were no longer providing care was the death or institutionalization of the care recipient (see Table 5.1). The average number of years of the caregiving episode was nearly identical between the family of origin and family of choice caregivers (8.4 and 8.3 years, respectively) (see Table 5.1a).

5.1: Comparison of Caregiving Experience Between Family of Origin and Family of Choice in Past Five Years (Percent)

	Family of Origin	Family of Choice
Provided Care in Past Five Years (y)^a	22	24
Currently Providing Care (y)	39	30
Reason Caregiving had Ended		
Death or institutionalized	89	85
Person no longer needed care	4	9
Someone else responsible for care	7	5
Caregiving became too difficult	0	0
Other reason	2	3

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Family of origin caregivers N=75; family of choice caregivers N=83

^a Proportions based on total sample (N=341), and total women (N=103) and men (N=233).

Provided Care in Past Five Years (Family of Origin N(y)=75; Family of Choice N(y)=83), Currently Providing Care (Family of Origin N(y)=29; Family of Choice N(y)=25), Reason Caregiving had Ended (Family of Origin N=47; Family of Choice N=60)

5.1a: Comparison of Caregiving Experience Between Family of Origin and Family of Choice in Past Five Years

Length of Episode Among Current Caregivers (years)

Family of Origin		Family of Choice	
M	SD	M	SD
8.4	10.0	8.3	8.4

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

5.2: Comparison Between Characteristics of Family of Origin and Family of Choice Care Recipients (Percent)

Relationship to Caregiver	Family of Origin	Family of Choice
Mother	63	0
Father	21	0
Son	4	0
Sister	3	0
Brother	4	0
Aunt	1	0
Female relative (unspecified)	1	0
Other relative (unspecified)	3	0
Partner/significant other	0	54
Female friend	0	5
Male friend	0	30
Female unspecified relationship	0	3
Male unspecified relationship	0	7
Other unrelated person	0	1

Note: N indicates the total number of individuals who answered each question.

Relationship to Caregiver (Family of Origin N=75; Family of Choice N=81)

5.2a: Comparison Between Characteristics of Family of Origin and Family of Choice Care Recipients

Age of Care Recipient at Start of Episode

Family of Origin		Family of Choice	
M	SD	M	SD
8.4	10.0	8.3	8.4

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

Characteristics of the Care Recipients. There were a number of differences between the two groups with respect to the person for whom care was provided (see Tables 3.2 and 4.2). By definition, the relationships of the care recipients differed between family of origin and family of choice caregivers. Among family of origin caregivers, the care recipients were primarily parents (84%), with the remaining 16% comprised of siblings, children, and other relatives. In contrast, the majority of caregiving for family of choice members was provided to same-sex partners (54%) or to friends (35%) (see Tables 5.2 and 5.2a). Differences in the relationships of care providers and recipients between these two groups resulted in significant differences in the gender and sexual orientation



of the person receiving care. Within the families of origin, 70% of care recipients were women and 95% were heterosexual, reflecting the demographics of the older population needing care. Among families of choice that largely involved males caring for partners or significant others with HIV/AIDS, three-quarters of care recipients were male (as were about three-quarters of family of choice caregivers), and 84% were lesbian or gay. However, 11% of care recipients in this latter group were heterosexuals and 5% were bisexuals (see Table 5.2b).

Living Arrangements. Fifty-five percent of family of choice caregivers lived with the care recipient—approximately the same proportion who indicated that the care recipient was their partner or significant other. Among the 45% who did not reside with their caregiver, most lived alone (see Table 5.2c). In contrast, only 27% of care recipients lived with their family of origin caregiver. The vast majority of family members for whom care was provided lived alone, or lived alone and were later institutionalized or moved in with other family members. The significant differences in the living arrangements of care recipients in each group have considerable implications for the types of assistance provided.

5.2b: Comparison Between Characteristics of Family of Origin and Family of Choice Care Recipients (Percent)

Gender of Care Recipient***	Family of Origin	Family of Choice
Male	30	75
Female	70	25
Sexual Orientation of Care Recipient***		
Lesbian or gay	3	84
Heterosexual	95	11
Bisexual	0	5
Transgender	0	0
Don't know	3	0

Note: N indicates the total number of individuals who answered each question.

Gender of Care Recipient (Family of Origin N=74; Family of Choice N=83), Sexual Orientation of Care Recipient (Family of Origin N=74; Family of Choice N=83)

***p < .001 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

5.2c: Comparison Between Characteristics of Family of Origin and Family of Choice Care Recipients (Percent)

Recipient Living with Caregiver***	Family of Origin	Family of Choice
Yes	27	55
No	73	45
If no, with:***		
Partner/significant other	2	6
Husband	2	0
Mother	2	0
Sister	4	0
Male friend	0	3
Neighbor	2	3
Other unrelated person	4	0
Alone	35	78
Alone, then with other family	14	3
Alone, then with other unrelated person	10	6
Alone, then institutionalized	26	0

Note: N indicates the total number of individuals who answered each question.

Recipient Living with Caregiver: Yes (Family of Origin N=74; Family of Choice N=82), Recipient Living with Caregiver: No (Family of Origin N=54; Family of Choice N=37), If no with: (Family of Origin N=51; Family of Choice N=32)

***p < .001 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

5.3: Comparison of Hospitalization and Reasons for Needing Care Among Care Recipients Between Family of Origin and Family of Choice (Percent)

	Family of Origin	Family of Choice
Care Recipient was Hospitalized (y)	81	83
Reasons Recipient Needed Care		
HIV/AIDS***	1	41
Physical illness	50	36
Disability	19	19
Mental illness	10	8
Alzheimer's disease/dementia***	35	7
Frailty due to old age***	42	8
Accident*	11	2
Other reason	10	7

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Care Recipient was Hospitalized (Family of Origin N(y)=55; Family of Choice N(y)=66)

*p < .05, ***p < .001 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

5.4: Comparison of Types of Assistance and Level of Involvement in Caregiving Between Family of Origin and Family of Choice Members (Percent)

	Family of Origin	Family of Choice
Personal Care and Mobility		
Personal care	38	31
Not provided	29	27
Only occasionally	11	13
Sometimes	22	29
Always or often	22	29
Mobility	15	20
Not provided	29	14
Only occasionally	23	28
Sometimes	33	38
Always or often	33	38
Transportation	17	15
Not provided	19	16
Only occasionally	25	20
Sometimes	39	48
Always or often	39	48

Note: N indicates the total number of individuals who answered each question.

Personal care (Family of Origin N=73; Family of Choice N=77), Mobility (Family of Origin N=73; Family of Choice N=79), Transportation (Family of Origin N=64; Family of Choice N=75)

Reasons for Needing Care. Family of choice caregivers were significantly more likely than family of origin caregivers to cite HIV/AIDS as the reason for which care was provided (41%). The next most frequently cited reasons among this group were physical illness (36%) and other disabilities (19%). Among family of origin caregivers, the reasons for providing care were related to the advanced age and frailty of the care recipients. While half of those caregivers cited physical illness as the reason behind their caregiving, this group was significantly more likely than family of choice caregivers to provide care in instances of frailty due to old age (42% and 8%, respectively) or Alzheimer's disease or dementia (35% and 7%, respectively). Family of origin caregivers were also more likely to be providing care following an accident (11%) than family of choice caregivers (2%). (Table 5.3 provides a comparison of these statistics.)

The caregivers in both groups were equally involved in providing care, and members of both groups had been providing care for an average of eight years. The nature of the relationships between caregivers and recipients differed between the two groups, and the major reasons for needing care reflect these differences. Family of choice care recipients were mainly partners and significant others living with the care provider, or friends who lived alone. The vast majority were LGBT themselves. Given the relatively young age of LGBT caregivers in the study, it is not surprising that fewer of



their care recipients required assistance because of age-related conditions. In contrast, family of origin care recipients were mainly parents, siblings, or children; predominantly heterosexual; and less likely to be living in the same household as the caregiver. The high proportion of women among care recipients in this group reflects the demography of the older population in general; among family of choice caregivers, the gender and sexual orientation of the care recipient more often mirrored the characteristics of the caregiver.

5.4a: Comparison of Types of Assistance and Level of Involvement in Caregiving Between Family of Origin and Family of Choice Members (Percent)

	Family of Origin	Family of Choice
Household Management		
Shopping/laundry	20	12
Not provided	20	10
Only occasionally	16	21
Sometimes	43	57
Always or often	43	57
Cooking**	34	23
Not provided	19	9
Only occasionally	20	14
Sometimes	27	53
Always or often	27	53
Cleaning house	37	20
Not provided	14	11
Only occasionally	14	24
Sometimes	37	44
Always or often	37	44

Note: N indicates the total number of individuals who answered each question.
 Shopping/laundry (Family of Origin N=74; Family of Choice N=77), Cooking (Family of Origin N=74; Family of Choice N=77), Cleaning house (Family of Origin N=74; Family of Choice N=79)

**p < .01 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

5.4b: Comparison of Types of Assistance and Level of Involvement in Caregiving Between Family of Origin and Family of Choice Members (Percent)

	Family of Origin	Family of Choice
Case Management Assistance		
Assist with health care providers***		
Not provided	1	17
Only occasionally	12	18
Sometimes	18	22
Always or often	69	43
Arrange for medical care*		
Not provided	10	24
Only occasionally	10	12
Sometimes	17	24
Always or often	63	40
Contact family and friends***		
Not provided	1	15
Only occasionally	10	13
Sometimes	17	30
Always or often	72	42
Provide medical care		
Not provided	59	44
Only occasionally	22	22
Sometimes	9	11
Always or often	10	22

Note: N indicates the total number of individuals who answered each question.
 Assist with health care providers (Family of Origin N=74; Family of Choice N=77), Arrange for medical care (Family of Origin N=71; Family of Choice N=75), Contact family and friends (Family of Origin N=71; Family of Choice N=79), Provide medical care (Family of Origin N=68; Family of Choice N=72)

*p < .05 ***p < .001 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

TYPES OF CAREGIVING ASSISTANCE PROVIDED

The characteristics of the care recipients and their living arrangements differed significantly between the two groups of caregivers. Family of choice caregivers were much more likely to live with the person for whom they were caring than family of origin caregivers (55% and 27%, respectively). This impacted the type of assistance each group of caregivers provided. (A comparison of that assistance appears in Tables 5.4–5.4d.)

