

Lesbian, Gay,
Bisexual and
Transgender (LGBT)
Issues and
Family Caregiving

DAVID W. COON, Ph.D.

AUGUST 2003



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DAVID W. COON, Ph.D.
INSTITUTE ON AGING, SAN FRANCISCO, AND
OLDER ADULT AND FAMILY CENTER,
VA PALO ALTO HEALTH CARE SYSTEM AND
STANFORD UNIVERSITY SCHOOL OF MEDICINE

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Family Caregiver Alliance
National Center on Caregiving
690 Market Street, Suite 600
San Francisco, CA 94104
(800) 445-8106
www.caregiver.org

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INTRODUCTION

Few subjects in our society fuel debates as heated as those pertaining to sex and sexual orientation. Such debates lead some professionals and heterosexual family caregivers to question whether or not lesbian, gay, bisexual and transgender (LGBT) caregivers need assistance that differs from the assistance needed by the majority community. However, this monograph, in line with other published views (Coon & Zeiss, 2003; Levine & Altman, 2002), takes the position that until LGBT individuals no longer experience the discrimination and social isolation that create barriers to receiving competent care, service providers and other professionals need to increase not only their understanding of the issues LGBT caregivers face, but also their competence in service provision to these family caregivers.

To date, most published accounts of LGBT caregiving appear in HIV/AIDS literature, describing outcomes based on the response to the epidemic by the LGBT community (Fredriksen, 1999; Wight, 2002; Wrubel & Folkman, 1997). To address the need for valid data on LGBT caregivers to older adults, results from several surveys in larger US cities (i.e., New York, San Francisco, San Jose) are emerging (Hoctel, 2002; Outword Online, 2000; Reiter, 2003; Shippy, Brennan, & Cantor, 2002). Preliminary results suggest that older LGBT individuals are involved in the care of not only their aging parents and other dependent biological family members, but also partners and friends. They also appear to provide assistance similar to that of their heterosexual counterparts, including hands-on assistance, care management activities (e.g., arranging home care), and emotional support. These surveys also suggest that older LGBT adults and LGBT caregivers experience a good deal of discrimination that discourages self-disclosure and creates barriers to service utilization.

Although the purpose of this monograph is not to debate whether LGBT identity serves as a separate culture, it does take the position that LGBT-identified individuals are members of a minority community with unique needs that in turn shape the development and delivery of competent services for its informal caregivers. Therefore, the purpose of this monograph is to raise aware-

ness of the unique components of the sociocultural context that impact LGBT caregivers and provide information and resources which will assist providers, program planners, researchers and policymakers in increasing their competence in serving this population. The monograph begins with a discussion of the definition of LGBT, and then is divided into four key sections and an appendix: (a) an overview of sociocultural contexts influencing LGBT caregiver service utilization, (b) an examination of barriers to service utilization, (c) suggestions for overcoming obstacles to service utilization, (d) a brief discussion of promising programs and services for LGBT caregivers, and (e) resources and readings.

Many of the challenges and corresponding responses described in this monograph represent the experiences of LGBT caregivers and helping professionals in cities like San Francisco, New York City and Los Angeles—cities that have larger, more visible LGBT communities, which suggests that the barriers and issues LGBT caregivers experience in smaller cities and rural areas may be intensified by fewer LGBT-friendly resources and greater social isolation (Coon & Zeiss, 2003). Yet, service providers, program planners and policymakers must also avoid the tendency to stereotype or fail to recognize the diversity of LGBT community members. LGBT caregivers and care recipients alike often experience great joys in the caregiving experience that counterbalance the hardships and obstacles presented in the pages that follow.

Diversity and Definition

The caregiving experience of LGBT people in our society crosses both cohort and cultural boundaries, ranging from younger caregivers caring for former partners, neighbors, and friends who facilitated their coming-out processes who have now grown older, to older LGBT caregivers caring for long-time partners or friends. LGBT individuals also take on the role of providing care for their parents or other older biological family members. LGBT caregivers represent a diverse group in terms of ethnicity, race, language, national origin and physical challenges. Many of these caregivers, depending upon their level of outness (the extent to which a person is willing to reveal their sexual orientation or gender identity to others), will be more or less reticent with agencies not known for serving the LGBT community. This may be particularly true for older members of the community who faced many years of discrimination and intolerance, which may now be compounded by experiences of ageism, sexism, racism or discrimination based on disabilities (Barón & Cramer, 2000). Therefore, providers must recognize that it is the predominantly “out” group of individuals who self-identify as LGBT that openly accesses LGBT-specific support services.

The fundamental point is that ignoring issues of sexuality and discrimination faced by LGBT caregivers permits society's heterosexism to drive service provision, thereby minimizing our helpfulness to all caregiver clients and their care recipients.

