



State of Connecticut
Department of Developmental Services

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DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY
BEFORE THE PUBLIC HEALTH COMMITTEE
February 28, 2018

Senators Gerratana and Somers, Representatives Steinberg and Betts and members of the Public Health Committee. I am Jordan A. Scheff, Commissioner of the Department of Developmental Services (DDS). Thank you for the opportunity to express concerns regarding **S.B. No. 218 AN ACT PROHIBITING INVOLUNTARY STERILIZATION OF PERSONS WITH DISABILITIES.**

This bill would prohibit the involuntary sterilization of a person with intellectual disability. Currently, and not changed by the bill, an individual with intellectual disability who does not have a guardian may provide informed consent for a sterilization procedure. For an individual who has a guardian, an application may be made to Probate Court Administration to permit a sterilization procedure upon a careful consideration and determination by the Probate Court that it is in the “best interest” of the individual. Without the provision for this process, there is no way for an individual with intellectual disability who wants the procedure, but is unable to provide informed consent, to have the procedure. As a protection, a guardian is not legally allowed to make this decision for an individual for whom they are guardian. (Section 45a-677(e)(3) CGS specifies lack of guardian authority to consent to sterilization.)

The current statutes provide a process for an individual with intellectual disability who has a guardian and wish to be allowed to undergo a sterilization procedure, although they are unable to provide the necessary informed consent because they have a guardian. Without an individual’s informed consent, the Probate Court must establish that it is in the individual’s best interests through a careful and objective process. The bill would eliminate this process and thereby restrict these individuals’ access to sterilization for whatever reason. It should be noted that this decision is statutorily taken out of the guardian’s purview which helps to ensure that an application is not granted merely for convenience. The Probate Court process ensures that any decisions in these cases are made in the “best interests” of the individual.

Probate Court involvement triggers the appointment of a three-member panel chosen from an interdisciplinary group consisting of physicians, psychologists, social workers and others, who then opine on the individual’s ability to provide informed consent. If the ability to provide informed consent is found, the individual may undergo sterilization. Under the current law, after finding an absence of ability to provide informed consent, the court then is required to determine whether, in the absence of such ability, it remains in the individual’s best interest to undergo sterilization. The definition of best interests in section 45a-690 (4) CGS is a specific compilation of factors to be considered in weighing “best interest”. This deliberative process is intended to direct attention to the significance and irrevocability of

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the sterilization procedure. Those considerations are addressed quite solemnly in Probate Court hearings with: (1) the appointment of an attorney for the respondent, (2) notice to Disability Rights Connecticut representatives and DDS, and (3) the presence and reports and testimony of panel members and opponent witnesses, as appropriate. The proposed legislation eliminates this provision of balancing the individual's best interests and, in doing so, denies to individuals with intellectual disability who cannot consent, access to a procedure other individuals in the general population may undergo.

Some examples to help illustrate our concern include:

1. An individual has a medical condition such as a seizure disorder for which a pregnancy could threaten the health of the individual. Under this proposal, if the individual has a guardian, they couldn't have a sterilization procedure because there would be no process for the individual to prove informed consent or for the court to determine that the procedure is in the individual's best interest.
2. An individual has a guardian for medical purposes only. The individual knows they do not want to conceive, carry, deliver, or raise a child but are unable to provide informed consent because they have a guardian. Absent the best interest portion of the current statute, this individual would be denied access to sterilization procedures that individuals without intellectual disability may undergo.
3. An individual with intellectual disability requires medication that would be harmful to themselves or their fetus when taken during pregnancy. Under this proposal, if the individual has a guardian, the individual would be denied the opportunity to have these considerations addressed in a balancing of best interests.
4. An individual has both the capability and opportunity for sexual activity, but does not understand the concepts of reproduction or contraception, and may not be capable of carrying a child to term without serious health risks. The inability to consider best interests would eliminate the discussion of psychological implications that a pregnancy and delivery may impose on an individual who does not demonstrate the capacity to comprehend the reproductive process, and it would exclude the discussion of an individual's inability to care for a child. Additionally, there are also medical risks for the individual which may be inherent in a refusal to consider best interests.

To reiterate, current law provides that individuals with intellectual disability who have a guardian (at minimum for medical issues) are presumed not to have the capacity to consent to sterilization. However, if a physician seeks a guardian's consent for a sterilization procedure, the guardian is not empowered to consent to sterilization and must seek authorization from the Probate Court (Section 45a-677(e)(3) CGS). Even if a physician has adequately explained the procedure to the individual, believes the individual understands the procedure and the risks, and believes that the individual is capable of providing informed consent, the physician must still seek consent from the guardian who does not have authority to give it. Therefore, our primary concern is that the elimination of the best interest language could result in discrimination to a significant number of individuals with intellectual disability who simply because they have a guardian, would be unable to access a sterilization procedure.

The current process is most consistent with two key tenets of DDS's vision statement that individuals with intellectual disability may (1) make informed choices and take responsibility for their lives and experience the dignity of risk, and (2) know their rights and responsibilities and pursue opportunities to live the life they choose. The proposed changes this bill contemplates would potentially diminish certain individual's rights to live this vision.

Thank you again for the opportunity to express the above concerns regarding [S.B. No. 218 AN ACT PROHIBITING INVOLUNTARY STERILIZATION OF PERSONS WITH DISABILITIES](#). I would be happy to answer any questions you have at this time. You may also contact Christine Pollio Cooney, DDS Director of Legislative and Executive Affairs at (860) 418-6066 with additional questions.