

# “Stop thinking you know what to expect”

Don Kulick



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*Don Kulick*

## “Stop thinking you know what to expect”

When writing a book, knowing what to leave out is just as important as deciding what to put in. And one valuable lesson I have learned over the years is that sometimes one has to sacrifice detail in order to achieve narrative coherence.

In *Loneliness and its Opposite: sex, disability and the ethics of engagement*<sup>1</sup>, the book I co-authored with Jens, I made a decision not to include some material that I thought was compelling and thought-provoking, but that, had we included it in the book, would have risked derailing the book’s cohesion. The material concerned the life of person whom I will call Trine, even though she wouldn’t object to me using her real name. Trine is a bubbly, fast-talking, discretely flamboyant Danish woman, then in her early forties, who uses a wheelchair and has to lie down in a prone position most of the time because she has rheumatoid arthritis (*leddegigt* in Danish).<sup>2</sup>

On a sunny day in June 2011, I spent an afternoon with Trine in her tiny one-bedroom apartment, where her large queen-size bed occupies much of the cramped, bohemian-style living room (the other room is given over to Trine’s around-the-clock personal assistants, so that they might

take a break, or leave Trine alone when she wants privacy, and where they rest during their night shifts).

Trine and I talked about sex, and about sex work. Now, during my research for the *Loneliness* book, I spent a lot of time with other Danes, too, talking about sex, and sometimes about sex work as well. But Trine was unique, in that she was a person with a disability who didn't just have opinions about sex work; nor did she *buy* sex (as did, for example, a woman named Frigg, whom we discuss in the book).

Instead, for several years in the early 2000s, Trine, an individual with a significant physical impairment, had *sold* sex to clients who paid her 500-600 Danish kroner an hour.

Sex work is a touchy topic, and one of the first decisions Jens and I had to make when planning the *Loneliness* book was how much space we should devote to discussing prostitution. As we document at length in the book, one of the most significant differences between Sweden and Denmark concerns contrasting stances towards sex work. The book details how Swedes generally are vigorously condemnatory of everything having to do with sex work, in stark contrast to Danes, many of whom are neutral or affirmative in relation to sex work and sex workers. Many Swedes firmly believe – because of ignorance and because of purposeful misinformation provided by Swedish television programs and newspaper reports – that in Denmark, men with disabilities are provided with a kind of stipend from the government that allows them to pay regular visits to sex workers. (Whether any corresponding assistance might magnanimously be provided for disabled Danish women is not a question we ever heard considered by any Swede who confidently proclaimed their knowledge of “how things are” in Denmark).

Because we wrote extensively about Sweden in our book, and because, in Sweden, the topic of sexuality and disability inevitably ends up with disability being forgotten, superseded and replaced by the to-be-or-not-to-be question of prostitution (unlike in Denmark, where, generally speaking, there is a much more ample and complex understanding of both disability and prostitution), Jens and I were well aware that we needed to grasp the bull by the horns and examine prostitution. At the same time, though, we didn't want to devote too much attention to prostitution, which is

something, after all, that most people with disabilities – just like most people without disabilities – never consider or encounter.

So we needed to contemplate disability and sex work, but we did not want our book to be *about* disability and sex work.

In the end, we confined our exploration of sex work to a single chapter (of seven). I wrote that chapter; in fact, it was the first chapter produced for the book. I wrote the chapter on prostitution first partly to get a firm handle on the phenomenon and try to establish a balanced narrative tone. But I also wanted to write it first because the experiences I had gathered from my interviews with adults with disabilities, their helpers and parents, and from sex workers, inspired and moved me. I felt that if I was able to do justice to the complexity of those experiences, I would be able to approach the more general topic of sexuality and disability with confidence and tact.

As I progressed in my writing, it dawned on me that I wouldn't be able to include Trine. The chapter on sex work came to detail different perspectives of adults with disabilities who purchased sex, on the one hand, and the reflections of sex workers on their experiences of selling sex to adults with disabilities, on the other. The fact that Trine was a person with a disability who *sold* sex made her perspective unique. But it was a perspective that didn't fit comfortably with the rest of the chapter – precisely because it was so unique. To include it would have risked unbalancing the text, swallowing it up with a personality and a set of experiences that were so remarkable that readers unavoidably would have been left with many more questions than answers. To include Trine would also have opened the floodgates for critical voices (from Sweden, we anticipated, mostly) which might have accused us of implying that Trine somehow was representative of women with disabilities.

