



## CONFERENCE REPORT

# Locating Sexuality in Disability Experience, A Report From Disability Studies: Theory, Policy, and Practice, The Inaugural Conference of the Disability Studies Association

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Brian R. Grossman, Russell P. Shuttleworth, and Philip M. Prinz

The first annual United Kingdom Disability Studies Association meeting, entitled Disability Studies: Theory, Policy and Practice, was held at Lancaster University September 4 through 6, 2003, and attracted over one hundred and fifty participants. Jointly organized by the Department of Applied Social Science at Lancaster University, the Centre for Disability Studies at the University of Leeds, and The Social Policy Research Unit of the University of York, the conference generated interest from across the United Kingdom and the globe, with presenters hailing from Venezuela, Israel, Norway, Canada, Australia, and the United States. The program included presentations on a variety of topics relevant to disability studies, from direct care to disabling policies, reflecting a wide range of academic disciplines and methodological traditions. Select conference papers are posted on the conference website archive: [http://www.lancs.ac.uk/fss/apsocsci/events/ds\\_archive.htm](http://www.lancs.ac.uk/fss/apsocsci/events/ds_archive.htm).

However, despite the diversity of topics, the multidisciplinary nature of the presentations, and the international pedigrees of the presenters, there was at least one area of inquiry that was under-represented throughout the conference: sexuality in the lives of disabled people. Of the over seventy papers and posters presented, sexuality (using the broadest definition) was addressed in very few of them, specifically, in three

individual papers, Natalia Gerodetti's (2003) "Disabling' Femininities and Eugenics: Sexuality, Disability, and Citizenship in Modern Switzerland," Mark Sherry's (2003) "Overlaps Between Disability and Queer Studies," and Rannveig Traustadottir's (2003) "Gender and Disability Research in Nordic Countries," and in one symposium, "Toward an Interactive and Integrative Model of Disability and Sexuality Research," for which the authors of this report served as presenters and Tom Shakespeare served as discussant.

Because the primary focus for the three papers that addressed sexuality at all was on other topics, respectively, citizenship, queer studies, and gender studies, these presentations did not attempt to develop theory about the experience of sexuality for disabled people or to explore and map the multiple intersections between these two experience/identity categories. In contrast, the symposium was intentionally structured to explore the overlapping conceptual spaces between disability and sexuality as part of a broader aim to develop a holistic model of sexuality for disabled people. Consequently, the three presentations in the symposium and the discussion that followed them serve as the focus of the rest of this paper.

Correspondence concerning this article should be addressed to Brian R. Grossman, Department of Social and Behavioral Science, University of California, 3333 California Street, Suite 455, Box 0612, San Francisco, CA 94143-0612. E-mail: [bgrossma@itsa.ucsf.edu](mailto:bgrossma@itsa.ucsf.edu); Russell Shuttleworth, 6010 Sacramento Ave, Richmond, CA 94804. E-mail: [shuttleruss@juno.com](mailto:shuttleruss@juno.com); Philip Prinz, Special Education & Human Sexuality Studies, San Francisco State University, 1600 Holloway Ave., Burk Hall 154, San Francisco, CA 94132. E-mail: [pm@sfsu.edu](mailto:pm@sfsu.edu)

## **Toward an Interactive and Integrative Model of Disability and Sexuality Research**

Each of the three papers presented in this symposium was written as a unique piece of a larger project with the aim to develop a dynamic, comprehensive model of sexuality for disabled people. As a means to this end, the first paper, presented by Russell Shuttleworth, focused on the expansion of traditional notions of access invoked in the disability arena to include "sexual access," a framework that was infused throughout the content of the symposium. Philip Prinz followed with a paper that examined the intricacies of sexual communication through the introduction of a conceptual model that explores the influences of environmentally and socially mediated access to interpersonal interactions and the various available means through which people communicate on the construction of sexual meanings. Brian Grossman presented the final paper, which focused on the lack of engagement between disability studies and psychological models of sexual identity development and called for the rejection of traditional developmental models that are based on the notions of homogenous bodies and minds and of linear progression, in favor of those that embrace difference, disability, and discursiveness. As discussant, Tom Shakespeare concluded the symposium by identifying concepts that cut across the three papers and by outlining an agenda for future research on sexuality in the lives of disabled people.

