

Sexual Expression, Health, and Relationships of Persons with Disabilities

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People with disabilities were created as sexual beings, just like people without disabilities. Many caregivers and many family members (and the public at large) assume that a person's disabilities preclude any interest in or about appropriate sexual expression, health, and relationships – when nothing could be further from the truth. It may be more challenging to discuss these matters with a person who has one or more disabilities, but that is no excuse for ignoring this basic human need or hoping it will never become relevant in the person's life.

The failure to address these issues appropriately can lead to numerous adverse outcomes, including peer-to-peer sexual abuse, breaking societal "rules of sex," or even criminal liability and a lifelong label as a sexual predator. People with disabilities deserve mutually fulfilling interpersonal relationships – with or without sexual expression – but many must be taught how to engage with others in this sensitive area.

Persons with Disabilities Need to be Taught "The Rules of Sex"

In her seminal publication "The Rules of Sex: Social and Legal Guidelines for Those Who Have Never Been Told," Dr. Nora Baladerian highlights a commonsense conclusion: if no one discusses the "rules of sex," a person will not know what sexual behavior is "okay" and "not okay." An untaught person may unwittingly break a societal rule of sex and face long-lasting consequences for the legal or social conduct violation. For many persons with disabilities, asexual act in and of itself is generally not the problem; rather, not knowing where it should be done, when it should be done, and with whom it should be done is typically the root cause of breaking the rules of sex. Legal or social rules that a person with a disability unknowingly violates on the where-when-with-whom spectrum are stumbling blocks for many persons whose parents or guardians feel ill-equipped to impart this important knowledge.

Dr. Baladerian's workbook answers in "plain English" some of the most frequently asked questions about sex, which can be comprehended by persons 18 years of age or older, with or without intellectual or developmental disabilities. The Rules of Sex workbook is mercifully easy to work through, even for those neuro-typical adults who never got "plain English" answers to these questions when they were children. Those questions include the following:

- What is "having sex"?
- Who can you have sex with?
- What happens if you have sex?
- Can I have sex in my bedroom?
- When is it okay to touch someone?
- When can you talk about sex?
- What is "privacy"?
- What are my "sexual rights"?
- Where can I do sexual things?
- What kind of sex is against the law?

Studies have shown that the failure to educate persons with disabilities about the societal "rules of sex" increases the likelihood that they will perpetrate sexual abuse on their peers or other persons. If parents or guardians cannot (or will not) impart this education, there are many licensed psychologists, certified sex therapists, and certified sex educators to whom this task may be delegated. Appropriate sex education is also essential for persons with disabilities to recognize and articulate their sexual preferences (and to determine what kinds of sexual expression are not for them). People with disabilities of all ages are thinking about sex and are having sex, whether or not their parents or guardians are comfortable with that reality.

Sexual Health of Persons with Disabilities

Medical professionals who work with persons who have disabilities have long recognized that such persons are sexual beings (just like everyone else). However, there are many impediments to the healthy sexual development of children and adolescents with disabilities, including:

Societal and psychosocial barriers.

- The often unpredictable timing of puberty.
- Inaccessible medical equipment, including examination tables, weight scales and imaging devices.
- Lack of appropriate routine and preventative gynecological and urological care.
- Lack of examination adaptations to accommodate the person's physical or neuromuscular challenges.
- Lack of information regarding abstinence, contraceptives, and the impact of contraceptive drugs on a person's overall health.
- Historically inappropriate imposition of sterilization as the default approach to preventing persons with disabilities from procreating.
- Lack of "developmentally appropriate" sex education for persons with disabilities.
- Complete avoidance of topics such as sexual orientation, gender identity, sexually transmitted diseases, contraception, and abstinence.
- The failure of IEPs (Individualized Education Programs) to require developmentally appropriate sex education for students with disabilities.
- The adverse impact of the cultural, religious, and personal experiences of parents or guardians on their willingness to facilitate the sexual education of their children with disabilities.