For both family of origin and family of choice caregivers, providing emotional support, and visiting and telephoning were overwhelmingly the most important types of assistance provided, followed closely by giving advice. Family of origin caregivers were slightly more likely than family of choice caregivers to visit or telephone often or sometimes (98% and 91%, respectively), reflecting differences in living arrangements; however this difference is not statistically significant. In contrast, family of origin caregivers were significantly more likely to provide advice or decision-making support often or sometimes (92%) compared to family of choice caregivers (86%), reflecting that older parents, including some suffering from dementia, were the primary care recipients in the former group (see Table 5.4d).

Family of origin caregivers were significantly more likely to provide case management assistance and medical care at least sometimes (89%) than family of choice caregivers (72%). The most frequently reported type of assistance in this area was contacting family and/or friends on the behalf of the care recipient. Family of origin caregivers were also significantly more likely to provide other case management functions, like arranging for medical care or dealing with health care providers, at least some of the time (80% and 87%, respectively). Only 64% of family of choice caregivers arranged for medical care, and 65% dealt with health care providers, at least some of the time. The

5.4c: Comparison of Types of Assistance and Level of Involvement in Caregiving Between Family of Origin and Family of Choice Members (Percent)

Case Management Assistance	Family of Origin	Family of Choice
Received training for medical/personal care (y)	25	34
Who trained medical/personal care?		
Partner/significant other	0	5
Physician/specialist	8	10
Nurse	67	35
Home health care aid	25	50

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Received training for medical/personal care (Family of Origin N(y)=12; Family of Choice N(y)=22), Who trained medical/personal care (Family of Origin N=12; Family of Choice N=20)



5.4d: Comparison of Types of Assistance and Level of Involvement in Caregiving Between Family of Origin and Family of Choice Members (Percent)

	Family of Origin	Family of Choice
Emotional Support		
Not provided	1	0
Only occasionally	1	0
Sometimes	13	7
Always or often	84	93
Visiting or Telephoning		
Not provided	1	4
Only occasionally	0	4
Sometimes	8	9
Always or often	90	83
Advice or Decision-Making*		
Not provided	4	4
Only occasionally	4	10
Sometimes	15	32
Always or often	77	54
Financial Help		
Not provided	31	36
Only occasionally	10	13
Sometimes	19	7
Always or often	40	44
Managing Money		
Not provided	18	25
Only occasionally	11	8
Sometimes	11	20
Always or often	60	47

Note: N indicates the total number of individuals who answered each question.

Emotional Support (Family of Origin N=75; Family of Choice N=82), Visiting or Telephoning (Family of Origin N=72; Family of Choice N=69), Advice or Decision-Making (Family of Origin N=74; Family of Choice N=79), Financial Help (Family of Origin N=72; Family of Choice N=75), Managing Money (Family of Origin N=72; Family of Choice N=75)

5.5: Comparison of Frequency of Caregiving and Contextual Issues Between Family of Origin and Family of Choice Members (Percent)

	Family of Origin	Family of Choice
How Often Provide Care		
Every day	47	58
Several times per week	24	23
Several times per month	25	16
Once a month or less	4	4
Someone Else Helped with Caregiving (y)*	77	63
Level of Care Involvement		
Respondent was sole provider	37	43
Respondent provided most care	30	25
Respondent shared caring equally	23	25
Respondent did less than others	10	8
Any Difficulty with Family/Friends (y)	33	23
Different Family Expectations of Caregiver Due to Sexual Orientation		
They expect more	34	30
They expect less	4	7
Makes no difference	61	63

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

How Often Provide Care (Family of Origin N=72; Family of Choice N=83), Someone Else Helped with Caregiving (Family of Origin N=58; Family of Choice N=52), Level of Care Involvement (Family of Origin N=73; Family Choice N=80), Any Difficulty with Family/Friends (Family of Origin N(y)=24; Family of Choice N(y)=19), Different Family Expectations of Caregiver Due to Sexual Orientation (Family of Origin N=70; Family of Choice N=73)

*p < .05 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

divergence again reflects the differences in the characteristics between the care recipients in each group: frail, older recipients in the family of origin group may have been less able to handle these tasks independently than the younger care recipients in the family of choice group (see Tables 5.4b and 5.4c).

The vast majority of caregivers in both groups were not involved in providing medical care. Among the small proportion that did, a greater proportion of family of choice caregivers reported providing it at least sometimes (33%), compared with family of ori-

gin caregivers (19%), although this difference is not statistically significant. The statistics on receiving training in providing such care are similar for both groups.

Over half of the caregivers in both groups provided financial help and money management assistance at least sometimes. While family of origin caregivers were somewhat more involved in providing financial help compared with their family of choice counterparts (60% and 51%, respectively), this difference is not statistically significant. Approximately two-thirds of both groups of caregivers provided assistance with money management at least some of the time (see Table 5.4d).

The greatest differences between family of choice and family of origin caregivers were expected in the area of hands-on personal care and household help, given the larger number of caregivers and care recipients who lived together among the former group. Family of choice caregivers did report providing help at least sometimes with shopping and laundry, cooking, and cleaning house (78%, 68%, and 68%, respectively) more often than family of origin caregivers (69%, 47%, and 50%, respectively). However, only the difference in those helping with cooking is statistically significant (see Table 5.4a).

Family of choice caregivers were also more likely to report helping at least sometimes with mobility-related tasks than family of origin caregivers (66% and 56%, respectively), although the difference is not statistically significant. Nor are there significant differences in the frequency of providing help with transportation: approximately two-thirds of each group provided such help at least some of the time. More intriguingly, about 40% of both groups provided help with personal care tasks like bathing, dressing or grooming at least sometimes, but the largest proportions of caregivers did not. Because only about two-fifths of both groups were the sole providers of care, other caregivers, including paid help, may have been more involved in personal care tasks (see Table 5.5).

The greatest differences between family of choice and family of origin caregivers were expected in the area of hands-on personal care and household help, given the larger number of caregivers and care recipients who lived together among the former group.

SUMMARY

The type of assistance provided by this study's caregivers was influenced by the characteristics of those for whom they were caring, and whether they lived with that person. However, there were far more similarities than differences between these two groups of caregivers. For example, there were very few differences between family of choice and family of origin caregivers in providing emotional support and advice, which comprised the cornerstone of caregiving assistance and was provided by nearly all caregivers in the study, regardless of their relationship to the caregiver. Family of origin caregivers were most often involved with older parents, less likely to live in the same household as the care recipient, and significantly more likely to perform a case management role. Because family of choice caregivers were more likely to live with the care recipient, they were more involved in household management tasks.



Table 5.5a: Comparison of Frequency of Caregiving and Contextual Issues Between Family of Origin and Family of Choice Members

Number of Caregiving Hours Per Week**				
Family of Origin		Family of Choice		
M	SD	M	SD	
29.0	35.2	47.0	48.0	

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

CONTEXTUAL FACTORS AND THE IMPACT OF CAREGIVING ON LGBT PROVIDERS

Previous sections of this report examined the similarities and differences between family of origin and family of choice caregivers. Before addressing issues related to the stresses and burdens involved in providing care, this section contextualizes those findings with regard to the amount of care provided; interactions between caregivers and family members and friends; and issues of legal and medical authority.

Amount of Caregiving Provided. Family of choice caregivers were more likely to live with the care recipient, and consequently spent more time on average per week providing assistance (47 hours) than their family of origin counterparts (29 hours), who tended to live apart from their care recipients (see Table 5.5a). Though deeply involved emotionally and in a case management role, family of origin caregivers were less likely to be involved in the direct provision of assistance which, by its nature, is more time consuming. Nonetheless, the frequency of care provision did not differ significantly between the two groups: the majority of both provided assistance at least several times per week. It is therefore not surprising that 77% of the family of origin caregivers shared the responsibility with someone else, significantly more than the 63% family of choice caregivers who reported sharing caregiving duties. There were no significant differences in the extent to which the caregivers provided care: about two-fifths of each group reported being the sole provider, while approximately one-quarter of each group said they were the primary provider of care or shared that responsibility equally with another person.

Relationships with Other Family Members and Friends. Information from focus groups conducted prior to the study suggested that conflicts about the caregiver’s sexual orientation might arise in their relationships with other family members and friends. In fact, nearly one-third of family of origin caregivers and one-quarter of family of choice caregivers reported such problems (the difference is not statistically significant). Although the study did not collect information on the details of these difficulties, family of choice group information suggests that they stemmed at least in part from the caregivers’ sexual orientation. And about one-third of each group reported that more was expected of them as caregivers because of their sexual orientation. Focus group par-

Nearly one-third of family of origin caregivers and one-quarter of family of choice caregivers reported conflicts about the caregiver’s sexual orientation in their relationships with other family members and friends.

5.6: Comparison of Medical Authority and Legal Issues for Family of Origin and Family of Choice Members (Percent)

	Family of Origin	Family of Choice
Someone Had Authority for Medical Decisions (y)*	81	67
Who Had Medical Authority?		
Respondent	57	55
Someone else	28	39
Shared with family	15	5
Someone Had Authority for Legal Decisions (y)	74	67
Who Had Legal Authority?		
Respondent	59	54
Someone else	26	41
Shared with unrelated person	15	4

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered “yes” to that question.

Someone Had Authority for Medical Decisions (Family of Origin N=60; Family of Choice N=55) , Who Had Medical Authority? (Family of Origin N=60; Family of Choice N=56), Someone Had Authority for Legal Decisions (Family of Origin N(y)=53; Family of Choice N(y)=55), Who Had Legal Authority? (Family of Origin N=50; Family of Choice N=55)

*p < .05 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

Table 5.7: Comparison of Burden and Strain Between Family of Origin and Family of Choice Caregivers (Percent)

Caregiving Burdens (y)	Family of Origin	Family of Choice
Placed limits on my social life	65	52
Had to take time off work	56	43
Don't have enough time for myself	51	41
Had difficulty with other care providers	44	41
Worry about cost of care	39	28
Problems with family members**	36	16
Lack of privacy	35	35
Health suffers	29	20
Strained my relationship with my partner	23	14
Requires constant attention	23	26
Forced me to conceal my sexual orientation	13	15
Forced me to come out*	3	11

Note: (y) indicates that percentages listed represent those individuals who answered “yes” to the question

*p < .05, **p < .01 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

Participants indicated this expectation derived largely from familial perceptions that LGBT caregivers had fewer of their own family responsibilities than other family members. Other information about the extent and quality of the caregivers’ relationships with their biological families disproved the belief that many LGBT people are estranged from their families.

