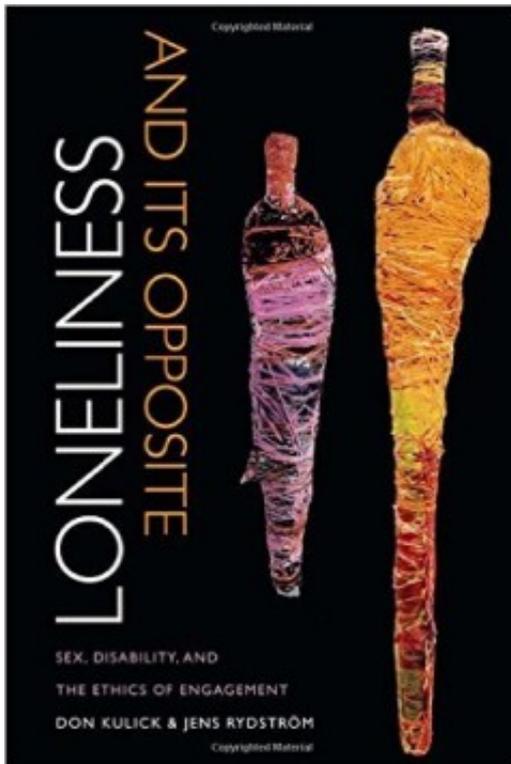


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Kulick and Rydström's "Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement"

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By Narelle Warren



[Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement](#)

by Don Kulick and Jens Rydström

Duke University Press, 2015, 376 pages

Access to opportunities for the expression of sexuality occurs in a (fairly) unproblematic way for most of us. Alone or with others, sexual desires can be identified and fulfilled as the need arises, in encounters that involve only the people engaged in such expressive moments. This presumption—very rarely interrogated—is based, at least in part, on the conflation of sexuality with adulthood. The realisation of these opportunities, too, is unproblematic, taking place in private domains that (largely) exist outside of the purview of the nation state. In their innovative

ethnography, *Loneliness and Its Opposite*, Kulick and Rydström take as their focus these mundane realities of people's intimate and erotic lives, and the assumptions that underlie them, to focus on the experiences for whom access to sexuality is not easily, if ever, made possible: those living with significant disabilities who not only require assistance in their everyday lives but who also require help in interpreting, accessing and realising their sexuality.

The authors are concerned to move away from a consideration of sexuality as a human right, with this perspective's implicit goal of producing a set of 'lessons to be learned', in order to focus on the social and relational effects of different forms of engagement in allowing people with disabilities to live lives that have both quality and dignity. To do this, they draw on the 'capabilities approach', developed by Amartya Sen and subsequently refined by Martha Nussbaum, to take a social justice lens in considering how layered contexts of disability in particular settings shape sexuality. It is precisely because sexuality has been largely overlooked by disability scholars, and disability overlooked by theorists interested in sexuality, that the research question is so important to address, and why the authors take such an approach. Kulick and Rydström employ a comparative approach to examine how the state, through discourse and policy, creates a set of social and political conditions that acts to either promote and support or deny and repress the fundamental entitlement to sexuality of significantly disabled adults. In focusing on two Scandinavian welfare states, Denmark and Sweden, both regarded globally as socially progressive and with similarities in social welfare and disability policies, the authors illustrate the profound impact of nuances in discourse in shaping the possibilities of erotic life for people with disabilities.

The central contention of the poetically named and beautifully written *Loneliness and Its Opposite* is this: even when the state—or the individuals employed by the state to act for the state—takes a stance to do nothing (as in the case of Sweden), they engage in particular, and potentially regressive or harmful, ways. In this way, such passive engagements themselves give rise to ethical dilemmas. Ethical engagement, one of the topics of interest, goes beyond 'doing no harm' to involve active and progressive engagement with marginalised people. Of course, the irony of the Swedish case is that these regressive effects occur in stark contrast to a raft of other progressive social reforms aimed at reducing and eliminating other forms of social injustice.

