

Prospects for Identity Formation for Lesbian, Gay, or Bisexual Persons with Developmental Disabilities

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ABSTRACT *The theoretical and practical constraints of identity formation for lesbian, gay, and bisexual (LGB) persons with developmental disabilities are explored. Firstly, disability and queer theory and conceptions of identification and community are presented. This is followed by a synopsis of some of the common societal myths about disability and about homosexuality. Thirdly, we trace how these myths affect and filter into caregiver attitudes, lesbian and gay communities and communities of persons with disabilities, including developmental disabilities. All these factors conspire to inhibit self-identification as LGB for persons with developmental disabilities. It is further argued that neither disability theorists nor queer theorists have adequately accounted for such complex identities, and that, perhaps, a fusion of disability theory and queer theory may provide a more comprehensive lens to capture these complexities. We conclude with tentative yet practical suggestions to begin to create community for LGB persons with a developmental disability.*

The new challenges that disability advocates now face is to critically reconceptualize disability within a specific and interlocking context that can also account for their experiences of oppression on the basis of race, class, caste, gender and *sexual orientation* [italics added]. (Erevelles, 1996, p. 520)

From the theoretical standpoint of understanding identity formation for a subgroup of lesbian, gay, and bisexual (LGB) persons with developmental disabilities, Erevelles' challenge has particular salience. It will be shown that our most sophisticated theoretical resources fail to adequately represent the identities and communities of these persons. "Homophobia creates many obstacles that may not be visible to

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people who are sensitive only to issues of disability discrimination” (O’Toole, 1996, p. 222). We pinpoint some of the failures of contemporary theories (and indeed practices) of identity, ability and community as these account for the challenge of identity formation of LGB persons with developmental disabilities.

Purpose

The purpose of this article is to provide an overview of both the theoretical and practical issues involved in attaining and maintaining an identity as a LGB person with a developmental disability. In attempting to accomplish this purpose, aspects of three areas will be presented: theory, culture, and community. The first section provides a profile of theoretical conceptualisations of disability and homosexuality. Disability theory provides a framework to understand contextual issues of persons with disabilities. Similarly, “queer” theory furnishes an environment to understand the contextual issues of LGB persons. This is followed by an examination of disability theory as it applies specifically to persons with developmental disabilities. The second section explores cultural myths about disability and homosexuality. We include here definitions of homophobia, heterosexism and heteronormativity.

Attitudes toward homosexuality in caregiver communities, communities of persons with developmental disabilities, and lesbian and gay communities are the focus of the third section. This section closes with an examination of identity management strategies of the few LGB persons with developmental disabilities who have dared to “come-out.” This illustrates both the scope and the limits of both disability theory and queer theory as vehicles to comprehend and to construct possible identity management strategies for these persons. An argument about the need for both theoretical and empirical work capable of understanding and engaging the complexity of identity formation for LGB persons with developmental disabilities concludes this examination.

Disability Theory

Both queer theory and disability theory have relevance in attempting to conceptualise the lives of LGB persons with developmental disabilities. Theories of standpoint or cultural theories are born of experience and place these experiences at the heart of any analysis. Disability theorists almost unanimously frame disability as a collective and social experience rather than an individual or medical one. For example, Oliver (1990) suggests that disability is experienced as forms and degrees of social exclusion, and that these forms vary. Exclusion occurs since able-bodied people tend to characterise the “problem” of disability as residing within an individual. For example, able-bodied persons tend not to attribute disability to ill-suited or inflexible environments. Therefore, little effort is expended to make such environments more inclusive and accessible. In this light, the “causes” of disability derive both from environments that are not built with the foresight to accommodate a range of abilities, and also from assumptions about agency, identity, and community which reflect the world of the fully-able. These assumptions, we argue, are myopic and uninformed in relation to persons with disabilities. The Social

Model of disability, by contrast, situates itself against the kinds of singular and biological accounts of disability (Oliver, 1990, 1992, 1996). More important, disability must be understood as having a material cause. Disability theorists do not ignore economic hardships imposed on persons with disabilities, but rather point to “the inextricable and essential social elements in what is a material base for ideological phenomena” (Abberley, 1987, p. 12; see also Oliver 1990, 1992, 1996).

