# THE CASE FOR A FOCUS ON SEXUAL ACCESS IN A CRITICAL APPROACH TO DISABILITY AND SEXUALITY RESEARCH

Paper Presented at the 1<sup>st</sup> Annual Disability Studies Association Conference Lancaster, England, Sept. 2003

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# INTRODUCTION

Today, I want to argue for the use of a heuristic concept of access to address issues of disabled people's sexuality. Accessibility is one of the cornerstone concepts of the Disability Rights Movement and its academic offshoot disability studies. As Gold states, "The distinction between accessible, archetypical environments and those which are not, is central to the social model of disability, in which the lived experience of disability mirrors the accommodation of the disabled to everyday environments." (forthcoming). Yet this cornerstone concept has been minimally applied to disabled people's sexuality. Speaking more generally, Shakespeare, Gillespie-Sells and Davies assert, disability studies research, "has failed to problematize sex and relationships" (1996: 6). Despite increased attention to sexuality by disability studies scholars and researchers since the publication of Shakespeare, Gillespie-Sells and Davies' landmark book, The Sexual Politics of Disability, which has begun applying a critical lens to a range of sexual issues (see for example Block 2000, Tepper, 2000; Mona and Gardos 2000; Shakespeare, 2003; Wade, 2002; Hamilton, 2002; Wilkerson, 2002; McRuer and Wilkerson, 2003), the concept of access has not yet been rigorously utilized to interrogate disabled people's sexual issues. Constructionist sexuality studies has likewise not perceived the utility of this notion for its research on the sexuality of oppressed minority populations. I believe that focusing on sexual access for disabled people can assist in politicizing what has until recently been viewed as a personal issue. In this paper, I first offer a critique of disability studies and sexuality studies and their poor record of focusing on sexual access. After providing a more complex understanding of sexual access with the goal of increasing its heuristic power, I then show this concept's usefulness by applying it to several research issues.

# LIMITATIONS OF PREVIOUS RESEARCH

Until recently, the Disability Rights Movement and disability studies tended to focus on what they saw as more immediately pressing concerns such as architectural access, economic barriers and access to employment opportunities (Shakespeare, Gillespie-Sells and Davies, 1996; Shuttleworth, 2000a, 2000b). However, in the U.S. during the late 1970s and early 1980s, there was a brief time when disability and sexuality was in vogue. In fact, there was a disability and sexuality unit at the University of California, San Francisco, which incorporated a social understanding of disability and sexuality issues (Jacobsen, 2000). While some of this work criticized the asexual social attitudes and cultural prejudices directed toward disabled people and focused on educating professionals who worked with them, a politically charged critique was never a sustained practice. And when the money dried up, in the early Reagan years, this unit had to close up shop.

In the mid-1980s through the mid-90s, there were a few lone voices in disability studies that advocated for focusing a critical and political lens on disability and sexuality issues. In the U.S., I am thinking of people like Barbara Waxman (1994; also see Waxman and Finger, 1989), Harlan Hahn (1981; 1989)

and Carol Gill (1989). These scholars and others railed against the dominance of medical model research and the lack of social and political analysis of disability and sexuality issues. But their call was not seriously taken up until the mid 1990s. The publication of Tom Shakespeare, Kath-Gillespie-Sells and Dominic Davies, <u>The Sexual Politics of Disability</u> in 1996, was a major turning point. This important study conducted in the United Kingdom put sexuality squarely on the political map of the Disability Rights Movement and disability studies. The work by Shakespeare and Company is the first systematic study of disability and sexuality that has prioritized the relatively simple goal of discovering what disabled people think and feel about their sexuality. These researchers chronicle both the sexual oppression encountered by disabled people as well as their more positive sexual experiences.

