

# When Privacy and Secrecy Collapse into One Another, Bad Things Can Happen

by Don Kulick

This article discusses privacy and secrecy in relation to the sexual lives of adults with significant disabilities. It compares ideologies and practices of privacy in two Scandinavian countries that diverge dramatically when it comes to sexuality and disability. In Sweden, the sexual lives of adults with disabilities are hindered and blocked by the people the welfare state pays to assist them. In Denmark, those same kinds of assistants facilitate sexual lives. A reason for this difference hinges on how “privacy” is conceptualized and practiced. In Denmark, to label something as “private” configures a particular kind of ethical space of engagement. In Sweden, “private” means “secret,” “off limits,” “beyond the boundary of knowledge or engagement.” This collapse of privacy and secrecy into one another has dire consequences for people with disabilities.

Secrets are always social. Even secrets that people keep from themselves—awarenesses they decline to consider, perceptions from which they avert their eyes, realizations they push back from confronting—even private secrets of the most intimate kind are inevitably linked at some level to sociality and to living in a world together with others. The unconscious, that vast ocean of secrets we keep from ourselves, partly in order to be able to carry on living at all, is not just something we have with us from birth, like a brain or a heart. Any psychoanalytic theory tells us that the unconscious is made, constructed through the repression of instincts and desires that threaten to dismantle, overwhelm, or destroy our relations with others.

Because secrets are social, they are also socially distributed. They get embodied, they become enfolded. The social distribution of secrets, in practice, means that some kinds or some groups of people come to be expected to have few or no secrets; other kinds or groups of people are expected or even required to have secrets. Nationally known politicians, to take the most obvious example, are culturally incited, these days, to be transparent. This is why any revelation that individual politicians do have secrets (especially secrets pertaining to sex or money) makes easy news and frothy scandal. On the opposite end of the spectrum is the kind of view that prevailed during the Cold War with regard to homosexuals: the McCarthyite insistence that gay men and lesbians were inherently and dangerously secretive, duplicitous, treacherous, and threatening.

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The mechanisms through which secrets become socially distributed in ways like this are not obvious or explicit. They are, themselves, a secret—hence the outrage that can follow their exposure. Edward Snowden’s revelations that the American National Security Agency regards all of us as under suspicion of having secrets that it wants access to demonstrates, furthermore, how the social distribution of secrecy is never innocent or neutral. It is always a reflection of relations of power and of the desire of some people to manage or control the behavior of others.

Snowden’s revelations also make evident what can happen when people who are supposed to embody secrets protest and direct attention to the assumptions and structures that figure them in that way. When that happens, the exposure of arrangements that had operated in secret can foster a rift in public perception and generate a template of engagement that has the potential to resignify bodies and social relations. One result of such resignification can be the acknowledgment of rights that a veil of secrecy previously had prevented from being perceived, a realignment of practices that reproduced inequality and prejudice, and perhaps a vigorous public debate about social justice.

This article discusses such a process in relation to a class of people whose lives in many ways are imagined to be secret. That group is adults with significant physical and/or intellectual disabilities. These are people who may not be able to speak because of a physical impairment such as significant cerebral palsy. Or they can communicate, but because of an intellectual impairment such as Down syndrome or autism, understanding what they want to say may take time, patience, and sometimes years of experience working with or caring for them. Although “secretive” is perhaps not the *mot juste* to characterize the general social impression of adults with significant disabilities, the fact that their desires and inner lives

are often regarded by nondisabled people as mysterious and perhaps inaccessible implies a kind of invisibility or concealment that is fundamental to the notion of secrecy, and that easily flows into perceptions and images of secrecy.

Furthermore, some vital dimensions of the lives of adults with significant disabilities are unambiguously “secret,” and in the view of many nondisabled people, should stay secret. The most evident one is their sexuality. Disabled people are not supposed to have a sexuality or be sexual. In 1996, in a groundbreaking book titled *The Sexual Politics of Disability*, the authors spent 200 pages presenting material from questionnaires and interviews in order to conclude that disabled people “can talk about sex. We can have sex—we are entitled to have sex and find love. We do face oppression, abuse and prejudice, but we can fight back and we can demand support and the space to heal” (Shakespeare, Gillespie-Sells, and Davies 1996:207, emphasis in original). That such startlingly self-evident truths needed to be asserted with such insistence as recently as 20 years ago testifies to the staggering resistance that confronts people with disabilities simply to be regarded as adults.

This resistance, which is also reflected in an almost utter scholarly silence on the topic, is nurtured and sustained by deeply ingrained prejudices.<sup>1</sup> Many commentators have pointed out that the widespread belief that “disability = helplessness” encourages people to associate disabled adults with children, and hence, with sexual innocence and asexuality. Others have described alternative reasons that might explain the incomprehension and sometimes naked hostility that expressions of sexuality among disabled individuals can provoke in nondisabled people. Alison Lapper, a British artist born in 1965 with no arms and shortened legs, spent her childhood and youth in various institutions. At one point, when staff suspected she might be engaging in “activity below the waist” with a male friend, the couple were whisked away and interrogated separately by “a board consisting of the headmaster, the warden, the deputy warden and just about everybody else who had any rank” (Lapper 2006:129). Lapper was forced to undergo a gynecological examination, and she and her male friend were forbidden to meet, talk, or even look at one another ever again. They were also both ordered to undergo separate sessions with a psychotherapist. The reason for this extreme (but, in the late 1970s, common) reaction, Lapper thinks, is because “the general view among the staff was that we shouldn’t be thinking about sex at all. . . . Firstly, they thought we were too repulsive physically for anyone able-bodied to possibly consider us sexually attractive. Secondly, there was something so fundamentally wrong about our shapes that it would not be right for us

to contemplate any sexual activity even with each other, even if we felt the inclination” (Lapper 2006:129).