Legal and Medical Authority. In most cases, caregivers in both groups reported that someone besides the care recipient had the authority to make legal and medical decisions. Family of origin caregivers were significantly more likely to report someone had authority for medical decisions (81%) than family of choice caregivers (67%); the person with that authority in both groups was most often the LGBT caregiver (see Table 5.6). The proportion of each group that either shared authority over medical decisions, or did not have such authority, was not significantly different. About three-quarters of the family of origin caregivers and two-thirds of family of choice caregivers reported that someone had the authority to make legal decisions for the care recipient. Similar proportions of caregivers in both groups indicated that they were the ones who had that authority. There were no significant differences between the two groups in the proportion of each that shared legal authority, or did not have it at all.



CAREGIVER BURDEN AND STRAIN

Differences between family of choice and family of origin caregivers are largely due to the nature of the relationship between the caregiver and the care recipient, and the situation that prompted the need for caregiving. This section examines whether these differences resulted in differences in the stresses and burdens experienced by caregivers.

Table 5.7 provides the list of the caregiving burdens presented to the caregivers in this study's survey. For both groups, the limits caregiving placed on their social lives and the necessity of taking time off from work were most frequently mentioned, followed closely by not having enough time for themselves. That caregiving presents such impediments to personal pursuits and employment pursuits clearly represents a major source of burden. The next highest-ranked caregiving burden was difficulty with other care providers, including those providing both formal and informal sources of assistance. Concerns about the cost of care was the fourth most frequently cited burden; approximately 80% of each group reported spending up to \$100 per week on care (see Table 5.7a).

Caregivers for family of origin members were significantly more likely (36%) to report problems with family members than family of choice caregivers (16%). Family problems were closely followed by lack of privacy, reported by about one-third of caregivers in both groups. The health of many caregivers often suffers as a result of caregiving, and

5.7a: Comparison of Burden and Strain Between Family of Origin and Family of Choice Caregivers (Percent)

How Much Spent on Caregiving Per Week?	Family of Origin	Family of Choice
Less than \$50	53	64
\$50 to \$100	31	21
\$100 to \$500	17	14
\$500 or More	0	1

Note: N indicates the total number of individuals who answered each question.

How Much Spent on Caregiving Per Week? (Family of Origin N=74; Family of Choice N=68)

5.7b: Comparison of Burden and Strain Between Family of Origin and Family of Choice Caregivers (Percent)

Caregiving Strains	Family of Origin	Family of Choice
Emotional		
Little or none	4	13
Some strain	14	14
Moderate strain	22	27
A lot/A great deal	61	47
Physical		
Little or none	36	38
Some strain	18	20
Moderate strain	27	22
A lot/A great deal	19	21
Financial		
Little or none	43	52
Some strain	16	22
Moderate strain	26	18
A lot/A great deal	16	8

Note: N indicates the total number of individuals who answered each question.

Emotional (Family of Origin N=74; Family of Choice N=79), Physical (Family of Origin N=73; Family of Choice N=77), Financial (Family of Origin N=73; Family of Choice N=77)

this was the next most frequently cited item, but was not a serious source of burden among respondents. A care recipient requiring constant attention and problems with a partner or significant other were mentioned by less than one-quarter of each group. Family of choice caregivers were significantly more likely to say they had been forced to reveal their sexual orientation (11%) as compared to only 3% of family of origin caregivers. This may be because approximately half of them were caring for a partner with HIV or AIDS, an issue for which sexual orientation is of prime importance.

The personal restrictions on caregivers are a source of serious burden, a finding consistent with the general literature on caregiving: the pressures of being responsible for another's health and well-being can cause considerable strain and affect one's health, work and financial standing. To obtain a more detailed picture of the amount of stress caregivers experienced, the survey asked about emotional, physical, and financial strain. Caregivers felt they made the greatest contribution in the area of emotional support; it is therefore not surprising that 47% of family of choice caregivers and 61% of family of origin caregivers reported significant levels of emotional strain. Only 47% of family of origin caregivers and 13% of family of choice caregivers reported little or no emotional strain. (The difference between the two groups is not statistically significant.) Providing constant care to someone, even voluntarily, is an emotionally draining experience well-documented in the caregiving literature. It can be particularly difficult to watch the physical or mental deterioration of the person receiving care (see Table 5.7b).

Only about one-fifth of caregivers in both groups reported significant levels of physical strain. About one-quarter in both groups reported moderate levels of physical strain. Similarly, the majority of both groups reported little or no financial strain, and few in either group reported significant levels of financial strain.

REASONS FOR PROVIDING CARE

Most caregivers in both groups had strong reasons for assuming the caregiving role (see Table 5.8); many centered on the caregivers' sense of responsibility. Four-fifths of respondents said the person being cared for deserved such assistance. Many also provided care out of a sense of obligation and responsibility. Family of origin caregivers were significantly more likely to say so (79%) than their family of choice counterparts (58%), a likely reflection of the long-term and reciprocal nature of parent-child relationships, as well as social norms regarding filial responsibility toward aging parents. This is further illustrated by the finding that family of origin caregivers were significantly more likely to report that their families expected them to provide care (44%), as compared with only 8% of family of choice caregivers, and that they were significantly more likely to provide care to avoid feelings of guilt and/or regret (25%) as compared with 10% of caregivers for family of choice members.

The next most frequently cited reasons for providing care centered on the care recipient and a desire to keep them at home. Close to two-thirds of caregivers in both groups provided care so that the recipient could remain at home (64% of family of origin and 58% of family of choice caregivers). Sizable proportions of both groups of caregivers provided such assistance because no one else was available.



Table 5.8: Comparison of Reasons for Providing Care Between Family of Origin and Family of Choice Caregivers (Percent)

	Family of Origin	Family of Choice
Sense of Responsibility (y)		
Care recipient deserved care	89	83
It was respondent's responsibility***	79	58
Family expected me to provide care***	44	8
To avoid feelings of guilt/regret**	25	10
Avoidance of Institutionalization (y)		
Care recipient able to stay home	64	58
No one else was available	35	49
Personal Reasons (y)		
Part of respondent's nature	64	58
Emotionally/spiritually nurturing	31	41
Provided respondent sense of purpose	28	35
Made respondent a better person	23	36
Became closer to respondent's family***	19	1

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Sense of Responsibility (Family of Origin N(y)=178; Family of Choice N(y)=126), Avoidance of Institutionalization (Family of Origin N(y)=74; Family of Choice N(y)=85), Personal Reasons (Family of Origin N(y)=123; Family of Choice N(y)=137)

p < .01, *p < .001 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

Table 5.9: Comparison of Formal Organizations Used by Family of Origin and Family of Choice Caregivers (Percent)

	Family of Origin	Family of Choice
Long-Term Care (y)		
Visiting nurse service	40	38
Home care agency	43	31
Emotional/Psychological Support (y)		
Support groups**	17	37
Therapy	21	32
Clergy	23	17
Community-Based Services (y)		
Senior LGBT organization**	1	14
Other LGBT organization**	1	16
Senior center	16	9
Informational Assistance (y)		
Phone information line	11	6
Internet	21	14
Other (y)*	24	11
Difficulties with Formal Service Providers (y)*	41	26

Note: (y) indicates that percentages listed represent those individuals who answered "yes" to the question. N indicates the total number of individuals who answered each question. When the N is followed by (y), this indicates the total number of individuals who answered "yes" to that question.

Long-Term Care (Family of Origin N(y)=62; Family of Choice N(y)=56), Emotional/Psychological Support (Family of Origin N(y)=46; Family of Choice N(y)=70), Community-Based Services (Family of Origin N(y)=14; Family of Choice N(y)=31), Informational Assistance (Family of Origin N(y)=23; Family of Choice N(y)=16), Other (Family of Origin N(y)=18; Family of Choice N(y)=9), Difficulties with Formal Service Providers (Family of Origin N(y)=30; Family of Choice N(y)=20)

*p < .05, **p < .01 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

A large number of both groups (64% of family of origin and 58% of family of choice caregivers) said that being a caregiver was intrinsic to their nature. Thirty-one percent of family of origin and forty-one percent of family of choice caregivers said caregiving was emotionally or spiritually nurturing, and both groups endorsed the idea that being a caregiver provided a sense of purpose about equally (28% and 35%, respectively). A similar share felt that caregiving made them a better person. And 19% of family of origin caregivers reported that providing care brought them closer to their families. Overall, there were more similarities than differences between the two groups in their reasons for becoming caregivers; they responded to others in need, regardless of the relationship to that person.

ASSISTANCE FROM THE FORMAL COMMUNITY-BASED SYSTEM OF HEALTH AND SOCIAL SERVICES

Caregivers are sometimes willing to look for help from those in the community in a position to mitigate some of the stress and burden associated with caregiving, although family members often wait to ask for help until the level of care required surpasses their ability to provide it. That less than half of the LGBT caregivers in either group turned to any formal or community-based resource was not unexpected.

The most frequently utilized type of formal assistance was home health care and visiting nurse services, each accessed by approximately 40% of caregivers in both groups (see Table 5.9). Given the nature of the illnesses and disabilities among care recipients discussed earlier in this report, these levels of utilization of long-term care services are completely plausible. Fewer caregivers in both groups sought help for themselves with the stress and burden of the caregiving situation. Family of choice caregivers were more likely to attend support groups (37%) than family of origin caregivers (17%). There were no significant differences between groups in the proportion of caregivers using individual therapy, which ranged from 21% to 32% among family of origin and family of choice caregivers, respectively. About 20% of both groups had turned to members of the clergy for advice and support—23% of family of origin caregivers and 17% of family of choice caregivers.