Perhaps because of their commitment to letting disabled people finally tell their sexual stories, Shakespeare, Gillespie-Sells and Davies did not provide much in the way of theory beyond reference to the social model of disability. I would suggest, however, that the development of theory is crucial to making sense of many of the sexual issues that confront disabled people, as well as essential in developing strategies to contend with these issues. Further, a pragmatic critical theory must develop conceptual frames that prepare the empirical ground for the hard analytical work across the full range of relevant contexts. I believe a focus on access is one theoretical frame that can meet some of the analytical and interpretive demands of a critical disability and sexuality studies. However, because its application has been limited to easily demarcated contexts such as schools, workplaces and the built environment, the concept of access has remained relatively untheorized. Truth be told, a rather legalistic and technical understanding of the term holds sway that does not appreciably alter even when programmatic access becomes the analytical target (see for example Burgstahler, S., 1994). Embodied feelings, communicative processes and the symbolic aspects of disability are generally not much taken into account. Complex cultural contexts and social fields that do their exclusionary work via hegemonic, hierarchizing everyday perceptions and practices require a critical understanding that incorporates existentialphenomenological, communicative and symbolic interpretations of the lived reality of access or exclusion for disabled people.

A narrow technical understanding of access is one reason that disability studies has been slow to interrogate sexuality as a cultural context and social field of possibility that is exclusionary for many disabled people. As part of the problematization of disability and sexuality that Shakespeare and Company call for, the deployment of a more theoretically articulate understanding of the concept of access is necessary. Yet caution must be used in deploying this not unfamiliar term in regard to sexuality. The concept of sexual access as currently used by bio-evolutionary scholars (see for example Buss, 1994), similar to its use generally in disability studies, renders it an instrumental access. In fact, sexual access in this area of study simply means access by males to sex with females. In gendered terms, sex is the resource that women own and men desire. Yet this instrumental, masculinist and heterosexist understanding of access does not render the concept itself flawed but only the interpretational framework upon which it is based. A reworking and (re)deployment of the concept of sexual access beyond its current hegemonic biases might lead to insights into disabled people's sexual issues. But exactly how should this term, which has been used to fix the evolutionary imperative in human mating, as well as to interrogate buildings, programs, organizations, workplaces, be reconceptualized for interrogating the range of contexts that relate to sexuality? More precisely what would an expanded sense of the term sexual access actually mean?

This is a guestion that one might think has been posed by constructionist sexuality studies on the sexuality of marginalized groups and oppressed minorities. But important theoretical debates in sexuality studies, propelled by Foucault's influence (see especially Foucault, 1978), feminist discourse and gay and lesbian studies, have for the most part chosen to focus on the construction of gender and sexuality identities (see, for example, Stanton, 1992; Stein 1990; Halperin, 1990; Butler, 1990, 1997). This emphasis on identity construction may have inadvertently deterred constructionist attention away from using other conceptual frames such as sexual access. Sexuality studies' focus on the construction of gender and sexual identities was necessary for analysis of some of the important issues facing feminists and the gay and lesbian movement. And their analysis is critical to continue deconstructing hegemonic masculinity and heteronormativity in our society. But in most of this scholarship, negotiating sexual intimacy with another in and of itself is not problematized as an issue to investigate, and neither is interrogating the access barriers to gender and sexual identity formation. In short, the problem of accessing interpersonal contexts in which sexual negotiations become possible, as well as investigating the impediments to the psychological and sociocultural supports underlying gender and sexual identity formation or success in love, have not structured theoretical debates within constructionist approaches to the study of sexuality. Yet, sexual access is perhaps the most significant area of concern for those disabled people who are more than mildly impaired, whatever their sexual or gender identity.

