

**Solidarity and Support:
Lesbians with and without Disabilities as Allies for Each Other**

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This article is an attempt to explore ways in which support and solidarity between lesbians with and without disabilities is impeded and fostered. Special emphasis will be placed on lesbians in human services, especially developmental disability services. While the article speaks about lesbians, I hope that the discussion can be seen as having some application to support and solidarity between gay, bisexual, and transgender people with and without disabilities as well, including the support we can offer to each other (Corbett, 1994). I also hope it will pertain to the many straight people, disabled and nondisabled, who are passionately committed to the idea that all people belong. The focus is on lesbians because that is the culture and identity I know best, and because my attempts to broaden it to all resulted in too great a degree of abstraction - I did not feel comfortable assuming that these points were relevant to men, bisexual women, or transgender people, for example, because I know their cultures less well.

The thoughts and opinions given here are my own, but are based on interviews and workshop discussions about this topic, as well as on data I collected for the study referenced below. I especially want to thank Jo-Ann Armandez-Lefebber, who contributed or expanded upon many of the ideas presented here, the 45-50 participants (mostly but not all lesbians) in a discussion session I facilitated at the 1997 TASHI conference on this topic, and a number of disabled queer people who have shared their perspectives and experiences with me. I myself work at the Center on Human Policy at Syracuse University and am an older, white, nondisabled lesbian parent and family member of people with various disabilities, and have been involved in the self-advocacy movement of people with developmental disabilities since 1975.

One Woman's Story

Several years ago, I wrote a chapter (Shoultz, 1995) based on a qualitative research study of my friend "Lucy Rider,"² a woman with a traumatic brain injury who, because her injury occurred during her late teens, is classifiable as having a developmental disability. Lucy and I met at a 1987 Gay Pride workshop on "Being Gay and Disabled." At the time she was very isolated, living above a sibling's store and getting out only rarely, when friends could take her. Of course, it was very difficult for her to meet and make friends. She was firmly convinced that she was a lesbian, however, and was able to befriend a gay man who was a store customer. It was he who organized the Gay Pride workshop session and made sure that she attended. I got involved because her story touched me and I wanted her to have the opportunity to meet lesbians and be involved in the Syracuse lesbian community.

Much later, after several years of just the two of us going places together and

getting to know each other, Lucy befriended two other lesbians. She asked all of us to help her leave her family and move out on her own, and we did. There were many difficulties, but she now lives in an apartment and has a variety of services coming into her home; some are provided by the developmental disabilities system and some by the home health services system in our county. All of her services at present are funded by Medicaid, a federal program that pays for long term care in the US; because of her developmental disability label she is able to have a richer mix of services than she could otherwise obtain.

That label, however, has also meant that she must continually deal with more than one agency, and with a case manager and workers, many of whom are heterosexual, who have varying attitudes toward her self-identification as lesbian. Her lesbian friends, both within and outside of the primary agency that supports her, are crucially important to her as advocates and support persons, and she is important to us as a friend. That agency is generally a safe place for lesbians and gay men, and some of that agency's lesbian workers have good connections with Lucy and have been able to stay with her through many difficulties. Because that agency has an open climate, many of its heterosexual workers have given admirable support to Lucy as well. Others have had difficulty with what she calls "my lesbian ways," but they no longer work for her.

Why Solidarity and Support?

The issues arising in a consideration of support and solidarity between lesbians with and without disabilities who are also a part of the service system, either as workers or as recipients of services, can be used to illuminate some of the broader issues for the queer community in general. On the face of it, solidarity and support between lesbians with and without disabilities who are involved in various aspects of the service system might seem to be a natural outcome of proximity and mutual understanding, and, as Lucy's story shows, such an outcome can occur. Because lesbians do face discrimination, we have created a lesbian community that purports to provide a safe haven for lesbians (as well as being fun, nurturing, dynamic, conflictual, and so on). That community should be able to welcome and support lesbians with varying disabilities. More than that, the lesbian community needs lesbians with disabilities, just as it needs white lesbians, lesbians of color, young and old lesbians, and lesbians with other identities. Lesbian community is richest when everyone is present, when all voices are heard. This need includes a need for lesbians with extensive support needs.