Disability Theory and Persons with Developmental Disabilities.

Not only are persons with *developmental* disabilities especially disadvantaged economically and thus participate on the periphery of “able-bodied” society, but they also are on the fringes of the larger disability movement. “Even the well-intentioned disabilities movement has not yet reached out to embrace persons with [developmental disabilities] ... as integral members of their counsels, as many persons once labeled ‘mentally retarded’ ... have pointed out with some bitterness” (Dudley, 1997, p. vii). Barb Goode, a self-advocate with a developmental disability from Vancouver, BC, personally recalls such an experience:

A few years ago I was active with DAWN — (Disabled Women’s Network). I think the main reason that I dropped out was because, a lot of people don’t agree with me, but this is the way I feel, a lot of other disabled groups don’t want developmentally handicapped people involved. And they don’t want us involved because they feel that we are not at the same level as them. (Dybwad & Bersani, 1996, p. 45)

Some theorists note that the same is true of disability theory—theories about *disability* are really theories about *physical disability*. “*Disability* becomes, in effect, a synonym for *physical disability* [italics in original] in much of the writing about the disability rights movement. It is as though some writers decide that the way to avoid the difficulty of fitting in severely and profoundly mentally retarded people under the umbrella concept of social construction, is to decide arbitrarily that they are no longer even disabled” (Ferguson, 1990, p. 207, see also Ferguson, 1996). Perhaps, even among disability theorists, persons with developmental disabilities may seem so different that “culture seems beside the point; where physiology has gone so far awry that it threatens to overwhelm the social context” (Ferguson, 1990, p. 207). This lack of theorising occurs despite the fact that “the vicissitudes in the life of the mentally retarded individual result primarily from the status and role assigned him [sic]” (Farber, 1968, cited in Oliver, 1990, p. 15).

Perhaps disability theorists for the large part exclude people with developmental disabilities because they are using a theory that is based on the social model. These theorists tend to posit stable identities (Oliver, 1990). In such positioning, complexities can be lost; complexities of competing identities between and within individuals. Current theorists argue that it is time to problematise the complexities of sexual orientation, gender, race, ethnicity, social class, or even kinds and degrees of disabilities within the context of disability theory (Humphrey, 1999; Vernon, 1999). What is required is a paradigm that accounts for disability in all its different-ness.

Queer Theory

On the other hand, queer theory posits only moments of identity or partial identities. Identities are always becoming and never “just out there.” Identity, accordingly, is complex, and always dynamic, always transforming and changing. In short, identity is not stable either as an ontological or ideological construct. Queer theory is rooted in post-structural critiques of the stable and coherent unitary subject of modernist thinking. Within its terms, any gender is “a drag” (a production; a performance), and so-called deviant sexual identities, such as that of “the lesbian,” are re-read and re-written as identity scripted by culture (Terry, 1991), adorned with artifacts and performed within a dialogical social sphere populated with other performances and characters. Within academic worlds, lesbian and gay studies have embraced, with little or modest critique, post-structural theories of homosexual identity as performance rendered under the umbrella of queer theory (Warner, 1993).

The Material Queer. Morton (1996) makes a distinction helpful to our purpose between experiential and critical understandings of queer theory. He argues that experiential queer theory offers descriptions of “various and emerging cultural groups, and its goal is to give voice to their un- or little-known experience” (p. xvi). For the present purposes, LGB persons with developmental disabilities may be understood as just such a “little-known” cultural group. Critical queer theory “‘moves beyond’ experience and understands the materiality of culture as the historical conditions and the social and economic—the material—structures which in fact produce that ‘experience’” (p. xvi). Morton seeks to premise the language of queer theory with the material theory of Marxism.

Although queer and disability theorists argue that cultural experiences must be understood as having been produced materially, neither has seriously engaged the plight of persons with developmental disabilities as a subject, let alone LGB persons with developmental disabilities. This theoretical reticence occurs despite significant material and social oppression for these LGB people. One factor that contributes to these oppressions is the construction and circulation of myths about disability and homosexuality.

