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This presentation is for informational and educational purposes only and does not constitute legal advice. Specific legal questions should be directed to qualified counsel. If you need legal assistance or wish to discuss how these issues apply to your organization, please feel free to contact the presenters directly.

GUARDIANSHIP and END-OF-LIFE DECISIONS:

Developmental Disabilities and Do-No-Resuscitate Changes and Consent

General Rule

39-4503. Persons who may consent to their own care. Any person, including one who is developmentally disabled and not a respondent as defined in section 66-402, Idaho Code, who comprehends the need for, the nature of, and the significant risks ordinarily inherent in any contemplated health care services is competent to consent thereto on his or her own behalf. Any health care provider may provide such health care services in reliance upon such a consent.

COMPONENTS OF CAPACTIY

 COMPRHENDS THE NEED FOR, THE NATURE OF, AND THE SIGNIFICANT RISKS OF THE HEALTHCARE SERVICES

Legal Standard	(based on
Idaho Code § 39	-4503)

Understanding of the condition or treatment

Appreciation of the consequences

Reasoning about options

Ability to express a choice

What to Ask/Observe

"Can you tell me what the doctor wants to do?"

"What could happen if you don't do it?"

How to Document

"Individual states: 'They want to give me a shot so I don't get the flu.'"

"Individual says: 'I might get really sick if I don't.'"

"States: 'I could wash my hands, but the shot is better.'"

"Clearly states: 'Yes, I want the shot.'"

[&]quot;Are there other things you could do instead?"

[&]quot;What would you like to do?"

Capacity Cont.

If not 66-405 and lacks capacity, Consent can be established through the hierarchy contained in Idaho Code § 39-4504:

- Court Appointed guardian
- Person named in Advanced Care Plan
- Adult child
- Parent
- Person delegated parental authority
- Any relative
- Any competent individual representing themselves as responsible for the person's healthcare
- In medical emergency, an attending healthcare provider if deemed appropriate.

TYPES of GUARDIANSHIP

- Incapacitated Adult = Not DD, and the appointment is necessary or desirable as a means of providing continuing care and supervision of the incapacitated person. Person is suffering, or is likely to suffer, substantial harm due to an inability to provide for his personal needs for food, clothing, shelter, health care, or safety, or an inability to manage his or her property or financial affairs
- Minor Child
- → <u>DEVELOPMENTAL DISABILITY</u> ←

WHEN IS GUARDIANSHIP NECESSARY? LOOK TO "CAPACITY"

Autonomous

- Cognition and expression adequate
- Capable of informed consent
- Independent SDM

Rudimentary

- Need support to reach adequate understanding
- Capable of expressing consent
- SDM assistance

Incapacity

- Complete inability to form understanding
- Unable to maintain understanding
- Unable to express desires

SPECTRUM of SUPPORT *in order of Consideration*

No Legal Framework

- Complete Autonomy(?)
- Communication
- Natural Supported Decision Making

We are focusing on THIS area

Supported Decision Making

- Power of Attorney
- Formal Agreement?

Guardianship and/or Conservatorship

- Limited?
- Full?
- Requires Supported Decision Making

DEVELOPMENTAL DISABILTIY GUARDIANSHIP REQUIREMENT

- <u>I.C. 66-405(3)</u>:
- "Developmental disability* and is unable to manage some financial resources or meet some essential requirements for physical health or safety,"
- "Developmental disability" = chronic disability prior to age of twenty-two (22); (like intellectual disability, cerebral palsy, epilepsy, autism, etc.) and 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;

Different rules and regulations as Guardianship for non-DD, incapacitated adults

FULL VS LIMITED GUARDIANSHIP

- Partial / limited guardianship = exempting areas of certain decisions:
- EXAMPLE: individual can maintain employment decisions, social interactions (friends), manage finances, or healthcare?
- ALL / Most = full guardianship, no exempted areas

**** Practice Tip: you could make an Advanced Directive decision part of the Guardianship Order ****

Americans With Disabilities Act

The ADA and Rehabilitation Act require healthcare providers to ensure that DNR decisions are not based on discriminatory assumptions about the value or quality of life of individuals with disabilities.

Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990). https://www.ada.gov/pubs/adastatute08.htm

Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (1973). https://www2.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html

I.C. § 66-405 The Former Standard

- Focused on QUANTITY and not QUALITY of life.
- prohibited withholding or withdrawing artificial life-sustaining treatment unless the treating physician and one other physician certified that the person had an "imminent" terminal condition (i.e. days or weeks) regardless of the life-sustaining procedures.
- Did not allow for consideration of totality of circumstances, such as pain and suffering.