Lesbians who are very involved in the service system, however, are rarely a part of lesbian community. Lucy's situation is not common. She is publicly out as a lesbian, and is fortunate in that she receives services from an agency that does not discriminate against her for her sexual orientation. Other women with developmental disabilities may be wanting to explore their own sexual orientation or, if certain that they are lesbian, are closeted or silent about it. Many lesbians with disabilities, whether out to the world or relatively closeted, report great difficulty in accessing the lesbian community, and in managing the issues and oppressions arising around both their sexual orientation and their disability (see back issues of *Dykes, Disability, and Stuff*, a newsletter for disabled lesbians, for more descriptions of the difficulties many disabled lesbians encounter). Some of the difficulties arise because of barriers produced by the service system, and others have to do with the lesbian community's

attitudes toward disability, lack of willingness to incorporate social and physical accommodations, and lack of accessibility.

Impedances to Solidarity

Lesbians with disabilities who live with their families or who receive extensive services have many difficulties that lesbians without disabilities do not, for a number of reasons that have much to do with the upside-down structure of most services today. When self-directed services (where a disabled person has an individual service budget that he or she can use as he or she sees fit, with or without the assistance of family and friends) become the norm, many of the barriers listed here may be resolved.

Today, however, many people live in congregate care facilities such as group homes, nursing homes, adult or board-and-care homes, or with members of their family, rather than in homes of their own, and depend on the people with whom they live (or who operate their "home") for their survival. Fear of homophobia in the caregivers they depend on is realistic and extremely inhibiting. Second, even if they live in their own homes, many people have little control over who comes into their homes and their lives if they receive many hours of services each day or week. Third, they have major problems with practical matters such as money, transportation, scheduling, and physical accessibility, making it very difficult to attend lesbian community events. If they use wheelchairs or have mobility impairments, events, meetings, or parties held in private homes may not be accessible. If they have cognitive and/or speech disabilities, they may not feel welcome or may experience difficulty in interacting or communicating with lesbians they meet. Fourth, the sexual interests and capacities of people with extensive support needs are typically denied or discounted by families and by service system workers; the idea that a person might have a nonheterosexual orientation is often not even considered or is viewed as inappropriate. Fifth, the more a person is dependent on others to meet basic survival needs, the greater the likelihood she will fear rejection, attempts to control or correct her sexual expression, and outright punishment if she self-identifies as lesbian.

Conversely, from the point of view of lesbian service system professionals and workers, many considerations may operate to hinder them from providing direct support and solidarity to lesbians with disabilities. For one, lesbian professionals and workers are vulnerable themselves. They may not be out at work - that is, they may not have told co-workers or administrators about their own sexual orientation. If they are out at work, they may still face attitudes and concerns by others about themselves that could inhibit or prevent the provision of support - for example, the worker could be suspected or accused of exerting an undue influence over someone who was exploring a lesbian identity, of "recruiting" the person into the lesbian community (a common stereotype held by straight people is that lesbians actively try to recruit, either through seduction or through influence).

Lesbian professionals and workers may be viewed as projecting their own issues onto the person, or as not having sufficient objectivity about the person; the potential support they could offer, through suggestions and recommendations, could be neutralized. For example, an agency might label a disabled woman's attempts to explore her sexual identity as inappropriate or challenging behavior that needs to be corrected. A powerful culture of domination is often created within agencies, and an individual worker who disagrees with

such a label or with the programs that are instituted as a result may be discounted, silenced, or sanctioned. The worker's fear of such consequences may constrain her from offering valuable guidance to other workers and even from spending much time with the person. Considerations such as these require work at the service system level.

Other inhibiting factors may rise within workers without disabilities. First, in spite of the fact that many lesbian cultural events make sincere attempts to provide accommodations, the lesbian community tends to have ableist attitudes toward disability. Knowing and feeling that, a lesbian without a disability may fear that a show of solidarity - even something as mild as "hanging out" with a person with a disability at lesbian community events - will result in rejection or distancing by her community, a kind of stigma by association.