Disability in itself does not necessarily disqualify an adult from the realm of the erotic. Spinal cord injury, for example, is popularly portrayed as compatible with sex, and even sexy, in films such as *Murderball*, a multiple-award-winning 2005 documentary about swaggering disabled men who play wheelchair rugby; *Coming Home*, a 1978 feature film starring a buff young Jon Voight (nowadays better known as Angelina Jolie’s father) as a Vietnam veteran who returns home to California in a wheelchair; and the 2011 French blockbuster *Intouchables*, about a suave billionaire who became disabled as the result of a paragliding accident.

Spinal cord injuries, though, are usually acquired impairments. And when thinking about practically anything having to do with disability, particularly sexuality, the distinction between acquired and congenital impairments is crucial. Many nondisabled probably find it possible to express understanding of and sympathy for the sexual desires of, say, a good-looking 23-year-old hockey player who breaks his back and ends up a paraplegic in a wheelchair, for example. Far fewer people have comparable levels of understanding and sympathy when the person with sexual desires is a 54-year-old man with Down syndrome or a woman born with cerebral palsy so severe that she has no verbal language, drools occasionally, and has arms and legs that need to be strapped to a wheelchair to help control spasticity. That a man or a woman like that might have a sexuality they need assistance in understanding and realizing is a thought that disturbs many people, who would much rather prefer not to have to think about such things. But those kinds of significantly disabled adults are the ones who need the most help in realizing their sexuality. They are the ones who present the biggest challenge to the way we think about things such as equality, justice, ethical engagement, and the nature and function of the secret.

In 2011, I spent a year researching the sexual lives of adults with disabilities in two Scandinavian countries, Sweden and Denmark. The impetus for the research was a lecture I had heard in Sweden several years previously by a counselor who advised people with disabilities about sex. This counselor recounted an incident involving a quadriplegic woman who lamented to him that after many years of having no erotic sensation, she had begun experiencing orgasms when her male attendants lifted her out of her wheelchair to bathe her. The problem she had was that those attendants had stopped doing that when they noticed that she found being lifted pleasurable.

This relationship between care and suppression became the focus of my recent work with a Swedish historian (Kulick and Rydström 2015).<sup>2</sup> The book that has resulted from that work

1. There is little academic literature about sexuality and disability. There are medical texts concerned with rehabilitation, advice books to professionals or parents, sex advice manuals to people with disabilities, and memoirs by adults with disabilities that mention sexuality (such as the one by Alison Lapper [2006]). But scholarly engagement with this topic is exiguous. See Kulick and Rydström (2015:7–11) for a review.

2. The analysis presented in the book is based on 98 interviews with a wide variety of people, archival research, and ethnographic fieldwork in three group homes, two for adults with physical impairments and one for adults with intellectual impairments.

contrasts Sweden and Denmark. In Sweden, it turns out that the story told by the counselor is typical. Throughout that country, the sexual lives of adults with significant disabilities are consistently and purposefully denied and blocked by the very same individuals whose job it is to help disabled women and men participate as fully as they can in social life. In Denmark, in contrast, that same group of people understands basic human dignity to include the possibility of erotic expression, and they consider it part of their jobs to encourage and facilitate sexual exploration and contact. Differing conceptualizations of privacy and secrecy play a central role in accounting for this contrast.

### How to Impede and How to Facilitate the Erotic Lives of Adults with Disabilities

Sweden and Denmark are both prototypical welfare states that share much history and have grammatically similar languages and recognizably similar cultural traditions. Their many historical and structural similarities make all the more perplexing their dramatic divergence in ideologies and practices regarding the erotic lives of people with significant disabilities.

In Sweden, whenever professionals, social workers, and caregivers discuss the sexuality of significantly disabled individuals, two phrases recur that succinctly sum up the Swedish approach to disability and sexuality. One is the proverb *Väck inte den björn som sover* (Don't wake the sleeping bear); the second is the adage *Om jag inte gör något så har jag i alla fall inte gjort något fel* (If I don't do anything, at least I haven't done anything wrong).

The first of these two sayings is the Swedish equivalent of the English-language proverb "Let sleeping dogs lie"—do not draw attention to something that is not seeking it. Here the idea is that disabled people's sexuality is not something that necessarily naturally expresses itself. This might be because the person with the disability either does not understand that he or she has erotic desire, or because the desire the person may have is satisfied in ways that do not involve genital eroticism, such as by hugging, holding hands, or by giving people kisses on the cheek. In cases like these, for anybody to raise the issue of sexuality—for example, in educational programs, group discussions, or private conversations—is to project his or her own sexuality onto a sexual innocent and thereby risk awakening in that person a theretofore secret desire that can manifest in unforeseen, unhappy, and possibly even uncontrollable ways.

