

Sterilization of Minors With Developmental Disabilities

ABSTRACT. Sterilization of persons with developmental disabilities has often been performed without appropriate regard for their decision-making capacities, abilities to care for children, feelings, or interests. In addition, sterilization sometimes has been performed with the mistaken belief that it will prevent expressions of sexuality, diminish the chances of sexual exploitation, or reduce the likelihood of acquiring sexually transmitted diseases. A decision to pursue sterilization of someone with developmental disabilities requires a careful assessment of the individual's capacity to make decisions, the consequences of reproduction for the person and any child that might be born, the alternative means available to address the consequences of sexual maturation, and the applicable local, state, and federal laws. Pediatricians can facilitate good decision-making by raising these issues at the onset of puberty.

ABBREVIATION. AAP, American Academy of Pediatrics.

Parents or other legal guardians approach pediatricians, pediatric surgeons, obstetrician-gynecologists, or other health care professionals about the possibility of surgical sterilization of children, adolescents, and young adults with developmental disabilities. This policy statement updates the previous American Academy of Pediatrics (AAP) statement entitled "Sterilization of Women Who Are Mentally Handicapped," published in 1990.¹ That statement was published as a companion to policy from the American College of Obstetricians and Gynecologists.² This revised policy relies on the concepts developed in the earlier statements, but applies to males and females.

SOCIAL CONTEXT

The topic of sterilization, primarily of girls and women, has stirred considerable moral, political, and legal debate and action in the United States. At the beginning of the 20th century, in conjunction with prevalent ideas about the social utility of "improving" human genetic stock (eugenics), sterilization was encouraged or even required by state laws and practiced in ways now regarded as discriminatory and abusive. Women were prevented from reproducing based on physical disability, behavioral characteristics, or membership in socially disfavored groups or because of cognitive disabilities that did

not necessarily prevent them from fulfilling parental roles.³⁻⁵

However, in 1942, in accord with more enlightened social and biological perspectives, support for reproductive freedom was growing. In that year, the US Supreme Court declared human procreation to be a fundamental right, prompting major changes in the legal landscape.⁶ Obtaining authorization to sterilize individuals, including those with developmental disabilities, became substantially more difficult, if not prohibited in some jurisdictions.⁷ Beginning in the 1970s, regulations prevented the use of federal monies to perform sterilization procedures on those deemed mentally incompetent.⁴ The complexities of federal rules, state laws, and judicial rulings have created a confusing and contradictory array of restrictions on surgical sterilization of persons with developmental disabilities.

More recently, ethical precepts and public policy have emphasized the importance of providing the least restrictive life alternatives for persons with cognitive and other disabilities or disorders. The result has been proscriptions on limits on reproduction, including sterilization. At the same time, expanded social opportunities have increased the likelihood that individuals with developmental disabilities will engage in sexual contact that can lead to pregnancy. A proportion of these pregnancies will endanger the health of the pregnant individual or be unwanted. Some will be the result of sexual exploitation or assault. A few parents and other guardians retain an interest in male sterilization either to simply preclude impregnation of others or with a belief that it may help prevent sexually aggressive behavior by males. Sterilization of females is similarly sought to prevent pregnancy, especially when those responsible for a person with severe mental disability believe that she cannot adequately care for a child.

INTERESTS OF THOSE WHO MIGHT REPRODUCE

Persons who have adequate mental capacity to make a decision about their health and health care are entitled to do so based on their own interpretations of their interests, without undue influence from health care professionals, family members, or others. Thus, the first step in decisions about sterilization of a person with cognitive disabilities generally involves assessing the individual's capacity to decide matters specifically concerning reproduction. Such assessments should be made with the help of professionals skilled in and experienced with evaluating the capabilities of persons with disabilities. The assessment should focus on the individual's ability to

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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understand appropriately presented information about the possibility of reproducing, the consequences of procreation, and the benefits and risks of, and alternatives to, pregnancy and childbirth. In actual practice, evaluating a person's ability to provide consent may be quite complex. Ultimately, competence is a legal attribute, and legal standards for determination of competence vary greatly. Some states require judicial review with representation of the individual by an attorney and guardian ad litem, and a competency evaluation. In those states without such a legal requirement, in the case of an elective procedure with permanent consequences, all possible efforts should be made to conduct the determination of competence fairly. Among the issues that may need to be considered are language and cultural background, quality of information provided to the person (clarity, completeness, lack of bias), and fluctuations in a person's comprehension resulting from, for example, various stressors and medications.⁸ A person who can demonstrate adequate capacity to comprehend the facts and associated concepts and express choices about these matters can provide informed consent or refusal for contraception, including sterilization.