The contemporary discrepancies in policies and practices between Sweden and Denmark documented throughout the chapters of this volume have their genesis in two conferences on the sexual lives of people with disability that took place, six months apart, in 1966 and 1967 (respectively). Despite taking place nearly 50 years ago and both being

concerned with the 'normalization principle', which advocates for the lives of disabled and nondisabled people to be as similar as possible, the specific perspectives taken at this time continue today. In Sweden, sexuality was downplayed alongside a simultaneous focus on love, trust, attachment and care; on one hand, this minimised the importance of erotic lives and, at the same time, positioned disabled people's sexuality in terms of the potential (and even likelihood of) 'danger'. Carers were and are therefore instructed not to independently raise questions of sexuality, but instead to respond when this is introduced by the disabled person. Given the limited expressive capabilities of many people with significant disabilities, as well as barriers introduced by power relations, this leaves sexuality avoided, ignored (through a cycle of referral), or 'disciplined'.

Contrasting this example, sexuality for people with disabilities in Denmark was understood as an equally important aspect of 'normalization', and it was therefore seen as something that needed to be facilitated and supported through the development of policies and practices. Following considerable debate and consultation with human rights movements, genuine action produced both a guidelines document for supporting sexuality and an education-focused strategy whereby social workers could specialise in supporting disabled people to have an erotic life. In consequence, as the authors argue, sexuality in Denmark is "acknowledged, discussed and facilitated" (p.4). These historical accounts are detailed, but provide a necessary background against which current practices can be framed and interpreted. It is worth emphasising that that authors extend their analysis of the reasons behind the differences to consideration of broader societal regulations and norms placed on the behaviour of the citizenry, cultural ethos and the translation of ideological perspectives (such as feminism) into practice.

Loneliness and Its Opposite is provocative in its consideration of people who have been overwhelmingly voiceless (and thus powerless) in most work on disability and sexuality. Yet this provocation underlies the entirety of the ethnographic account: the reification of politically-correct language in Sweden, as Kulick and Rydström demonstrate, displaces the locus of action around sexuality. This overemphasis on the importance of particular language forms means that action is rarely translated into practical or political domains, and so the debate around sexuality for disabled people remains fixed; while this seems antithetical to the state's socially progressive agenda, it is explained also in terms of other competing discourses which highlight the importance of managing risk and minimising danger. Language is problematic not only in that it prevents real action, but also because it reveals deeply embedded and troubling, even Orwellian, views of the personal lives of people with significant disabilities. The language around disability in Denmark, in contrast, is far less politically correct. Disabled and nondisabled Danish people use terms that

sit as uncomfortably with the reader as they did for Kulick when conducting observation in group home settings. These terms are employed throughout the ethnography, providing an important illustration of the precise argument being made here about the role of language, both as a historical artefact and a contemporary practice, in producing social conditions that either support or deny sexuality for people with significant disabilities.

Ethnographic accounts were obtained through interviews with 98 people who were involved, in a range of ways, in the erotic lives of people with disabilities. Two-thirds of these people were Danish, due to the explicit interest on those instances whereby sexuality is facilitated and supported. This data was supplemented with three intensive periods of observations in group homes, as well as written literary and scholarly accounts. Drawing on this data, the authors challenge bodily and social boundaries in multiple, complex ways; through the practices of family members and care workers, the boundaries of concern are translated and reconfigured to develop a space within which erotic lives can exist and flourish. Where these boundaries remain fixed, as in the case of Sweden, these erotic lives are hindered and made close to impossible.

The separation of public and private domains is problematised through situating the ethnography in group homes: while people with significant disabilities live in these settings, and thus they represent the safe and affective spaces of home, these group homes are also the workplaces of other people. Thus, the intimate activities that occur in these settings are no longer private, but are necessarily brought into the public domain. If the state is responsible for the goings-on in the public domain, then it becomes an integral part of the constitution of these home spaces, too; part of the problem that the Swedish state, in particular, has been unable (or, as is perhaps more relevant, unwilling) to rectify is how to manage the private domain needs of some people (i.e. to sexuality) in the public work domain assurances provided by others (i.e. the right to a safe workplace). The recognition of sexuality for workers in group homes in Denmark demonstrates one form of re-interpretive practice and offers one way to address this tension, as does the specialist training as sexual advisors for some social workers.