The second formulation that occurs very frequently in Sweden when sex and disability are discussed among personal assistants and others who work with disabled adults—the mantra, "If I don't do anything, at least I haven't done anything wrong"—is related to the "sleeping bear" perception that anything having to do with sex is potentially harmful to people with disabilities because they may not understand the implications of sexual activity. So rather than offer any help to understand those implications, it is better not to do anything, "just in case." The "not doing anything" part of the "If

I don't do anything" formulation is misleading, however, because personal assistants, staff in group homes, and others who use the phrase do not actually do nothing. The "nothing" they believe themselves to be doing is always actually "something," usually something that discourages sex or impedes it. This can take the form of interrupting an intertwined couple on the dance floor of an arranged dance for adults with intellectual impairments, telling the couple it is time for a coffee break in order to pry them apart. It can be a refusal to insert a pornographic DVD into the DVD player of the person one is assisting, because one is opposed to pornography, or a refusal to assist a couple with mobility impairments who need help to lie together and caress one another, because one does not consider helping people have sex to be part of one's job. It can be an insistence that a disabled person take down pinups that he has had a friend help him tape to his bedroom wall, because the disabled person's home is one's workplace, and to be confronted with sexual images in one's workplace is a form of sexual harassment.

In contrast, during the time I spent doing fieldwork in group homes in Denmark, I never heard anyone cite a mantra that corresponded to either of the Swedish ones. If one existed, it would likely be the inverse of what Swedes say—it would be, "If I don't do anything, then I *have* done something wrong."

Unlike its northern neighbor, Denmark has a set of national guidelines that advise people who assist adults with disabilities how to engage their sexuality. Since 1990, it also has had an educational certification course that social workers can take to become what are known as *seksualvejledere*, or "sexual advisers" (the verb *vejlede* means to "advise" or "supervise" in the sense of guiding and offering counsel and support). There are currently nearly 400 certified sexual advisers in Denmark, and three different diploma programs for the qualification exist in the country.

The national guidelines that advise about disability and sexuality are titled *Vejledning om seksualitet: uanset handicap* (Guidelines about sexuality: regardless of handicap). These guidelines offer instructions for how people who work with adults with disabilities can help facilitate their access to an erotic life. The *Guidelines* document begins with an assertion that "People with a reduced physical or psychological functionality [*Mennesker med nedsat fysisk eller psykisk funktionsevne*] have the same basic needs and rights as other people." It then continues:

A significant goal with a social intervention is to improve an individual's social and personal functionality and their possibilities to develop. The intervention shall also help improve the individual's possibility to develop his or her own life by assisting with, among other things, contact and being together with others. This context includes the question of support and help in connection with sexuality.

In the UN Standard Rules for Equalization of Opportunities for People with Disabilities (rule 9), it is empha-

sized that people with reduced functional ability shall have the possibility [*skal have mulighed*] to be able to experience their own sexuality and have sexual relationships with other people, and that they, in accordance with this, shall be supported through legislation and relevant counseling. (Socialministeriet 2001:5)<sup>3</sup>

The document details how this kind of support might be organized. It explicitly prohibits sexual relations between a helper and the person being assisted, it forbids providing sexual assistance to anyone who has indicated in any way that he or she does not want it, and it prohibits any form or sexual assistance with children under 15 years of age. But the following kinds of assistance are permitted: assistance can be provided in learning how to masturbate (*hjælp til oplæring til onani*), assistance can be provided to persons who wish to have sexual relations with one another, and assistance can be provided to contact a sex worker (Socialministeriet 2001:33).

The *Guidelines* document does not make it obligatory for the staff at group homes and personal assistants paid for by the state to carry out any of these forms of assistance. However, it does make it a duty for the person who is asked for assistance to see to it that the adult who has asked for help gets it one way or another. The way this is formulated in the document is as follows: “A helper should be aware that he or she should be able to counsel and support an individual in relation to sexuality. However, a helper may not be ordered by his or her workplace to help an individual learn to practice sex. If a person needs assistance to practice sex, then *the helper, however, does have the duty to see to it that another helper or a qualified expert is referred to that person*” (Socialministeriet 2001:13, emphasis added).

This qualification ensures that the burden of responsibility for securing assistance is not placed on the adult with a disability. In other words, the individual who needs help is not required to keep on asking people until he or she perhaps eventually finds someone who is willing to help purchase a vibrator or assist a couple to lie in the same bed. The person with a disability only has to ask once, and the helper she or he asks is then responsible for seeing to it that she or he gets the assistance. If the helper does not have the expertise or the time to help, or if she or he thinks the whole idea of sex and disability is too problematic to deal with, then it is *that person's* responsibility to find someone else who can help.

How does this happen in practice? How is it possible to facilitate something like masturbation without actually engaging in sex with the person one is assisting?

3. In this article I discuss the 2001 edition of the *Guidelines*, partly because that was the edition in effect when I conducted fieldwork in 2011, and partly because the 2001 edition of the *Guidelines* is more progressive than the version that followed it. The 2001 *Guidelines* document was superseded in 2012 by a new “Handbook” that weakens both the status of the *Guidelines* as well as several of the key formulations I discuss here. See Kulick and Rydström (2015:258–261).

In Sweden, discussions about sexuality and disability run aground on questions like that. No one seems able to imagine that it is possible to facilitate sex for a disabled person without either contacting a prostitute who would have sex with that person (which would mean engaging in a criminal activity in Sweden, because purchasing sexual services or helping someone purchase sexual services is illegal there) or, barring that, by actually sexually servicing the person being assisted. Even individuals in Sweden who recognize and lament the fact that adults with disabilities are impeded from having sex do not consider that helping them have sex could involve something other than prostitution or sexual servicing.

