

Americans with Disabilities Act removes barriers for wide range of patients

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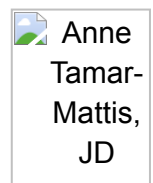
Nicole is a young woman with complete androgen insensitivity syndrome who is about to head off to college. She is also thinking about starting the process of dilation to enlarge the shallow vaginal opening she was born with as a result of her condition. She may need to spend several hours a week attending to this intimate procedure, and she is apprehensive about how she will accomplish this in a dorm setting with roommates.

When I learned of this problem in the course of consulting with her family about an unrelated legal matter, I suggested that she could ask her doctor to write a letter to her university requesting that she be given a private room as a reasonable accommodation under the Americans with Disabilities Act. Nicole and her parents were surprised to hear of this option — they had never considered androgen insensitivity syndrome (AIS) to be a disability.

...Broad reach of the act

For many, the term “disability” calls up very specific images. The most obvious effect of the Americans with Disabilities Act is in the proliferation of accommodations such as wheelchair-accessible spaces and Braille signs, but the Americans with Disabilities Act is meant to ensure opportunities for full participation in society for all people with disabilities, not just those with visible or major disabilities.

The definition of disability in the Americans with Disabilities Act includes impairments that limit endocrine, reproductive and genitourinary functions. The degree of impairment can be fairly minor. For example, the need for daily medication may indicate an impairment, even if the person functions quite well when taking the medication. Under this definition, it seems that AIS would qualify for protection, along with most other differences of sex development (DSD) and many other medical conditions encountered by endocrinologists.



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It is helpful for medical providers to have a sense of when a patient’s medical issues may trigger Americans with Disabilities Act protection because, similar to Nicole’s family, many are not aware of the broad reach of this law. If a person’s medical condition meets the definition of a disability under the Americans with Disabilities Act, then she is protected from discrimination on the basis of that disability by employers, schools, public accommodations, government agencies and commercial facilities. These entities must also make reasonable accommodations or modifications to policies to enable participation by those with disabilities.

Range of protection

To make this a bit more concrete, I will provide some examples of how the Americans with Disabilities Act can work to make life easier for those with DSD. I am focusing on DSD because it is my area of specialty, but the rules apply to a range of other conditions that endocrinologists encounter.

Kayla is a 4-year-old with congenital adrenal hyperplasia (CAH). Her parents wanted to enroll her in a private nursery school. However, when the school learned about the possibility that Kayla would experience adrenal crisis, they told her parents they were not prepared to accept the responsibility and refused to take her as a student. They were unwilling to talk with her parents or doctor about potential strategies for management.

When Kayla's parents spoke to a lawyer, they learned that her CAH probably qualified as a disability under the Americans with Disabilities Act because it substantially limits her endocrine function. Although the school would not be required to enroll a student with a serious medical condition that they were truly unable to handle, they were obligated to individually assess Kayla's situation to see if there is some reasonable accommodation that would make it possible for her to safely participate. For children with mild-to-moderate CAH, it ought to be possible for most schools to arrange a strategy that would allow participation.

Steve was born with partial AIS. He and his wife wanted to adopt a child through open adoption. When the adoption agency requested a medical history from his doctor, it learned that Steve had been assigned female at birth and reassigned as male early in his childhood. The agency then told Steve that it did not think birth parents would be comfortable choosing someone such as him as an adoptive parent and refused to serve him. Under the Americans with Disabilities Act, it is likely that this would be considered impermissible discrimination. Steve's doctor recommended that he consult an attorney.

These examples give a sense of the range of situations in which the Americans with Disabilities Act may provide some protection for those with DSD or other medical conditions. When doctors recognize that their patients have faced discrimination or that there are obstacles to their full participation in society that could be removed, it can be helpful to point out the broad coverage of the act. Although a letter from a doctor is not required in all cases, such a letter can often do a lot to smooth the way.

Strategic communication

It is important to be strategic about how medical information is communicated in these cases to protect the patient's privacy and minimize stress on the patient and family. In Steve's case, for example, his doctor had offered too much information on the medical history by going into detail about his history of gender misassignment. The adoption agency was looking for information about his ability to care for a child, and that particular detail was not relevant. If the medical history had been limited to the minimum information necessary, the discrimination may never have occurred.

For Kayla, the school may need very specific information about how her endocrine disorder is managed on a daily basis, but it probably does not need to know about any history of genital atypicality. In Nicole's case, school officials may wonder why a young woman with no visible disability would need a private room, which could lead to intrusive and unnecessary questions. A letter from a physician, simply stating that she has a medical condition and requires privacy for her daily care may forestall questions and get the university

focused on providing the needed accommodation. In most cases, it is a good idea to focus on verifying the medical need for accommodation, rather than offering unnecessary details about the particular medical condition.

In some situations, self-advocacy, even with support from a doctor, will not be enough. If patients continue to encounter unreasonable barriers to school, employment or use of public facilities, it may be necessary to refer them to an attorney or to a local disability advocacy group.

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