The result of those deliberations was that Trine didn't make it into the book. I have always lamented that exclusion, partly because Trine is such a charismatic person. Lying prone on her bed while I spoke with her, blonde hair falling across the pillow on which she rested her head, crimson lipstick perfectly applied to her quick-to-smile lips, it was apparent to me that Trine was a singularly clear-headed, no-nonsense woman who possessed a quiet dignity that drew people to her.

But the other reason I mourned being unable to include Trine in the *Loneliness* book was that I believe her perspective adds something valuable to an understanding of how complex and surprising individual lives can be. At the very least, Trine exemplifies the bracing diversity of people's lives in general, and the lives of people with disabilities, in particular.

I take the opportunity of this festschrift to Jens Rydström, to offer an edited, translated transcript of the conversation that I had with Trine in 2011. In order to preserve Trine's anonymity, I have omitted details that would allow her to be easily identified, and I focus on those portions of our conversation that concerned her experience of sex work.

And rather than provide an analysis of the transcript, as I would have done had we included Trine's story in the *Loneliness* book, here, I let Trine speak for herself. I ask readers to read through our conversation and draw your own conclusions, in light of the material that we present in *Loneliness and its Opposite*.

The portion of our conversation I document below occurs right after Trine has told me about her first sexual relationship with a man, which happened when she was twenty years old. She told me that her main feeling afterwards was one of enormous success: "*Yes, nu lykkedes det!*" (Yes, I did it!).

Soon after that, Trine started selling sex. Why?

T: Well, I wanted to feel at least as attractive as everybody else, and maybe even more attractive than other people. And now that the ball was rolling (*når jeg nu var igang*), I thought, "Success, you know, that is really nice (*dejligt*)". And so I thought, "Well, maybe I can actually earn some money doing it, because if I get better at it, one should get something out of it, right?". So I put an ad in the newspaper, that men were welcome.

D: What did you write?

T: Not very much. I mentioned that I had a physical disability and that I sometimes used a wheelchair, but that otherwise I was sweet and kind and ordinary (*sød og rar og almindelig*). It was a short ad.

And I got an incredible number of responses. I'm telling you – in case you want to research it – that there are so many men out there who don't get their needs fulfilled. I can testify to that. My ad appeared for a single day, and the letters just kept pouring in. It was unbelievable. It surprised me.

So I called some of them up. The ones I thought were weird, I didn't contact. I only contacted the ones who seemed right in the head, you know (*ikke*)? The ones I thought sounded OK. There were a few who seemed a little "off", and them I didn't want to talk to. And maybe that's why I have never experienced anything unpleasant. Never.

D: At that time, this wasn't done online. We're talking written letters and telephone calls, right?

T: Yeah, ordinary letters.

D: And you would call up the men you wanted contact with?

T: Yeah, I called them. In the ad, I asked for a photo, a letter and a telephone number. So I called them up. I only called up three or four at a time, and I took maybe a couple weeks to get to know them on the phone. I wasn't in a hurry because I wasn't doing this fulltime. I wasn't running an industry.

D: And who were the men? Did they have disabilities?<sup>3</sup>

T: No, no, none of them, not a single one. Later, after I stopped for a while and then started again, I got some men with disabilities. But mostly it was ordinary men (*belt almindelige mænd*). There's a lot of men out there who are [sexually] starving, apparently.

D: Do you think they wanted to come to you because you have a disability?

T: No, I think I made it clear to them that that wasn't important for me. It wasn't important for them either.

D: How long did you continue selling sex?

T: About five or six years, with pauses in between. I only did it when I felt like it (*når jeg havde lyst till det*), and when I felt that I was in a position where I had time and felt relaxed enough to do it well. It has always been important for me to do it with my heart. I think that basically, sexuality is a way of showing love without words. And I feel that it is really important for me to give that to others. So this wasn't something I did cynically. And when I discovered that I began thinking too much about the money I was earning, I stopped. Because I didn't want to be like that.