Second, a lesbian who works with people with disabilities may feel strongly that she needs to bracket her personal life, to create boundaries that will keep people with disabilities at a distance from her private affairs, even if they are lesbian.

Third, she may unconsciously make assumptions that a woman with a disability has little to contribute to a relationship or to the lesbian community, or she may hold stereotyped standards of beauty and the body that do not include women with disabilities. Factors such as these are internal problems within the nondisabled lesbian that need righting - especially because she works with people with disabilities. By looking within, we may find our own ways of acknowledging that these are issues and overcoming the barriers we create as a result.

A fourth level of difficulty - an area where many changes need to be made - is at the level of lesbian community, which reflects the dominant culture's lack of understanding and acceptance of disability. Lesbians with disabilities and lesbians who work in human service professions are among the most likely women to initiate the necessary changes in lesbian community, such as accessibility and attitudinal changes. Women who work together for change in lesbian community can learn about becoming allies and can bring their learnings to the work they do to effect change in human services - assuming there are similarities between dismantling structures of ableism in lesbian community and dismantling structures of homophobia in human service work.

At the TASH conference workshop, one participant said, "We need to unpack the baggage of our (ableist) privilege - only then can we know what solidarity is." She meant that because of the oppression we experience as lesbians, we forget that we have privilege that is not available to lesbians with disabilities. Some of the baggage of our own privilege includes:

- having the power to exclude people with disabilities
- having the choice not to provide accommodation
- being able to avoid the kinds of categorization and stereotyping that are endured by disabled lesbians
- having more opportunity for exposure to and experience with lesbian community culture
- having transportation
- having money
- not having to schedule our leisure time around the schedules of workers, and
- not having to deal with the loss of privacy that occurs when one receives services.

If nondisabled lesbian workers were truly to give up their privilege, or to work to ensure that lesbians with disabilities had the same privilege as they have, they could begin to know what it might mean to stand in solidarity with disabled lesbians.

Issues Related to Family Members

Whether and what to tell our family members is a common issue for lesbians. When lesbians work within developmental disability service systems, however, many more issues arise in regard to family members, because many of the people they serve have family members who are actively involved in their lives. When a person with a developmental disability begins to grapple with sexual identity issues, many questions must arise with regard to family members. Most importantly, the person needs to be in charge of what and how much is shared with her family members - not the agency, and not individual workers or friends. Does she want to come out to them? If she does, does she need support in so doing? Is another lesbian the best person to give that support, or will she be blamed by the parent for her daughter's announcement? How does the agency deal with questions such as these?

This article cannot provide answers to these questions, but they must be dealt with. Parents often have a powerful decision-making role in their daughter's life as guardian or surrogate decision-maker (Thompson & Andrzejewski, 1988). Like other parents, they are likely to have varying degrees of aversion to homosexuality, ranging from mild to ingrained and absolute. Even in those who are accepting of homosexuality in others, parents who hope that their child will be accepted as a part of the broader community may find it hard to hear that their daughter or sister is a lesbian. Strong, overpowering fears that she will be doubly rejected may arise for such parents. As one woman's mother said to her when she came out, "Don't you remember how it felt when the other kids tormented you about your disability? Why would you choose to do that to yourself again?" Thus, we can assume that for a woman with a developmental disability, coming out to her family members will be even more difficult and complex than coming out to family is for a nondisabled lesbian.

Whether or not the disabled woman decides to come out to her parents and other family members, the agency should but too often does not give sensitive thought as to how to meet the woman's needs for emotional and practical support in dealing with her family in regard to her sexual orientation. An agency that has not dealt with sexual orientation in the workplace (either tacitly, by promoting an atmosphere where queer workers can be out at work without fear of reprisal or of being discounted, or directly, by offering inservices on cultural competence in sexual orientation issues) will not be able to provide the kinds of support that are needed by the people it serves.