A number of studies report ranges of LGBT prevalence from two and three percent upwards to about 18 to 20 percent (Sell, Wells, & Wypij, 1995; Tanfer, 1993; for a concise summary see Cahill, South, & Spade, 2000). The number is hard to capture due to respondent fear of stigma associated with LGBT self-identification, as well as complexities surrounding the personal and professional definitions of “lesbian,” “gay,” “bisexual” and “transgender.” In general, “sexual orientation” refers to emotional and sexual attraction to others of a particular sex. Despite being commonly defined in the United States as being synonymous with sexual behavior (Herek, 1986), sexual orientation is no longer considered by human sexuality experts as a dichotomy between homosexuality and heterosexuality (Dworkin, 2000; Fox, 1996; Markowitz, 1995). Rather, sexual orientation can be conceptualized as: (a) a continuum from exclusively heterosexual to exclusively homosexual; (b) multidimensional encompassing behavior, affiliation, feelings and desires, and spiritual components (Alquijay, 1997; Coleman, 1987); and (c) developed along a temporal dimension from one's past through the present and into thoughts about the future (Kimmel, 1978; Klein, Sepekoff & Wolf, 1986; Money, 1988). Transgender individuals can self-identify as heterosexual, homosexual or bisexual, but in addition, they express a strong sense of incongruity between their gender identity and their birth sex. As a result, transgender individuals can experience discrimination based not only on their sexual orientations, but also their gender identities. Finally, cultural, cohort and regional differences often influence LGBT acceptance and use of self-descriptors (e.g., homosexual, bisexual, gay, lesbian or queer). Acceptance of such “labels” can add yet another layer of complexity to self-identification and self-definition processes.

So, is it important to determine how many caregivers identify as LGBT? Is it important for service agencies and providers to understand how their own clients self-identify? For organizations and staff interested in building their capacity, competency and effectiveness, the answer is “yes.” Identifying the number of LGBT caregivers who need LGBT-friendly services is central to the creation, evaluation and dissemination of resources identified as particularly useful to LGBT caregivers. However, this information is *not* essential to increase organizational and provider competence in the development and delivery of effective programs and services tailored to meet LGBT caregiver needs. The fundamental point is that ignoring issues of sexuality and discrimination faced by LGBT caregivers permits society's heterosexism to drive service provision, thereby minimizing our helpfulness to all caregiver clients and their care recipients (Coon & Zeiss, 2003). To meet this challenge, professionals need ongoing training and

consultation to increase awareness of the sociocultural contexts that impact LGBT caregivers and to enhance professional competence in suitable service development and delivery.

EXPLORING SOCIOCULTURAL CONTEXTS INFLUENCING LGBT CAREGIVING

The sociocultural contexts surrounding LGBT caregivers, like their heterosexual counterparts, substantially influence their beliefs and expectations about illness (Kleinman, Eisenberg, & Good, 1978) and family caregiving, as well as their views of caregiver stress and burden, the appropriateness of help-seeking behavior, and the palatability of available services (Gallagher-Thompson et al., 2000; Gallagher-Thompson et al., 2003; Yeo & Gallagher-Thompson, 1996). Several components of the larger sociocultural context emerge in unique ways for LGBT caregivers and merit additional discussion, including issues related to cultural, spiritual, social support and legal, financial and employment contexts.

Cultural Contexts

Cultural contexts can differ substantially in their openness about sexuality, acceptable forms of sexuality, and the consequences for ignoring sexual proscriptions (Choi, Salazar, Lew & Coates, 1995; Fukuyama & Ferguson, 2000; Moore, 1997; Ross, Paulsen, & Stalstrom, 1988). For example, disapproval may not arise from same-sex sexual behavior itself, even when an individual is involved in same-sex relationships or sexual relations with same-sex partners for years, but rather from an individual's self-identification as gay, lesbian or bisexual (Fukuyama & Ferguson, 2000; Zamora-Hernandez & Patterson, 1996). Similarly, cross-cultural tensions can arise between the individualistic nature of mainstream U.S. culture and more collectivist ways of being. The sociocultural contexts of some cultural groups stipulate that coming out is not an individual privilege but rather is disrespectful and disruptive to the family. Family also can help protect LGBT caregivers of color against racism, so choosing to be "out" and risk losing familial support may be particularly traumatic (Moore, 1997). Such contexts magnify the perceived risk associated with self-disclosure to service providers (Fukuyama & Ferguson, 2000).

Spiritual Contexts

Religion and religiosity are frequently assumed and often found to be key coping mechanisms for caregivers (National Alliance for Caregiving/AARP, 1997). Even though some religious organizations are reexamining, or have made changes in their views on homosexuality, few religious organizations truly welcome "out"

LGBT individuals. Institutionalized religion in general has remained an agent of intolerance and oppression of the LGBT community since the early Middle Ages (Boswell, 1980). LGBT persons may often struggle to maintain, adapt or reject religious doctrine and spiritual beliefs discordant with their sexual orientation (Kellems & Fassinger, 2003)—a struggle most of their heterosexual caregiving counterparts never confront. Still, while many LGBT caregivers may not feel that they can turn to religious or spiritual coping during personal crises, the heterogeneity within the LGBT community suggests that many others, particularly LGBT persons of color, may find their religious communities and spiritual beliefs to be of immense importance in coping with life stressors such as caregiving struggles (e.g., Davidson, 2000; Fukuyama & Ferguson, 2000; Kellems & Fassinger, 2003). Moreover, exceptions to these negative stances do exist, such as the Metropolitan Community Church created for gays, lesbians and their biological and chosen families, as well as churches and temples in urban areas with large LGBT populations that seek to serve the community.