Danes are more imaginative. Here is an example of how it is possible to assist a disabled person to have sex without having sex with her. Helle is a young woman in her late twenties who lives in a group home for adults with cerebral palsy. Helle has no verbal language. The only part of her body in which she has even limited movement is her head. Helle communicates with her eyes, by smiling and making a variety of sounds, and also with the help of a laser strapped to her head that she can use to point to symbols on what is known as a Bliss board (named after the creator of the symbols, Karl Blitz, who fled Nazi Germany and changed his name to Charles Bliss). The following is a plan of action (*handleplan*) for Helle, handwritten by a sexual adviser who works as a social worker in Helle's group home.

#### Plan of Action for Helle Rasmussen

Helle would like help in positioning her sex aid. Helle is laid naked on her bed. A large mirror is placed at one end of Helle's bed, so that she can see herself. A pillow under her knees, legs spread. Put lubricant on the sex aid and on her privates. Place the sex aid on her privates. The helper asks Helle how long she would like to lie alone, 5 minutes or 10 minutes or 15 minutes. Helle will nod at the exact number of minutes she wants. The helper goes back in when the agreed on minutes are up and asks Helle if she is done. If she says no, ask again how much longer Helle would like to lie in bed. When Helle is finished, wash the sex aid and ask Helle if everything is OK.

A “plan of action” like this is made possible by the *Guidelines* document, because that document makes it clear that *persons with a disability are entitled not just to a sexuality but to sex*, and it obligates helpers to be observant about sex and to provide or find someone who can provide help to anyone who expresses a desire for such help. “Plans of action” break down a sexual activity such as masturbation into its component acts in a way that allows a helper to facilitate sex without performing it or without intruding any more than necessary on the privacy of the person who needs the help to have sex. They exemplify a fundamental feature of the help sexual advisers provide: they help individuals have sex, but they do not *have sex* with them—in fact, as I have noted, helpers are

explicitly prohibited by the *Guidelines* document from engaging in sexual relations with the women and men they help.

This means that sexual advisers who facilitate the erotic lives of adults with disabilities are not sex workers or what are sometimes called “sex surrogates.” They are social workers with special training and competence. One reason sexual advisers give for writing “plans of action” like these is that they help guard against abuse—on both sides. If a contract like this exists, the person with a disability has grounds for saying “You transgressed our agreement” if the helper does something not in the agreement. And the person providing the help knows exactly what she or he is agreeing to—she or he can also refuse to do anything beyond what is made explicit in the agreement.

Plans of action like that for Helle are not public documents. In a group home, they are not part of a resident’s file in the way his or her medical needs might be. Instead, they are agreements between a resident and a particular sexual adviser or some other staff member who is willing to assist, and they are kept with the sexual adviser or staff member. If the person receiving assistance ever wanted a copy of such an agreement, they would be given one. What *is* public knowledge among full-time staff in a group home is that particular staff members assist some residents to have an erotic life. This is discussed in staff meetings. So everyone working in Helle’s group home, for example, would know that Helle relies on the sexual adviser who wrote her plan of action, and perhaps several other staff members as well, for assistance with sex. But the details of that assistance—exactly what it consists of, when and how often it occurs—are not known by others.

Agreements like the one with Helle come about through conversations with staff members of group homes, who often take an active role in talking about sex. They organize discussion groups in which men and women sit together in same-sex gatherings and talk about sex, relationships, love, jealousy, contraception, parenthood, and anything else they want to talk about concerning their intimate lives. Some group homes in Denmark stage role playing, where people with disabilities act out scenarios—such as how one manages a situation such as seeing that one’s boyfriend wants to dance with someone else or where one feels attracted to someone but does not know what to do.

Some group homes also have printed policy documents about sexuality that are handed out or read aloud to anyone who moves in. Titled “Sexual Politics of (name of group home),” those documents say things like “All people are sexual beings and have the right to a sexual life,” “If residents ask, staff will help with counseling and the procurement of sex aids, or they will refer the resident to a sexual adviser,” and “Staff are obliged to wash and clean used sex aids for residents.”

Documents like those, together with discussion groups and role-playing sessions, contribute to an atmosphere that makes it clear to residents that sexuality is a possible and acceptable topic of discussion. This, in turn, permits both residents and staff to broach the subject of sex with individuals, some of whom have never discussed sexuality before in their lives.

When Ingrid, a 26-year-old woman with cerebral palsy, moved into the group home she now lives in 5 years ago, she received a brochure like the one just quoted. This led her to ask a staff member about sex, as she explained to me.

I didn’t know I had a sexuality. We had had some lessons about sex in the school for the handicapped I went to, but it was talk about how we had uteruses and would get menstruation. I didn’t know I had a sexuality. So when I got here, I asked, and they told me, “Yes, you do, and you can receive help to explore it if you want, and there is a lot of different kinds of sex aids that are available.” I was really happy [*rigtig glad*] to learn that, because I didn’t know.

