

# BOOK REVIEW

## **DON KULICK & JENS RYDSTRÖM: *LONELINESS AND ITS OPPOSITE: SEX, DISABILITY, AND THE ETHICS OF ENGAGEMENT* (2015)**

*Paul Chappell\**

---

*Durham and London: Duke University Press. 1-345; i-xiii. ISBN 978-0-8223-5833-6.*

### **1 Introduction**

This aptly titled book, *Loneliness and its opposite*, does much to highlight the complex boundaries surrounding sexuality and disability. Based on ethnographic research conducted by Don Kulick and Jens Rydström in Denmark and Sweden, this 'must-read' book explicitly focuses on the sexual and erotic lives of adults with significant physical, communication, and intellectual disabilities, and how these lives are either facilitated or impeded by those who work and care for them. What makes this book unique and, undoubtedly one of its main strengths, is that it intertwines the personal accounts of those with severe disabilities (who, for the most part, are invisible in global disabled sexuality scholarship) with those of their parents, sexuality and disability professionals (that is, academics, sexologists, occupational therapists and sexual advisors), sex workers, and caregivers in group homes. Although the context of this book is situated in Scandinavia, the research presented provides critical and insightful scholarship that could equip African-based disability academics who are interested in promoting the sexual citizenship of people with disabilities.

Central to the context of the book, Kulick and Rydström contend that adults with significant congenital and intellectual disabilities are sexual beings. However, due to the severity of their impairments, these

\* BSc (UCN), MSc (UCL), PhD (UKZN); Postdoctoral Research Fellow, Centre for Social Development in Africa (CSDA), University of Johannesburg.

individuals, especially those situated in group homes or institutions, are more likely to be dependent on others to enable them to explore and experience their sexuality. This, Kulick and Rydström contend, creates significant socio-political and ethical challenges for those who care for adults with disabilities, especially in terms of dealing with subjects such as masturbation, having a sexual partner, or purchasing sexual services from a sex worker or sexual surrogate.

Interestingly, unlike the *African disability rights yearbook*, which focuses on the United Nations (UN) Convention for the Rights of Persons with Disabilities (CRPD), the authors of *Loneliness and its opposite* make no explicit reference to the Convention and actually favour the past UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.<sup>1</sup> Kulick and Rydström contend that, in their opinion, the Convention is both too conservative and less progressive than the Standard Rules, as it makes no reference to sexual expression outside the realm of marriage and reproduction. Further to this, in using a capabilities approach, Kulick and Rydström contend that engaging with the sexual lives of adults with disabilities goes beyond a simple matter of rights, and constitutes questions surrounding ethics and social justice.

## 2 Book structure

*Loneliness and its opposite* is comprised of seven chapters, which provide the reader with valuable insight into the historical, socio-political and practical context of facilitating the sexual and erotic lives of adults with severe disabilities in Denmark and Sweden. Although both countries are believed to be liberal states, the way in which they deal with the sexual lives of some adults with disabilities<sup>2</sup> is in total contrast to each other. For instance, in Denmark, the sexual lives of people with disabilities are acknowledged and facilitated. In Sweden, however, the attempts at sexual access of people with disabilities are often denied or suppressed.

In the first chapter,<sup>3</sup> Kulick and Rydström begin by outlining the significance of sex and its interrelationship with disability in academia, the media and the disability movement itself. In addition, the authors provide details of the research methodology and study population. Central to their discussions and reasons for undertaking this study, the authors are critical of the wider cultural/social disability scholarship who, in their opinion, do not really engage with the needs and desires of individuals with severe disabilities.

1 UN General Assembly, Standard Rules on the Equalisation of Opportunities for Persons with Disabilities: Resolution adopted by the General Assembly, 20 December 1993, A/RES/48/96.

2 The sexual experiences of adults with acquired disabilities, eg spinal cord injuries, strokes, etc., are not included in the study.

3 pp 1-38.

Chapter 2<sup>4</sup> provides an historical overview of how disability activism and caring practices from the late 1960s began to engage with the sexualities of people with disabilities in the two countries. This chapter is central to the whole theme of the book as it sets out the varying socio-political reasonings that led to the Danes' active engagement with disabled sexualities, and the Swedes' depiction of disabled sexualities as a problem. On reflection, the Swedes' 'silence' surrounding disabled sexuality resonates with the approach taken in many African countries.

