

Disability and Sexuality: Toward a Focus on Sexual Access

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Introduction to the Symposium

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Three recent conferences mark the coming of age of a mature disability and sexuality studies discipline: Disability, Culture and Sexuality: Experiential and Societal Perspectives, 2000, San Francisco State University; Gender and Disability Studies, 2001, Rutgers, New Jersey; and Queer and Disabled, San Francisco State University, 2002. The papers presented within these conferences reveal an increasingly political framing of research issues in disability and sexuality from the both academic and advocacy communities (see Mona and Shuttleworth, 2000; Shuttleworth and Mona, 2000; Hutchinson and Smith, in-press). However, despite this recent critical scholarship, the editors feel that the sexual lives of disabled individuals still remain veiled at various levels. Multidisciplinary research focusing upon disability and sexuality has addressed issues around gender, sexual identity, sexual orientation, and sexual behavior, yet less attention has been paid to "sexual access" for members of the disability community.¹ While advocacy efforts and policy development within the disability community have focused on broad ideas of universal access, equal access to sexual relationships and sexual activity have often been excluded in these endeavors.

Historically, within the disability community, the issue of disability and sexuality has been framed in medicalized, apolitical, and individualist terms. This individualizing focus has tended to draw attention away from the socio-structural relations between disabled and non-disabled people, the symbolic meanings of disability and desirability in the larger culture, and the psychological implications of experiencing multiple barriers to sexual expression and establishing sexual relationships. This individualized, apolitical and uncritical emphasis was inadvertently reinforced by the Disability Rights Movement which

understandably focused its energy on issues that were more amenable to social change such as environmental access, employment, etc. (Shakespeare, Gillespie-Sells and Davies, 1996). With this in mind, as academics, advocates, community members, and those who identify under many of these roles, we are charged with beginning research agendas that incorporate broader conceptualizations of disability and sexuality.

Obstacles interfering with access to sexual expression and sexual relationships are often quite similar to those barriers faced in attempting to integrate into the majority society at symbolic, economic, social, architectural, psychological, and interpersonal levels. That is, attitudinal constraints, lack of monetary and/or programmatic access to personal assistance services, physical barriers, and communication issues and transportation difficulties can all contribute towards the prevention of full expression of sexuality. Unique to sexuality, however, are the cultural meanings of sexual attractiveness and desirability, which often combine with other barriers to compound the problem of sexual access for disabled people. Thus, we question the degree to which disabled people have been able to negotiate both logistical and sociocultural factors in their pursuit of satisfying sexual expression. We are also puzzled by the lack of attention to sexual access among disability scholars who have researched and advocated for the civil rights of people with disabilities for many years.

By sexual access we do not mean access to physical intimacy per se. Rather, we mean access to the psychological, social and cultural contexts and supports that acknowledge, nurture and promote sexuality in general or disabled people's sexuality specifically. For example, one area of cultural support for disabled peoples' sexuality might be a more positive sexual representation of disabled people in film and other media which for disabled individuals might result in a positive identification and heightened sexual self-esteem psychologically. Further, this more positive sexual representation of disabled people might also result in many non-disabled people perceiving them in a more sexual light. In this example, access to cultural, social and psychological supports synergistically improve the possibilities for sexual expression and negotiating sexual relationship for disabled people. Sorting out all the complex interrelations between these different dimensions of access and exclusion should be one of the primary jobs of disability and sexuality researchers.

Barbara Waxman-Fiduccia, known as the mother of the disability and sexuality advocacy movement, did not shy away from confronting the difficult disability and sexuality issues in all their complexity. In the late 1980s and early 1990s, she published a number of short papers calling for the politicization of sexuality in the Disability Rights Movement (see for example Waxman and Finger, 1989; Waxman, 1994), and she also published brilliant analyses on related topics such as violence against disabled people which included an analysis

