

## **Fulfilling Sex Lives: Understanding People with Disabilities and Sexual Desire in Denmark and Sweden**

**Review by John A. Carranza**

*Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement.*

by Don Kulick and Jens Rydström, eds

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Human sexuality has been considered by a variety of scholars across disciplines that focus on differing time periods and social contexts. These studies have yielded a wealth of information from which we can better understand the diversity of sexualities. However, the available literature on sexuality frequently focuses on the able-bodied. Don Kulick and Jens Rydström add to this literature with their monograph *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. In this book, Denmark and Sweden are the sites in which the authors consider people with disabilities' desires for sexual activity and to what extent policymakers, social workers, and caregivers allow or disallow such desires.

Kulick and Rydström combine their experiences as an anthropologist and historian, respectively, to present an ethnography that uses fieldwork, interviews, and archival materials to discuss the place of sexuality and disability in Denmark and Sweden. While each of the countries are welfare states and are within proximity to one another, the reader learns that policies and attitudes about sex and people with disabilities are in contrast. The authors highlight the differences by presenting points of view from caregivers, governmental policies, and the voices of people with disabilities.

The first chapter positions sexuality within the larger disability rights movement, which frequently sees it as one of the last items on the list of objectives to be attained by activists. This study was rooted in Kulick and Rydström's work on queer theory, which led them to embrace crip theory (the amalgamation of queer theory and disabilities studies). Although the authors embrace crip theory, they

question whether anything new can be learned in the approach to and the understanding of the lived experiences of people with disabilities. Another concern presented by the authors is disability studies' insistence that people with disabilities teach nondisabled persons about disability. Instead, the authors offer the concept of "ethical engagement and responsibility," (17) where they question the actions of the Danish and Swedish states in facilitating sex for people with disabilities by focusing on what both countries do socially and relationally for people with disabilities. Therefore, this study relies on the examination of how nondisabled people engage with disabled people and their sexual desires.

Chapter 2 gives the reader the historical foundation from which the discussion—or lack thereof—of sexuality and people with disabilities began to take shape in Denmark and Sweden. Beginning in the 1960s, governmental agencies in both countries began to question forced sterilization and large institutions that violated the human rights of people with disabilities. These issues combined with the sexual revolution of the time led to the acknowledgement that people with disabilities had a right to a fulfilling sex life. This chapter also focuses on the Scandinavian political and theoretical framework called the normalization principle, which was coined by the Danish reformer Niels Erik Bank-Mikkelsen that moves away from the medical model of disability and focuses on reshaping society to make it more inclusive. The normalization principle is slightly similar to the social model of disability, but was in use nearly twenty years before the social model.

The third chapter considers the precarious position in which caregivers are placed when assisting people with disabilities and ensuring that they are sexually fulfilled. Using interviews with caregivers in Sweden and Denmark, the authors present diverse perspectives for why a caregiver would not (i.e. accusations of sexual abuse) or would (wanting people with disabilities to fulfill basic needs) facilitate sex.

In chapter four, Kulick and Rydström explore what boundaries mean when examining sex and people with disabilities. This chapter is thought provoking because it considers sex and people with disabilities and the complicated personal and social boundaries around these issues. Taken together, the authors question the extent to which caregivers should facilitate sexual interactions for people with disabilities without being complicit in a crime (hiring prostitutes where it is illegal), dictating a person's sex life (when and where a person can have sex), or instructing them about sexual techniques such as masturbation (which could border on sexual abuse in some locations). However, they also consider boundaries between people with disabilities who have sex with one another by again questioning how caregivers might provide sex positive education about their bodies and what feels pleasurable.

Chapter 5 can be viewed as an extension of chapter four and its discussions of boundaries, but fleshes

out the ethics of allowing people with disabilities to purchase sex from sex workers. The authors consider whether caregivers should facilitate appointments with sex workers and whether those same employees should transport the individuals to those appointments. The legality of sex work in Denmark and Sweden and the debate about whether government funds disbursed to people with disabilities should be used to purchase sex workers.

The sixth chapter veers slightly away from people with disabilities and sex by digging deeper into the history of Denmark and Sweden to trace their political trajectories that led them to diverge in their treatment of sexuality and people with disabilities. This divergence results in Denmark being more progressive in allowing people with disabilities to have sex lives and the matter is discussed openly. Sweden is more conservative in that the matter is rarely discussed among caregivers, social workers, and politicians and usually focuses on negative aspects of sexuality such as abuse and rehabilitation.

The final chapter explores why the reader should care about sexuality and disability. A significant part of the chapter discusses sex and disability from a social justice and capabilities standpoint. The authors use John Rawls's work on social justice, which conveys the idea that a just society is one in which everyone desires an equal position, and so everyone must work together to create a society that one would expect to have access to if they were introduced to it with a disadvantage. Another viewpoint comes from a focus on capabilities as outlined by Martha Nussbaum. Nussbaum's view is that a just society helps a person expand their capabilities to the greatest extent. Nussbaum's capabilities approach provides for very basic entitlements for all people, capabilities are intertwined and a lack in one capability is not immediately fulfilled by an abundance in another, and each person is worthy of living a life with dignity. Rawls's and Nussbaum's works mesh well to give us a framework for understanding human rights. This discussion about human rights, disability, and sexuality is particularly useful because of the history that people with disabilities have had fighting for visibility and demanding a society that can be accessed by everyone. When sex is added, it contributes a new dimension to consider human rights and who should have access to one of the most basic of needs.

*Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement* is a significant contribution to the body of literature on disability studies because it shows how sex and disability are contested or accepted in a given society by using Denmark and Sweden as examples of how welfare states handle both issues. Kulick and Rydström are straightforward with their intent of making this monograph accessible for all readers, which is evident as the reader moves through the book unencumbered with excessive jargon and lofty theoretical ideas that the reader might skip over. In all

instances, the actors speak for themselves and the theory used is presented in a comprehensible manner. The lessons to be learned from the authors' work would be useful in affecting policy in the United States. Consequently, it also helps us to reconsider sexuality from a different perspective and how expressions of that sexuality vary from one person to another. This book is beneficial not only for students of anthropology, gender and sexuality studies, and disabilities studies, but also for students and general readers of history, public policy, and public health because of the added dimensions of thought, analysis, and consideration given to people with disabilities by the authors.

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