I.C. § 66-405 The Former Standard

- (8) A guardian appointed under this chapter may consent to withholding or withdrawal of artificial life-sustaining procedures, only if the respondent:
- (a) Has an incurable injury, disease, illness or condition, certified by the respondent's attending physician and at least one (1) other physician to be terminal such that the application of artificial life-sustaining procedures would not result in the possibility of saving or significantly prolonging the life of the respondent, and would only serve to prolong the moment of the respondent's death for a period of hours, days or weeks, and where both physicians certify that death is imminent, whether or not the life-sustaining procedures are used; or
- (b) Has been diagnosed by the respondent's attending physician and at least one (1) other physician as being in a persistent vegetative state which is irreversible and from which the respondent will never regain consciousness.

I.C. § 66-405(8) The Current Standard

- Focused on QUALITY and not QUANTITY of life.
- See (I.C. § 66-405(7)-(8))

NOTE: Section 66-405(7) starts out confusing, stating "Except as otherwise provided in subsection (8) of this section, a guardian appointed under this chapter shall have no authority to refuse or withhold consent for medically necessary treatment when the effect of withholding such treatment would seriously endanger the life or health and well-being of the respondent." --- Focus is on Section 8.

The Current Standard (I.C. § 66-405(8))

- ... 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 (1) of the following circumstances apply:
 - (a) The attending LIP [Licensed Independent Practitioner] and at least one (1) other LIP certifies that the respondent [individual with Developmental Disabilities] 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)

The Current Standard (I.C. § 66-405(8))

Summary:

One (1) Attending LIP and one (1) other LIP give written finding of one of following:

- chronic irreversible comatose state; OR
- Treatment would be ineffective or futile in correcting life-threatening conditions; OR
- Treatment futile in terms of survival AND inhumane under circumstances

Example Provider Letters:

To whom this may concern

is under my care for epilepsy. He also carries a diagnosis of Down syndrome, and has no verbal communication, and communicates by gestures. Over time he has had a decline in overall function especially since his recent seizures. This is a letter per patient's guardian request regarding making DNR. I agree that treatment would merely prolong dying and would not be effective in correcting all of the life threatening conditions.

If you have questions, please do not hesitate to contact me.

Sincerely,

Example Provider Letters:

To Whom it May Concern:

her request to apply DNR status has trisomy 21 and a seizure disorder that limit his long-term survival and quality of life. In the event of life-threatening condition providing resuscitation would likely prolong his suffering and would be virtually tutile in regards to long-term survival. With this in mind resuscitation would be inhumanc under these circumstances.

The Current Standard

What if Provider disagrees with Guardian?

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).

I.C. § 66-405(9) "Any person who has information that medically necessary treatment of a respondent has been withheld or withdrawn in violation of this section may report such information to adult protective services or to the Idaho protection and advocacy system for people with developmental disabilities, which shall have the authority to investigate the report and in appropriate cases to seek a court order to ensure that medically necessary treatment is provided."

The Current Standard

What if Provider Cannot Locate Guardian?

- I.C. § 66-405: "the health care provider or caregiver shall provide the medically necessary treatment as authorized by section 39-4504(1)(i), Idaho Code."
- I.C. § 39-4504(1)(i) If the person presents a medical emergency or there is a substantial likelihood of his or her life or health being seriously endangered by withholding or delay in the rendering of health care services to such person and the person has not communicated and is unable to communicate his or her wishes, the attending health care provider may, in his or her discretion, authorize or provide such health care services, as he or she deems appropriate, and all persons, agencies, and institutions thereafter furnishing the same, including such health care provider, may proceed as if informed valid consent therefor had been otherwise duly given.
 - (2) No person who, in good faith, gives consent or authorization for the provision of health care services to another person as provided by this chapter shall be subject to civil liability therefor.
 - (3) No health care provider who, in good faith, obtains consent from a person pursuant to either section 39-4503 or 39-4504(1), Idaho Code, shall be subject to civil liability therefor.

PROBLEM: What do we do with Pre-2017 DD Guardianships?

- β. The Co-Guardians are prohibited from consenting to the following without specific approval of the Court:
 - a. Consent to medical or surgical treatment, the effect of which permanently prohibits the conception of children by the Respondent unless the treatment or procedures are necessary to protect the physical health of the Respondent and would be prescribed for a person who is not developmentally disabled;
 - b. Withhold consent to life-saving treatment or procedures;
 - Consent to experimental surgery, procedures, or medications; or
 - Delegate the powers granted by this Order.
 - The Co-Guardians may act independently.