#### THE CONCEPT OF SEXUAL ACCESS

I second Shakespeare's (2003) recent caution "not to replace a traditional account of disabled people as tragic victims of bodily restrictions with a radical account of disabled people as inevitable victims of social oppression" (148). I recognize that many disabled people are in fact sexually active and do find love. While advocating for a critical focus on access, in several recent papers I have also shown, "disabled people resisting and exercising agency" (148) (see Shuttleworth, 2000a, 2000b, 2002, in-press, forthcoming). However, one should also guard against the opposite tendency, that is, of painting a too rosy picture of the current sexual situation of disabled people. My research with men with cerebral palsy in the San Francisco Bay Area revealed that despite successes, they also experience many difficulties in their sexual lives (Shuttleworth, 2000a, 2000b, 2001, 2003, in-press, forthcoming). It is imperative that we develop ways of theoretically apprehending the political and power-relational, structural,

symbolic, interpersonal and psycho-emotional dimensions of the range of sexual difficulties that disabled people may confront.

I have previously suggested incorporating an existentialphenomenological perspective into our understanding of the concept of accessibility (Shuttleworth, 2000a, 2000b, 2001). This point of view maintains that the social continuum of accessibility-obstruction is in fact basic to our (both disabled and non-disabled people) prereflective evaluation of the world-for-us (Shuttleworth, 2000b). That is, our felt sense responds to how accessible the objects (things, social contexts, cultural meanings, physical environments, etc.) of our intentions are as different kinds of expansion or obstruction (Freund 1990; Buytendijk 1950). The felt obstruction of an intention, however, can sometimes also be a cue to the lived experience of a sociocultural exclusion.<sup>1</sup> A social movement's struggle for access to the full range of societal contexts is actually a transposition of this personal sense of the access-exclusion to the experience of a social group within the contexts of liberal democracy and civil rights. Exclusionary and disabling practices are usually taken as the starting point for disability studies analyses, which generally do not perceive or acknowledge the social and cultural connections to intentional-felt sense structures.

Granting an existential-phenomenological ground to the lived experience of access, what do I mean by sexual access? I do not mean access to physical intimacy per se. Rather, my notion of sexual access, rooted in personal access transposed to desirous intentions (an access to sexual intimacy that is negotiated with or rejected by others), also embodies a sociocultural sense of inclusionexclusion. Firstly, there is a social group's relative access to the social and interpersonal contexts in which mutual desire is evoked and sexual negotiations become possible. That is, those less formal social contexts where one might express interest in the other as a sexual being and where the process of negotiating sexual intimacy begins, albeit sometimes innocuously. In U.S. society, the typical social contexts mentioned include parties, nightclubs, and on dates, but interpersonal encounters in the social realms of everyday life are also relevant such as interacting with a new teller at the bank who you are attracted to, or a cute stranger on the bus. However, I do not mean here simply physical access to these social and interpersonal contexts, I also mean aesthetic access (which includes a functional dimension—an aesthetics of function), psychological access, symbolic access, and social access. After all, if one is, for example, communicatively impaired and has dystharic speech or uses an augmentative communication device, then even if one occupies the physical space of a party or a nightclub, which are often meeting places for those interested in pursuing sexual relationships, one may be excluded from the social context of negotiating dates with many of the people there through one or more of a combination of disability relevant factors including the loud environment, poor lighting, body beautiful expectations, normative functional evaluations and/or negative cultural meanings of disability. In other words, opportunities for sexual negotiation will often tend to elude one's personal intentions. In my research on disabled men's search for sexual intimacy, they often reported this sense of being in a social

scene, but yet not feeling able to sexually negotiate in implicit or explicit ways with others (Shuttleworth, 2000a, 2000b, 2001).

A further meaning expands on the sense of access-exclusion as being hierarchically implicit in the social structures and cultural meanings of a society. Beyond the particular dynamics of interpersonal situations, in order for one to experience a sense of sexual well being, one must also have access to the psychological, social and cultural supports that acknowledge and nurture sexuality and the individual's right to sexual expression and to experience intimate relationships. Sexual well being is in fact reliant on psychological, social and cultural supports that sustain a positive sense of one's sexual self. Disabled people whether it be in their families of origin or institutional contexts often report experiencing a lack of support for their developing sexuality, that is, other's expectation that they will experience a love life and marriage (Shuttleworth, 2000a, 2000b, Mona and Gardos, 2000; Shakespeare, Gillespie-Sells and Davies, 1996; Rousso, 1993).