### Privacy as a Means of Keeping Things Secret

Sweden lacks a sexual adviser training program and anything resembling the Danish *Guidelines* document. There are historical reasons for this—for example, Swedish disability rights activists never highlighted sexuality, and the key individuals in Sweden who engaged with disability and sexuality during the 1960s–1980s, when the Danish *Guidelines* were being debated and formulated, were concerned with rehabilitation and acquired disabilities, not with people with congenital impairments. Those key individuals lobbied for state-subsidized sex aids, not sexual facilitation. There are also political reasons. The feminist backlash against the sexual revolution of the 1960s was powerful in Sweden, and the version of feminism that since the 1990s has become a form of “governance feminism” in the country attends to sexuality primarily in terms of the danger it is said to represent (Halley 2006; Kulick and Rydström 2015: 232–240). The enduring international stereotype of Sweden as a libertine playground is outdated and wrong. In political rhetoric, journalistic accounts, and popular debate, sex in Sweden today is habitually portrayed as an act that has a great potential to cause harm. Hence, vulnerable people need to be protected from it.

An important cultural reason for the absence in Sweden of anything resembling the Danish sexual advisers or the *Guidelines* document is the pervasive insistence in Sweden that sexuality is “private.” The affirmation that sex is private is partly motivated by the memory of the shameful history of institutionalization that still casts a shadow over how disabled people are treated in society. Until as recently as the 1970s, when the large institutions began to be dismantled, people with disabilities had nothing even approximating a private life. In 1972, a Swedish writer named Gunnel Enby published a memoir titled *We Must Be Allowed to Love*. Enby was a childhood victim of polio, and her book recounted her life in the institution in which she was raised during the 1950s and 1960s. For people with disabilities in that era, independence or privacy was unthinkable. “Let us describe what it was like to be young and handicapped in an institution,” Enby wrote; “How it felt to be put to bed in the afternoon in the summer when the sun was shining on the hospital walls and it felt pretty good to be

alive. The angst that tore at one's chest that made one want to cry out to everybody that here we lie, put to bed for the night at 7 o'clock when the young people in town are just getting ready to go out" (Enby 1972:37).

In the institution where Enby grew up, "One ate on schedule, was washed on schedule, was turned on one's side for the night and given one's medication, sleeping pills and drugs" (38). There was no such thing as privacy: "One isn't allowed to have any personal belongings in the room, except for a photograph and the usual toiletry items. The staff walk in and out without knocking, and one is often forced to share one's room with other patients—rooms that at any rate can't be locked" (1972:66–67).

Given a disturbing, oppressive, and still fresh historical legacy such as this—one that of course is far from exclusive to Sweden—it is understandable that issues of privacy should resonate powerfully for people with disabilities and everyone involved with them and that the right of disabled people to have a private life should be treated with the utmost respect. In Sweden, however, "privacy" tends to be invoked at precisely the moment when helpers might be called on to do something positive or helpful in relation to the sexual lives of disabled people. The point of insisting that sexuality is private seems to be not so much about accommodating or facilitating a private life as ensuring that such a life never emerges.

While maintaining that sexuality is private would appear, on the surface, to express respect for the integrity of people with disabilities, upon closer examination, privacy seems to function more as a shield or a fence to demarcate an area beyond the bounds of engagement.

The way privacy is invoked in Sweden to discourage engagement with the erotic lives of people with disabilities is summed up in a particularly distilled form in a review of two films about masturbation that were scripted by the sexologist Margareta Nordeman in the mid-1990s. Nordeman explained to me that she was inspired to make the films because at every group home or activity center she went to and lectured about sexuality, the problem of masturbation came up, and nobody seemed to know how to talk about it or what to do about it. The films, made with the support of the Swedish Association for Sexuality Education (Riksförbundet för sexuell upplysning [RFSU]) and which came out in 1996, consist of three scenes in which a nondisabled man masturbates to orgasm and three scenes where a nondisabled woman does the same thing.<sup>4</sup> They have been used in Denmark, Norway, and Finland, Nordeman told me. They have even been dubbed into Japanese.

But they were shot dead in the water in Sweden. As soon as they appeared, the films were reviewed in *Intra*, a respected journal for people who work professionally with individuals with intellectual impairments. The two editors of *Intra* excoriated the films, calling them "vulgar and indiscreet" (*vulgär och*

*oblyg*). They wrote that Nordeman and RFSU that financed the films were "clueless" (*aningslös*) and asserted that allowing intellectually disabled people to watch the films could easily be considered a form of sexual abuse. The editors ended their review with these forbidding words:

It is obvious that an intellectually impaired person [*den utvecklingsstörde*] has the right to his or her own sex life. The form that such a life takes is none of the staff or anyone else's business as long as it isn't directly offensive for others. In that case, the person can require help to close the door and protect his or her private life. Because at the end of the day, that is what this is about: that everyone has the right to a private life, and other people's well-meaning advice and meddling guidance [*beskäftiga handledningar*] is often more harmful than it is beneficial.

"The right to a private life" has a very specific, and very circumscribed, meaning here. For adults with disabilities, it means the right to hide sexuality, to keep it secret, to shut it up behind closed doors, out of sight and beyond the awareness of anyone else. For individuals who work with disabled adults, "the right to a private life" means that any attempt to offer advice, guidance, or assistance is not just "meddlesome"; most likely it is "more harmful than . . . beneficial." Privacy, in this understanding of sexuality, implies "don't get involved." It signifies "back off." It means—and the editors actually use this word at one point in their text—"Halt" (Grunewald and Hallerfors 1997).