This latter point gives rise to the second type of boundary redefinition: that between work and intimacy. Some people with significant disability, such as those described in *Loneliness and Its Opposite*, have limited or no movement without the assistance of other people. To support their sexual expression, the boundary between work and intimacy are necessarily blurred: the individuals themselves need to be positioned, as do others, or sex aids. Where the disabled person also experiences communicative or expressive impairments—not an uncommon occurrence for people with

intellectual disabilities—assistance may be required in identifying their sexual needs. At the same time, for these and other participants, assistance is required to procure access to sex workers, pornographic material or contraception (including putting on condoms). The latter area, as the authors identify, is a vexed area, giving rise to another type of boundary blurring: that between sex and reproduction. In Denmark, sexual advisors negotiated the tension between wanting to support the erotic lives of those with whom they worked but were extremely concerned about preventing pregnancy. Most women consequently had permanent contraception, although sterilisation was not uncommon, as the authors describe. Love and sex are blurred together, too, especially for mothers who were distressed by but wanted to support their disabled sons' burgeoning sexuality, as is detailed through several case examples. Gull-Marie's story, for example, highlighted the tensions faced by parents who want to give their children a full and dignified life, including a sexual life, but who face moral dilemmas in trying to establish the best way to facilitate this.

The boundary between abuse and affection highlights one of the key points of difference between Sweden and Denmark; sexuality for people with disability in the former is only seen as abuse, whereas this is an area where Danish sexual advisors and policy makers have devoted considerable attention to ensure that separation remains between the two. The fact that sexuality occurs for people living in Danish group homes is therefore not because these risks are not given importance, but because they are brought into the open, allowing sexual advisors to develop trusted relationships with the people with whom they work and thus to consciously develop ways of ensuring the physical and emotional safety of all involved in every sexual encounter. In supporting their opportunities for a sexual life, Alida was also involved in educating Dorte and Ragnor about what sexually pleasurable interactions were about; in this way, she didn't simply facilitate sex in an instrumental way, but also provided important information which enhanced the experience of sexuality. Through the presented case studies, each of the contested boundaries described compels care workers, scholars, activists and policy makers to think about engagement in different ways.

In addition to the contested boundaries identified and explicated by Kulick and Rydström, the cases presented here also challenge the idea that bodily capacity in some way shapes access to adult life experiences. While they require assistance, participants in their study are adults who have sexual desires that can be realised and supported by others. The innovation offered by the sexual advisors to facilitate sexuality, as illustrated throughout this volume, is demonstrated in multiple ways. In watching Rasmus's actions rather than relying only on his spoken desires, for example, sexual advisors engaged with him in a way that not only

supported him to achieve an erotic life, but also challenged heteronormative assumptions that often form the fall-back position of health workers, policy makers, and others involved in disabled sexualities.

As a medical anthropologist interested in chronicity and impairment, I'm more than a little in love with *Loneliness and Its Opposite*. It makes me attempt to take a more inclusive and daring approach, both in the topics I study as well as the work produced. The work is compelling and accessible, written in a style that captures the reader at the start and holds that interest throughout. By drawing on ethnographic accounts, historical material and cultural artefacts, Don Kulick and Jens Rydström demonstrate the complex layers of experience and reinforce the importance of anthropological considerations of context as extending to structural elements, as well as local processes. As they are concerned with the facilitation of, not impediments to, the erotic lives of people with disability, the ethnographic data collection is largely limited to Denmark. While this could be a criticism of this work, given the concern with social justice, this decision is appropriate. Indeed, any potential methodological shortcomings are addressed and explained, transforming such limitations into strengths. In framing their book in terms of the 'ethics of engagement', Kulick and Rydström highlight the contribution anthropologists and other social scientists can make in identifying and representing the fundamental aspects of human experience—and the importance of identifying, capturing, describing and interpreting the diversity therein.

[Narelle Warren](#) is a lecturer in Anthropology in the School of Social Sciences at Monash University. She is currently conducting research on neurological conditions in Australia and Malaysia, focusing on Parkinson's Disease and stroke, as well as the influence of health system factors. She has also recently completed a study on people's experiences of sexuality and non-traumatic spinal cord injury.

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