With respect to other assistance from LGBT community organizations, family of choice caregivers were significantly more likely to seek such help; only 1% of family of origin caregivers sought such assistance, compared with up to 16% of their family of choice counterparts. Given that the overwhelming proportion of care recipients in the former group were LGBT themselves, while care recipients in the family of origin were almost entirely heterosexual, this finding is not unexpected. What is particularly noteworthy is how few caregivers turned to any LGBT organization at all. Family of origin caregivers used senior centers at a higher rate (17%) than family of choice caregivers (9%), although this difference is not statistically significant. Nor were there significant differences between the two groups in the proportions using the Internet or telephone information services; the Internet was, however, used more frequently.

Among those accessing formal organizations for help, family of origin caregivers were significantly more likely to report having difficulties with service providers (41%) than family of choice caregivers (26%). This may be due, in part, to the greater case management role family of origin caregivers played, a further reflection of how the differences in relationships and living situations between family of choice and family of origin caregivers influence the nature of the caregiving.

About 20% of both groups had turned to members of the clergy for advice and support—23% of family of origin caregivers and 17% of family of choice caregivers.



6: Contextual Issues in the Lives of Older LGBT Adults

As noted in the previous sections, providing care to a family member, partner, or friend does not occur in a vacuum, but involves contextual issues in the lives of the caregivers, including how satisfied they are with their lives in general, their sense of acceptance and control over their lives, their level of depression (if any), and their ability to handle stress and strain.

This study sample included 341 older LGBT adults recruited widely from the community at large. Of this group, 46% indicated they are or were caregivers. However, the entire sample of 341 adults, including those who are not caregivers, provided information on who they were, their social networks, sense of well-being, and their opinions regarding the role of the LGBT community in assisting its older members. This section, concerning contextual issues, and the next section, concerning the role of the LGBT community, includes responses from the full sample of 341, whether or not they were involved in caregiving.

DISCLOSURE OF SEXUAL ORIENTATION

Particularly pertinent to LGBT adults is the extent to which they are comfortable with and disclose their sexual orientation to family members, friends, and colleagues at work or in organizations to which they belong, as well as to people in their place of worship. The extent to which they disclose their sexual orientation to their health care providers is also important to their health and well-being. All study respondents were presented with a list of persons and asked to indicate the extent to which they were open and honest concerning their sexual orientation with such persons (see Table 6.1). (The choices were: open to some, all, or none).

Almost half of the LGBT respondents were “out” to all the members of their biological family, while another 30% were out to some members of their biological family.

Almost half of the LGBT respondents were open to (or “out” to) all the members of their biological family, while another 30% were open to some members of their biological family. However, a small but sizeable group, about one-quarter, indicated they were open to none of their family members. Openness with respect to sexual orientation was, as would be expected, higher with regard to friends, with 59% indicating they were “open to all” friends, and another 30% to at least “some friends.” Virtually no one indicated being “closeted” to all friends.

With respect to openness to members of social and political organizations to which they belonged, as well as to colleagues at work, not surprisingly the proportion “open to all” dropped (38% with respect to members of social/political organizations and 33% among colleagues at work). However, between 40 and 45% were “open to some” of their organizational colleagues or those with whom they worked (44% and 42% respectively). Again, as in the case of biological family members, there was a small but sizeable group ranging from 1% to 25% who indicated being “open to none” of those with whom they worked or participated in social or political organizations. There was somewhat less openness to persons in the place of worship. Thirty-one percent were “open to all” while 45% were only open to some, and 28% were “open to none” in their place of worship.

Not surprisingly, people were less likely to be out in the workplace, at social/political organizations, or in their houses of worship. In each of these three situations, slightly over 30% were completely open and honest about their sexual orientations, with the largest population being more selective and open only to some persons in these situations. However, the difficulties faced by many older LGBT people with respect to openness concerning sexual orientation can be seen by the findings that in each situation, approximately one-quarter of respondents were open to no one.

It may be most important for people to disclose their sexual orientation to their health care providers. Disclosure of sexual orientation to a health provider may in many situations be crucial to receiving proper medical care. Although 46% of respondents indicated they disclosed their sexual orientation to health care providers, 34% only disclosed their sexual orientation selectively to some health care providers, and 20% of the LGBT seniors in this study indicated that they made such disclosure to none of their health providers. Therefore, over half of the respondents did not completely disclose their sexual orientation—or, presumably, information about their sexual behavior—to their health care providers. Such a situation has potentially dangerous repercussions, including the failure to learn about disease prevention techniques, a lack of attention to certain LGBT-related health care needs, and even misdiagnoses of medical conditions (Gay and Lesbian Medical Association [GLMA], 2001, 2002a, 2002b). Among older gay men who are not out to health care providers, early signs of HIV/AIDS are often misdiagnosed as normal signs of aging, and HIV tests are not routinely given (GLMA, 2002a). (The current standard treatment HIV/AIDS involves following early detection with a rigid adherence to treatment regimens, which often leads to a higher quality of life and better prognosis.) Older lesbians may be at higher risk for breast cancer (GLMA

The difficulties faced by many older LGBT people with respect to openness concerning sexual orientation can be seen by the findings that in each situation, approximately one-quarter of respondents were open to no one.

Over half of the respondents did not completely disclose their sexual orientation—or, presumably, information about their sexual behavior—to their health care providers. Such a situation has potentially dangerous repercussions.



2002b), and failure to disclose sexual orientation leaves doctors ignorant of that elevated risk.

The only difference between men and women with regard to disclosure issues involved health care providers: men were more likely to be open and honest with their health care providers than women, perhaps as a result of the impact of HIV/AIDS on gay men in general. In fact, it is possible that this higher rate of disclosure among men reflects a greater likelihood of testing

Older respondents were less likely to disclose their sexual orientation, regardless of gender.

6.1: Level of Openness and Honesty Concerning Sexual Orientation (Percent)

Biological Family	Total	Women	Men
All	48	49	47
Some	30	26	31
None	23	25	22
Friends			
All	59	58	59
Some	37	35	38
None	4	7	3
Social/Political Organizations			
All	38	36	37
Some	44	44	45
None	19	20	18
Colleagues at Work			
All	33	34	32
Some	42	40	41
None	25	26	27
Health care Providers*			
All	46	35	51
Some	34	38	31
None	20	26	18
Place of Worship			
All	31	31	32
Some	45	42	42
None	25	27	32

Note: Apparent disparities between row totals and the number of individuals in the male and female categories are accounted for by the inclusion of data from the four transgender persons who were not included in the male or female analyses.

Biological Family N=331, Friends N=333, Social/Political Organizations N=330, Colleagues at Work N=323, Health care Providers N=326, Place of Worship N=325

*p < .05 (Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

6.2: Psychological Well-Being (Percent)

Life Satisfaction	Total	Women	Men
Very satisfied	41	41	41
Somewhat satisfied	46	48	46
Not too satisfied	10	8	11
Not at all satisfied	2	3	2
Self-Reported Depression			
No	70	71	70
Yes	30	29	30
Happiness			
Very happy	29	35	25
Fairly happy	56	51	59
Not too happy	14	13	14
Not at all happy	2	1	1

Note: Apparent disparities between row totals and the number of individuals in the male and female categories are accounted for by the inclusion of data from the four transgender persons who were not included in the male or female analyses.

Life Satisfaction N=335, Self-Reported Depression N=332, Happiness N= 329

Table 6.2a: Psychological Well-Being

Ryff Well-Being Subscales¹

	Total		Women		Men	
	M	SD	M	SD	M	SD
Self-acceptance**	38.8	8.2	40.6	7.2	38.2	8.3
Autonomy*	38.7	5.9	39.9	5.5	38.1	6.0
Environmental mastery	37.8	6.4	38.4	6.2	37.7	6.5

M=Mean, SD=Standard Deviation (For a definition of mean and standard deviation see Appendix)

1. The range for the well-being scales was 9–54.

*p < .05, **p < .01 (ANOVA and Chi-Square Tests of Significance; For a definition of statistical significance see Appendix)

for HIV/AIDS, which in many cases involves self-disclosure. As might be expected, with regard to openness of sexual orientation, older respondents were less likely to disclose their sexual orientation than younger respondents, regardless of gender.

PSYCHOLOGICAL WELL-BEING

Considering the psychological impact of aging and caregiving provides a more dynamic representation of the respondents' lives, and several indicators of well-being were included in this study. Although life satisfaction and depression are often used to assess well-being, these indicators do not present a complete picture of psychological function. Life experience and the subjective interpretation of the effects of these experiences also affect one's psychological well-being (Hultsch & Plemons, 1979; Ryff & Dunn, 1985; Ryff & Essex, 1992). Most theories of psychological well-being have focused on three dimensions: positive and negative affect and life satisfaction (Diener, Suh, Lucas, & Smith, 1999; Watson & Tellegen, 1985). Others have used the absence of depression to calculate a level of well-being. (Lawton, 1984; Jahoda, 1958) However, Ryff (1989a) has proposed a model of wellness that moved beyond the relatively simple view that well-being and health were indicated when negative indicators like illness or depression were absent. This study included indicators of both approaches as described below.

Life Satisfaction and Depression: To ascertain the overall level of life satisfaction and degree of happiness with current life, respondents were asked to rate their life satisfaction as very satisfied, somewhat satisfied, not too satisfied, or not at all satisfied. The vast majority (97%) indicated either being very satisfied (41%) or somewhat satisfied (46%), suggesting that most respondents felt positively about their current life. But 12% were negative with respect to life satisfaction. When it came to feelings about happiness, the proportion feeling very positive dropped to 29%, with a larger group (56%) indicating some reservation (only fairly happy), while 16% were not too happy or not happy at all with their current life (see Table 6.2). Perhaps even more significant is the fact that 30% reported feeling depressed. This rate of depression is as high as that found in clinical populations including visually impaired elderly and is more than six times the average rate of 5% in the general U.S. population (Galea et. al., 2002).

Overall Level of Psychological Well Being: Three of Ryff's (1989b) well-being scales were chosen in order to obtain a sense of the overall level of psychological well-being experienced by elderly LGBT people. These three scales measure self-acceptance, autonomy, and environmental mastery, facets of well-being most germane to LGBT seniors. They were chosen because they assess additional aspects of positive psychological functioning that would be missed by traditional measures of well-being. Each of the three scales consists of nine items, including both positive and negative characteristics of the well-being domain, and were scored from 9 to 54, with higher scores indicating greater levels of well-being. Women reported higher levels of well-being than men on each of the three measures (see Table 6.2a).