Myths about Disability

Disability theorists and activists have illuminated the ways disability myths both create, and are projected onto, people with disabilities. For example, Shakespeare (1994) argues that “disabled people become ciphers for those feelings, processes ... characteristics [or myths] with which non-disabled society cannot deal. As a result, those negative aspects become cemented to disabled people” (p. 287) (see also Shakespeare & Watson, 1997). Morris (1991) makes a similar point:

Our disability frightens people ... so we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their

fear and discomfort by turning us into objects of pity comforting themselves by their own kindness and generosity. (p. 192)

Illustrative of the impacts of the myths of disability on issues of identity for persons with disabilities, two prevalent and interrelated myths will be discussed here: the myth of bodily perfection and the myth of asexuality.

Myths of Bodily Perfection. Stone (1995) defines this myth as “the myth that holds that we can and should strive to achieve perfect bodies” (p. 413). Wendell (1996) suggests in every cultural context there is an “ideal body,” although the particular form of that ideal changes through time. Some feminist disability theorists, such as Lloyd (1992), Morris (1991, 1992), and Stone (1995) point out that, at this time, there is an overwhelming barrage of idealised body images. People with and without disabilities are encouraged to compare themselves to these generally unattainable cultural ideals. For persons with disabilities, the work of passing in relation to this idealised appearance norm is even more difficult than it is for persons without disabilities. The work of passing is relentless and, as Wendell (1996) and other feminists have argued, passing objectifies the body. In fact, arduous passing can also serve to distance oneself from one’s own body.

The Myth of Asexuality. The myth of bodily perfection renders abject the disabled body. This is also related to what O’Toole (1996) and O’Toole and Bregante (1992) refer to as “the presumption of asexuality.” This prevalent misconception stretches across almost any particular disability (Appleby 1994; Corbett, 1994; Lloyd, 1992; Luczak, 1993; Tremain, 1996). “Amongst anti-ableist writers and activists, there is a consensus that non-disabled persons generally regard disabled persons as asexual beings” (Tremain, 1996, p. 15). Therefore, “much of the writing by disabled women [and men] attempts to invalidate this stereotype” (O’Toole, 1996, p. 223). O’Toole and Bregante (1992) discuss the lack of any socially sanctioned roles for persons with disabilities in society such that “there can be no room for [roles of] active, and sexual disabled women [and men]” (p. 165). Therefore, same-sex (able-bodied) life partners of persons with disabilities are most often assumed to be paid caregivers (O’Toole, 1996; Tremain, 1996). Nondisabled families often question the able-bodied person’s choice of partner, especially if the relationship is long lasting (see K. Thompson & Andrzejewski, 1988). Further, persons with disabilities report they rarely are asked about their sexual needs by health care workers, even by those workers with whom they are in daily contact (O’Toole, 1996).

Myths about Homosexuality

Just as there are myths about the disabled, so too there are many myths about persons who are LGB. For example, McAllan and Ditillo (1994) speak, as have many researchers/activists, of the need to be aware of the power of myths about LGB people, myths such as: “gay men want to be women and lesbians want to be men;” “gays recruit straights through intimidation;” and “if you talk about gays to young

people, they will become gay” (p. 27). In terms of the prevalence and impacts of myths on the formation of personal and social identities, persons identifying as LGB have had to endure similar kinds of prejudices, as do persons with disabilities. In this regard it is probably reasonable to assume that LGB persons with developmental disabilities are doubly disadvantaged, or experience simultaneous oppressions. The medical system has historically attempted to eradicate homosexuality; the legal system is in many ways biased against LGB persons (see K. Thompson & Andrzejewski, 1988); and educational systems have ignored the plight of young LGB persons. Teachers are reluctant to come-out to students (Rensenbrink, 1996) not only because of the myth that homosexuality is contagious, but also because of very real threats for some of job loss and other forms of discrimination and recrimination. As a result of being ignored by both straight and LGB communities, young LGB persons are committing suicide at alarming rates (Gibson, 1989). All these factors conspire to diminish opportunities for LGB identity formation in persons who are apparently not disabled and doubtless further diminish such opportunities for persons with developmental disabilities.