What might be an example of the way psychological, social and cultural supports reinforce each other to promote disabled people's sexual well-being? If disabled people were represented in the media in more sexually positive ways, for instance, this might result in a more positive sexual self-identification and heightened sexual self esteem for some disabled people. 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 contribute to improve sexual self-esteem and the possibilities for sexual expression and negotiating sexual relationships for disabled people.

Gender and sexual identity issues as they intersect with disability obviously continue to require interrogation. An access frame here should especially be concerned with the development or formation of gender and sexual identities. For significantly disabled people, especially those disabled people who live in more structured living environments such as nursing homes and group homes, applying the concept of access may assist in ascertaining the barriers to forming a gender or sexual identity and those factors that facilitate development. If sexual and gender access is socially restricted at every turn and one has minimal sociocultural support for sexual and gender expression and negotiating sexual relationships with others (Shuttleworth and Mona, 2002; Hamilton, 2002; Wade, 2002), then to what degree can one form a sexual or gender identity (normative or not), and a sense of one's self as a sexual agent?<sup>2</sup>

Several years ago at a Society for Disability Studies Meeting, a disabled woman in her late 50's described for me the arduous process of learning to be feminine after she began residing outside of institutions in her mid-twenties. She claimed that she had minimal opportunity to form a gendered sense of herself (normative or not) within her institutional childhood and young adulthood. Indeed, there has been minimal scholarly work or research that examines how disabled individuals form their gender and sexual identities (Grossman, 2003). Our conceptual frameworks are woefully inadequate to apprehend the process of gender and sexual identity formation and diversification in general but especially intersecting with the category of disability.

Sexual and gender identity issues, however, can also emerge from focusing on the interpersonal sense of sexual access. For example, in my research on the search for sexual intimacy for men with cerebral palsy, it is in relation to their restricted access to interpersonal contexts in which sexual negotiations become possible and through repeated rejection that for the mostly heterosexual disabled men with whom I talked the intersection of disability and masculinity appears as an issue to be reckoned with (Shuttleworth, 2000a, 2000b, in-press, forthcoming). This is, of course, because hegemonic masculinity like heteronormativity is implicitly assumed. Not measuring up, so to speak, sets in relief their distance from implicit, hegemonic masculine standards. For some men, the difficulties experienced in their sexual negotiations within the narrow parameters of hegemonic masculinity impelled them to incorporate alternative gender dispositions and practices into their masculine repertoire (see Shuttleworth 2000a, 2000b, in-press). A constructionist focus on sexual access in this interpersonal sense thus provided me with the theoretical entre to these men's crisis of masculinity.

#### CONCLUSION

A research focus on sexual access has much to offer a critical disability and sexuality studies. Firstly, it connects research in disability and sexuality to the Disability Rights Movement and disability studies through use of a familiar concept, that is, access, in a new context, sexuality. Despite the necessity of developing and sharpening this critical concept, maintaining continuity with Disability Rights and disability studies ideas is important to maintain a sense of continuity and history. Secondly, as I believe I have begun to show, the concept of sexual access is a significant critical heuristic device that can interrogate some of the sexual issues and sexual oppression that disabled people experience, as well as aspects of a range of components of their sexual well being-such as gender identity, sexual identity, social support and sexual communication. Obviously, however, what I have offered here is simply a beginning; the notion of sexual access needs to be further theorized and applied to additional disability and sexuality issues. Lastly, a focus on sexual access has the power to significantly expand the theoretical lens of sexuality studies and the sexual rights agenda through the inclusion of disabled peoples' sexual issues.