Social Support

Service providers must avoid the stereotype that all older LGBT persons do not have children or are inevitably alone. LGBT care recipients may receive assistance from biological children, grandchildren or stepchildren from past heterosexual unions, as well as other biological family members. Research (Berger, 1982; Grossman, D'Augelli, & Hershberger, 2000; Kimmel, 1978) also indicates that many LGBT seniors have expanded, multigenerational social and professional networks that can help them contend with discrimination and adjust more easily to growing older. However, more recent research suggests that while LGBT caregiver support networks encompass a variety of relationships, these networks may be somewhat truncated (Shippy et al., 2002), and social losses due to the AIDS epidemic have severely impacted the networks of many gay male cohorts (Coon, 2003). In contrast to older heterosexuals, LGBT care recipients may have let go of unrealistic expectations that blood relatives or friends will provide for them beyond a certain point (Kimmel, 1978; Quam & Whitford, 1992), and LGBT caregivers also may have let go of rigid sex roles or divisions of labor. As a result, they may be more willing to do many tasks once managed by their ailing partners. Still, LGBT individuals historically have had to create support networks on their own, with few community resources at their disposal (Grossman et al., 2000).

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Legal, Financial and Employment Contexts

Many privileges taken for granted by heterosexuals are often difficult to obtain or flatly denied to LGBT caregivers. They are usually excluded from their partners' health insurance and are frequently discriminated against, no matter the length of their partnership, in terms of survival benefits, inheritance rights and community property rights. Although extra legal fees help develop the necessary documents to try to ensure that wishes are honored, blood relatives often can challenge these wishes successfully, since few laws protecting LGBT partners are in place (Connolly, 1996; Ettelbrick, 1996). Blood relatives or facility personnel can also keep LGBT individuals from visiting life partners or care recipients in hospitals or long-term care facilities and dismiss them from the decision-making process. In addition, although caregiving often negatively impacts caregiver employment (National Alliance for Caregiving/AARP, 1997; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999), these issues are quickly compounded among LGBT caregivers through discrimination based on sexual orientation, where being "out" at work can result in both economic and psychosocial losses and distress (e.g., Alexander, 1997; Croteau, Anderson, Distefano, & Kampa-Kokesch, 2000).

IDENTIFYING BARRIERS TO LGBT CAREGIVER SERVICE UTILIZATION

Exploring the various sociocultural contexts of LGBT caregivers is an integral step in raising service provider awareness and moving that heightened awareness towards increased competence. Identifying barriers to LGBT caregiver service utilization is yet another essential step in strengthening provider competence. While family caregivers, in general, can face an array of barriers to service utilization across the caregiving career (Maslow & Selstad, 2001), LGBT caregivers in particular often must negotiate additional obstacles. These obstacles intersect multiple societal levels from the individual, the interpersonal and organizational/system levels to the community and policy levels. However, one common thread—that of hatred, discrimination and intolerance (DiPlacido, 1998; Herek, Gillis, & Cogan, 1999; Meyer, 1995)—is woven throughout these levels, and entangles LGBT caregivers and their service providers.

Hatred, Discrimination, Intolerance

In a society with few legal protections for LGBT people, fear of discrimination and intolerance, including fears of hate crimes (Fredriksen, 1999; Herek et al., 1999), loss of employment, and social stigma, stops many LGBT caregivers and care recipients from seeking or acquiring suitable care. They may feel the need

not only to withhold relevant information from health care and social service providers, but also to extinguish their help-seeking behavior altogether in order to protect themselves. LGBT care recipients and caregivers battling with their own illnesses may feel particularly vulnerable to hate crimes and other forms of discrimination, leading to increased social isolation. In our society, heterosexism compounded by ageism fuels particularly negative stereotypes, placing many LGBT care recipients and caregivers in a double, triple, or even quadruple jeopardy when they hold other minority status (Greene, 1994).

Individual and Interpersonal Barriers

LGBT caregivers, like their noncaregiving counterparts, were socialized in heterosexist societies and may struggle with internalized homophobia (Davison, 1991; Meyer & Dean, 1998) that impedes their help-seeking behavior. LGBT caregivers and care recipients, like all LGBT people, vary in their levels of outness across social groups (e.g., biological family, friends, and co-workers), and service providers must consider that the two individuals in an LGBT caregiver-care recipient dyad may be differentially “out.” Coming out is a very personal choice that may be a potential benefit on the one hand, or an additional burden on the other. Although coming out is related to positive mental health outcomes (Gillow & Davis 1987; Kurdek, 1988; Weinberg & Williams, 1974), the process may be too overwhelming for stressed caregivers who would need to juggle additional complexities, including the redefinition of self and the management of family and friends who conceptualized the caregiver within a heterosexual identity (Laird, 1996; Matteson, 1996). As a result, some caregivers and care recipients will choose to remain closeted.