Myths about (or Presumptions of) Heterosexuality

We present the concepts of homophobia, heterosexism, and heteronormativity here, because each represents a different way of describing how heterosexual privilege operates or, stated in another way, the myths of how heterosexuality is presumed better than homosexuality. Sears (1992) describes homophobia as “an irrational fear of homosexual persons ... [including] the internalization of negative feelings by homosexual men and women” (p. 38). Neisen (1990) describes heterosexism as “a form of oppression incorporating a belief in the inherent superiority of one form of loving over all others. The belief then is used to justify dominating those who do not subscribe to the privileged practice. [It] is the continual promotion by major social institutions of heterosexuality and the simultaneous subordination of all other lifestyles (that is gay, lesbian, and bisexual)” (p. 36). Hodges (1998), after Warner (1993), describes heteronormativity as “a word which is used to bring together, and make explicit the embedded assumptions of heterosexuality in the socially constructed relations of what constitutes ‘normal;’ to make visible what underwrites the practical ‘everyday’ assumptions about what is ‘always-already’ assumed about ‘being normal’” (p. 272). Because of the myth of bodily perfection, the myth of disability as asexuality, the myths about persons who are LGB, and because of homophobia, heterosexism, and heteronormativity, crafting an identity as a LGB person with a disability is profoundly difficult (Shakespeare, Gillespie-Sells, & Davies, 1996)—in some cases even dangerous, as we shall soon see.

Control Issues: The Case of Sharon Kowalski

The plight of Sharon Kowalski and her partner, Karen Thompson (K. Thompson, 1992; K. Thompson & Andrzejewski, 1988) represents, perhaps, the most salient example of a situation where disability advocates and LGB advocates campaigned

on the same issue. In November 1983 while traveling by car to Nashwauk, Minnesota, a drunken driver hit Sharon Kowalski. Sharon suffered a significant brain injury, and consequently was in a coma for many months. Karen Thompson, Sharon's partner, spent what appeared to be inordinate amounts of time at the hospital, since she was "just a friend of Sharon's." Eventually, Karen could not bear the strain of secrecy, and in the interest of Sharon's recovery, she came out to her own family and then to Sharon's parents, Donald and Della Kowalski. The Kowalski's reaction was seriously homophobic, and relations between the Kowalskis and Thompson became extremely laboured. Donald Kowalski was awarded legal guardianship of his daughter with the only concession being that equal access was granted to Karen to see all medical records and equal visitation time.

Karen, in collaboration with the Minnesota Civil Liberties Union, various lawyers and the St. Cloud Handicap Services Association, began a long and arduous battle to become Sharon's legal guardian. When legal recourse failed at various junctures, Karen began to go public. She appeared on several nationally syndicated talk shows, and began making speeches to LGB persons and disabled persons in New York and California. During this time, disability activists visited Sharon, giving her support for her relationship with Karen. At the same time, the lesbian and gay movement organised fund-raisers for the legal costs. This grass roots organising between disability and LGB activists culminated in the "National Committee to Free Sharon Kowalski". In the end, Sharon returned home with her partner, Karen.

Community and Identity for LGB Persons with Developmental Disabilities

Communities of Service for Persons with Developmental Disabilities

The case of Sharon Kowalski illustrates two of the persistent myths introduced at the beginning of this article: (a) that disability implies asexuality; and, (b) that if there is sexuality, it is heterosexual. These myths reinforce each other and inhibit non-heterosexual expressions/identities for persons with disabilities in general. Somewhat ironically, another myth which seems to be notably tagged to persons with developmental disabilities in particular is that they are over-sexed, that their sexuality may go out of control at any moment (see Brown, 1994; Hingsburger, 1990, 1993; Kempton & Kahn, 1991; Williams, 1991). From this perspective, sexuality has to be restrained, contained, and bordered. Service providers fluctuate between these two contradictory identities, non-sexual vs heterosexual, and no sexual desire vs uncontrollable sexual desire, to the detriment of the cared-for. Brown (1994), for example, argues that services for persons with developmental disabilities police, limit and survey their recipients' behaviours and attitudes. "An analysis of the discourse about people with [developmental] disabilities shows that one implicit role of services is the regulation of sexuality and the creation of sexual boundaries" (p. 123).

