

contemporary sexuality

The international resource for educators, researchers and therapists

CURRENT
ISSUE | **June 2015**

What Able-Bodied People Should Know About Disability and Sexuality

This summer—August 3-6 in St. Louis, MO—AASECT presents its latest [Summer Institute, The Sexual Kaleidoscope: Sexual Expressions for All Abilities](#). In its focus on disability, Institute planners intend to examine sexuality through the lens of people with physical, emotional, intellectual, and developmental disabilities, and with chronic illnesses. And while, on the one hand, this is meant as an opportunity for sexuality professionals to expand their skill set in working with the various things that can have an effect on our sexual lives, not all of the lessons to be learned come from sexuality professionals working in this area. Those who are disabled also have a lot to teach us about intimacy and sexuality. After all, "You don't have to break your neck to be a great lover," says Mitchell S. Tepper, Ph.D., M.P.H., co-director of this year's Institute, "but you can learn a lot from someone who has."

What Able-Bodied People Should Know About Disability and Sexuality

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Which is something people may find surprising. In fact, in a 2010 research paper published in [Disability and Rehabilitation](#), it was reported that individuals with disabilities are often viewed as asexual, due primarily to an idea of what constitutes "normal" sex, and also to the fact that many with disabilities are forced to operate outside of this box. The authors of this paper also reported that those with disabilities often internalize this stigma.

Only adding to this skewed self-perception is the high level of contact those with disabilities tend to have with medical professionals, due to the need for various medical treatments and surgeries. When one's relationship to the body revolves around health and safety, it can be difficult to see the importance of concepts like pleasure and intimacy.

Marylou Naccarato, DHS, ACS, CSE, on the faculty of this year's Summer Institute, echoes this point. "Because of this [reliance on various medical treatments]," says Naccarato, "the body may not be looked at as a source of pleasure but, rather, as a source of pain and embarrassment." Naccarato—a little person who began her career as a sex educator about 10 years ago—wanted to address this issue, and to help other little people with their desires because, due to this trend toward desexualization, she found that no one else was talking about it.

Chris Worth, a community organizer and an organizing team manager at Paraquad Inc. (an independent living center in St. Louis), born with cerebral palsy, who also identifies as queer, expands upon this idea, speaking of how people tend not to think of those with disabilities as sexual. He speaks of how, without this basic starting point to work from, it

can be difficult for those with disabilities to tackle some of the more complex questions about sex and sexual identity.

"When I came out of the closet as to who I was," says Worth, "first to my parents and then later when I was in my early 20s, other members of the 'gay' community freaked out because all of a sudden they realized I was sexual. And I wasn't sexual in the sense that I was subscribing to labels like straight, bisexual, or gay. I've never seen myself as completely heterosexual or homosexual. In the beginning, I switched back and forth between gay and bisexual. I know now that it's okay to be who I am."

Worth continues: "In truth, the hardest thing to 'come out' as was as a person with a developmental disability who was sexual! The thing is, I was given that opportunity. Could you imagine if someone is never given the opportunity to define that for themselves? That's amazing to me."

Worth continues to speak of those initial obstacles. "I've always been very engaged in the idea of sexuality not as something sterile and separate from who we are, but something that plays a part in everything we do," he says. For those with a disability, Worth explains, "sex is left out of the conversation much of the time or, if it's there, it's sterile, clinical."

As a result, it can be difficult to get past that initial barrier of not being seen as a sexual being. And once that hurdle is overcome, it can be just as difficult to find information on exploring sex as someone living with certain limitations.

"People who are born with disabilities get this impression that they're not normal," says Tepper, "because normal is this other thing they see around them. They don't see a depiction of themselves. There is a longer period of time before their first date, their first kiss, their first instance of intercourse."

And when they do begin to learn about sex, it may be from the perspective of abstinence-based sexuality education, with a focus on disease prevention which, while important, does not always lead to that related conversation about pleasure and intimacy.

"Fearmongering about sexual disease isn't really going to teach people how to be sexual beings," says Worth. "In fact, it's probably going to make them go further in the opposite direction than is healthy."