When the individual involved lacks the ability to consent to or refuse sterilization, the question becomes whether a surrogate may ethically authorize the procedure. Some individuals believe in an inherent freedom or legal (constitutional) right to reproduce, regardless of abilities to appreciate what it means to become a parent. From this perspective, sterilization will rarely, if ever, be acceptable.

A decision to have a child or to permanently prevent the possibility of becoming a parent is best made with full consideration of the burdens and benefits of parenthood. The burdens of pregnancy may be substantial for some with developmental disabilities and concomitant physical disorders. Pregnancy, birth, and parenthood also involve emotional stress resulting from the physical demands of labor, sleep loss, and the responsibility of caring for a helpless infant whose needs and wants are often difficult to discern. Of course, these difficulties must be balanced against the benefits of parenthood, including sharing love with the child and the joys of watching an individual grow and develop. In addition, some individuals with limited developmental capacity who desire to father or bear children may be able to assume that responsibility if provided with adequate social support. Pediatricians may have a role in encouraging communities to develop the resources necessary to provide sufficient support.

At times, the parties to decision-making may face a situation in which sterilization is the likely secondary result of recommended treatment of disorders of the reproductive system or anatomically adjacent areas (eg, benign or malignant tumors of the urogenital system or refractory painful uterine bleeding). Under these circumstances, the decision to undertake therapy that has a risk of causing infertility should be based on the medical condition without regard to the developmental disabilities of the patient.

INTERESTS OF OTHERS

No ethical analysis of possible sterilization of persons with severe cognitive disabilities should fail to consider the interests of their potential children. Children deserve adequate physical care, emotional support, and stimulation. Children require protection from hazards and special attention when disease develops. Thus, decisions to refrain from or proceed with sterilization must consider the abilities of the individuals and those with whom they routinely interact to provide for the needs of the children who may be born.⁹

Much of the past difficulty with sterilization of those with disabilities has arisen from the alleged value to society of eugenically eliminating "undesirable" or "defective" individuals from the population. These efforts were notable for being based on stereotypes and prejudice. In addition, as methods of contraception that provide alternatives to sterilization increase the available options, permanent sterilization becomes increasingly difficult to justify. This is especially true when there is uncertainty about the adolescent's eventual capacities and interests. Nevertheless, third parties have rightful interests in these matters when it is clear that the persons with disabilities who are involved can assume little or no responsibility for their own care during pregnancy or for their children after birth. Family members, other guardians, or those providing custodial care have substantive and reasonable concerns about how their own resources would be affected by new child care responsibilities.

LEGAL CONSIDERATIONS

The age of consent, including that for surgical procedures, varies from state to state. Some minors may be old enough under applicable laws to be considered eligible to agree to sterilization if otherwise capable of doing so. In such cases, a careful clinical assessment of decision-making capacity must be performed by a professional skilled in and experienced with evaluating the capabilities of persons with disabilities, such as a psychiatrist, licensed psychologist, social worker, or pediatrician. Adolescents who have been declared by judges to be mentally competent for the purpose of accepting or refusing sterilization are entitled to make whatever decision they believe furthers their own interests. In some states, laws or court precedent forbid procedures aimed primarily at accomplishing sterilization solely on the authorization of parents or other legal guardians consulting with appropriate physicians and surgeons. When the involved parties believe surgical sterilization to be the best option, application to the courts may provide the only lawful means to accomplish that goal. Physicians and surgeons should be familiar with the law that applies to the jurisdictions where they practice.

PRACTICAL ISSUES

Consideration of sterilization will ordinarily not arise until sexual maturation, although issues of sexuality may come up when the child is much younger.

Nevertheless, the development of secondary sexual characteristics presents opportunities for pediatricians to discuss the myriad consequences of puberty with patients, parents, and other guardians. This will allow for a review of facts, exploration of fears, and discussion of resources available for education, behavior modification, and available medical alternatives for prevention of reproduction.