Organizational/System Barriers

Service utilization barriers extend beyond the interpersonal interactions of LGBT caregivers and their providers. Many organizational obstacles in managed care systems, insurance companies or service agencies are grounded in discriminatory policies that discourage LGBT outness (Garnets, Hancock, Cochran, Goodchilds, & Peplau, 1991; Kauth, Hartwig & Kalichman, 2000; Phillips & Fischer, 1998; Winegarten, Cassie, Markowski, Kozlowski, & Yoder, 1994). This can create particularly sticky situations for people in small communities, where holders of the information may see one another frequently (D’Augelli & Garnets, 1995). However, limited information can lead to misdiagnosis and obstruct effective treatment and care management for LGBT care recipients and caregivers. In addition, few organizations provide domestic partner benefits, thereby exacerbating financial and

psychological stress for many LGBT partners. Other organizational barriers range from systems automatically handing decision-making power to biological relatives rather than longtime partners and refusing LGBT partner visitation rights, to ignoring LGBT issues in staff diversity training and openly discriminating against LGBT applicants in long term care.

Community Barriers

The discussion of sociocultural contexts raises other issues that create community-level obstacles, ranging from geographic regions or municipalities to communities of color or religious faith. Unfortunately, the LGBT community itself holds many of the same prejudices of these larger communities. LGBT persons of color seeking refuge in the LGBT community may experience both overt discrimination similar to that found in larger society, and subtler forms of discrimination, as in the absence of leaders of color in LGBT community organizations (Gock, 1992; Greene, 1994). As a result, LGBT caregivers of color may be reluctant to use formal LGBT community programs. Moreover, ageism is probably just as prevalent in the LGBT community and among its service providers as it is in society as a whole, and in turn can present a substantive obstacle for LGBT caregivers. Such ageism may be reflected in the few formal support systems available for older LGBT adults and their caregivers even in larger communities (Coon & Zeiss, 2003; Grossman et al., 2000; Shippy et al., 2002).

Policy Barriers

Policy barriers often extend beyond single organizational systems or communities, creating an overarching network of barriers that hinder effective service delivery to the LGBT community. These barriers range from lack of domestic partner benefits, including spousal benefits, disability benefits, and retirement benefits for same sex partners, to lack of anti-discrimination policies protecting employment, public housing and access and delivery of services based on sexual orientation (Cahill et al., 2000).

OVERCOMING OBSTACLES TO LGBT CAREGIVER SERVICE UTILIZATION

LGBT caregivers often struggle with caregiver duties and stress and the concomitant need for support and effective coping skills. At the same time, they face numerous obstacles of sociocultural discrimination that leave them justifiably suspicious and make it hard for service providers to easily identify and assist them. The complexity of these issues and their related contexts can seem insurmountable. However, providers, program planners and administrators alike must remember that shifting one brick often

changes the face of the wall—the overall durability of an obstacle—and potentially helps caregivers' situations become more manageable (Coon & Zeiss, 2003). In order to maximize the effectiveness of services for LGBT caregivers, efforts to enhance the caregiving experience must cross multiple levels of barriers. Following is an introductory set of strategies to overcome obstacles to LGBT caregivers' service utilization organized by these levels. This list warrants ongoing review and expansion in order to foster the development and integration of effective services for LGBT caregivers.

Individual/Interpersonal Level

- Explore caregivers' target complaints within their own varied sociocultural contexts by encouraging and respecting the sharing of their family stories and using their labels and descriptors.
- Build on caregiver strengths and avoid characterizing LGBT identity and the coming out process solely as stressful. Older LGBT adults are likely to have spent years building a repertoire of effective coping mechanisms to deal with hostile environments (Fassinger 1997; Kimmel, 1995). Capitalize on effective coping skills by redirecting useful, familiar strategies towards caregiving stressors and augmenting them with additional skill development.
- Reconceptualize social support beyond the traditional family, and even the “chosen family.” Explore informal networks and formal care resources, including LGBT-sensitive resources, as potential sources of support and practical assistance for caregivers (Coon & Zeiss, 2003).
- Understand that older LGBT caregivers and their life experiences differ dramatically from younger LGBT cohorts. In contrast to their heterosexual contemporaries, they faced decades of a hostile society that regarded them as perverts, religious groups that shunned them as sinners, health and mental health professionals who diagnosed them as mentally ill, and police who harassed them as criminals (Fassinger, 1997; Kimmel & Sang, 1995).
- Recognize that although leading professional groups have stopped labeling an LGBT identity as a mental illness, too many professionals still hold this view (Garnets et al., 1991; Phillips, & Fischer, 1998). Research suggests LGBT people have justifiable concerns about negative views held by professionals and the impact of these views on their health care and receipt of social services (Kauth, Hartwig, & Kalichman, 2000; Shippy et al., 2002). Con-

sider that these concerns may be indicators of “healthy paranoia,” and openly discuss limits to confidentiality and the steps taken to protect client privacy.

- Work effectively across a continuum of “outness.” Recognize the pervasive impact of discrimination, respect individual levels of outness in light of relevant sociocultural contexts, and facilitate the processes needed to support unique caregiving situations.