### **Part I: The Case for a Focus on Sexual Access in a Critical Approach to Disability and Sexuality Research**

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. (Shuttleworth, 2003b, p.4)

Medical anthropologist Russell Shuttleworth introduced the symposium. In his paper, he argued that the idea of "access," which has been successful in expanding rights for disabled people in other arenas of social life (e.g., physical access to buildings and legal

access to employment), can and should be applied to sexuality as well. His intent in introducing this concept is to add to the vocabulary through which researchers and disabled people alike can discuss both the sexual successes and difficulties of disabled people, as documented in his research (Shuttleworth, 2000a, 2000b, 2001, 2002, 2003a, 2004, forthcoming).

Shuttleworth clearly differentiated his concept of sexual access from a similar term used by bio-evolutionary scholars to refer to the degree to which males of a species have access to sex with the females. Instead, his concept of sexual access is a process of negotiation situated within a sociostructural framework of inclusion-exclusion that encompasses not only physical access to places like bars and parties, where desire may be negotiated, but other dimensions of access as well, including the aesthetic, the psychological, the symbolic, and the social.

Shuttleworth offered the example of the disabled person who has a communication impairment resulting in either speech that is difficult to understand or the employment of an augmentative communication device. Even if this person is able to gain physical access to a setting like a party, she may nevertheless be denied access to negotiating dates with others attending the party because of any one or a combination of the following: the noise level, dim lighting, singular notions of beauty, and the stigma often associated with being disabled.

Furthermore, Shuttleworth explored this notion of sexual access in relation to structures that support the psychological, social, and cultural development of an "individual's right to sexual expression and to experience intimate relationships" (p. 6). He discusses the potential double-impact that a shift in media representation, such that the sexuality of disabled people is better (re)presented, might have on the sexual access of disabled people. Provided with models for positive sexual self-identification, disabled people's sexual self-esteem would likely increase and result in more sexual confidence. In addition, non-disabled people would be more likely to perceive disabled people as sexual beings.

Shuttleworth also suggested that the notion of sexual access could be usefully employed in the study of gender and sexual identity formation in disabled

people, especially those who live in more structured living environments such as nursing homes and group homes. His discussion implied the question: What are the barriers and facilitative factors to forming a gender/sexual identity in these restrictive contexts?

Shuttleworth concluded by discussing the three benefits of a research agenda that includes sexual access: a) the application of a familiar concept (access) to a new context (sexuality) forges links between the study of disability and sexuality, the Disability Rights Movement, and disability studies; b) the notion of sexual access begins to illuminate and provide a means to explore the sexual oppression experienced by disabled people; and c) a focus on the sexual access issues of disabled people can significantly expand both the sexuality studies theoretical frame and the sexual rights agenda.

## Part II: Communicative Dimensions of Sexuality, Deafness, and Disability: An Exploration of Themes and Issues

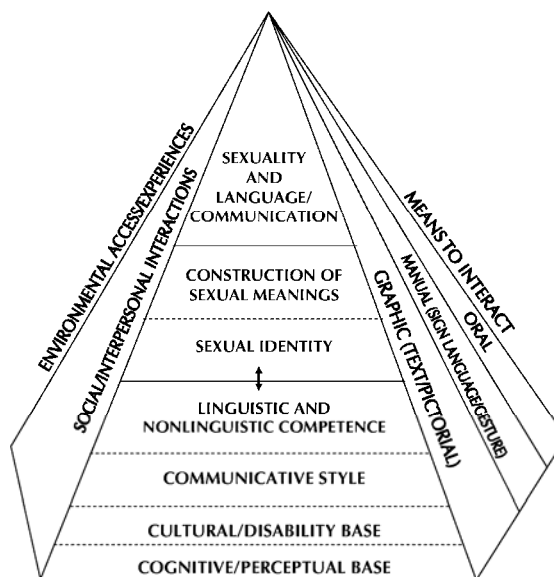
Deaf and disabled people often encounter linguistic barriers to their communicative attempts and ultimately romantic and/or sexual expression. (Prinz, 2003, p.6)

Philip Prinz, a development psycholinguist who specializes in language acquisition and the assessment of sign language in Deaf individuals, presented the second paper, in which he presented a general model for communication/language and sexuality in Deaf and in disabled persons. His model (see Figure 1) is shaped like a pyramid with the forward most face, representing sexuality and language/communication, being influenced by factors described on the two lateral faces, respectively, environmental access/experiences on the left and the means to interact on the right.