It was nice to earn money, because I felt like I was valued. But it wasn't for the money – it was to give something of myself. And that was why I only did it for limited times. Because it takes a lot of consideration (*meget overvejelse*), you know?

D: And why did you stop?

T: I had enough. And I met the love of my life, and so obviously I wanted to only be with him, you know?

D: OK. But is that the guy you aren't together with anymore?

T: Yes.

D: And when the relationship ended, did you start again?

T: Yeah, in fits and starts. But only for a month or so at a time. Sometimes some of the old acquaintances (*nogle af de gamle bekendte*) call me up and say, "Can't I come by for a little visit?". And sometimes I think, OK, for old times' sake, you know? So I say yes every now and again. But right now, it isn't something that I do very often. I have a lot else going on, you know? But I have done it during limited periods.

D: OK. But when you were most active, if you think back, how many times a week did you do it? Once a week?

T: Sometimes two. Once or twice a week.

D: And can you tell me what happened when men arrived?

T: It was all very natural. They come in and they're always a bit embarrassed and ask if they can sit down. And I give them a cup of coffee or something. Then I talk to them for a little while. You know, if you're good a reading body language you can quickly see when they relax, when you can start to hold their hand or whatever. Most of them were easy to read. And then we were together, whatever they wanted to do, and afterwards we talked for a while and then they left. It was all very natural.

D: And what about your personal assistants?

T: I told them about it when I hired them. I said, "Sometimes I have clients who come, and it's important that you are discreet and stay in the assistant's room [i.e. the bedroom in Trine's one-bedroom apartment, used by her personal assistants]. I'll open the door for them". They weren't involved other than they knew that I had clients who came to the apartment.

D: But they assisted you.

T: Well to change my clothes and that kind of thing. And afterwards.

D: When you interviewed them before hiring them and told them about the clients, did any of them ever say, "No, I couldn't do that".

T: Most of them said, "Wow, how cool", "Oh boy" (*hold da op*), or "That's great". But a few said "Oh, I think that's strange and I don't want to be a part of it". And they didn't get hired. Once I tried to hire someone who said, "I think this is morally wrong". So I said, "OK, but can you live with it?" And she said, "I can, but not if it happens during my shifts".

And so, I didn't have clients during her shifts, and everything worked out. But I wouldn't do it again, because it's a little annoying (*træls*) when everything depends on who one has as a helper on any given day, you know? Plus, one feels it's a bit unpleasant when you



know that someone disapproves and thinks that what you are doing is wrong, you know?

D: Of course. And you had both male and female helpers?

T: At that time, yes. But now I only have women.

D: How come?

T: A lot of men think about sex in one way or another. It's always in the air, and I don't want to think about that now. And there are problems when one goes to the swimming hall, and so on. So right now I don't want to deal with things like that.

D: Do you have experience of things like that?

T: Yeah, it's always there, no matter how well one gets along with one's helper. If it's a male helper there is always something, some little flirt in the air or something sexual. I think it's human nature. There's nothing wrong with it, but I don't want to deal with it right now.

D: How much did you charge as a sex worker?

T: In the beginning I took 500 kronor an hour. Then it was 600. I always stayed in that range.

D: That's not so much.

T: No, it isn't.

D: Did you decide the price?

T: Yes, I decided. I thought, "How much do I need?" And I thought, well, it gives me a little pocket money. If I really wanted to make money I felt I ought to offer something completely special, something technical, and I couldn't do that. I just wanted to give my heart.

D: OK. Earlier we spoke a little about your interest in SM [sodomasochism]. Can you talk a bit about that?

T: What do you want me to talk about?

D: How you discovered it.

T: Hmm, how I discovered it. I almost can't remember. I think it was a film or something – no, wait. I read *The Story of O*. That was it. And I thought it was very beautiful (*smukt*). Because it was so strange (*underlig*). I'd never read anything like that before. I thought, how strange that some people do that. But I thought it was tremendously fascinating. And once I was with a boyfriend in a SM club and we asked, "What's it like? What do you do here?", and stuff like that.

So we agreed to try it. We both thought it was wildly exciting. And we kept it up for a while.

D: When you say you tried it, what do you mean?

T: Well we became members of the club and we went once a week and were together with the others and practiced it.

D: And which roll did you play?