Toward Solidarity

What can be done to move toward solidarity between disabled and nondisabled lesbians, and in particular between those who are involved in human services? First, communication and trust must be fostered between individuals, as well as in the workplace in general. This can be done through many means: training and inservices (Zuckerman, 1996), example-setting, study circles and/or support groups open to anyone who wants to examine

issues related to sexuality and sexual orientation. An atmosphere where lesbians and gays, whether they are workers or people who receive services, can talk openly about their lives and their relationships, requires the support of straight administrators and co-workers. Indeed, without heterosexual people who are able to be allies to gays and lesbians, little progress will be made within human service agencies toward mutual support between lesbians with and without disabilities. At the same time, as Hingsburger (1996) points out, communication and trust must also include respect for individual privacy; as he says, "without privacy there is no appropriate sexual behavior." Communication must not be sought at the expense of privacy.

Agency policies that effectively inhibit or punish exploration of sexuality and sexual orientation should be examined, perhaps by a committee that is made up of straight and gay workers and service recipients. Examples might include: agency policies on privacy, on confidentiality, on sexuality, on informed consent, on scheduling of workers in the home, on matching of workers to people with disabilities, on communication (including augmented communication), on staff conduct (see Harris, 1997, for an example of how staff conduct codes were a barrier for a gay disabled man needing accompaniment to gay men's spaces and events) and on behavioral support. Hingsburger (1993, 1996) makes specific suggestions for human service workers wanting to offer real support: they can arrange for gays and lesbians with developmental disabilities to meet with religious personnel from gay-friendly churches, provide travel and accommodations so that lovers can date and form relationships, and assist people to find lovers they have lost through moves (from institutions, from group settings in the community, etc.). These suggestions might require agency policy change.

Second, nondisabled lesbians can advocate within the lesbian community for greater accommodation for disabled lesbians. Because of the lesbian community's ableism, many activist disabled lesbians identify most closely with, and get most of their support from, the disability rights community (Appleby, 1991; Panzarino, 1994), where straight and gay disabled people work toward common goals. At ADAPT (Americans Disabled for Attendant Programs Today) rallies and actions, for example, disabled and nondisabled queers are supported and are seen as valuable to the work of attaining passage of legislation establishing a federal self-directed attendant care program - legislation which would undoubtedly make life as a disabled queer better because it would allow choice and control over vital aspects of services that now are too often controlled by others.

The understanding by disabled people, straight and gay, of our issues, does not just exist in organizations like ADAPT. People with developmental disabilities have developed a strong self-advocacy movement that now encompasses local, state or provincial, and national organizations that are linked together. These organizations have various names (People First is perhaps the most common) and are led by men and women with disabilities. In the U.S., the national organization, Self Advocates Becoming Empowered, was formed in 1991. I have been an advisor (advisors are nondisabled helpers for self-advocacy groups and are found in almost all such groups) to their board since it began, and I have come out to the board members. They have been very accepting and supportive of me, including extensions of sympathy and caring during and after a breakup. At one point some years ago one member, learning that I was a lesbian, tried to tell the others that they should get rid of me as an advisor. They responded, "What do you mean? Haven't we learned how wrong it is to

discriminate against someone for who they are?" I know many other lesbian and gay advisors who have had the same kinds of experiences as I have had.

Disabled lesbians have the need to feel as supported by the lesbian community as by the disability rights community, and nondisabled lesbian human services workers can contribute greatly to the making of supportive lesbian community. Much can be done to create a more accessible lesbian community. Workshops on disability at Gay Pride events can be hosted by gays and lesbians with and without disabilities. Physical and environmental accessibility can be made a higher priority in events where currently little thought is given to accessibility. Lesbian and gay counselors can learn more about disability, so that they can respond appropriately to lesbians and gays with disabilities. Gay-friendly churches and businesses can ensure that they are accessible both physically and emotionally to people with disabilities. Some of the advocacy needed to make these changes could be done by human service system workers interested in being allies to disabled gays and lesbians, as well as by disabled people themselves.

Lesbians who work within or receive services from the service system must enter into the ongoing lesbian dialogue on how our community can be made more accessible; we must begin a simultaneous dialogue on how best to support disabled lesbians who are struggling with the systems that are supposed to serve them. As people who identify as queer, whether or not we have disabilities, we have much in common. It behooves all of us to explore the areas in which we can support each other.

Notes

1. TASH's mission is "To eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities." Its members include professionals, parents, and people with disabilities.
2. A pseudonym used in the chapter.

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