Prinz began by addressing the factors listed on the lateral faces. Starting with environmental access/experiences, Prinz, like Shuttleworth, discussed the potential both for Deaf and for disabled people to experience restricted physical access to social settings like bars or night clubs that may result in limiting opportunities for sexual negotiation. He further explained that even if Deaf and disabled people have

physical access to these venues, they may still be limited in their access to social interaction/interpersonal relations that might lead to avenues for sexual encounters (as the result of such environmental factors as loud music in a bar for a hard of hearing person and physical barriers to “cruising” for a partner for blind people).

Figure 1. A model for communication/language and sexuality in disabled individuals



Next, Prinz discussed the right side of his model, the means to interact, highlighting three modalities for communication: oral (spoken language), manual (American Sign Language or less formal gestures), and graphic (letters, symbols, and pictures). He indicated that it is through these means of interaction and communication that individuals interact with the physical and social environments in which they are situated.

Another major component of Prinz's communication sexuality model is a shared cognitive and perceptual base in sexual communication. Some individuals have cognitive and/or perceptual problems that affect the ability to conceptualize and communicate effectively. Developmentally disabled individuals frequently use augmentative and alternative communication including signed languages,

speech synthesizers, computers, communication boards and/or voice interpreters. In addition, Prinz discussed another dimension of the model, the cultural/disability base, that also influences one's sexual communication. Cultural and disability factors impact communicative style, which is described as the way in which expression is mediated through communicative modes (vocal, gesture-based, and textual). According to Prinz, communication (comprised of both linguistic and nonlinguistic elements) is the means through which individuals connect romantically and sexually, as well as the ways that people develop meaning for these connections.

Ultimately, it is through communicative style that linguistic and nonlinguistic competencies are expressed by individuals in specific situations, which in turn shapes the development of sexual identity and eventually the construction of sexual meanings. These different dimensions of the model account for the variable access to sexual relationships available to disabled people based on their ability to effectively communicate sexual meanings and desires.

Prinz concluded with the identification of a number of research questions to guide the exploration of the connections between sexuality and communication for disabled people. The questions focus on issues like the role of language/communication in the social construction of positive sexual identities and successful sexual relationships for Deaf and for disabled individuals, the ability of Deaf and of disabled individuals to communicate their sexual needs and desires, and the benefits and challenges of using nonhuman augmentative and alternative communication (AAC) devices and systems in communicating about romantic and sexual desires and feelings.

### **Part III: Understanding Disability and Sexuality Identity Development: Theory, Method, and Future Directions**

The notion of development tends to homogenize bodies and minds, sensations and emotions, with the description of one trajectory for all people within a given population. As a result, the sexual identity development trajectories of disabled

people are disciplined with silence for their unwillingness (or inability) to conform to the standard. (Grossman, 2003, p.2)

Brian Grossman, a doctoral student in medical sociology, presented the third and final paper in the symposium. He focused on an exploration of the concept of sexual identity development as it has (and has not) been addressed in the lives and experiences of disabled people. In addition to reviewing the literature on the topic, he offered suggestions for the expansion of developmental models to include sexual identity in disabled people, who have been ignored for too long.

Grossman's presentation was divided into five parts beginning with an examination of certain problematics in the concepts both of sexual identity and of development. He criticized the former for its pervasive heterosexism (in general, only queer people have been discussed in terms of sexual identity), reliance on the singular (i.e., sexual identity vs. sexual identities), and focus on stable products (rather than dynamic processes) while critiquing the latter for its assumptions of homogenous bodies and minds and its reliance on a model of continual, unidirectional progress.

Next, Grossman briefly reviewed existing psychological models of sexual identity development, beginning with the 1970s and continuing to the present. In addition to explaining the major components of each of these models, he documented their consistent exclusion of disabled people as evidenced by the sampling procedures employed (that not only privileged non-disabled people, but also focused on those who are white and male), their general failure to engage in a life course approach, and their underlying assumptions about the stability of the mind and body across time.