Scotti, Slack, Bowman, and Morris (1996) and Scotti, Ujcich et al. (1996) explored the sexual "toleration boundaries" afforded to persons with developmental

disabilities. The researchers found that caregivers seem to tolerate masturbation the most; followed by heterosexual petting and kissing; then heterosexual oral sex; heterosexual intercourse; and finally, lumped into a queer confine, *anything* homosexual in nature (Scotti, Slack et al., 1996). This toleration continuum from least to most explicit sexual behaviour breaks down, surprisingly, for *any* same-sex behaviour. Furthermore, “other sexual behaviors, including same-gender activity, and risky sexual activities (including anal intercourse and intercourse without using condoms) were viewed as unacceptable” (p. 260). Notice how “risky sexual activities” are conflated with “*any* same gender activity.”

Hingsburger (1993) traces the evolution of caregiver attitudes towards same-sex behaviour of persons with developmental disabilities. This evolution makes things even more explicitly queer. In the not so distant past, when institutional-living was practically the only residential option for persons with developmental disabilities, same-sex behaviour, although publicly renounced by caregivers, was tolerated in private. Hingsburger found paradoxical caregiver attitudes for heterosexual behaviour. Publicly, caregivers tended to approve of opposite-sex activities, but privately restricted them. Recently, these “twists of mates” have not been viewed in the same ways. Specifically, heterosexuality is now both privately and publicly sanctioned more than any private or public display of homosexuality. Heyman and Huckle (1995) have pointed out that some service providers may feel directly responsible for the consequences of the sexual behaviours of the persons with disabilities in their care. In the past, caregivers were concerned about pregnancy (heterosexual behaviour), but perhaps are presently more concerned with AIDS and other sexually transmitted diseases (which, for some caregivers, may be conflated with same-sex behaviour).

Persons with Developmental Disabilities: Attitudes toward Same-Sex Behaviour and LGB People

Not surprisingly, persons with developmental disabilities have internalised some of these negative attitudes about homosexuality. McCabe and Schreck (1992) conducted a literature review on the sexual knowledge, experience, feelings and needs of persons with developmental disabilities before sex education. In that review participants reported ambivalent feelings about sexuality and definite negative attitudes towards homosexuality. “Thirty-seven percent of respondents [with developmental disabilities] regarded masturbation as wrong; 31% viewed heterosexual intercourse as wrong; 86% indicated that homosexuality was wrong ... The strongest taboo was on homosexual behavior” (McCabe & Schreck, p. 77) (see also Lunsy & Konstantareas, 1998; McCabe, 1993; McCabe & Cummins, 1996; Whitehouse & McCabe, 1997). Angrosino (1992, 1997) conducted an ethnographic study in a residential care centre in the US and, not unexpectedly, found that persons with developmental disabilities “do not admit to an awareness of the many choices involved in adult sexuality; they scoff at the possibility of consensual homosexuality” (Angrosino, 1997, p. 107).

Lesbian, Gay, and Bisexual Communities

If LGB persons with developmental disabilities are not provided with supportive education for sexual identity formation, what resources are provided for them in their own communities? Sadly, the answer turns out to be not very much at all (Harris, 1997; Shakespeare et al., 1996). The preceding section discussed potential impediments for people with developmental disabilities to identify as LGB. Ableism, as has been shown, operates within the larger disability movement to impede the participation of those with developmental disabilities, and ableism is manifested too, within the larger LGB communities. It has become increasingly clear that in, among, and between the LGB communities, the naive notion of solidarity has been discarded (see e.g., Weeks, 1995). Far from being communities that “celebrate diversity,” these communities are rife with power differentials as noted in the gay male community (Ridge, Minichiello, & Plummer, 1997, p. 168).

Men with developmental disabilities, often without much social or financial leverage, are at the bottom of the gay pecking order (Ridge et al., 1997). Further, aspects of the gay male community worship the “body beautiful,” and stigmatise any “deformities” (Corbett, 1994, p. 345). In lesbian communities, persons with disabilities seem to fare better, but are often not fully embraced. A participant in Appleby’s (1994) study noted that acceptance and accommodation in the lesbian community are two entirely different issues. In short, ableism defines and limits participation and identity within the LGB communities, as it does in the larger society. To say it another way, LGB persons with disabilities must contend with simultaneous oppressions, heterosexism and ableism.