Regular and preventative medical examinations of a person's reproductive body parts and systems contribute to their overall health. They may even lead to the discovery of past or ongoing sexual abuse. Finding medical providers of sexual health care for persons with disabilities can be a challenge. The American College of Obstetricians and Gynecologists recommends regular screenings of persons with disabilities for cervical cancer, breast cancer, prostate cancer, and sexually transmitted diseases. These tests are just as essential for persons with disabilities as for persons without disabilities, due to a similar incidence of these conditions in both populations. However, because many medical providers see people with disabilities as "asexual" patients, they neglect to ask about the person's past or present sexual activity, or any history of sexual abuse, nor do they routinely recommend such regular screenings for diseases of their sexual body parts.

Medical providers often fail to consider that a patient's atypical physical symptoms could indicate underlying problems with their sexual health (e.g., abdominal pain that could be a symptom of a sexually transmitted infection). At a minimum, medical providers and their staff should be prompted to ask if a patient with a disability: has special needs or

circumstances that must be accommodated before and during a physical examination; needs a longer appointment to address their unique needs during an examination; needs an accessible exam room with adaptive equipment; or, requires assistance with safe transfer techniques to position the patient on an examination table or platform scale.

Advising the medical provider of the anticipated presence of one or more support personnel during a scheduled examination can be essential to the visit's success.

Sexual Relationships of Persons with Disabilities

For many families, their child or loved one with a disability is first exposed to sexual relationships and encounters at a traditional college or university, or during an inclusive post-secondary educational program hosted at a campus environment. The National Council on Disability has issued reports about the scope of sexual assault on campuses as it pertains to students with disabilities, as well as the programs and policies maintained by educational institutions to minimize sexual assaults on campus and to address those that do occur. Federal efforts (including the Department of Justice and the White House Task Force to Protect Students from Sexual Assault) have repeatedly excluded disability status as a demographic in sample "campus climate surveys."

A recent study by the Association of American Universities did include disability status as a relevant demographic, finding that one-in-three female undergraduates with a disability reported non-consensual sexual contact involving physical force or incapacitation (compared to one in five female undergraduates without a disability).

Although modest strides have been made on both the federal and state levels regarding the development and enforcement of sexual assault policies (including reporting, investigating, and redressing sexual assault on campus), many barriers remain for victims of on-campus sexual assault, often stemming from accessibility challenges and a lack of relevant accommodations. Many colleges fail to identify students with disabilities as a population at increased risk of sexual assault, nor do they recognize the consequent need for novel programs and policies to address their unique vulnerabilities. Before students with disabilities formally enroll in colleges or universities of interest to them, families should conduct rigorous research regarding the efforts of each institution to implement effective and robust sexual abuse prevention policies and to offer resources and accommodations that are appropriate for and accessible to individuals with disabilities.

Even if students with disabilities are well-advised about the relevant federal, state, and local laws regarding the prevention of on-campus sexual assault and the remedies and

rights of the victims of sexual assault, personal counseling customized for each student may also be essential to minimize this risk. Such counseling often includes an assessment of whether a student with a disability has the capacity to consent to sexual activity under relevant state statutes and case law (which can vary widely). Professionals skilled in the fields of disability, psychology and forensic interviewing are trained to apply a standard by which a person's capacity to consent to sexual activity can be accurately measured by direct appropriate questioning about sex.

Finally, it is essential to maintain an ongoing dialog with students while they are attending an on-campus program regarding their sexual safety (as awkward as that may be). Families need to remind themselves continually that all students – with and without disabilities – are exposed to and exploring sexual behavior.

Many of the inclusive post-secondary educational programs for students with disabilities offer specific courses on developing appropriate peer-to-peer friendships and intimate relationships as part of a "life skills" curriculum (from which many neuro-typical students also could derive great benefit). Thus, an increasing number of people with disabilities are entering into civil unions (most of which do not involve marriage) and establishing households together. Whether or not their extended families approve, these unions often involve consensual sexual relationships (and occasionally result in the birth of children). Even in the context of communities comprised exclusively of persons with disabilities, residents are having sex (notwithstanding a community's formal "No Sex" policy).

Although staff counselors can make some progress with residents, supplemental input from supportive family members, parents, and guardians is frequently needed to help persons with disabilities protect themselves from unhealthy personal and intimate relationships in such settings. The first step towards this end is to acknowledge that: talking about sex is difficult and awkward; people with disabilities will have sex whether or not they are counseled about it; and families and clients need our guidance and support on their journey in assisting loved ones with disabilities to establish healthy sexual relationships.

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