Organizational/Systems Level

Pulling Down Institutional Barriers

- Consistently challenge discriminatory language, thinking, behavior and policies. Use inclusive language in conversations, printed materials and intake forms.
- Increase service accessibility and utility by keeping available magazines, newspapers, newsletters and brochures that are inclusive of as well as specific to the LGBT community.
- Educate staff about LGBT resources pertinent to caregiving. Remember LGBT clients consider service providers’ familiarity with LGBT resources an important factor in choosing providers (Liddle, 1997; Matteson, 1996).
- Request feedback on referrals to determine their LGBT friendliness and senior acceptance. Experiencing ageism from an LGBT referral can be just as distressing as experiencing homophobia or heterosexism from an elder-care or caregiver support referral.
- Organizational policy and employee behavior should promote respect for LGBT employees. Even still, LGBT staff outness can be only fostered, not forced.
- Create a “safe place symbol” system that uses an easily identifiable symbol that would appear in newsletters and on intake forms, and could be clearly posted to indicate that staff and service providers are not only sympathetic to LGBT concerns, but also have received specific training in working with LGBT community members (Coon & Zeiss, 2003).

Staff Training and Consultation

- Established competence with LGBT clients should determine staff suitability to work with community members. It is incorrect to automatically assume the most appropriate service providers for LGBT clients must be LGBT-identified. Such an assumption rests on the prem-

ise that “LGBT” functions as unidimensional category (Coon & Zeiss, 2003).

- Choose teachable moments wisely and incorporate a variety of training modes and material. Unveil and acknowledge the pervasiveness of homophobia and heterosexual privilege—then, educate. Competence requires ongoing training, supervision and consultation. Encourage and support staff attendance at LGBT-relevant continuing education presentations, consultation with knowledgeable colleagues, and formal staff trainings focused on LGBT topics. Case presentations and consultation in team meetings or supervision groups provide particularly salient opportunities to extend knowledge and expand skill sets.
- Increase opportunities for students in gerontology, social science and health care academic programs to receive training in LGBT issues, as well as supervised experiences seeing LGBT clients. Many graduate students report insufficient training in LGBT issues and lack confidence in their abilities to work effectively with LGBT clients (Allison, Crawford, Echemendia, Robinson, & Knepp, 1994; Buhrke, 1989; Glenn & Russell, 1986; Pilkington & Cantor, 1996).
- Intertwine training on LGBT issues with other aspects of diversity to build effective skill sets. Identify and appropriately adapt training material on LGBT issues (e.g., APA, 2000; Buhrke & Douce, 1991; Cabaj & Stein, 1996; Greene & Croome, 2000; Phillips, 2000).

Community and Policy Levels

- Take advantage of the inclusive definition of the National Family Caregiver Support Program (NFCSP) to assess needs of LGBT community members and develop service components to meet those needs.
- Encourage LGBT community support for older community members and informal caregivers through the development and maintenance of programs and services.
- Promote community support for the use of “safe place symbols” in various arenas.
- Review ageist and heterosexist organizational policies and practices that can negatively impact LGBT help-seeking behavior and perceived utility of services (Phillips & Fischer, 1998; Winegarten et al., 1994). Refer LGBT caregivers and care recipients to competent colleagues when policies and practices have not yet been changed.

- Adopt a zero-tolerance policy for subtle and overt discrimination, across all levels of service provision which applies to all employees from top management to front-line staff.
- Educate communities about the need to revise the Family and Medical Leave Act to include same-sex partners, to eliminate unequal treatment in “Medicaid spend-down,” and to support domestic partner benefits (Cahill et al., 2000).

PROMISING SERVICES & SERVICES TO SUPPORT LGBT CAREGIVERS

Recent professional literature reviews have been unable to identify *the* magic bullet to ease family caregiver distress and its sequelae, particularly for caregivers of individuals with memory loss (e.g., Bourgeois, Schulz, & Burgio, 1996; Coon, Ory, & Schulz, 2003; Dunkin & Anderson-Hanley, 1998; Kennet, Burgio, & Schulz, 2000; Pusey & Richards, 2001; Schulz, et al., 2002). However, several promising programs have proven effective in reducing caregiver emotional distress or burden and are seen as useful by caregivers. These programs include services and other intervention approaches that do the following:

- Teach caregivers skills to effectively handle their care recipients’ problem behaviors or effectively manage their own thoughts, feelings and behavior in response to caregiving stressors (e.g., Burgio, Stevens, Guy, Roth, & Haley, 2003; Gallagher-Thompson et al., 2003; Ostwald, Hepburn, Caron, Burns & Mantell, 1999; Teri, Logsdon, Uomoto & McCurry, 1997);
- Modify the caregiver’s and care recipient’s physical and social environments to help support their activities (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gitlin et al., 2003);
- Capitalize on technological approaches ranging from telephone-based technologies to online support combined with skill-focused education (Czaja & Rubert, 2002; Mahoney, Tarlow, & Sandaire, 1998; Steffen, 2000; Steffen, Mahoney, & Kelly, 2003);
- Integrate multiple program components to be comprehensive and intensive in nature, including caregiver counseling, support and education that is individually tailored (Mittelman, Epstein, & Pierzchala, 2002; Whittier, Coon & Aaker, 2003).