Many requests for sterilization of individuals with developmental disabilities are based on confusion between desires to permanently prevent reproduction versus wishes to avoid other consequences of sexual maturation.¹⁰ Very often, the latter concerns predominate and may be addressed with different, less intrusive interventions. For example, difficulties with menstrual hygiene frequently, but not always, improve with developmentally appropriate educational programs. The inconvenience of problems dealing with normal menstrual bleeding is generally an inappropriate indication for surgical sterilization. Abnormal menses (eg, excessive flow or bleeding for many days each cycle) should be treated as it would be for a patient without mental disability. Similarly, distress of the caregiver over expressions of sexuality does not justify consideration of sterilization. Most individuals with developmental disabilities respond to efforts to teach socially acceptable demonstration of affection. In some instances, behavior modification may be useful. Some parents and other caregivers request sterilization by orchiectomy for the purpose of decreasing sexual aggressiveness in males. There is little valid evidence that surgical castration accomplishes the desired goal; trials of behavioral and, if warranted, pharmacological management deserve primary consideration.

Many who care for persons with developmental disabilities are understandably concerned about the sexual exploitation of those for whom they have responsibility. Although sterilization of vulnerable girls usually will prevent conception and pregnancy, it will not substitute for the establishment and enforcement of a safe environment that minimizes the chance for exploitation, nor will it prevent exposure to sexually transmitted diseases.¹¹ Sexual abuse avoidance training may be an important tool in preventing exploitation of persons with developmental disabilities.

Even when the principal goal of sterilization is the prevention of reproduction, less permanent means of contraception may be available. The use of barrier methods, pills, injections, intrauterine devices, or subdermal implants depends on the functional abilities of the person with developmental disability and the reactions of the patient and the caregivers to nonsurgical methods to prevent pregnancy.¹² The consequences of the long-term use of hormonal means of contraception are not fully known, and the known complications must be carefully balanced against the hazards and permanency of surgery. The presence of a developmental or cognitive disability alone does not, in itself, justify either sterilization or its denial.

RECOMMENDATIONS

1. The AAP encourages pediatricians to use the development of secondary sexual characteristics in persons with developmental disabilities as an opportunity to explore the patients' and caregivers' understandings of the facts and implications of sexual maturation.
2. Consideration of sterilization should focus on whether there is a need for permanent prevention of reproduction. Concern about other consequences of sexual maturity or aspects of sexuality among persons with cognitive disabilities should focus on interventions substantially less radical than sterilization. The AAP encourages pediatricians to familiarize themselves with the resources in their community to which they might refer families for further information or for specialized education and counseling on such matters as appropriate expressions of affection and sexual drives, effective menstrual hygiene, sexual abuse avoidance training, and contraception. There are a number of resources available through the Internet. Such resources include The National Information Center for Children and Youth With Disabilities, www.nichcy.org; The Disability Rights Education and Defense Fund, Inc (DREDF), www.dredf.org; and Family Voices, www.familyvoices.org.
3. Whenever possible, pediatricians should involve their patients with developmental disabilities in decisions about reproduction and should advocate for the least permanent and intrusive method of contraception consistent with the lowest risk for the patient.
4. When a minor with developmental disabilities requests sterilization and an assessment determines that the minor has adequate decision-making capacity to consent to the procedure, the minor's views on the matter should be respected. Such decisions will generally benefit from the involvement of the adolescent's family, other adults close to the adolescent, or both.
5. Pediatricians should become familiar with the applicable law about sterilization of persons with developmental disabilities. Pediatricians should establish relationships with local agencies and attorneys knowledgeable about the legal complexities of sterilization of persons with developmental disabilities in their jurisdiction. There are a number of legal resources available through the Internet. The pediatrician can find and contact his or her state bar association using an Internet search directory, such as Yahoo at dir.yahoo.com/government/law/organizations/bar_associations. Most state bar associations maintain informatic Web sites, for example, the State Bar of Wisconsin at www.wisbar.org, the State Bar of California at www.calbar.org, and the Massachusetts Bar Association at www.massbar.org. As advocates for our patients, pediatricians have an obligation to make certain that persons with developmental disabilities are treated in accord with state and federal law, and with the respect for their interest in

procreation and the responsibilities involved in bearing and raising children. If sterilization is legally permissible on the authority of parents or other legal guardians and is chosen as the best course of action, substantial effort should be made to communicate the facts and implications of the sterilization to the patient. To the extent possible, the patient should participate in planning for the procedure.

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