

Legal and Ethical Issues

Note: This resource document contains general legal information; it is not legal advice and it does not create an attorney/client relationship. As laws and circumstances differ, the prudent health care practitioner should discuss these issues with his or her attorney before proceeding.

Guardianship

Guardianship is established by a legal proceeding in which a court determines if the severity of a person's disabilities renders him or her incompetent to make certain types of decisions. Other considerations are whether or not the person requires protection, and/or the options of a less restrictive alternative to guardianship. States vary in their definitions of mental incapacity and/or incompetency, as well as the required legal procedures to file for guardianship and the limitations of guardianship. The law presumes that all adults have the mental capacity to make their own decisions unless they have been found unable to do so through a formal legal process.

Depending on the specific state and the outcome of the guardianship proceedings, full (also known as plenary) guardianship may be declared over the person (thereafter referred to as "the ward"), or the court may declare limited guardianship, such as guardianship specifically related to financial or medical matters. It is important for the primary care provider to clarify the guardianship status of the patient, if it is in question. If the guardian has some type of limited guardianship, he or she may lack broad decision-making power with regard to the patient. The guardian should be able to produce paperwork which clarifies the type of guardianship. The primary care provider may wish to ask the guardian in advance to bring the paperwork to the appointment.

Not all individuals with intellectual and/or developmental disabilities (ID/DD) require guardianship. Guardianship, even limited guardianship, is a very serious procedure which results in severe limitations of the individual's rights. Full (plenary) guardianship essentially deprives individuals of decision-making authority in all major aspects of their life - including their ability to make legally binding decisions about medical care, where they will work, who they will marry (or divorce), and in some cases, when they will die.

There are several alternatives to full guardianship which preserve more of the person's rights and autonomy. These alternatives include the use of advisors and advocates, person-centered planning, mediation, protective orders, contracts, personal money managers, electronic bill-paying services, amenities trusts, conservatorship, durable power of attorney, and representative payee. Alternatives to guardianship which specifically relate to medical decision-making include durable power of attorney for health care and family consent statutes (e.g., KRS 311.631 in Kentucky).

If the primary care provider has concerns or questions about the patient's guardianship status, he or she can contact his or her state's Protection and Advocacy agency. The Protection and Advocacy agencies together comprise a national network of congressionally mandated, legally-based disability rights agencies. A directory of Protection and Advocacy agencies can be found at <https://www.ndrn.org/ndrn-member-agencies.html>

Informed consent for health care

Health care providers must obtain informed consent from patients (or their guardian) either through written or verbal means, depending on the specific situation. Minimally, the health care provider must establish that the patient understands his or her condition and proposed treatment, along with any associated risks, side effects, benefits, and/or alternatives. The patient does not have to have thorough technical knowledge of these aspects for informed consent. However, the necessary level of patient understanding varies according to the seriousness of the condition and the risks of the proposed treatment. For example, consenting to routine medical care does not require as great a threshold of understanding as a diagnosis of colon cancer with accompanying treatment decisions (Hurley & O'Sullivan, 2002).

Some primary care providers will seek written informed consent for nearly all procedures. In the case of written informed consent, care should be taken to ensure that the materials are presented in a way that is both accessible and developmentally appropriate for the patient. For example, diagnostic information may need to be explained in simple, concrete terms; more time may need to be provided for the patient to ask questions and receive explanations; and the format of the materials may need to be modified for patients using alternative forms of communication and/or

augmentative communication devices. The provider should also periodically check the patient's understanding as consent materials are discussed.

If the primary care provider is uncertain about the patient's capacity to consent to a particular procedure, he or she may request a review. For persons with intellectual disabilities, this review typically involves a multidisciplinary clinical team and formal assessment procedures. It is necessary to emphasize that most state laws do not permit a surrogate decision-maker to consent to treatment when the patient is resisting non-emergency treatment, such as a gynecological examination. State law may also require additional review by a board or court before a surrogate may consent on behalf of the patient for certain types of medications, sterilization, or abortion procedures. Primary care providers should educate themselves about the laws specific to their state.

Most states permit an exception to informed consent in the case of emergency. An emergency is defined as a situation in which there is "substantial risk of death or immediate and serious harm to the patient" (Hurley & O'Sullivan, 2002, p. 53). Once the situation is no longer a medical emergency, the provider is obligated to obtain informed consent.

Sterilization and Birth Control

Historically, reproductive management of many women with ID/DD was done through either sterilization or pharmaceutically-induced amenorrhea (Grover, 2002; Servais, 2002). From the 1920s to the 1970s, tens of thousands of people with disabilities were involuntarily sterilized in the United States. This practice had its philosophical basis in the eugenics movement. Most states have since passed laws which place significant restrictions on the ability of guardians or surrogate decision-makers to request sterilization procedures for patients with intellectual disability without their consent. With the exception of some genetic syndromes, the presence of an intellectual or developmental disability does not necessarily preclude fertility. Primary care providers should thus query patients with ID/DD about their sexual history and current sexual activity, and should not presume that the presence of the patient's disability renders them sexually inactive.

Women with ID/DD have the same rights to information about contraception as any other patient. The primary care provider should endeavor to provide as much information as is possible and appropriate concerning the advantages and disadvantages of various forms of contraception.