And this access to a very skewed picture of sexuality can affect one's body image and sense of self-worth. Tuppy Owens, Ph.D., another faculty member for the Summer Institute, and the founder of [Outsiders](#), a social club for people with physical and social disabilities,

addresses this issue. "For much of their lives," says Owens, "they may have been unable to accept themselves, let alone other disabled people. One of the first lessons is to learn self-acceptance and gain a positive body image."

Naccarato adds to this: "I often tell my clients when we talk about body image: I accept my body as imperfect. It gives me breath and it gives me life. What matters most is how I carry myself, not how my body carries me."

Once one has managed to contend with all of these negative messages, and to embrace the importance of sexual exploration, one is forced to grapple with the logistics of sex itself, perhaps redefining what sex means to them.

For example, in Naccarato's work with short-statured people, she has learned that a common problem is an inability to reach their genitals. "Most people don't realize this and they don't talk about it," says Naccarato. "And people who can't may have had a lack of experience while growing up in learning how to masturbate and touch themselves so, because of that, there might be some sexual immaturity in understanding what is pleasurable as they become adults. It doesn't mean they don't have any desires. It's just that they weren't able to explore that like everyone else."

In fact, in surveying 48 little people, Naccarato found that 25 percent [could not reach their genitals](#) (though Naccarato feels that if she were to sample a larger population of little people, the percentage would easily be much higher—perhaps even closer to 50 percent—based upon her observations of the most prevalent genetic dwarfism types who commonly have very short limbs). Of these 25 percent, only 11 percent felt they were sexually satisfied. As a means of working with this particular limitation, Naccarato scours the sex toy market, looking for toys that are longer or differently shaped that might enable those she works with to follow that path of sexual exploration. This is just one example of how those with certain disabilities are forced to think outside the box.

Because of this, much of our discourse on disability and sexuality is, understandably, centered upon those living lives of limitation. But considering the ways in which those with disabilities are forced to look at and approach their intimate lives in a different way—grappling with basics that able bodied people perhaps take for granted—there is actually much that able bodied people can learn from their sexual relationships.

"It forces you to be more creative in your sexual expression," says Tepper, who suffered a spinal cord injury later in life, of pursuing intimacy with a disability. "It forces you to adapt to new situations. It forces you to communicate more. It forces you to have a sense of

humor."

"You can realize there are other pathways to sexuality and intimacy and pleasure," adds Naccarato. "You can utilize other areas of your body and use other techniques. It's easy to get stuck in a routine where you're not trying different ways of doing things," she says, giving voice to a common lament among those who may not give as much thought to the question of how they approach sex.

Owens builds upon this idea of trying new things and moving past goal-oriented sex, a concept those with disabilities may be forced to let go of, perhaps for the better. "Orgasm isn't always the end game," says Owens. "It's about enjoying the sensation of what they can actually manage to do. Tantric practitioners teach people to love their own bodies and enjoy goal-free sex. They also support clients to gain pleasure from their various erogenous zones so that a quadriplegic might, for example, experience orgasm from the stimulation of the nape of their neck."

And speaking of erogenous zones, those who are disabled find that a heightened familiarity with their body helps them find these new pathways to pleasure. Owens speaks of this added advantage, saying that disabled people have mentioned to her that having a catheter or having a particular part of their body that needs their attention "forces them to actually know what their bodies do and how they work far better than most people. Being more aware of your body, instead of squeamish and prudish about it, is something we should all aim for."

"I think also what it does is it teaches people how to have patience with themselves and not get so frustrated," says Naccarato, touching upon more of the general lessons able-bodied people can learn from those with disabilities. "There can be a lot of performance anxiety in the general population. People with disabilities have to learn how to adapt and how to have patience. They have to learn how to not get frustrated so easily. They have to learn tenacity and persistence in order to make things work for them."

And then there is the issue of communication, a common barrier to optimal sex for many people. "I think it teaches people how to talk," says Naccarato. "If a person has a disability and needs help with something, they're more likely to ask for help."

For example, "people with Asperger's syndrome learn that they've got to say to their partner what they would like to happen," says Owens. "They're taught to always say specifically what they like, which is probably a good idea for most couples."