The notion of privacy also comes up in Denmark when disability and sexuality are discussed, for example, in the "Sexual Politics" brochures handed out to new residents in some group homes as part of their welcome package of information. But in Denmark, labeling sexuality as private does not shield it with the same forbidding armor that bars the Swedish usage. Danish social workers and others use the word "private" to mean "out of public view," as in "Residents who can manage their own sexual needs have the right to do so, in a private space." It also means confidential, as in "Individual residents' sexuality is not discussed, therefore, in staff meetings, etc., unless the resident has requested that it be." What it does not mean is "back off" or "halt." Referring to sexuality as private in Denmark does not consign it to the frozen outer limits of engagement. On the contrary, it configures a space of respect in which particular forms of engagement can occur.

This space is mutually constructed between helpers and people with disabilities even in cases where the person with a disability is quite significantly impaired. The plan of action worked out to help Helle explore sexual pleasure, for example, was a collaboration between Helle, who has no verbal language, and the sexual adviser who helps her. The adviser had long conversations with Helle to determine what kind of sex aid she wanted, and she helped Helle try out several before they settled on the ones Helle liked best. The sexual adviser added some details to the plan of action that Helle had not thought of herself—the instruction that a large mirror be

4. Kulick and Rydström (2015:126–134) is a detailed discussion of these films.

placed at the foot of the bed so that Helle could see her whole body was the sexual adviser's idea, because from many years of experience working with people who had spent their entire lives in beds and in wheelchairs, she knew that someone like Helle had probably never actually viewed her entire body naked.

In Denmark, those who usually take the initiative to discuss sex are the people employed to work with disabled people. They take this initiative because they know that many adults with disabilities have received little sexual education—at most they might at one point have heard the kind of uterus-and-menstruation anatomy lesson mentioned by Ingrid. Individuals who work with people with disabilities also know it is unlikely that many of them will have heard much about sex from the parents who cared for them before they came to live in the group home. Ingrid's surprise to discover as a 21-year-old adult that she even had a sexuality is not an uncommon occurrence among women and men with congenital impairments.

With little concrete knowledge about sex and no language to broach or explore the topic, people with significant congenital impairments are hardly in a position to start a conversation about it, particularly if they sense that the topic is distasteful to, or taboo among, the people employed to assist them. In such a context, Swedish instructions to personal assistants and group home staff not to talk about sex because it is private and because the form that a disabled person's sexual life takes is nobody's business are directives that effectively smother sex under the guise of respecting privacy.

Women and men with disabilities who require assistance to understand interpersonal relations or perform activities such as moving, bathing, and eating often define privacy and respect differently from the people who formulate and follow the rules about such things in Sweden. The disabled adults I spoke to in Denmark did not think it was such a big deal to ask for help with sex, because as far back they can remember they have always had people fussing with their bodies. Privacy in the sense demanded by individuals such as the editors of *Intra* magazine is an impossibility for many adults with significant impairments. They need assistance to undress, to get into bed, to position their bodies, to tidy up afterward. To insist that all this is private and therefore beyond the bounds of assistance is not to do nothing, as the adage that is so popular among Swedish helpers would have it. On the contrary, declining to assist in cases like this is a purposeful undertaking that actively deprives people with significant disabilities of the possibility to experience an erotic life. One man with intense cerebral palsy I interviewed was adamant that such a deprivation is not defensible. "Being able to have a sexuality and being able to explore my sexuality has made me a whole person," he told me, expressing a sentiment that few adults—disabled or nondisabled—could contest, deny, or condemn.

For nondisabled people to recognize not only that people with significant physical and intellectual impairments may have erotic desires but, also, that they require assistance to be

able to understand, explore, and express those desires is to do something important. It is to recognize both a fundamental sameness but also, just as important, a crucial, irreducible difference. The space between that familiar sameness and the in many ways unknowable difference is the space of ethics. It is the space of engagement and extension; the space where privacy and secrecy are disaggregated, not collapsed into one another.

### The Most Agonizing Secret of All

Danish acknowledgment that adults with significant disabilities can have erotic desires illustrates how the separation of privacy and secrecy can facilitate modalities of engagement and processes of change that are thwarted if one insists, like Swedes such as the editors of *Intra* do, that privacy and secrecy are synonymous. One realm where the collapse of privacy into secrecy produces particular anguish in relation to disability and sexuality is in the relationship that can develop between disabled individuals and their parents, as children mature into adolescence.

Parents of disabled children often find themselves having to become engaged in the sexuality of their children in ways they are not prepared for and that they find deeply discomfiting. They may have to deal with issues such as inappropriate language or public masturbation, or with the distress of trying to make sure that their intellectually impaired daughter is protected against possible pregnancy. Most disturbing of all, however, is the way that the love and the intense emotional and physical bonds that severely impaired children have with their parents—particularly, in most cases, their mothers—can transform as the child matures into an adult and begins to express an interest in sex. Especially in cases where the child has intellectual impairments, the boundary between care involving things such as bathing, dressing, or going to the toilet and erotic satisfaction can become murky, sometimes putting the mother in an intolerable situation.

This infected dimension of care for a disabled child—particularly a disabled son—is a source of tremendous shame among mothers. I came to learn that parents do not discuss this aspect of their child's sexuality with anybody, including with other parents of disabled children. One mother who is the exception to that rule, however, is a well-known Danish actress, Lone Hertz. In 1992 Hertz published *Sisyfosbreve* (The Sisyphus letters), a memoir about raising and living with her son Tomas, who has severe autism. The book discusses struggles, breakthroughs, emotions, and relationships that will be familiar to many parents of children with significant disabilities. But a part of the book that makes it unique is Hertz's insistence on also discussing sexuality. She relates in some detail how the love between her and her son gradually came to be eroticized as Tomas grew older and entered adolescence. Their relationship reached a crisis point when Tomas, who at the time was sixteen or seventeen and twice his mother's size, had an epileptic seizure in the middle of the night.

