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Withdrawing Care for Developmentally Disabled Persons: New Idaho Standards

Insight — 04/10/2017

Recent amendments will allow guardians and those treating developmentally disabled persons greater discretion in withholding or withdrawing artificial life-sustaining treatment, thereby avoiding situations in which developmentally disabled persons were forced to suffer painful, extended procedures which may be considered inhumane.

The Former Standard. Under Idaho law, the guardian or personal representative of an incompetent person may generally authorize the medically appropriate withdrawal of treatment for the patient. (I.C. §§ 39-4504(1) and 39-4514(3)). In the case of developmentally disabled persons, however, the former law prohibited guardians and physicians of developmentally disabled persons from withholding or withdrawing artificial life-sustaining treatment unless the treating physician and one other physician certified that the person had a terminal condition such that the application of artificial life-sustaining treatment would only serve to prolong death for a period of hours, days or weeks, and that death was imminent regardless of the life-sustaining procedures. (I.C. § 66-405(7)-(8)). Unfortunately, this standard looked only at the length of the patient's life without considering the pain that the patient may be forced to endure in the meantime. Because of advances in medicine, healthcare providers are often able to keep persons alive for months or years, but at a terrible cost in suffering to the patient and their loved ones. Application of the former standard sometimes resulted in heartbreaking situations in which developmentally disabled persons—often with little or no cognition—were relegated to an existence that offered nothing more than perpetual pain or discomfort instead of allowing the medically appropriate withdrawal treatment. By so doing, the standard deprived developmentally disabled persons of rights that were offered to others.

The Amendments. The new amendments, which become effective July 1, 2017, modify and ameliorate the harsh effects of the former standard in two ways:

1. Application. The amendments confirm that the limits on the ability to withdraw care only apply in those situations in which a guardian has been appointed for a developmentally disabled person under the process set forth in Idaho Code § 66-401 *et seq.* "Developmental disability" is defined as:

a chronic disability of a person which appears before the age of

twenty-two (22) years of age and:

- (a) Is attributable to an impairment, such as intellectual disability, cerebral palsy, epilepsy, autism or other condition found to be closely related to or similar to one (1) of these impairments that requires similar treatment or services, or is attributable to dyslexia resulting from such impairments; and
- (b) Results in substantial functional limitations in three (3) or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency; and
- (c) Reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and individually planned and coordinated.

(I.C. § 66-402(5)). Section 66-404 establishes a process by which a court will evaluate a person to determine whether he or she is developmentally disabled and, if so, the extent of their disability. If warranted, the court will appoint a guardian whose authority depends on the functional capabilities of the developmentally disabled person. The limits on the guardian's ability to withdraw or withhold care in 66-405 only apply if the parties have gone through the process in § 66-404; it does not apply in situations in which a guardian has been appointed pursuant to other statutes or if no guardian has been appointed. (I.C. §§ 66-405(7) and (11), effective July 1, 2017).

2. New Standard for Withholding or Withdrawing Care. In those situations in which a guardian has been appointed pursuant to § 66-404, a guardian may now authorize the withholding or withdrawal of treatment other than appropriate nutrition or hydration, and a practitioner may act on such authorization, if one of the following circumstances apply:

- (a) The attending [licensed independent practitioner ("LIP")] and at least one (1) other LIP certifies that the [patient] is chronically and irreversibly comatose;
- (b) The treatment would merely prolong dying, would not be effective in ameliorating or correcting all of the respondent's life-threatening conditions, or would otherwise be futile in terms of the survival of the respondent; or
- (c) The treatment would be virtually futile in terms of the survival of the respondent and would be inhumane under such circumstances.

(I.C. § 66-405(8), effective July 1, 2017). The new standard was drafted to parallel the federal "Baby Doe" regulations which apply to the withdrawal of care of disabled infants, thereby aligning Idaho standards with existing federal law and Idaho regulations. (See IDAPA 16.06.05). While protecting developmentally disabled persons, the standard allows guardians and healthcare providers greater discretion in determining the appropriate course of treatment for such patients after considering the totality of the

circumstances, including not only the person's chances of survival but also the pain and suffering the person would be forced to endure in the meantime. Healthcare providers who believe that the guardian is acting improperly may still decline to follow the guardian's directive, and potentially report the guardian for possible neglect. (See I.C. §§ 66-405(7), 16-1605, and 39-5303).

For questions regarding this update, please contact:

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