Identity Management of LGB Persons with Developmental Disabilities

Given the ideology of disability as asexuality at best, and rampant, uncontrolled heterosexuality at worst, and given how a range of destructive myths filter into the communities of persons with developmental disabilities through anti-sexist/heterosexist caregiver attitudes, biased sex education curricula, and LGB communities unwelcoming to the disabled, it is to be expected that any discussion of LGB identities of persons with developmental disabilities are extremely rare in the literature. Some limited discussions, however, are found in sex education curricula (Hingsburger, 1990, 1993; Kempton, 1988; Monat-Haller, 1992), in AIDS prevention material (McCarthy & Thompson, 1994; D. Thompson, 1994), in disability newsletters (see Harris, 1997), in qualitative research studies (Edgerton, 1967, 1993), and in contemporary anthologies (Hingsburger, 1999; Shoultz, 1995). Identity management for LGB persons with developmental disabilities, therefore, is a constant struggle for affirmation. Edgerton (1993) notes the family’s rejection of the only openly gay man in his study. Shoultz (1995) describes how Lucy Rider’s identity, a lesbian with a developmental disability, was controlled by her family, her church associations, and medical staff. Lucy has fought persistently “to be” a lesbian:

... when she came out to her family, they told her, “You *can’t* [italics in

original] be a lesbian!" This was her first exposure to the label that refers to her sexual preference for women. Over the years and through many arguments, she was insistent about who she was, and she believes that her family has come to accept what she calls "My lesbian ways." (p. 161)

Other persons with developmental disabilities are either not aware of LGB communities/identities or only know of the stigma attached to them. Therefore, some persons with developmental disabilities engage in same-sex activities, but do not identify as LGB (D. Thompson, 1994).

Conclusion

What kind of reading would a fusion of materialist queer/disability theory permit of the identity management strategies of LGB persons with developmental disabilities? How would queer/disability theory represent LGB persons with developmental disabilities as its subjects? Probably the most significant critique of queer theory for our purpose here concerns the political ambiguity of the project of queer theory, as well as its (ironic, and) strong tendency to abandon the material world in favour of a currency of representations and discourse. And so it is of particular interest to look at the possibilities for agency available to LGB persons with developmental disabilities as represented through such a queer/disabled lens. Brodribb (1992) elucidates the need for community in order to express one's sexuality:

Postmodernist theories of sexuality increasingly speak of texts without contexts, genders without sexes, and sex without politics. These theories of gender and "sexualities" [italics in original] (Derrida: 1978a, p. 129) construct psychoanalysed bodies without sexes. Yet power is based on sex, not gender. Without reference to sexual politics, theories of sexuality are ideological and metaphysical. *What we need to freely express ourselves sexually is a realization of community* [italics added]. (p. 143)

In this article, we have elucidated the need for better support, better understandings, better theories and practices, if LGB persons with developmental disabilities are to be enabled to forge and to maintain identities with which their desires are a ground of pleasure and affection, not merely further pathologisation. We have tried to show the necessity, in realising such a goal, of the possibility of participating in a community of practice. The question, and our collective challenge, is simply thus: How does one build community for LGB persons with developmental disabilities?

In closing, our wish is not to create an exhaustive list of activities to be completed towards the accomplishment of this goal, but to make tentative suggestions as possible starting points. First, we need to sensitise social service workers for people with disabilities to issues of homophobia and heterosexism. Similarly, we need to sensitise support professionals who deal with queer persons in issues pertaining to disability. In order to achieve this, a commitment from professionals to see beyond their often-limited mandates or service provision criteria is required. As an adjunct to this, professionals need to examine and work around their own biases with respect

to homosexuality and disability. Second, we need to create safe-spaces, such as support groups, for LGB people with developmental disabilities. These groups would allow people to process their experiences, know that they are not alone, and access information concretely. Third, as activists and political agents, we need to recognise oppressions in all its forms and resist it, wherever we encounter it—even in the queer movement or the disability movement. Finally, and most importantly, we need to really listen to what LGB people with developmental disabilities are saying. Listening will give us the greatest guidance of all in helping to build community.

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