This last point was graphically illustrated during the summer of 2001. A student was taking an independent study with me as part of the first Summer Institute on Sexuality, Society and Health at San Francisco State University. This woman was familiar with some of the sexual issues of cognitively impaired persons because she has a cognitively impaired, teenage son and has also worked with similar youths on sexuality related issues in a counseling capacity. She told me that in one of her other classes there was a pause in the discussion as everyone congratulated each other on the recent strides in acceptance of sexual diversity occurring in U.S. society. To which she responded that there was

one group who were still completely sexually powerless—disabled people with developmental or cognitive impairments who reside in structured living environments such as nursing homes or group homes. Students in the class appeared shocked with the turn of the discussion, but some positive talk followed. She told me that quite a few students approached her after class and wanted to know more; they felt concerned that they had not even thought of the issue she had brought up. I contend that this problem was invisible to these students because they had not even broached the problem of sexual access in their sexuality studies education as a theoretical frame or an empirical issue.

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# NOTES

<sup>&</sup>lt;sup>1</sup> In order for an obstruction of our intentions to be personally interpreted as a social exclusion, particular obstructions need to be defined and articulated as such within a society. In other words, to recognize social exclusion in not being able to access a building in which a city council meeting is being held, one has to connect the personal sense of obstruction to the social sense of exclusion for a group of which one is a representative member given the right within our society that any person can attend city council meetings. It is much more difficult to discern and/or verify exclusion in the interpresental landscape of encounters and

relations than in those situations that can be addressed in terms of political or legal rights (that is, whether the fact of one's obstruction from accessing interpersonal contexts and relations does in fact point to socially exclusive prejudices being used in personal evaluations). For example, many of the disabled men in the research I conducted told me that when they tried to move a relationship with an acquaintance or friend to a more sexual place, the other person would say they just wanted to be friends. Even though they often suspected that their impairment was the primary reason for the rejection, with the awkwardness of the desired other being their primary cue, they usually could not confirm this suspicion without a shadow of doubt.

<sup>2</sup> The tendency in constructionist sexuality studies to focus on the contingency of identity categories as socioculturally and historically produced is not oriented to the problem of an individual or group's relative access to those identity categories. The struggle for access to the process of negotiating and forming one's gender and sexual identities by some significantly disabled people, especially those residing in structured living environments such as nursing homes or group homes, is thus easily overlooked by constructionist disability and sexuality studies scholars working on identity terrain (see, for example, Shakespeare, 1998; Tremain, 2000; Atkins and Marston, 1998; O' Toole, 1996; Asch and Fine, 1988; Appleby, 1994; Butler, 1999; McRuer and Wilkerson, 2003). This body of work for the most part assumes an unproblematic access to the process of negotiating sexual and gender identities. Following constructionist logic, identities are negotiated and constituted in social and interpersonal spaces. For those forming alternative or transgressive sexual or gender identities, one defines oneself to a large extent against oppressive structures and relations that manifest in one's everyday day life. Less conscious awareness is expended in forming hegemonic identities because these are assumed in the structures and relations of everyday life. Yet for either normative or alternative sexual or gender identities, access to the process of negotiation is taken for granted. An implicit assumption of independent living guides these analyses and oppressive structures are viewed as relatively transparent in the interactive dynamics of everyday life. But what if interaction and communication are vastly constrained by the institutional aspects of more structured living environments? Post-structural influences further urge us to subvert the current binary sexuality and gender regimes for the sake of diversity. Thus, scholarly attention to the issue of accessing gender and sexual identity formation may appear as irrelevant or perhaps even contrary to the goal of subversion, especially if one reads formation as development (see Grossman's paper at this conference). In today's progressive climate of inclusive sexual rights there is still too little attention paid to the gender and sexuality identity issues of significantly disabled people. Yet there need not be a reliance on developmental models or a prescription of binary genders/sexualities if access to the identity formation process and not particular identities is acknowledged as a liberatory goal.