of sexual abuse (Waxman, 1991). With her passing in April 2001, we are calling for a renewed effort to engage not only on a political level, but to especially focus on the issue of sexual access. Harlan Hahn's (1981) early call for more study of the social component of disability and sexuality implied the notion of sexual access, but his call has only been intermittently taken up. It is as if disability and sexuality researchers do not want to do the empirical work necessary to substantiate their claims that disabled people are often viewed as asexual by the larger society and that multiple barriers exist to frustrate their sexual expression and development of sexual relationships. We, of course, do not want to be seen as doom and gloom disability researchers. As Shakespeare et al. (1996) emphasize, disabled people are also realizing successes in the area of love and sex. Acknowledging this fact, however, we feel that by focusing on the issue of access we are initiating discussion about inclusion, exclusion, and satisfaction of this very important life domain. Given that "disability life" is influenced continually by a variety of internal and external forces, we must thoroughly explore factors affecting sexual access before we can begin to make sense of this complex phenomenon.

Based upon these ideas and the editors continuing dialogue on sexual access for disabled people, a search for a deeper understanding of sexual policy and rights for people with disabilities was sought for this issue of DSQ. We envisioned this special sexuality issue of DSQ as a first step in rectifying neglect of the problem of sexual access. A group of papers were solicited that interrogated the multiple kinds of access issues related to sexual expression and to negotiating sexual relationships for disabled people. We sought scholarship that discussed disabled people's resistance to the myth of asexuality, their sexual access problems and strategies and also their successes in love. We also wanted to include research and writing on difficult topics such as facilitated sex, sexual surrogacy, sex work and the access opportunities of those disabled people residing in institutions and more structured living environments. We presented some example questions that we thought might provide good starting points for scholars reflection and lead to the writing of challenging papers: 1) What are the policy changes required that will enable all disabled people access to their sexual rights? 2) Are there perils in losing credibility within the disability civil rights movement if arguments for sexual rights is on a broader agenda? 3) How are people with disabilities engaging in sexual expression and establishing sexual relationships given the potential obstacles faced at both meta and micro levels? We are happy to report that we must have "hit a chord" because the majority of papers submitted critically engaged with the theme of sexual access for disabled people and posed similar kinds of questions as the basis of their papers. In addition, we received and are including a select number of poems and personal writings that highlight the sexual access theme and are expressed from a

more direct, experiential perspective.

The Contributions

The collection of writings presented within this issue represent a wide range of sexual access across disability issues. We are pleased that the perspectives of these manuscripts encompass individual, societal, cultural, and political views and address sexual access and disability directly, scholarly, and poignantly. Below we offer a brief glimpse into this important edition of DSQ and hope that these writings provoke additional thinking, research, and writings on sexual access and disability.

Holly Wade's paper is a significant contribution to the disability and sexuality literature which focuses on access concerns. She presents a cultural indictment of the widespread discrimination and exclusion of people with "intellectual disabilities" (who may or may not experience a sensory or physical disability) from access to sexuality education and sexual expression. She sets the context for a discussion of some of the conflicts that pervade this issue by providing an important history of legislation, policy and services related to the sexuality of these disabled people. One of the many conflicts that she highlights is that between protection of those perceived as "vulnerable" and their rights to sexual expression. Protection has so far outweighed sexual rights in this equation. Wade suggests the development of a new policy that "reflects the needs of all constituencies." Further suggestions aimed at rectifying the many conflicts that contribute to excluding this population from sexual expression and relationships are the need for a comprehensive sexuality education program, the development of policies that enable the accurate and individualized assessment of competency and consent, and policies that foster the self-determination of people with "intellectual disabilities."

The piece written by Susan Fitzmaurice provides real life data on the sexual development of her developmentally disabled child. This author, a well-known disability advocate, provides her account of the obstacles and successes faced when attempting to raise a sexually healthy child with Down Syndrome. This article offers great insight into the sexual access issues faced by parents of children with developmental disabilities and in turn relays tangible child rearing information useful to both community members and service providers working with people with developmental disabilities.