T: I was mostly his submissive. But if I had a client who wanted me to be dominant, I could also do that. Because even if one is submissive oneself, you can still play the other roll. You can easily imagine what the submissive wants if you're one yourself, you know?

D: But you prefer being the submissive?

T: Yeah, back then. I don't know what I would do today, to be honest. But back then, it was the dream I wanted to live out.

D: Do you know why?

T: No, I don't. I don't think anyone knows why they desire what they do.

D: But haven't you wondered? Because I'm thinking that if one is disabled, one is often in a submissive position. And one might think that in a sexual scene, in fantasy, you can take on another role.

T: No, that's not right. First of all, I spend my entire days telling my helpers what to do to help me, so I'm not submissive to anyone.

In my day-to-day life, I'm the dominant! And second, I don't think that sexuality, for me, has anything to do with my disability. I think that's why I am so fortunate (*heldig*). Because sure, you might think, as you say, that I am dependent, or something like that. But that's separate from me. My identity is not as a disabled person. For that reason, my sexuality doesn't have anything to do with that. That's also why I think the men who came to me were attracted to me.

D: But did you ever talk about your disability with your clients?

T: No.

D: It never came up?

T: Yeah, if it was natural. If they said something like, "It doesn't hurt you when I hold your arm like this?", something like that. Obviously.

D: That surprises me. That they didn't say "OK, let's talk about this". But they didn't?

T: No. You know, that wasn't the most interesting thing going on in that moment.

D: What about contact with other sex workers? Did you have any?

T: A little, because sometimes one wants to talk to others: How do you do X? What do you do if a client wants you to do something you don't want to do? That sort of thing. Why are there so many men who are unfaithful to their wives and girlfriends? Whatever. One of the men who came to me was going to get married a month later. Another one had just gotten married. And I thought: why? That was one of the reasons I stopped for a while, because I felt bad about the women who didn't know anything. And I needed to talk to other people about that.

So I found a woman who a friend has gone to for a long time [i.e. a sex worker]. I called her and we had some good conversations. But I felt that she was a little more "hard core" than I was. She had a lot

of clients, you know. And I didn't. For her, it was a lifestyle, but it wasn't that for me. But it was great to talk with her.

D: Do you have a message you want to convey to people?

T: I have two. The first is that disability doesn't have anything to do with one's sexuality. The other message is that I think that sexuality should be about love and one's inner life force (*en indre livskraft*). You should never see things in a predetermined way. It's like when people ask, "Who is God? Is he a man with a long beard? Who is he?" I've always felt that it isn't important to know what he looks like, because you might be surprised, you know? He might be the person knocking at your door in a little while. That's my message.

Not many people expected a young woman in a wheelchair to sell sex. I wanted to give them the experience of: Stop thinking you know what to expect. Because you don't.

## Endnotes

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- <sup>1</sup> Don Kulick and Jens Rydström, *Loneliness and its Opposite: Sex, Disability and the Ethics of Engagement* (Durham & London: Duke University Press, 2015).
- <sup>2</sup> I am extremely grateful to “Trine” for taking the time to read this text and give her permission to publish it. I also thank a good friend of hers for facilitating that contact.
- <sup>3</sup> The Danish word used throughout this conversation for what I here translate as “disability” was “*handicap*”. In the Introduction to *Loneliness and its Opposite*, we discuss the fact that Danes generally do not use what people outside Denmark would regard as politically correct language when they speak about disability (This is also the theme of Don Kulick, “Butler, spastics, mongoloids and dwarves”, in *Philosophy on Fieldwork: Critical Introductions to Theory and Analysis in Anthropological Practice*, eds Nils Bubandt and Thomas Thomas Schwarz Wentzer (London and New York: Routledge, in press). In the *Loneliness* book, for reasons we elaborate there, we translate the Danish words literally. Here though, I have decided to translate *handicap* as “disability”, in order to not introduce any potential obstacles for readers who may feel that a word like “handicap” is a barrier to engagement with the substance of the topics that Trine and I discuss.

**Don Kulick** is Distinguished University Professor of Anthropology at Uppsala University and Chair Professor of Anthropology at Hong Kong University. His latest book is *A Death in the Rainforest: How a Language and a Way of Life Came to an End in Papua New Guinea* (Algonquin Press, 2019).