Hertz heard Tomas flailing about, and she rushed into his room, half-naked, throwing herself on her son's bed in order to help him as she had always done. "It's important to hold your arms," she writes in the narrative mode of direct address to her son that she uses throughout the book, "so that the convulsions don't wrench your shoulders out of their sockets, and to wipe your mouth regularly so that you don't choke on your vomit. And to push all the blankets and pillows out of the way, so that they don't get drenched in pee when the convulsions wear off and your bladder becomes slack and empties. I'm always thankful when that happens, especially if you don't defecate, too." That night, Hertz continues,

You came out of it and became clear minded sooner than you usually did. You pulled me down into bed so that I would lie with you and take care of you like I've always done in all the years of your convulsions—often they come back, several in a row. That night you wouldn't let me pull up a blanket around me, you kept pulling it off and throwing it out of the bed. I tried not to resist, because I was familiar with your mood swings that almost always followed right after a seizure. I feared them more than the convulsions. You became unpredictable and despotic. I needed to calm you down and not provoke you.

I tried to play, like it was a game of exchange, so I took your blanket, but the game didn't work. You made your darkest sound, a throaty howl that I felt was a warning. You took my arm and threw me up against the door, and you pressed up against me . . .

I had thrown my undershirt on, because this was very wrong, I knew that. I understood that. You stood there naked, with an erection, and touched yourself. Not violently, more like searchingly, innocently, like you were trying to find some answer there. You stood and looked at me, sat beside me, and lay down on top of me. Like you were in doubt, like you were trying something out. I let you take charge and I tried to keep calm and collected, emotionless, to pretend that it wasn't me. But during all this I knew that unless I took control somehow, this would end very badly. You had so much strength and an enormous desperation. If nothing else, the whole thing would have ended very badly for me. I tried to tell myself that I was just imagining this, that you didn't have these wild feelings. That this wasn't really happening. That it wasn't you I was afraid of, I was afraid of my own apprehension. But that wasn't true. I was afraid of you, Tomas. It's pitiful to be afraid of your own child. I forced myself to be calm. I spoke calmly to you at the same time as I edged toward the door. And with an awkward kind of shrimplike flip, I was out in the corridor, where I tried to turn the key to the door. You ran after me with surprising energy, you grabbed the door so that I couldn't lock it. We pulled back and forth on the doorknob, like a parody, and you shrieked and roared, until I couldn't take it anymore. I don't know how I did it, but suddenly I gave you

a big push into the room, and I turned the key and pulled it out.

In the middle of all this horror, Tomas, the saddest part of all is perhaps an admission I have to make to myself that my work as an actress stayed with me, even in that "naked" situation that we were both in there. Despite the despair, I was coolheaded enough to think, in the middle of it all, that I really need to remember this, in case one day I should play a scene like "mother with a psychotic son." (Hertz 1992: 304–306)

Here, and in several other places in *Sisyfosbreve*, Hertz discusses, with the kind of tough wryness she displays here, the anguish she felt in relation to her son's developing sexuality. She felt desperate as she came to understand that her son wanted to have sex with her, and she felt utterly forsaken as she realized that there simply was no one to whom she could turn for help or advice. In the mid-1980s, when Hertz was confronting Tomas's sexuality, Danish professionals were still uncertain about how to engage with the sexuality of people with significant disabilities. The *Guidelines* document was just being formulated, and at the time there were as yet no certified sexual advisers who could offer a mother like Hertz any meaningful guidance about sex. In the end, she sought help in the only place she could imagine finding it—she helped Tomas purchase sexual services from a sex worker.

Lone Hertz may be unique in publicly airing some of the normally unspeakable issues that can arise between parents and their children who have significant impairments as the children enter puberty and begin to seek ways of understanding and expressing their erotic desires and needs. But Hertz is far from unique in having the kinds of experiences she describes.

Gull-Marie is a soft-spoken, matronly Swedish woman in her fifties. She has a son in his late teens who has been diagnosed with a condition she described as a combination of mental retardation and autism (*en utvecklingsstörning med autistiska drag*). She and I had been talking about the differences between Sweden and Denmark, and I had just mentioned that it did not seem to me that in Sweden parents were given much information or advice about disability and sexuality. This remark seemed to unleash something in Gull-Marie. She became flustered, and she spoke quickly, in a gush. "I think it's terrible, completely, awfully terrible [*jobbigt, helt frukstansvärt jobbigt*]," she said. "It's exactly like you say. When he was a teenager," she said, talking about her son,

He started to masturbate everywhere. And it's hard as a mother. You move to a new neighborhood . . . he likes to be on the playground where children are. I went around and knocked on all the neighbors' doors and told them—because I thought it's better to be open about it. Then the parents won't be scared, anyway, and they'll come to me if anything happens.

I looked everywhere for help, everywhere. Doctors, everywhere, and everybody said the same thing: "We don't



know what to do.” Or else they said, “It’ll pass when he’s no longer a teenager.”