Carol Hamilton's paper provides significant empirical support for Wade's major points, albeit her research was conducted in New Zealand. She interviewed two support workers on the access issues for "intellectually disabled" people. While her sample may be small, the examples from these workers' practice demonstrate a range of sexual access issues that those with "intellectual disabilities" can experience. Working from these interviews, her analysis shows that people with "intellectual disabilities" confront multiple barriers to

their sexual expression, and that sexual expression only becomes a possibility for those persons who are articulate enough and doggedly persistent in their quest. Hamilton emphasizes, however, that there is absolutely no guarantee that even if someone is articulate, persistent and comprehends the difference between appropriate and inappropriate places for sexual expression that they will be provided access to such places and the necessary support to express themselves sexually. She concludes her paper by asking, what would an "ordinary sexual life" look like for "intellectually disabled" people if there were explicit acknowledgement and working through of the emotional, social, cultural and physical interconnections experienced by the individual, the family, the support organization and the wider community.

Karen Shue and Ana Flores discuss the unique sexual access issues faced by a woman with a brain injury living in a structured living facility. These authors discuss the broad issues of sexual rights within a structured facility, opportunities for sexual decision making when family members have power to override personal decisions, legal competency, personal assistance for sexual expression, and the personal struggles for sexual fulfillment articulated by the disabled woman herself. Wider issues are brought to life by specific examples and quotations of the individuals involved in this case. This article edges the reader towards sexual access issues on multiple levels and calls for additional research and education needed to expand ideas of sexuality among persons with brain injury.

Lawrence Shapiro presents a clear and well-argued opinion piece on the situation regarding the use of sexual surrogates by disabled people in the Canadian province of Ontario. He argues convincingly that disabled people should have the cost of sexual surrogates incorporated into their government-sponsored personalized funding program. This would provide a significant degree of access to those who may need this important service.

Corbett O'Toole's paper is a provocative and complex treatment of the barriers to sexuality for disabled mothers. She provides an overview of the sociocultural and sexual situation of disabled mothers in the United States and notes the lack of research on the topic. She also examines in detail cultural assumptions about sexuality, motherhood and disability and the many barriers to having a sex life for disabled mothers. Along the way, she makes several important suggestions to increase access to sexuality for disabled mothers and for social science research on this important topic. For example, in terms of the latter, O'Toole suggests that instead of focusing on the problems of disabled motherhood, researchers need to begin exploring the resilience and problem solving that disabled mothers can often demonstrate.

David Howard and Mary Young provide an important understanding of how leisure is a major factor in setting the context for the negotiation of sexual relationships in general

and how there are often many barriers for disabled people to access leisure. The authors provide detailed definitions of leisure related terminology, historical perspectives on leisure, a discussion of the discipline of recreation therapy and the impact of leisure on disability and sexuality. Theirs is a call to focus on the under researched link between access to leisure experiences and access to sexual experiences for disabled people.

An analysis of representations of disability and sexuality within art is given in Ronda Gowland's paper. She provides a historic context for exploring disability and sexuality visual imagery through the Social Model of Disability and then proceeds with showcasing the ways in which three different artists have used traditionally stereotypical images to challenge notions of attractiveness and desirability. This paper confronts sexual access from artistic, political, and societal levels and reminds the reader of the importance of visual imagery in conceptualizing issues related to disability, sexuality, and power.

Disability, sexual fantasy, and desire are examined by Kath Duncan and Gerard Goggin within their exploration of a 1998 Australian TV documentary entitled *My One-Legged Dream Lover*. This documentary highlights Kath Duncan's excursions into the world of amputee fetish and includes discussion of the often controversial topic of devoteeism within the disability community. The manuscript is provocative in its content and presentation and offers an important view of disability sexual access issues in terms of challenging traditional notions of sexuality, desire, and "appropriateness" within the disability community.