Thirty percent reported feeling depressed. This is more than six times the average rate in the general U.S. population.

Given the frequently hostile attitude of society toward LGBT people, it is important for them to achieve a high level of self-acceptance. Women reported significantly higher average levels of self-acceptance than men.



Self-Acceptance: A self-accepting person possesses a positive attitude toward the self; acknowledges and accepts multiple aspects of the self, both good and bad; and feels positive about his or her past life. Given the frequently hostile attitude of society toward LGBT people, it is important for them to achieve a high level of self-acceptance, so that even when society is unsupportive, they can maintain a positive outlook on life. Most respondents scored above the median for the scale (M=38.8). Women reported significantly higher average levels of self-acceptance (M=40.6) than men (M=38.2).

Autonomy: Autonomous individuals are self-determining and independent, and able to resist social pressures to think and act in certain ways. They judge themselves by their own set of standards and regulate their behavior based upon these standards. Autonomous individuals may be better able to help others during stressful life events, making them good candidates for the role of caregiver. Again, most of the people in the sample scored higher than the median (M=38.7), and women scored significantly higher (M=39.9) than men (M=38.8).

Environmental Mastery: An individual who scores high on this scale makes effective use of surrounding opportunities, and is able to choose or create contexts suitable to personal needs and values. This particular domain of well-being is integral to an older LGBT person's ability to live in a society in which the expression of a homosexual orientation is frequently eschewed or actively suppressed. Although the mean score on this dimension of well-being was the lowest of the three examined, it was still above the median (M=37.8). The difference between the scores of men and women is not statistically significant.

Environmental mastery is integral to an older LGBT person's ability to live in a society in which the expression of a homosexual orientation is frequently eschewed or suppressed.

SUMMARY

Looking at the responses to various measures of well-being and satisfaction with life, one is struck by the relatively positive evaluations given by the respondents. The majority are either somewhat or very satisfied with their lives, although they are more circumspect in indicating their level of happiness, with a larger proportion suggesting some reservation in how happy they are. With respect to the general measures of well-being, the respondents scored above the midpoint on all three scales (i.e. self-acceptance, autonomy, and environmental mastery). However, these scores were not at the top of the scale, again suggesting some indication of the effect of being an older LGBT adult in a society that is far from welcoming of differences, particularly in the area of sexual orientation.

The difficulties faced by many LGBT people are reflected in the higher than usual rate of depression found in the study sample. The apparent contradictions between the results of the various measures of psychological well-being illustrate the complexity of issues of mental health in this population. Future research that can help tease apart some of these contradictions is clearly warranted. Additional research is needed with respect to the psychological well-being of LGBT older adults and the nature of the pressures they experience living their lives according to their own choices.

The difficulties faced by many LGBT people are reflected in the higher than usual rate of depression found in the study.

7: The Need for Assistance and the Role of the LGBT Community

This study attempted to better understand the role of the LGBT community in the formal social support of older adults. Thus, respondents were asked about their needs for assistance and their perceptions of the role the LGBT community played in meeting the needs of older community members.

CAREGIVING AND OTHER NEEDS OF LGBT SENIORS

When asked about their own needs for caregiving assistance, 8% of respondents said they currently needed such assistance. Another 19% said they had needed such assistance in the past. In addition, participants were asked to indicate various types of assistance and services that they wanted the LGBT community to provide for its seniors (see Table 7.1).

Respondents reported needing social and emotional support more frequently than any other kind. Over one-quarter (26%) reported needing psychological and emotional support, nearly one-fifth (19%) were interested in visiting services, and about one-tenth requested age-inclusive social venues. These figures are consistent with the one-third of respondents who reported needing more emotional support from their social networks in the previous year (see Table 2.9). About one-fifth (19%) said they would like to have LGBT retirement and assisted living facilities available, and 14% wanted assistance with the activities of daily living. Less than one in ten were interested in other caregiving related services, such as long-term care facilities, or training and respite for caregivers.

Fewer than 10% of respondents expressed the desire for assistance from the LGBT community in political and policy advocacy. Eleven percent saw a need for consumer advocacy, followed by advocacy for LGBT-friendly mainstream services (8%). The relatively low interest in the area of political advocacy may reflect, in part, cohort effects: on



7.1: Types of Assistance Requested by LGBT Respondents (Percent)

	Total
Social and Emotional Support	
Psychological or emotional support	26
Friendly visitors	19
Social outlets that are age-inclusive	12
Senior centers for LGBT people	2
Romantic/sexual connections	1
Telephone support/outreach	2
Spiritual/religious support	0
Longterm Caregiving Assistance	
Retirement/assisted living facilities	19
Assistance with activities of daily living	14
Long-term care facilities	9
Training for caregivers	7
Visiting home care	7
Respite care	6
Intergenerational caregiving	3
Political/Policy Oriented Consumer Advocacy	
Advocate for LGBT friendly mainstream services	4
Fight against ageism in the LGBT community	5
Keep LGBT seniors active in the community	4
Political lobbying for LGBT needs	3
Health care Services	
Health care	10
Other Community Services	
Emergency financial assistance	5
Legal counseling	5
Transportation services	5
Financial planning	2
Other	13
Not Sure	3

Note: Multiple responses (up to three per respondent) account for the total percentage being greater than 100%.

7.2: Why The LGBT Communities Should Help Seniors (Percent)

	Total
The LGBT community is my family	17
Older LGBT people are isolated in society	14
We know ourselves better than others	13
It is easier to be open with other LGBT people	12
We should take care of our own	10
Homophobia/heterosexism	9
Fight ageism within the community and society in general	4
The LGBT community should advocate for equal treatment	3
Mainstream services are unwelcoming	3
To prevent the need to go back into the closet	2
To provide financial assistance	1
Encourage intergenerational contact within the LGBT community	1
Other	11
I don't know	1
There is no specific need	1

average, LGBT people 50 and older have historically been less politically active than younger LGBT people. The need for LGBT health care services was brought up by 10% of respondents. Only about 5% of respondents mentioned other community services, such as legal counseling or transportation services. It is likely that in the relatively rich service environment of New York City, LGBT seniors feel that these types of services can be easily accessed through existing formal service structures.

WHY THE LGBT COMMUNITY SHOULD ASSIST ITS OLDER MEMBERS

When asked why the LGBT community should help its senior members, most respondents said that the LGBT community was best at caring for its own, reflecting an underlying belief in the persistence of discrimination and lack of understanding on the part of the mainstream health care and social service systems (see Table 7.2). The other most frequently cited reasons included familial feelings for the LGBT community; discomfort with mainstream services; the isolation and stigmatization suffered by LGBT seniors; and homophobia or heterosexism. Such findings not only indicate that there are a sizable number of LGBT seniors who would prefer receiving services within the community, but also point up the need for extensive advocacy, outreach, and education to mainstream service providers about making their programs more LGBT friendly and accessible.

When asked why the LGBT community should help its senior members, most respondents said that the LGBT community was best at caring for its own, reflecting an underlying belief in the persistence of discrimination.



8: Conclusions

The preceding sections have cataloged the caregiving experiences of older LGBT adults in New York City, the extent of their social networks and social interactions, their levels of psychological well-being, and the role they envision for the LGBT community in serving its older members. The results are detailed and extensive. Some findings directly address the research questions posed below, and have important implications for policy and practice.

What are the characteristics of older LGBT adults? To what extent are they involved in caregiving? To whom is such care provided?

- Respondents in this study were LGBT adults 50 years of age and older. Most were highly educated, worked in white-collar occupations, and had correspondingly high income levels. This is not necessarily representative of gay and lesbian people as a whole (Badgett, 2003). Self-rated health in this group was lower than typically reported among adults of this age.
- Respondents had extensive informal support networks. Most were highly involved with their families of origin, indicating that, at least among this group, few were estranged from their biological families.
- One-third reported that their emotional support was inadequate, suggesting a need for more opportunities to be close to social network members.
- A substantial proportion of the sample was involved with caregiving; nearly half were providing care or had provided care in the past five years to members of their biological families or to partners, significant others, or friends.

What are the caregiving experiences of those assisting parents and other family of origin members?

- Similar to older heterosexuals, older LGBT people are heavily engaged with their families of origin, and are deeply involved in caregiving and other forms of social support.

- Of the 341 respondents in this study, close to one-quarter were or had been involved in the care of a family of origin member in the previous five years. The care recipient was most often a parent suffering from an age-related illness.
- Family of origin caregivers were unlikely to live with the care recipient, and many of their caregiving activities were related to case management. Many were responsible for making legal and health decisions for the care recipient.
- LGBT family of origin caregivers provided as much or more care as other family members. Very few said they did less than other family members.

What are the caregiving experiences of those assisting partners and/or friends?

- One-quarter of the sample reported providing care to a person who was not related by blood to the caregiver.
- Partners and/or significant others with HIV, AIDS, or other physical illnesses were the focus of much of the family of choice caregiving.
- About two-thirds of caregivers in this group had authority to make medical or legal decisions for the care recipient.
- Most family of choice caregivers lived with the care recipient and provided a great deal of hands-on care.

What are the similarities and differences between the two types of caregivers—LGBT caregivers for members of their families of origin, and those providing care to partners or close friends?

- Members of both groups of caregivers felt that emotional support was the most important type of assistance they provided.
- Family of choice caregivers played a more hands-on role, while family of origin caregivers were more likely to serve as case managers. This stems largely from differences in relationships to the care recipient, living arrangements, and the reasons care recipients required care.
- There were few gender-based differences in caregiving activities, but women did do more hands-on work traditionally associated with stereotypically female gender roles.
- Sexual orientation was problematic for a small minority of family of origin caregivers.
- LGBT caregivers in both groups needed the same sort of support as other caregivers, including respite, support groups, and other services.
- Most caregivers were employed during the caregiving episode, and had to negotiate the competing demands of caregiving and the workplace.

What is the degree of disclosure of sexual orientation in this group of older LGBT adults?

- About one-fourth of the sample was not open and honest about their sexual orientation with biological family members. Another 29% were only out to some members of their family of origin, while nearly half (48%) were completely open and honest with their biological families.
- Among friends, the degree of disclosure was higher: 59% were completely out, and an additional 37% were out to some of their friends. Respondents were less likely to be out in the workplace, within social/political organizations, and in places of worship.