In addition, "some disabled people have to re-assess what sexual interactions with a partner might be best for them, which able-bodied people rarely have to do," says Owens. "What disabled people gain from this is a refreshed level of intimacy involving discussions, laughter, experimentation, and the tremendous feeling of being on a sexual journey."

Unfortunately, it is rare for an able-bodied person to be particularly educated about intimacy among disabled populations, usually because they feel it's not relevant to their lives. But, says Naccarato, "You can become disabled at any time from an accident, an injury, an illness."

"We're also living longer," she points out. "So it's likely that either you or someone you know is going to acquire a disability or an illness or a health issue or chronic pain."

"It [disability] can affect anybody at any time," continues Naccarato, "and you might be in the position where you might be that person's partner or it might be you. So it would be good to understand that there are options so, if you or your partner do lose certain abilities, you don't think your sex life is gone. You lose a limb or you lose a function later in life and it's like going through the stages of death and dying. It's very real and it can happen to anyone. Suddenly, your life is different."

"We don't tend to question things until there's a problem," says Tepper. "When we acquire a disability, we need to look other places if we still want pleasure in our life. We need to look inward. We need to look around, look other places. We need to learn things that, previously, we didn't have a need to learn."

This year's Summer Institute will be an ideal jumping off point for those who have not previously spent a lot of time building their knowledge in this area. And hopefully, it will only be the beginning of a larger, ongoing conversation.

Additional Reading and Resources for Those Interested in Learning More:

- [Outsiders](#)
- [Sexual Health and Disability Alliance](#)
- [The Sexual Respect Tool Kit](#)
- [TLC Trust](#)
- [Ask a Sexual Advocate Professional](#)
- [Little People of America](#)

- Carol Queen's *Exhibitionism for the Shy*
- Bob Guter and John R. Killacky's *Queer Crips – Disabled Gay Men and their Stories*
- Alex Comfort and Susan Quilliam's *The New Joy of Sex*
- Paul Joannides's *Guide to Getting It On*
- Miriam Kaufman, Cory Silverberg, and Fran Odette's *The Ultimate Guide the Sex and Disability*
- Charles Moser's *Health Care without Shame*
- Tuppy Owens's *Supporting Disabled People with their Sexual Lives*
- Mitchell Tepper's *Regain that Feeling*

And for Those Interested in Attending This Year's Summer Institute:

Disability is a universal human experience that is sometimes permanent, sometimes transient. It is not something restricted to a small part of the population. Examining sexuality through the lens of people with physical, emotional, intellectual and developmental disabilities, and chronic conditions will add a new dimension to your practice; expand your skill set; and open your eyes to new possibilities, making you an even better educator, counselor, or therapist for all clients.

The faculty for this year's Summer Institute includes:

- Ellen Barnard, MSSW
- Marylou Naccarato, DHS, ACS, CSE
- Christina Meneses, MSW
- Mary Jo Podgurski, RNC, Ed.D., CSE, CSC
- Tuppy Owens, Ph.D.
- Mitchell Tepper, Ph.D., MPH, CSE, CSC, CSES

Co-directors:

- Susan Stiritz, Ph.D., MSW, CSE, CSE
- Jessica Naslund, MSW, CS
- Mitchell Tepper, Ph.D., MPH, CSE, CSC, CSES

The Summer Institute will garner you 21 AASECT CE Credits. AASECT Member tuition is \$800. Non-member tuition is \$900. Student Member tuition is \$500. Tuition includes two lunches and one starlit rooftop dinner on the rooftop New Moon Terrace of the Moonrise

Hotel, overlooking the Delmar Loop, with the St. Louis Arch in the distance.

You can find the Summer Institute schedule and registration information [at the AASECT website](#). Registration is open May 1 - July 31. The Institute is limited to 50 participants. The Summer Institute is hosted by the Brown School, Washington University in St. Louis.

The Institute hotel is the Clayton Crowne Plaza, with charges of \$109 for a single and \$114 for a double. Transportation to and from the airport and to Brown School, and full breakfasts, are included. For more information, contact Susan Stiritz at [sstiritz@gmail.com](mailto:ssstiritz@gmail.com) or Jessica Naslund at jnaslund@ywcastlouis.or.