In his paper, Leslie Harris provides a semiotic understanding of representations of disability and sexuality in film. He first presents a brief and very clear lesson in aspects of semiotic analysis using disability imagery. Then he examines several films aimed at the larger film going public that involve disabled characters and also adult videos specifically produced for the devotee market. While he shows that there are sometimes both negative and positive portrayals of sex involving disabled characters in film and video, even when disabled characters are portrayed in a sexually positive light, negative representations are apt to creep in and undermine any positive meanings. The predominance of negative imagery of disability and sexuality in the media cannot help but adversely impacts public perceptions and thus likely also influences disabled people's access to sexually meaningful relationships.

Our symposium concludes with a set of writings that reflect sexual access from personal perspectives and serves to "bring home" the ideas put forth in the manuscripts discussed above. Mitch Tepper's movie review of Flavia Fontes' "Forbidden Wedding" provides a critique of a recent film depicting disability and sexuality themes. This review reminds us of the information highlighted in Leslie Harris' paper and

reminds us of the importance of visual representations of disability and sexuality in the media. Lorre Leon Mendelson's poem entitled "Voices" is a powerful piece giving voice to the difficulties and potential strategies apparent within the sexual relationships of people with psychiatric disabilities. Similarly, Scott Snedecor's brief personal reflection on the search for intimacy and romantic relationships while living with psychiatric disability exhibits the intense yearning to establish a romantically meaningful relationship. We conclude with a piece by Katie Ball that summarizes her life journey in accessing sexual relationships and her sexual self-identity as a disabled woman. This piece provides "life" to many of the social, political, and personal arguments made within this volume and reminds the reader of the importance of searching for yet a deeper understanding of sexual rights and sexual expression among the disability community.

Notes

1. While research such as that conducted by Shakespeare, Gillespie-Sells and Davies (1996) does include attention to barriers to sexual access, this focus is still too rare in disability and sexuality studies. A forthcoming paper by one of the editors (Shuttleworth, forthcoming) argues that the constructionist trend in human sexuality studies as a whole has also not interrogated the problem of sexual access/exclusion for minority members of societies (most notably disabled people) choosing to empirically and theoretically focus on oppression in relation to sexual identity and gender identity (and to some extent the development of sexual subjectivity). These are important scholarly and research topics and are assisting feminist and gay and lesbian activists in their struggles for human and sexual rights and societal access in general; however, a primary sexual issue for most disabled people who are more than mildly impaired is sexual access. The editors would like to see more research, especially constructionist research, which focuses on the problem of access/exclusion to sexual contexts for disabled persons who identify with the diversity of sexual and gender orientations (i.e. gay, lesbian, bisexual, transgender, heterosexual) taking into consideration of course any identity issues that are relevant.

References

Hahn, H. (1981). The Social Component of Sexuality and Disability: Some Problems and Proposals. *Sexuality and Disability* 4: 220-233.

Hutchinson, B. and Smith, B. (In-Press). *Gender and Disability Studies*. New Jersey: Rutgers University Press.

Mona, L., and Shuttleworth, R. (Guest Editors), (2000). Introduction: Special Conference Issue 1. *Sexuality and Disability* 18(3): 155-158.

Shuttleworth, R. (forthcoming). Toward a Constructionist Approach to Disability and Sexuality and the Inclusion of Disabled People in the Sexual Right's Movement. In *Sexuality Inequalities: Case Studies From The Field*. Niels F. Teunis, Editor. New York: Columbia University Press.

Shuttleworth, R., and Mona, L. (Guest Editors), (2000). Introduction: Special Conference Issue 2. *Sexuality and Disability* 18(4): 229-231.

Shakespeare, Tom, Gillespie-Sells, Kath, and Dominic Davies (1996). *The Sexual Politics of Disability: Untold Desires*. New York: Cassell.

Waxman, B. F. (1991). Hatred: The Unacknowledged Dimension in Violence Against Disabled People. *Sexuality and Disability*, 9(3): 185-199.

Waxman, Barbara (1994). It's Time to Politicize Our Sexual Oppression. In *The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag*. Barrett Shaw, ed., pp. 82-87. Louisville: The Avocado Press.

Waxman, Barbara, and Anne Finger (1989). The Politics of Sex and Disability. *Disability Studies Quarterly* 9(3): 1-5.