Although few formal services exist for older LGBT adults, care recipients and caregivers, several promising practices are continuing to emerge around the United States.

In line with these findings, the National Family Caregiver Support Program recognizes the need for a variety of caregiver services to meet the multiplicity of caregiving challenges. The NFCSP requires the 50 States to work in partnership with their Area Agencies on Aging and local community service providers to provide five basic services: 1) information about available services, 2) assistance locating services, 3) individual counseling, organization of support groups and caregiver training to assist the caregivers in making decisions and solving problems relating to their caregiving roles, 4) respite care, and 5) supplemental services.

In addition, the multiple levels of obstacles encountered by family caregivers in today's world reveal the corresponding need for multiple levels of intervention (i.e., interventions at the individual, interpersonal, organizational, community and policy levels). These interventions, programs and services could begin by building on strategies aimed at the obstacles to LGBT caregiver service utilization mentioned earlier and by developing linkages between successful intervention elements identified at each level (Emmons, 2001). Table 1 provides examples of existing and suggested types of programs, services and other interventions categorized by intervention level. These can range from services outlined in the NFCSP (e.g., support groups, caregiver skill training) tailored to meet the needs of the LGBT community to policy-level advocacy designed to include sexual orientation in all anti-discrimination policies protecting employment, public housing, and access and delivery of services.

Although few formal services exist for older LGBT adults, care recipients and caregivers, several promising practices are continuing to emerge around the United States. However, these practices have yet to be formally evaluated and focus on the basic areas of information and referral, published material and support groups. Hopefully, the information described here is preliminary; that is, it is introduced not only to augment information contained in Table 1, but also to encourage the identification and sharing of existing services for LGBT clients, the adaptation of successful "mainstream" caregiver services to meet the needs of LGBT caregivers, the development of new service components for LGBT caregivers, and the formal evaluation of caregiver programs and service components for the LGBT community.

Information and Referral

Various LGBT organizations (see Resources in Appendix A) have compiled local and national LGBT resource directories. For example, Senior Action in a Gay Environment (SAGE) in collaboration with the American Society on Aging's Lesbian and Gay Aging

Issues Network (LGAIN) developed a list of useful resources related to LGBT aging, organized by state. As another example, two Seattle-based groups (Red Dot Girls and Queen City Community Development) recently surveyed more than 150 of Washington's city, county, state and nonprofit aging services agencies to determine their level of LGBT-friendliness. While not focusing on LGBT caregivers, the guide uses the survey results to describe more than ninety services of potential interest to LGBT seniors (some of which are very useful to caregivers). This seventy-page guide is organized into categories such as "Information and Referral" and "Advocacy" and is available on the web at www.reddotgirls.org/ResList/index.html. In addition, a growing amount of useful published material is available (See Appendix A) such as the LGBT Fact Sheets from Family Caregiver Alliance (*LGBT Caregiving: Frequently Asked Questions and Legal Issues for LGBT Caregivers*) and *Outword* from the American Society on Aging.

Educational Workshops, Support Groups and Counseling

LGBT caregiver education and support groups, similar to those for other populations, can take a variety of forms, from traditional grass roots information and support to more structured approaches that incorporate educational lectures. For example, Family Caregiver Alliance (FCA) in San Francisco initiated the Caring Community Project in January 2002 in collaboration with several other Bay Area organizations (Reiter, 2003). Using funds from the NFCSP administered through the local San Francisco Office on Aging, it cosponsored one workshop focused on mainstream and LGBT-specific community resources for caregivers and another based on legal rights and protections for LGBT older adults. FCA also added an innovative support component to the Caring Community Program in April 2002—an ongoing LGBT Caring Community Online Support Group. The group gives LGBT caregivers of individuals with chronic health problems an opportunity to give and receive information and support from one another.

In addition, face-to-face support groups for caregivers of older adults, particularly adults with memory impairment, are available in a number of areas in the country, with several sponsored by local Alzheimer's Association chapters (Ceridwyn, 2002; Gollance, 2003; Levine & Altman, 2002). Some are the outcome of unique cosponsorships, such as one between SAGE and the New York City chapter (Levine & Altman, 2002). Cosponsors can share a variety of responsibilities for LGBT caregiver support groups, including lending facility space, identifying co-facilitators and supporting assorted marketing strategies. These groups pro-

Although LGBT support group members share concerns similar to other caregivers (e.g., acceptance of the disease process, information on services, grief and loss), several themes appear specific to LGBT caregivers.

vide a safe place for LGBT caregivers to share their concerns and get support without the added burden of hiding their sexual orientations, identities and relationships.