In chapter 3,<sup>5</sup> Kulick and Rydström build on the previous chapter by outlining the situation in the two countries today. In particular, by drawing on various practical examples, the authors demonstrate how the actions of caregivers of adults with severe disabilities are strongly influenced by cultural attitudes that either facilitate or impede the erotic lives of adults with severe disabilities. The chapter also discusses how these contrasting attitudes influence the emergence of sexual policies and guidelines in Denmark and Sweden.

Chapter 4<sup>6</sup> continues to provide particular examples of how the erotic lives of adults with severe disabilities are facilitated in Denmark and impeded in Sweden. These practical examples cover topics such as positioning a disabled client for sex with another person, aid in masturbation or assistance in acquiring a sex worker. Kulick and Rydström discuss these practical examples in terms of varying boundaries that individuals with severe disabilities and their caregivers need to consider and negotiate in relation to sexuality and disability. The boundaries discussed in the chapter include:

- public/private;
- work/intimacy;
- love/sex;
- affection/abuse;
- sex/reproduction.

In discussing these boundaries, Kulick and Rydström address some of the major practical and ethical concerns (and obstacles) often raised by caregivers, professionals and parents, in relation to addressing the sexualities of adults with severe disabilities. This chapter is significant as it could provide a useful background for the development of sexuality-related policies and guidelines that protect the rights of caregivers who work with people with disabilities in the African context.

4 pp 39-77.

5 pp 78-118.

6 pp 119-173.

Chapter 5<sup>7</sup> discusses the emotive boundary between money and sex and, more specifically, the issue of disability and sex workers. The chapter begins by outlining the differences in legislation regarding sex workers in the two countries (in Denmark it is legal whereas in Sweden it is prohibited), and some of the debates concerning disability and prostitution. Drawing from interviews with male and female disabled people who paid for sexual services, caregivers, and sex workers (both gay and straight), Kulick and Rydström explicitly discuss what happens when individuals with severe disabilities approach paid sexual services. Through this chapter, the authors critically outline how dealing with the sexual lives of adults with severe disabilities also coincides with the political issue of decriminalising sex work.

In Chapter 6,<sup>8</sup> Kulick and Rydström discuss in more detail how two Scandinavian welfare states, such as Denmark and Sweden, can be so similar but yet differ so widely in terms of sexuality and disability. The authors argue that these differences pertain to historical and cultural differences in the relationships between individuals and the state, the attainment of feminist discourse over the past 40 years, and the role key stakeholders have played in enhancing or impeding the facilitation of the sexual lives of adults with disabilities.

In the final chapter,<sup>9</sup> Kulick and Rydström provide a critical reflection of their findings in relation to varying theoretical positioning, in particular Nussbaum's capability approach for social justice. In focusing on three capabilities appearing on Nussbaum's list of central human capabilities (bodily integrity, emotions and affiliation), the authors reiterate their main argument that failing to engage with the sexual lives of adults with severe disabilities is a failure of basic social justice. In this context, Kulick and Rydström conclude that what occurs in Denmark 'is ethically superior'<sup>10</sup> to the situation in Sweden, and more respectful and just.

### 3 Conclusion

Throughout *Loneliness and its opposite*, Kulick and Rydström clearly tackle a number of difficult issues in relation to dealing with the sexual and erotic lives of adults with severe disabilities. These issues include communication, desirability, protection against sexual harassment and abuse (both for disabled adults and caregivers), privacy, sexuality education and sexual policy formation. Although the book makes no reference to the CRPD or youth with disabilities, it does, however, offer a catalyst through which to challenge current African disability and

7 pp 174-216.

8 pp 217-261.

9 pp 262-295.

10 p 264.

sexuality rights discourse, and the importance of recognising sexual access as a basis of social justice. As articulated by Kulick and Rydström:

If both disability and sexuality; by their very natures, each separately disturbs decorum and transgresses boundaries, then it stands to reason that their combination in the sex of people with disabilities will constitute a particular pungent challenge to a wide range of sensitivities, identities, divisions and relations.<sup>11</sup>

Based on these reflections, *Loneliness and its opposite* is both a powerful and insightful book that is not just essential reading for disability academics and activists but also for policy makers, occupational therapists, sexuality researchers and anyone else who is interested in sexual citizenship (and social justice), sex work, agency, diversity and transformation.

11 p 172.