In addition, Grossman reported on the lack of cross-fertilization between researchers focused on sexual identity development and those engaged in disability studies. Searching the literature in multiple academic databases (PsycInfo, ERIC, CINAHL) for the term "sexual identity development" in combination with "deaf," "blind," "mental retardation," or "wheelchair," respectively, he was not able to identify a single source. Two relevant citations were obtained

through searching on Yahoo.com, *Disability: A Lifecourse Approach* (Priestley, 2003) and *The Sexual Politics of Disability* (1996) by Shakespeare, Gillespie-Sells, and Davies, both of which addressed sexual identity development only minimally.

Grossman then attempted to re-envision and redefine the concepts of sexual identity and development in an effort to impact future research. He began by calling for sexual identity to be pluralized, multiplied, temporally situated, contextualized within the history of individual bodies and minds, and de-centered so that every sexual identity is available for exploration and identification, avoiding and disrupting the taken for granted status previously afforded to heterosexual identity. He went on to reshape development by replacing its usual linearity with discursiveness and stability with dynamism (not only for bodies and minds, but for physical and politico-ideologic environments as well), and by suggesting that methods of documenting sexual identity trajectories would accurately reflect these new complexities.

Grossman concluded by situating these new notions of sexual identity development for disabled people within the conceptual frameworks of sexual access and communication that had been previously introduced by Shuttleworth and Prinz. He specifically referred to Shuttleworth's notion of sexual access as a potential tool for (re)politicizing the notion of sexual identity development and to Prinz's focus on linguistic and non-linguistic competence as potential indicators of the process through which sexual literacy is acquired and refined across the lifecourse in tandem to sexual identities.

#### Part IV: Discussion

Following the presentation of the three papers, Tom Shakespeare, Director of Outreach at the Policy, Ethics and Life Sciences Research Unit at the University of Newcastle and co-author of *The Sexual Politics of Disability* (Shakespeare, Gillespie-Sells, & Davies, 1996), provided comments and outlined research priorities for a continued focus on sexuality in the lives of disabled people.

First, Shakespeare acknowledged the challenges of discussing the sexualities of disabled people without

pathologizing or essentializing them. He then situated the struggle for visibility of the sexuality of disabled people within larger efforts to overcome the divide between the public and the private spheres. Additionally, he encouraged those in attendance to take bodies more seriously in both their future research and political action and highlighted the difficulty that researchers face in attempting to theorize desire in terms of its dimensions, its presentation, and its communication to others.

Shakespeare concluded by enumerating four research priorities for the field of disability studies to better represent sexuality. First, identifying the strength of qualitative research methods in exploring the area of sexuality and developing illustrative data, he called for more stories of individual disabled people. He noted that generating narratives is particularly important for reversing the invisibility of the sexualities of disabled people.

Next, Shakespeare suggested a focus on the role of internalized ableism, a culturally mediated privileging of able-bodiedness by disabled people, as a barrier to sexual access. Drawing parallels between the marginalization of disabled people and that of other social groups (e.g., women, people of color, queer people), he expressed interest in applying the concept of internalized oppression as the next step in constructing theory about the sexualities of disabled people. Shakespeare also stressed the importance of the plural and the dynamic in attempts to explore the processes of developing, maintaining, and presenting/communicating sexualities by disabled people. Echoing sentiments raised by the presenters, he indicated that it is through the appreciation of the multiple that theories of sexuality can recognize the importance of both personal and global historical situations and geopolitical environments.

Finally, Shakespeare addressed the importance of applying the concepts of sexual citizenship and sexual rights to disabled people and their sexual selves, emphasizing in particular the right to be free from abuse, sterilization, confinement, and interference with the body, the right to information access, and the right to reproduction.

## Conclusion

The papers and subsequent discussion that composed the symposium, "Toward an Interactive and Integrative Model of Disability and Sexuality Research," provided a deliberate first step toward a synthesis of disability studies and the sexual lives and experiences of disabled people. Approaching the intersections of sexuality and disability from different levels of analysis and indicating varied opportunities for inquiry, the four panelists were united in their common desire to encourage scholars and activists in both disability studies and sexuality studies to take the sexuality of disabled people seriously as they conduct research, teach, and advocate in the arenas of policy, practice, and theory. ♦

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