The Sure 2 Framework (Sharing and Support, Unhelpful thinking and Understanding, Reframes and Referrals, and Education and Exploration) has been used successfully in an LGBT caregiver support group in San Francisco and also can be applied to LGBT caregivers through individual, couple and group counseling arenas (Coon & Zeiss, 2003). Grounded in an empowerment perspective and basic cognitive and behavioral techniques known as CBT (Beck, Rush, & Shaw et al., 1979; Lewinsohn, Muñoz, Youngren & Zeiss, 1986; Thompson, Powers, Coon et al., 2000), caregivers are encouraged to reframe their thinking and change behavior through basic problem-solving, positive reframing and other techniques and to elicit ideas from the group. These ideas include recognition of the obstacles LGBT people face as a result of their sexual orientation, such as difficulty finding LGBT-sensitive services, and the sharing of referrals when competent professionals and organizations are identified.

Although LGBT support group members share concerns similar to other caregivers (e.g., acceptance of the disease process, information on services, grief and loss), several themes appear specific to LGBT caregivers (Coon & Zeiss, 2003; Levine & Altman, 2002):

- LGBT caregivers report insensitivity and ignorance on the part of their biological family members, who automatically assume that all caregiving responsibilities should be given to the LGBT person as a “single” child or family member, thereby ignoring LGBT primary partnerships or nontraditional family relationships.
- As a result of these expectations, LGBT caregivers may be forced either “out” or further “in” the closet. This can compound caregiver stress, impact their family-of-choice relationships, and attenuate potential positive aspects of the caregiving experience.
- Still other LGBT caregivers may be asked to care for an individual who shunned them because of their LGBT orientation and was the perpetrator of years of emotional, physical or other abuse. These caregivers may endure ongoing overt or subtler forms of homophobia from the perpetrator and/or other family members across the course of caregiving.
- Conflicts with employers can also arise, even for “out” LGBT persons, given some people’s assumption that a

primary LGBT partnership or lifelong friend is not a “real” relationship.

- LGBT caregivers frequently encounter or express concerns about homophobia in home health and long-term care settings, reporting that some institutions impede LGBT caregivers’ access to their care recipients or refuse to allow LGBT partners to openly express affection for fear that other patients and caregivers will be uncomfortable.
- LGBT partners may express a heightened sense of stress and vulnerability in conflicts with biological relatives over substitute decision-making, given the limitations of various local, state and federal laws, and particularly when relevant legal documents are not in place.

CONCLUDING COMMENTS

The future of successful service provision for LGBT caregivers and care recipients suggests the need for multiple levels of intervention, from individuals to organizations, communities, and overarching policies. In order to more effectively assist this nation’s diverse population of informal caregivers, today’s emerging LGBT caregiver services focused primarily at the individual or interpersonal levels will need to be merged with tomorrow’s organizational, community and policy-level changes. Moreover, LGBT families, like other segments of society, could benefit from programs and services focused “upstream” in the caregiving process, intervening from a prevention perspective before caregivers find themselves drowning in a sea of caregiving crises. Caregiver programs and services, including those directed at LGBT caregivers, must span multiple settings and life domains, utilize multiple delivery points for intervention messages, deliver interventions through multiple channels, and embed interventions into ongoing community programs and activities (Coon, Ory, & Schulz, 2003; Coon & Zeiss, 2003). Thus, providers and agencies working with LGBT caregivers need to expand their mission beyond solely the individual intervention level, and actively search for new ways to establish successful linkages across intervention levels, from daily practice to national policy. Only by increasing our awareness of the unique issues facing LGBT caregivers and strengthening our professional competence through ongoing education and training can we become effective change agents, ensuring an LGBT identity no longer automatically places LGBT caregivers at risk of receiving incompetent, ineffective or inappropriate services.

Table 1. Multiple Levels of Caregiver Intervention Programs and Services

Level	Examples of Current or Potential Programs and Services
Individual	<ul style="list-style-type: none"> – LGBT-sensitive information and referral for caregivers. – Face-to-face and online support groups for LGBT caregivers. – LGBT caregiver respite weekends.
Interpersonal	<ul style="list-style-type: none"> – LGBT caregiver skill training workshops to provide information and teach caregivers to effectively navigate legal, financial and service delivery barriers. – Caregiver and care recipient education and support groups for LGBT friends and partners.
Organizational	<ul style="list-style-type: none"> – Conduct in-service training for national and local staff of senior and LGBT advocacy agencies on the unique needs of LGBT seniors, care recipients and caregivers. – Pool resources and develop partnerships between LGBT community-based organizations, senior service organizations, health care organizations and AAA's to create more effective pathways of care for LGBT caregivers and their care recipients, such as friendly visitor and respite programs for LGBT caregivers. – Addition of LGBT information on program intake and survey information (particularly important is the identification of opportunities to share such information anonymously). <p style="text-align: right;"><i>continued on next page</i></p>

Continued: Table 1. Multiple Levels of Caregiver Intervention Programs and Services

