

RE: Menstrual Management for Adolescents With Disabilities

In the Clinical Report “Menstrual Management for Adolescents with Disabilities,” Quint et al¹ review options for assisting adolescent girls with disabilities and their families in decision-making related to menstruation. Although we appreciate the careful attention the authors paid to the topic, we have several concerns about important issues that were omitted, as well as the inclusion of sterilization as an option for menstrual management in adolescent disabled girls.

The United States has a shameful history of curtailing the reproductive rights of people with disabilities, including the eugenics movement that resulted in the forced sterilization of over 65 000 Americans.² Medical professionals cannot afford to overlook this important historical and cultural context. Moreover, the report failed to state that international standards, such as the World Health Organization and the International Federation of Gynecology and Obstetrics, forbid compulsory sterilization, except when medically necessary and no less intrusive options exist.³

Quint et al¹ omitted a full discussion of supported decision-making, a practice recommended by the World Health Organization and increasingly favored in the United States.³ Indeed, the vast majority of people with disabilities have the capacity to make informed decisions, if properly supported.³ For the small number who lack capacity, the American College of Obstetrics and Gynecologists states that decisions concerning sterilization must be based on the best interests of the individual, while, at the same time, preserving her autonomy to the maximum extent possible.⁴ Although the report briefly mentioned the best interest standard, the authors

neglected to clarify that sterilization for the purpose of reducing “burden” on family members and caregivers is not commensurate with the best interest of the disabled individual.² The adolescents, not their caregivers, are the pediatrician’s patients. They deserve the same care and respect as nondisabled patients.

The report’s failure to explicitly condemn sterilization as a way to prevent abuse is equally dangerous. Although women with disabilities are at greater risk of sexual abuse, research consistently finds sterilization does nothing to protect from abuse and may actually serve to perpetuate these crimes due to perceived reduction in the detection of such perpetration.² Importantly, sterilization also does not prevent sexually transmitted infections. We believe that sterilization as a means to control menstruation and prevent sexual abuse must be explicitly condemned by all professional organizations.

Although this report is presented as techniques for menstrual “management,” all included recommendations are for menstrual suppression. It is crucial for medical providers to understand disabled adolescents have the same desires as their nondisabled peers, and deserve access to comprehensive health services and information, including sexual and reproductive health.⁵ Increasingly, people with disabilities are choosing to become parents.² It is vital clinicians do not stereotype people with disabilities as asexual or incapable of appropriate sexual relationships. Pediatricians play an important role in the lives of adolescents, and they must ensure they do not presume their disabled adolescent patients are incompetent, and instead take steps to ensure their maximum autonomy and personal agency in these sensitive and important decisions.

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Author's Response

RE: comment

Thanks to Powell and colleagues for their comments. The guideline hopefully makes clear that doing a hysterectomy for menstrual management is NOT supported by this document or the American Academy of Pediatrics. This document was not meant to address sterilization, which is a different topic than

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