What is the psychological status of this group of older LGBT adults?

- Over half of the respondents did not completely disclose their sexual orientation, or, presumably, their sexual behaviors, to their health care providers, potentially resulting in a failure to monitor health care needs specific to their homosexuality.
- Although over four-fifths (88%) of the participants said they were at least somewhat satisfied with their lives, 30% reported being depressed. This rate of depression is as high as some clinical populations and is more than six times the average rate of depression in the general population in the United States.
- Respondents reported relatively high levels of psychological well-being in the domains of self-acceptance, autonomy, and environmental mastery, as compared with the general population. Women scored higher on average than men in self-acceptance and autonomy.

In what ways should the LGBT community be a source of formal social support for these older adults?

- Eight percent of LGBT elders said they currently needed caregiving assistance. Another 19% said they had needed such assistance in the past.
- One-quarter of respondents reported needing social and emotional support—the support most frequently cited. Similarly, one-third reported needing more emotional support in the previous year.
- When asked why the LGBT community should help its senior members, most said the community is best at caring for its own, reflecting the persistence of discrimination and lack of understanding on the part of the mainstream health care and social service systems. This underscores the need for mainstream and LGBT community agencies to provide outreach to older members of the LGBT community.

9: Policy Implications

There are four major policy issues raised by this study of the caregiving needs and practices of lesbian, gay, bisexual and transgender (LGBT) New Yorkers age 50 and older. The following section provides discussion of and context for these issues, with an emphasis on existing or proposed legislation that can address the needs highlighted by this study.

POLICY IMPLICATIONS: RELIEVING STRESS RELATED TO CAREGIVING EXPERIENCES

Nearly three-quarters of LGBT caregivers surveyed in this study reported emotional stress related to caregiving that ranged from “moderate” to “a great deal.” Caregiving can result in substantial emotional, physical and financial strain. Yet, as the Lifespan Respite Care Act currently pending in Congress notes, “Available respite care programs are insufficient to meet the need...leaving large numbers of family caregivers without adequate support.”¹¹ The bill also states that of the approximately 26 million Americans currently provide caregiving assistance to one or more adult family members or friends who are chronically or terminally ill or disabled, only 42% are under age 65. In other words, the majority of people caring for the elderly are also elders.¹² Therefore, support services for caregivers, including respite care, information and referral, and assistance in securing services, counseling, and support groups, are critical to minimize the emotional, physical, and financial stress involved in caregiving.

The majority of people caring for the elderly are also elders. Therefore, support services for caregivers are critical to minimize the emotional, physical, and financial stress involved.

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

As a first step toward meeting the needs of caregivers, Congress passed the National

11. S. 538, 138th Cong. (2003).

12. Ibid.



Family Caregiver Support Program (the Caregiver Support Program) in 2000. This law uses a definition of “caregiver” that includes LGBT individuals who are caring for same-sex partners, close friends, and members of their families of origin. The act also states, “The term ‘family caregiver’ means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual.”¹³ This program provided \$125 million to states in 2001 (increased to \$155 million in FY 2003) for a variety of services for family caregivers. These services, to be provided in partnership with area agencies on aging and local community-based service providers, include:

- Providing information to caregivers about services available to them
- Assisting caregivers in accessing support services
- Counseling of individual caregivers, the organization of support groups, and training to help caregivers make decisions and solve problems related to their caregiving roles
- Providing respite care so that caregivers can have a temporary relief from their caregiving responsibilities
- Providing some limited supplemental services directly to people in need of care, which can complement the services provided by their existing caregivers¹⁴

Community-based LGBT organizations—particularly those serving LGBT elders like Pride Senior Network, Senior Action in a Gay Environment (SAGE), Griot Circle, and Old Lesbians Organizing for Change, as well as LGBT community centers and health centers—should contact their local Area Agencies on Aging (AAAs) regarding the availability of funds under the Caregiver Support Program. They should also bid for contracts to provide some of these services. Furthermore, AAAs and elder services departments at the local, state and federal level should be urged to target funding to LGBT organizations, just like they currently target organizations serving ethnic minority elderly populations. It is essential that the LGBT community establish liaisons with community-based agencies currently providing services under the Caregiver Support Program to ensure that LGBT individuals and organizations are included in their outreach efforts and service provision. These agencies are mandated by the Caregiver Support Program to liaise with all members of the community who meet the definition of family caregivers, including LGBT caregivers.

Information about local AAAs can be found on the National Association of AAAs website (www.n4a.org), which has many helpful links and publications. The National Directory for Eldercare Information and Referral, which can also be ordered at the AAAs website, lists all Area Agencies on Aging, Title VI grantees, and state Units on Aging to which community-based organizations can apply for funding. The directory also provides a complete listing of local and state agencies on aging, as well as Native American aging programs. It is a leading resource for purchasers of products and services for elders in the U.S.

The National Family Caregiver Support Program uses a definition of “caregiver” that includes LGBT individuals who are caring for same-sex partners, close friends, and members of their families of origin.

It is essential that the LGBT community establish liaisons with agencies providing services under the Caregiver Support Program to ensure that LGBT individuals and organizations are included in outreach efforts.

13. Older Americans Act Amendments of 2000, H.R. 782, 136th Cong. § 372 (2000).

14. Ibid.

The Elder Care Locator (www.eldercare.gov, 1-800-677-1116) also has extensive information on specific elder support programs. This directory assistance service of the U.S. Administration on Aging helps people locate aging services in every community throughout the United States. It includes information on state services, area agencies on aging, and local community aging programs and services.

It is important that LGBT people understand that they are eligible for services under the Caregiver Support Program. To help meet this objective, AAAs and elder services departments should be urged to provide support and funding to educate LGBT individuals and organizations about their rights under the Caregiver Support Program. Public education is a critical first step, both within and beyond the LGBT community.

While we encourage LGBT elder groups to apply for funding to provide services, for most LGBT elders, caregiving support services will most likely be offered by mainstream, non-LGBT specific service providers. The caregiving policy change that would have the greatest impact on LGBT elders around the country, and even in large metropolitan areas like New York City, would be mandating these service providers to conduct outreach and provide culturally competent services to LGBT community members. Approximately one-third of respondents in this survey reported that they had experienced barriers when accessing services in the broader community, including homophobia, feeling uncomfortable with non-LGBT service providers, and receiving unequal treatment from these agencies. This finding supports the need for better outreach and service provision. As noted previously, advocating for “LGBT-friendly mainstream services” was the top reported priority for policy advocacy among the LGBT elders in this survey.

It is important that LGBT people understand that they are eligible for services under the Caregiver Support Program.

The most important caregiving policy change would be mandating service providers to conduct outreach and provide culturally competent services to LGBT community members.

OTHER BILLS PENDING

The Lifespan Respite Care Act of 2003 (S. 538), which would provide \$90 million per year to assist family caregivers in finding and accessing quality, affordable respite care so that they can have a break from their caregiving responsibilities, also defines caregiver in such a way as to make same-sex partners and close friends eligible for the act’s services: “The term ‘family caregiver’ means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.”¹⁵ The Lifespan Respite Care Act was passed the Senate in 2003 but has not yet been passed by the House of Representatives (National Alliance for Caregiving, n.d.). This bill would provide an important source of assistance for LGBT caregivers, whether they are caring for members of their families of origin or for their families of choice. This is particularly important for caregivers of families of choice, as they are most likely to be living with the care recipient and involved in ongoing, hands-on caregiving activities. This law would benefit LGBT caregivers and deserves the support of the LGBT community.

The Lifespan Respite Care Act would provide an important source of assistance for LGBT caregivers, whether they are caring for members of their families of origin or for their families of choice.

15. S. 538, 138th Cong. (2003).



POLICY IMPLICATIONS: LGBT CAREGIVING FOR FAMILY OF ORIGIN MEMBERS

Despite the high degree of reported emotional strain, few LGBT caregivers for family of origin members turned to community services or organizations for emotional support. And even fewer accessed any other service or organization during the time they were providing caregiving assistance. In fact, only 1.3% of those providing care to a family of origin member (only one respondent) reported accessing the services of an LGBT community-based organization. New York City has at least three well-known LGBT elder service organizations. This dramatic underuse of these community resources underscores the need for these organizations to become more involved in providing supportive services to caregivers, and additionally, to conduct more successful outreach. This low rate of accessing community-based LGBT elder services emphasizes the need for LGBT elder organizations to apply for and receive funding through the Caregiver Support Program described earlier.

Despite the high degree of reported emotional strain, only one respondent reported accessing the services of an LGBT community-based organization.

RELIANCE ON HOME HEALTH CARE AND HOME CARE

In order to ensure that adequate care is provided to their family of origin members, LGBT caregivers, who also act primarily as case managers, need to be aware of and access available community services, especially if they do not live with the person for whom they are caring. In this study, only 40% of family of origin caregivers used a visiting nurse service, and 43% used a home care agency. Though the cause of this underuse is not completely known, a recent report from the United Hospital Fund and the Visiting Nurse Service of New York noted “the widespread distrust about the home care workforce” due, in part, to “media reports of fraud and abuse.” It also warned that “[c]aregivers’ concerns must be addressed candidly and forthrightly so that those who need help can confidently welcome workers into their homes or the homes of their loved ones.” (UHF, 2000).

While there is little research on homophobia in health care and home care, what little there is indicates LGBT caregivers and care recipients may be particularly vulnerable to bias at the hands of caregiving assistants.¹⁶ For example, one home care assistant threatened to “out” a gay client if he reported her negligent care (Raphael, 1997). Training of home care assistants in diversity and tolerance—including sexual orientation diversity—is critical if LGBT caregivers or LGBT elders in need of caregiving assistance are to access home health care and home care.

16. A 1994 study by the Gay & Lesbian Medical Association found that two-thirds of doctors and medical students reported knowing of biased caregiving by medical professionals. Fifty percent of respondents reported witnessing it, and nearly 90% reported hearing disparaging remarks about gay, lesbian, or bisexual patients. (Schatz & O’Hanlan, 1994).