Family members and service providers often seek out sterilization or other forms of surgically-induced amenorrhea as a solution to concerns that the individual with ID/DD may become pregnant as a result of sexual victimization. Parents and guardians who have been legally entrusted with the right to make medical decisions on behalf of the patient should be informed that there are a variety of contraceptive options that are less permanent and invasive than surgical sterilization. Family members, guardians, and service providers may need to be educated about the prevalence of sexual abuse in people with ID/DD, as well as the reality that neither sterilization nor contraception can substitute for a safe living environment for the individual.

Ethical considerations for the provider include the need to provide as much information as the woman is able to understand, to support her ability to make family-planning choices, and to ensure autonomy for the patient. Promotion of self-determination can be achieved by considering possible sources of influence and coercion in the patient's life (including service providers and family members with strong opinions on the patient's course of action), and by providing private time for the patient to discuss her contraceptive concerns outside the presence of her family members or service providers. Medical considerations for the use of contraception in women with ID/DD are discussed elsewhere in this module (see the resource document on Reproductive Management).

Consent to sexual activity

Individuals with ID/DD **do** engage in sexual activity, though research studies tend to find that they are less sexually active than peers with physical disabilities and the general population (Servais, 2006). Typically people with ID/DD have very little exposure to sex education, which has a significant impact on their ability to meet legal requirements to consent to sexual activity.

Overall, the topic of consensual sexual activity and people with ID/DD is fraught with legal ambiguity and social taboos. Historically, a person's IQ score was the yardstick by which his or her ability to consent to sexual activity was measured. However, this method of assessing competency has since been discredited (Stavis & Walker-Hirsch,

2002). Agencies, families, and guardians are now faced with the challenge of harmonizing the right of all individuals, including individuals with ID/DD, to sexual expression, with the responsibility to protect vulnerable individuals from sexual abuse.

State statutes governing capacity to consent vary, and the language of the statutes is usually far from definitive. **Knowledge, voluntariness, and consent** are required components of consent to all types of sexual contact. The required extent of a person's capacity to consent and the burden of proof required typically increases as the decision-making becomes more complex, with more serious consequences. For example, activities such as dancing, masturbation, friendship, and access to sexual health information do not require formal legal consent. However, sexual activity involving more than one person (e.g. mutual masturbation, sexual petting, etc.) legally require clear, mutual agreement by both (or all) parties engaging in these acts. Sexual intercourse elicits the highest level of scrutiny. In order to ensure that an individual with ID/DD can consent to sexual intercourse, an assessment and review of the individual's ability to consent should take place. Targeted sex education can improve an individual's ability to consent to sexual activity; many states require that the individual "understand the nature and quality" of the act in question. If an individual is found to lack the capacity to consent to sexual intercourse but shows an interest in sexual expression, it may be worthwhile to explore other, less risky sexual activities which require less complex decision-making.

The primary care provider is not expected to make a determination of the patient's capacity to consent to sexual activity. However, if the primary care provider suspects that the patient is being sexually victimized in any way, or if the provider is aware that the patient is engaging in sexual activity and has serious doubts about the patient's capacity to voluntarily and knowledgeably consent, the provider should take action according to the laws of his or her state and his or her professional code of ethics.

Mandatory reporting requirements

Most states require primary care providers to report cases of suspected abuse of children, the elderly, and other "vulnerable adults" (including people with ID/DD). These laws usually exempt reporters from liability resulting from false reports to the primary care provider. The definition of abuse and neglect, as well as the definition of what constitutes reportable abuse and neglect varies from state to state, as do the reporting procedures. Typically the primary care provider must contact an agency such as Adult Protective Services to report suspected abuse or neglect of a vulnerable adult. If the primary care provider is unsure about whether a situation is reportable, it is advisable for the provider to contact the relevant protective agency for advice. It is not the responsibility of the primary care provider to investigate and verify the details or validity of alleged or suspected abuse. Primary care providers have the ethical responsibility to report suspected abuse as required by law in their state and their own professional ethical code, and to familiarize themselves with the applicable statutes and regulations in their state.

Disclosure of abuse suspicions or diagnosis to caregivers

The determination to immediately notify or not to notify caregivers/guardians when suspicion or diagnosis of abuse arises is both challenging and delicate for the primary care provider. If the caregiver is clearly not the abuser (this may be difficult to ascertain), discussion of the primary care provider's findings and suspicions with the caregiver may provide an opportunity for the provider to explain their obligation to report and the reporting process. Failing to notify the caregiver/guardian can have serious consequences for the therapeutic alliance between the primary care provider, the patient, and the caregiver. It should be noted that the caregiver does not necessarily have a legal right to receive information about suspected or diagnosed abuse, particularly if the primary care provider suspects that the caregiver may be involved in the abuse or neglect in some way. Caregivers, spouses, family members, or other third parties should only be notified of abuse with the informed consent of the patient. Care should be taken to ensure that the abuse suspicions and diagnosis are discussed privately with the patient.

If the primary care provider has any suspicion that that caregiver is involved in the suspected abuse or neglect, the provider should refrain from discussing his or her findings and suspicions with the caregiver, even if the caregiver has medical or plenary guardianship of the patient. Disclosure of the primary care provider's suspicions and intent to report abuse and/or neglect may lead to the caregiver retaliating against the victim, taking steps to conceal evidence of abuse, or avoiding authorities.

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