Level	Examples of Current or Potential Programs and Services
Community	<ul style="list-style-type: none"> – Adopt media and community/service campaigns within the LGBT community to increase LGBT caregiver awareness of available resources. – Support media and community/service campaigns within the professional community to increase provider knowledge of the distinct needs of LGBT community care recipients and caregivers. – Encourage newly forming LGBT retirement communities to incorporate community education, training and support interventions to help inform the entire community about caregiving.
Policy	<ul style="list-style-type: none"> – Increase the recognition of LGBT families through adoption of spousal benefits, disability benefits, retirement benefits for same-sex partners, and elimination of unequal treatment in “Medicaid spend-down.” – Revise the Family and Medical Leave Act to include same-sex partners. – Champion the National Family Caregiver Support Program’s broad definition of “family,” which can help support services for LGBT caregivers and friends and partners providing care to LGBT seniors. – Develop government and private foundation support for needs assessments, caregiver intervention research and demonstration projects targeting the LGBT community. – Require LGBT sensitivity training as part of state and federally supported programs for seniors and their caregivers. – Include sexual orientation in all anti-discrimination policies protecting employment, public housing and the access and delivery of services. – Support the Joint Commission on the Accreditation of Healthcare Organizations’ (JCAHO) addition of respect for “residents’ habits and patterns of living (including lifestyle choices related to sexual orientation)” to the requirements in its accreditation manual for assisted living facilities.

APPENDIX A

Resources and Readings

RESOURCES

Administration on Aging

NFCSP Resource Guide for the Aging Network on the website.
Chapter 8: Designing the NFCSP in the Context of Diverse
Caregiver Populations.

www.aoa.dhhs.gov/carenetwork/nfcsp-resource-guide.html

American Society on Aging

Lesbian and Gay Aging Issues Network (LGAIN)
(415) 974-9600

www.asaging.org/lgain

Outword: Newsletter of the Lesbian and Gay Aging Issues
Network (LGAIN).

Outword Online is a monthly e-mail update designed to bring
members of the American Society on Aging's LGAIN timely
announcements and occasional brief articles relevant to aging
issues for lesbians, gays, bisexuals and transgender folk.

Family Caregiver Alliance

690 Market St., Suite 600
San Francisco, CA 94104

www.caregiver.org

(415) 434-3388 and (800) 445-8106

e-mail: info@caregiver.org

LGBT Caring Community Program and Online Support Group

www.caregiver.org/lgbt-sptgroup.html

Gay and Lesbian Medical Association

459 Fulton Street, Suite 107
San Francisco, CA 94102

(415) 255-4547

www.glma.org

Email: info@glma.org

Gay Men's Health Crisis

The Tisch Building
119 West 24 Street
New York, NY 10011

(212) 367-1000

www.gmhc.org

Gay Yellow Pages

www.gayyellowpages.com

Go to Organizations/Resources: Age-Group and Senior Focus.
Provides a national directory of programs and groups for LGBT older adults.

Lambda Legal Defense Fund

National Headquarters

120 Wall Street, Suite 1500

New York, NY 10005-3904

(212) 809-8585 phone

(212) 809-0055 fax

www.lambdalegal.org

National Association on HIV over Fifty

www.hivoverfifty.org

See Bibliography on Caregiving.

National Center for Lesbian Rights (NCLR)

870 Market St., Suite 570

San Francisco, CA 94102

(415) 392-6257

www.nclrights.org

National Gay and Lesbian Task Force

1325 Massachusetts Ave., NW, Suite 600

Washington, DC 20005-4171

(202) 393-5177

www.ngltf.org

New Leaf Outreach to Elders

(formerly GLOE/Gay & Lesbian Outreach to Elders)

San Francisco, CA

(415) 255-2937

www.newleafservices.org

Old Lesbians Organizing for Change

P.O. Box 980422

Houston, Texas 77098

www.oloc.org

Pride Senior Network

22 W. 23rd St., 5th Floor

New York City, NY 10010

(212) 675-1936

www.pridesenior.org

Senior Action in a Gay Environment

305 Seventh Avenue, 16th Floor

New York City, NY 10001

(212) 741-2247

www.sageusa.org

Senior Pages

www.seniorpages.com

Click on Gay Seniors for a listing of national organizations that support LGBT older adults.

Transgender Aging Network

www.forge-forward.org/TAN

READINGS

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Information Seeking Behaviour, Gay, Lesbian, Bisexual and Transgender Youth. "Transgender-friendly Medical Colleges and Hospitals: a Dream Worth Chasing". The acronym LGBT refers to groups of people who are lesbian, gay, bisexual and transgender, groups historically marginalized, mistreated, ignored by society and the health care delivery systems, including hospice and palliative care services. The purpose of this literature review was to explore the characteristics, history, health and health care disparities, social support systems and legal issues of LGBT persons with a particular focus on older adults, end-of-life care, and ways in which hospice and palliative care organizations can better meet their needs. People who are lesbian, gay, bisexual, or transgender (LGBT) are members of every community. They are diverse, come from all walks of life, and include people of all races and ethnicities, all ages, all socioeconomic statuses, and from all parts of the country. The perspectives and needs of LGBT people should be routinely considered in public health efforts to improve the overall health of every person and eliminate health disparities. More. Learn what CDC is doing to protect the health of LGBT: Spotlight on Hepatitis and Gay/Bisexual Men. LGBT Health Services. Find health services by state an