POLICY IMPLICATIONS: LGBT CAREGIVING FOR FAMILY OF CHOICE MEMBERS

FAMILY AND MEDICAL LEAVE

Given the large number of hours caregivers reported providing care to partners and friends, the ability to take time off from work to provide that care would be a godsend. Unfortunately, the Family and Medical Leave Act (FMLA), a federal law passed in 1993 that provides such an opportunity to married spouses and common-law, opposite-sex partners, discriminates against same-sex partners. It provides up to 12 weeks of unpaid leave after the birth, adoption, or foster placement of a child; to facilitate recovery from a “serious health condition”; or to care for an immediate family member who is extremely sick. To qualify for family leave under this law, an employee must have worked for more than 1,250 hours in the previous 12 months in a company with more than 50 employees. Most importantly for those in same-sex relationships, family is defined in very specific terms to exclude those headed by gay or lesbian individuals. For instance, the legislation states that “[s]pouse means a husband or wife as defined or recognized under state law for purposes of marriage in the state where the employee resides, including common law marriage in states where it is recognized.”¹⁷ Consequently, this law in its current form prevents gay men and lesbians from taking care of their same-sex partners in a manner equivalent to that of their heterosexual counterparts, and it exposes them to additional vulnerability in the workplace. It also prevents close friends from taking unpaid leave to provide extended care for members of their families of choice. It is unclear whether same-sex spouses married and residing in Massachusetts will be eligible under the federal family leave law. This will likely be contested in the courts in the near future.

California’s Family and Medical Leave Law, however, which was enacted in 2002, allows employees to take six weeks of paid leave (as opposed to 12 weeks unpaid leave through the FMLA) to care for an ill relative—including a domestic partner—or after the birth, adoption, or placement of a foster child. Most workers are paid at a rate of about 55% of their salary. The program, which will begin in 2004, will be completely employee-funded, with average annual payments of approximately \$26 per worker (Jones, 2002). Similar amendments to the FMLA would allow gay people to care for their same-sex partners without having to worry about losing their jobs.

Although nearly two dozen states besides California have family leave plans that provide unpaid leave, they do not cover same-sex domestic partners, except for in Hawaii and Vermont, where reciprocal beneficiary and civil union laws added same-sex partners as eligible family members. However, the California family leave law is unique in that it not only provides paid leave, but also includes domestic partners as a matter of course, rather than adding them to a pre-existing law. In order to ensure equal treatment of same-sex couples under family and medical leave policy, more inclusive definitions of family should be included in state and federal laws. This would not only benefit LGBT people, but also all individuals taking care of a loved one.

The Family and Medical Leave Act prevents gay men and lesbians from taking care of their same-sex partners on equal terms with their heterosexual counterparts.

More inclusive definitions of family should be included in state and federal law. This would not only benefit LGBT people, but also all individuals taking care of a loved one.

17. The Family and Medical Leave Act of 1993, 29 C.F.R. § 825.800 (1993).



MENTAL HEALTH ISSUES

One-third of respondents reported that their families expected more help from them due to their sexual orientation or gender identity, while only 4% said their families expected less from them because they were LGBT. Additionally, one-third of those providing care also reported problems with family members or friends of the care recipient because of their sexual orientation or gender identity. Thirty percent of the 341 respondents reported being depressed—a rate six times the rate among the general population. However, the level of depression between caregivers and non-caregivers in the sample was not significantly different. This finding differs sharply from other studies of caregiving among the general, mostly heterosexual population. In those studies, there were significant differences in reported rates of depression between caregivers and non-caregivers (Pinquart & Sorensen, 2003). Nonetheless, the ability of caregivers to access mental health support services is critical.

One-third of respondents reported that their families expected more help from them due to their sexual orientation or gender identity.

Mental health care may be hampered by reluctance on the part of mental health professionals to address issues of sexuality in elderly populations, and the role it may play in mental health issues. Treatment approaches that are dependent on group therapy or support groups may also be problematic for LGBT people who are concerned that disclosure of their sexual orientation or gender identity may result in peer disapproval. Discrimination following disclosure of sexual orientation in nursing homes, senior centers, domestic violence centers, and other auxiliary care settings has been reported (Dean et al., 2000). A recent study found that one in four lesbian and gay people who sought mental health counseling reported receiving inappropriate treatment (Nystrom, 1997).

Support groups have been shown to help caregivers adjust to the rigors of providing care on an ongoing basis. LGBT organizations should consider providing support groups for LGBT caregivers in which participants can share their experiences and problems. Outreach by LGBT organizations to mental health professionals is an important means of sensitizing them to issues particular to LGBT caregivers and LGBT elderly. Where appropriate, clergy should be involved in this outreach process. Particularly in the case of caregivers of family of origin members, clergy were turned to for support by almost one-quarter of such respondents (23%). But in general, caregivers for both family of choice and family of origin members tended not to seek support from others. It is likely that, for many of these caregivers, mental health services—particularly support groups run under the auspices of the LGBT community—could be an important source of assistance.

Discrimination following disclosure of sexual orientation in nursing homes, senior centers, and other auxiliary care settings has been reported.

HEALTH CARE

The American Association of Retired People (AARP) lists the three most important things to do when caregivers are communicating with health professionals about the person they are caring for:

- Ask the right questions to get the information they need to make decisions
- Give health professionals the information they need about the care recipient to make informed judgments

- Get the information, services, and quality care the care recipient deserves (AARP, 2003)

For those providing care to same-sex partners and close friends who are LGBT, it is critical that they provide information about the care recipient's sexual orientation, as LGBT people are at greater risk for certain health issues (GLMA, 2002a; GLMA, 2002b; GLMA, 2001). Due to homophobia in health care, or fear of homophobic treatment at the hands of health care providers, caregivers and care recipients who are LGBT may be less likely to disclose their sexual orientation to health professionals.

HEALTH INSURANCE

Two-thirds of Americans receive health insurance coverage through their employers. In 2002, however, 43.3 million people under the age of 65 were uninsured (Medicare covers most people over age 65) (Kaiser Commission on Medicaid and the Uninsured, 2003). The majority (82%) of these individuals lived in families in which one member was employed either full time (70%) or part-time (12%). Most were without health coverage because their employers did not provide it, or because the premium they had to pay was too high given their income (Ibid.).

Lesbians and gay men often face significant difficulties in acquiring health care coverage, as they are ineligible for the health care benefits that employers frequently extend to their employees' legally married spouses. Moreover, the children of lesbian or gay couples may also be excluded from coverage if their nonbiological or nonlegal parent is the only person in the family with employer-provided health insurance (Cahill, Ellen, & Tobias, 2002).

Significant advances have been made in increasing health insurance access for same-sex couples and their families through domestic partner benefits and equal benefits ordinances that require contractors with a city, county, or state to provide such benefits to their employees. However, tax laws prevent unmarried partners from getting these on the same terms as married partners. For example, employer-provided spousal and family health care coverage is exempt from federal income tax liability: employees with legal spouses get tax-free insurance benefits. However, domestic partner health coverage is taxed as income by the federal government. As a result, many LGBT employees face an additional federal tax bill in the hundreds if not thousands of dollars, depending upon their tax bracket and the cost of the benefits plan. Some accept this inequity because they can afford the tax bill. Others are forced to decline the coverage and hope that any needed medical care will not exceed the cost of the tax.

Lesbians and gay men often face difficulties in acquiring health care coverage, as they are ineligible for benefits frequently extended to employees' legally married spouses.

Many LGBT elders are partnered and would benefit greatly from partner recognition by governmental entities and public policy frameworks.

PARTNER RECOGNITION AND INCOME SUPPORT

Many LGBT elders are single, often due to the death of their partner. Many, however, are partnered, and would benefit greatly from partner recognition by governmental entities and public policy frameworks. Recognition of same-sex marriages would mean that sources of income and family security that heterosexual marriage couples rely upon would also be available to married same-sex couples. Over the course of a lifetime, these unaccessed income streams, addi-



tional expenses, and tax penalties mean individuals in same-sex relationships cannot accrue as much savings to use in old age, and as a result, have fewer financial resources later in life. This often has implications regarding what kind of caregiving assistance individuals can afford to access.

Full equality under partner recognition policies would benefit low- and moderate-income LGBT seniors most. For example, although domestic partnership and civil unions offer concrete benefits like health insurance coverage and, in the case of California, coverage under the state's Family and Medical Leave law, only access to the institution of civil marriage would accord same-sex couples full equality under all state *and* federal policies. Same-sex couples have to spend thousands of dollars to create legal contracts that protect their relationships in the event of sickness or death. (Often such contracts are not recognized by various social and governmental institutions anyway.) Similarly, nonbiological parents would not have to draw up contracts—such as second-parent adoption documents—recognizing their parental relationships with their nonbiological children.

Some of the major issues in this policy area include:

- **Social Security and Pensions:** Surviving same-sex partners are not eligible for Social Security survivor benefits, even though they've paid FICA taxes into the system for their entire lives. Gay partners are also ineligible for spousal benefits, which allow a partner to earn half his or her life partner's Social Security payment if this sum is higher than the individual's own benefit. In addition, partners of workers with defined-benefit pensions do not receive the same legal protections provided to married spouses. Ineligibility for Social Security survivor and spousal benefits alone costs LGBT elders at least \$100 million a year in unaccessed benefits. Unequal treatment under pension and other retirement plans costs LGBT elders much more, particularly when calculated over the course of their retirement. Strong majorities of Americans support treating same-sex couples equally under Social Security policy (68%) and inheritance rights (73%) (Kaiser Family Foundation, 2001). While the current political environment makes any policy change in this area highly unlikely in the short term, the Democratic National Committee did call for equal treatment of same-sex couples by the Social Security Administration in January 2002. And nearly all of the 2004 Democratic presidential candidates supported equal treatment of same-sex couples in social security-related policy (Cahill, Hernandez, Hill, & Varghese, 2003).
- **Unequal Tax Treatment of Same-Sex Couples:** Federal tax law is another policy area in which gay people face discrimination. Same-sex couples do not enjoy the tax exemptions that married couples do with regard to gift taxes and estate taxes. Gay and lesbian partners are also liable for taxes on any domestic partner benefits they receive. Finally, gay men and lesbians face obstacles in claiming their partners as dependents.
- **Medicaid Spend-Down Requirements:** Following the death of a spouse in a nursing home or assisted care facility, Medicaid regulations allow the surviving widow or widower of a married heterosexual couple to remain in the couple's home for the rest of his or her life without jeopardizing the right to Medicaid coverage. Upon the sur-

Ineligibility for Social Security survivor and spousal benefits costs LGBT elders at least \$100 million a year in unaccessed benefits.

vivor's death, the state may then take the home to recoup the costs of terminal care. Because same-sex couples cannot marry, they can be forced into choosing between keeping their home and life's savings, or medical coverage (Dean et al., 2000).