But what was I supposed to do? I couldn’t follow him around everywhere and guard him. He just disappears from home sometimes, and I don’t know where he goes, and you can imagine, before I find him . . . I don’t know what anyone has done to him, or what he has done to anyone, you know?

But then I talked to a sexologist—who was from Denmark, in fact—and she said, “Has he ever ejaculated?”

“I don’t know,” because I said that he can carry on for hours.

And she said, “You have to help him to ejaculate.”

Gull-Marie paused here and looked at me with an expression that was both plaintive and resigned.

It feels very strange to hear that as a mother, you know? But I went around and thought about it all the time and I thought, “I’ll ask his brothers.” He has two brothers who aren’t disabled, and I thought they could help him in the sauna or somewhere. They wouldn’t. My husband wouldn’t help him either.

So I thought, “Well, the only one left is me.” I was so afraid—you know how it is here in Sweden with people phoning up the police and everything. And so I talked to him and I thought to myself, “Now, today, I’m going to do it.”

On the day I thought that, he comes out of his room and says, “Mama, mama, this white stuff came out of my wiener” [*snoppen*].

And so I didn’t have to do it.

Gull-Marie’s story articulates a dilemma so sensitive and traumatic that it is hardly surprising that parents who share dimensions of her experience do not often talk about it, not even with one another. The love that a mother has for her child and the desire to keep him out of harm’s way—and to keep him from harming others—becomes explicitly linked, in a situation like this, to satisfying him sexually.

The advice the Danish sexologist gave Gull-Marie is common in these kinds of contexts (e.g., Johansen, Thyne, and Holm 2001:136; Nordeman 2005:68–69; Vallberg 1982:89–93). The theory behind the advice is that some young people with intellectual disabilities have a difficult time discovering on their own that masturbation can actually result in something pleasurable. “Many mentally retarded people [*udviklingshæmmede*] get afraid when they feel that it starts to tingle [*kilde*] and that sort of thing,” one sexual adviser told me. “They think, ‘What’s going on?’” So they stop or they redirect their focus without ever understanding that manipulating their genitals can have a purpose and an endpoint.

Danish sexual advisers recommend that individuals who seem to have that problem be taught to masturbate. If this cannot be done through verbal counseling alone, then other methods are sometimes used—one sexual adviser said he has

helped some men learn to masturbate by writing a plan of action that permits him to sit in the same bedroom with the person he is helping. The sexual adviser holds a dildo, which he strokes to demonstrate to the person learning to masturbate what to do. That person then imitates the adviser’s actions on his own penis. Sexual advisers say that once individuals discover that masturbation has a purpose, they can be taught to go into their bedrooms or some other private space when they feel like obtaining sexual pleasure.

Unfortunately, when the individual who has the problem understanding masturbation does not live in a group home in which a Danish sexual adviser or someone else with knowledge of these issues is employed, the delivery of advice such as “You have to help him to ejaculate” is often accompanied, as it was in Gull-Marie’s case, with no further counseling or practical help. Mothers like Gull-Marie are left on their own.

What some mothers in Denmark do decide to do is publicly insist that their children’s sexuality is not their responsibility. This was one of the reasons why Lone Hertz discussed her son’s sexuality so candidly in *Sisyfosbreve*—she wanted public acknowledgment of the predicament she depicted, and she wanted help, for herself and other mothers in similar situations.

The director of a Danish group home for adults with cerebral palsy once recounted to me her personal encounter with a mother who had a similar message. This director remembered very clearly that one of her first encounters with the sexuality of people with disabilities occurred in 1988, when the group home where she still works was built and residents started moving in. The mother of one of the young men who moved in insisted on having a meeting with all the staff members. The director recalled,

She sat there, the mother. And she says, “There’s something I want to say to you all”—and we didn’t even know one another, we had just all started together in this completely new group home. “One thing I want to say to you. My son has tried going to a prostitute, and it was good for him. You all need to damned well follow up on this.” His mother said that. She slammed her hand down on the table and said that. And so we were all forced to figure this out, even though we didn’t even know one another and we’d never even spoken about things like sexuality.

The director said the mother’s insistence that the group home staff acknowledge her son’s sexuality was the spark that led to conversations and to engagement with the sexuality of the residents.

We began to develop some basic policies around sexuality. And then after about 2 years, the same woman’s son got a girlfriend, who was also in a wheelchair. And they wanted to have sex. That was a bit difficult because they weren’t able to do it by themselves, and at that time the idea that we might go in and help them was really new.

And so in comes his mother again. And she says, “They want to have sex. Surely it can’t be reasonable that I, his mother, should be the one to go into his room and lift them up onto and down from the hydraulic lift. That’s your job. I don’t want to know anything about it. Because I am his mother. I shouldn’t have to have anything to do with this. But you should.”

“She was fantastic,” the director said of this cantankerous, plainspoken woman. “She was completely adamant.” This adamant mother also illustrates the way that parents can use their status as parents to bring about change. The ingenuous argument that “surely it isn’t reasonable” to expect a mother to get actively involved in her child’s sex life is a difficult one to counter. By declaring that she was not going to accept that a private activity like sex should also be a secret, this mother was delegating responsibility and demanding that others engage with both her and her son.

That simple declaration demonstrates the significant power that parents can have in contexts such as these to compel others to take seriously the reality of their disabled child’s sexuality and to devise ways of helping to facilitate an erotic

life. It demonstrates the kinds of changes that become imaginable when the social distribution of secrecy is made explicit, and thereby challenged.

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