ISSUES RELATED TO THE ROLE OF THE LGBT COMMUNITY IN PROVIDING CAREGIVING ASSISTANCE

More than one in four respondents in this study reported needing psychological and emotional support. One in five (19%) expressed interest in visiting services, and one in ten respondents requested age-inclusive social venues, such as an LGBT elder center or an age-diverse LGBT community center.

Two decades ago, LGBT people rallied around the thousands of gay and bisexual men devastated by AIDS in the United States. So did the families and straight friends of gay people with AIDS. In the face of government passivity and outright hostility, LGBT people and their straight allies built a community-based infrastructure to provide services, to prevent transmission of HIV through safer-sex education and the distribution of condoms, and to challenge prejudice and stigma through public education. Many volunteered as “AIDS buddies,” visiting and providing caregiving assistance to people living with AIDS. While the caregiving needs and practices of LGBT elders require a public policy response, they also require a similar community response.

The Caregiver Support Program authorizes the Assistant Secretary of the Administration on Aging to “award grants or enter into contracts with eligible organizations” for “Demonstration Projects for Multigenerational Activities” that are perfectly suited for projects that mobilize young and middle aged volunteers to provide caregiving assistance to LGBT elders in need of caregiving assistance. Section 417 of the Caregiver Support Program states that grants and contracts “may” be provided to “eligible organizations with a demonstrated record of carrying out multigenerational activities.”¹⁸ However, under the Bush Administration, the Caregiver Support Program has not yet distributed any funds through this provision.¹⁹ Private foundations and other charitable contributions could provide pilot funds to meet this need, which could later be supplemented with government funds through the Caregiver Support Program and the Older Americans Act.

Although fewer than 10% of respondents in this study expressed the desire for assistance from the LGBT community in political and policy advocacy, such support is clearly needed and warranted to help meet their caregiving needs. In order to advocate for LGBT elders in the most effective way, LGBT organizations must acknowledge and address the ageism that inhibits their ability to meet the needs of LGBT elders. In addition to LGBT elder organizations like Senior Action in a Gay Environment, non-elder LGBT organizations and non-gay elder advocacy organizations should also expand their agendas to include the particular concerns of LGBT elders, including caregiving issues.

LGBT organizations and non-gay elder advocacy organizations should expand their agendas to include the particular concerns of LGBT elders, including caregiving issues.

18. Older Americans Act Amendments of 2000, H.R. 782, 136th Cong. § 417 (2000).

19. Personal conversation with Administration on Aging staff. (2003, October 30). This staffer noted that the only programs of this kind were projects that were funded through separate appropriations advanced by individual members of Congress for their districts.



Already LGBT elders are organizing to participate in the next White House Conference on Aging, scheduled for 2005. These conferences, which have occurred approximately once per decade since President Harry Truman instituted the practice in 1950, assess the challenges emerging from the growing population of elder Americans. They also serve as a forum in which to evaluate current needs and make recommendations to the President and Congress regarding amendments to the Older Americans Act for the next decade. In 1995 lesbian and gay elders were listed as a “special population” in the conference’s report for the first time, and sexual orientation was added to the conference’s statement of nondiscrimination. Given the myriad anti-gay actions of the Bush Administration, it will be interesting to see if LGBT elder issues are explicitly addressed. As in previous White House Conferences on Aging, caregiving promises to be a prominent issue. It is essential that the LGBT community stress the importance of caregiving among their members, and insure that their needs are given equal consideration in policy directives that result from this conference.

LGBT elders are organizing to participate in the next White House Conference on Aging. It is essential that this community insure that their needs are given equal consideration at this conference.

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Appendix

STATISTICAL SIGNIFICANCE

In this study, tests of significance were performed on survey data to determine whether or not differences between groups or categories of study participants (i.e. male vs. female participants) simply occurred by chance. The Chi-Square test of significance is most frequently reported in this study. It is used when researchers want to see if statistically significant differences exist between the observed or actual frequencies and the expected or hypothesized frequencies of variables presented in a table. The ANOVA (Analysis of Variance) test of significance is used to see if statistically significant differences exist between the mean or average scores of two or more groups on one or more survey variables.

To report the extent of any statistically significant differences, statistical procedures and “cut-off” points widely accepted in social science research were used. If the relationship was likely to happen by chance less than five times out of 100, one asterisk (*) was included next to the result. If the relationship was likely to happen by chance less than one time out of 100, two asterisks (**) were included next to the result. If the relationship was likely to happen by chance less than one time out of 1000, three asterisks (***) were included next to the result. In social science research, such outcomes are often referred to as “significant at the $p < .05$ level,” “significant at the $p < .01$ level,” and “significant at the $p < .001$ level,” respectively.

MEAN (M) & STANDARD DEVIATION (SD)

In social science research, “mean” simply refers to the average of a given set of values. “Standard deviation” is a more complex statistic that shows the spread or dispersion of values in a given set of values. It is a measure of the average amount the values in a given set deviate from the mean. The more widely these values are spread out, the larger the standard deviation.



Acknowledgements

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Thanks to the following, who helped conceptualize and guide this project over the last several years. (Institutional affiliations reflect the groups these individuals worked with while involved with this project.)

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The following have generously provided general operating and program-related funding:

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We extend our thanks to the following companies for their generous support:

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Wyndham Bel Age Hotel, West Hollywood

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COMBINED FEDERAL CAMPAIGN

Special thanks to the many individuals who enabled the Task Force to receive contributions through the Combined Federal Campaign. (CFC#2262).

LEADERSHIP COUNCIL

We extend a heartfelt thanks to our Leadership Council members for their continued and generous support of the the Task Force Foundation and NGLTF, Inc. Leadership Council members make an annual pledge of \$1,200 or more in non-event related contributions and give the Task Force the flexibility to push for LGBT rights across the nation.

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National Gay and Lesbian Task Force Policy Institute *bestsellers*

Education Policy

ISSUES AFFECTING
LESBIAN, GAY, BISEXUAL,
AND TRANSGENDER YOUTH

by Jason Cianciotto and Sean Cahill

Education Policy provides a comprehensive overview of social science research on the extent and impact of harassment and violence against LGBT students, as well as the public policy interventions that support LGBT students and make schools safer. It includes the first in-depth analysis of how President Bush's No Child Left Behind Act affects LGBT students, profiles eight students who stood up to anti-LGBT abuse, and articulates an agenda for future research and policy analysis. (November 2003; 168 pp.; \$20.00; www.thetaskforce.org/library/)

Transitioning our Shelters

A GUIDE FOR MAKING
HOMELESS SHELTERS SAFE
FOR TRANSGENDER PEOPLE

by Lisa Mottet and John M. Ohle

The problem of unsafe shelters for transgender people is pervasive. *Transitioning our Shelters* is a guide designed for shelters that want to provide safe shelter for transgender people but are not sure how to do so. A joint publication of the Task Force and the National Coalition for the Homeless, the Guide provides many answers to concerns about safety and privacy for transgender residents based on successes at real shelters across the country, the bulk of which are addressed without monetary expenditures. (January 2004; 168 pp.; \$20.00; www.thetaskforce.org/library/)

Campus Climate

FOR GAY, LESBIAN, BISEXUAL,
AND TRANSGENDER PEOPLE:
A NATIONAL PERSPECTIVE

This report, by Susan R. Rankin, details the experiences of GLBT people at 14 colleges and universities across the country. Based on a survey of nearly 1700 students, faculty, and staff, *Campus Climate* documents anti-GLBT bias and harassment, along with levels of institutional support for GLBT people. It highlights differences in experiences between various identity groups and concludes with recommendations for creating an inclusive and supportive environment for GLBT people. (May 2003; 70 pp.; \$10.00; www.nglftf.org/library/)

Family Policy

ISSUES AFFECTING GAY, LESBIAN,
BISEXUAL AND TRANSGENDER FAMILIES

By Sean Cahill, Mitra Ellen and Sarah Tobias. Groundbreaking in its breadth and depth, this report examines family policy as it relates to GLBT people and their loved ones. It provides information useful to those advancing supportive legislation and policy, particularly at the state and local levels. Covers partner recognition; antigay adoption and foster policies; youth and elder issues; health care and end-of-life concerns; and the impact of welfare reform and the faith-based initiative. (December 2002; 216 pp.; \$20.00; www.nglftf.org/library/)

Say it Loud and I'm Black Proud

BLACK PRIDE SURVEY 2000

This largest-ever study of Black GLBT people is the result of a two-year collaboration between nine Black GLBT Pride organizations, the NGLTF Policy Institute, and five African-American researchers: Juan Battle, Cathy J. Cohen, Dorian Warren, Gerard Ferguson, and Suzette Audam. The survey of nearly 2,700 respondents documents significant and often surprising demographics, experiences, and policy priorities of Black GLBT people. (March 2002; 86 pp.; \$10.00; www.nglftf.org/library/)

Transgender Equality

A HANDBOOK FOR ACTIVISTS
AND POLICYMAKERS

A handbook providing activists and policymakers with the tools they need to pass transgender-inclusive nondiscrimination and anti-violence legislation. Written by Paisley Currah and Shannon Minter, with an introduction by Jamison Green. This handbook is an invaluable resource guide providing model legislative language, talking points, responses to frequently asked questions, and a comprehensive resource listing. (June 2000; 96 pp.; \$10.00; www.nglftf.org/library/)

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The **National Gay and Lesbian Task Force Policy Institute** is a think tank dedicated to research, policy analysis and strategy development to advance greater understanding and equality for lesbian, gay, bisexual and transgender people.

The **Pride Senior Network** is a not-for-profit agency founded to encourage and promote services that foster health, well-being, and quality of life for the aging lesbian, gay, bisexual, and transgender community through advocacy, education, and research.

This publication may be downloaded for free at
www.thetaskforce.org