These Letters are issued to evidence the appointment, qualification, and authority of said Co-Guardians.

Solutions:

1. Take comfort knowing the law has changed and the Court Order should be unenforceable and void as to old language; or

2. Require updated Letters and Order.

In the Matter of:
,
a person with developmental disabilities.

Case No.

MOTION FOR AMENDED LETTTERS

Petitioners ___, Co-Guardians and Co-Conservators in the above-entitled matter, by and through their counsel of record, ___, move this Court for Amended Letters of Co-Guardianship. The proposed Amended Letters of Co-Guardianship are submitted herewith. A redlined copy showing the changes is attached hereto.

The proposed Letters are revised as follows:

- The Idaho Department of Health and Welfare is now needing to have both guardians sign off on all documents unless the letters specifically state that they may act individually. In addition, the Courts seek to understand who serves as the Primary Guardian.
 The attached Letters have been revised to meet these objectives.
- To clarify the terms of compensation of a Guardian for services provided on behalf of the Respondent.
- 3. To reflect the change in Idaho Code § 66-405 which allows the Co-Guardians to consent to withholding or withdrawing treatment other than appropriate nutrition or hydration to a respondent when "(a) ... the respondent 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."

EXAMPLES LANGUAGEFor Orders/Letters with Updated Language

- I. Pursuant to Idaho Code section 66-405(8), the Co-Guardians may consent to withholding or withdrawing treatment other than appropriate nutrition or hydration to the Respondent, and a health care provider may withhold or withdraw such treatment in reliance upon such consent, when the treating LIP's reasonable medical judgment any of the following circumstances apply:
 - a. The attending LIP and at least one (1) other LIP certifies that the Respondent is chronically and irreversibly <u>comatose</u>;
 - 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.

Pursuant to Idaho Code Section 66-402(10) "Licensed independent practitioner" or "LIP" means:

- A licensed physician or physician assistant pursuant to section 54-1803,
 Idaho Code; or
- A licensed advanced practice registered nurse pursuant to section 54-1402,
 Idaho Code.

THE COURT HEREBY FINDS THAT:

- The Respondent has a developmental disability;
- The Respondent's ability to meet essential requirements for physical health or safety and manage financial resources has been <u>evaluated</u>;
- The ability of the proposed Co-Guardians to act in the Respondent's best interests to manage the Respondent's financial resources and meet essential requirements for the Respondent's physical health or safety has been evaluated;
- The nature and scope of Co-Guardianship services necessary to protect and promote the Respondent's well-being have been <u>determined</u>;
- 5. The ability of the Respondent or those legally responsible to pay the costs associated with the judicial proceedings and <u>fix</u> responsibility therefor <u>has</u> been evaluated. The Respondent will be legally responsible to pay the costs associated with the judicial proceedings subject to any waiver hereafter sought and <u>approved</u>;
 - The Co-Guardians and Co-Conservators may act jointly or independently;
- The appointment of Co-Guardians will best serve the interests of the person with a developmental <u>disability</u>;
- The persons to be appointed as Co-Guardians will work together cooperatively to serve the best interests of the person with a developmental disability.

THEREFORE, IT IS HEREBY ORDERED:

 Petitioners 	and	are hereby appointed Co-Guardians of	and may ac
independently:			

- Upon qualification and acceptance, Letters of Co-Guardianship shall be issued to the Co-Guardians. Letters of Co-Guardianship shall reflect that said Co-Guardians have all the authority pertaining thereto, as enumerated in section 15-5-312(1)(a) through (d), Idaho Code, without limitation:
- 3. Within thirty (30) days after appointment, the Co-Guardians shall file with this Court a Proposed Guardianship Care Plan in accordance with the requirements set forth in Idaho Code § 15-5-303, with copies to the Petitioners' attorney and Respondent's attorney;
- 4. Petitioners, as Co-Guardians, shall file with the Court at least annually on the anniversary date of May 23, 2025, a status report of the protected person, pursuant to Idaho Code § 15-5-312, with copies to the Petitioners' attorney and Respondent's <u>attorney</u>;
- Pursuant to Idaho Code § 66-405(6), the Co-Guardians shall file a final report with the Court, with copies to the Petitioners' attorney and Respondent's attorney, upon the Respondent's death or the termination of this <u>Guardianship</u>;
- The Court finds that the subject of this proceeding is a person to whom the provisions
 of 18 USC 922(d)(4) and (g)(4) may apply.

DATED:	

The What Hasn't Changed?

- I.C. § 66-405(10) No partial or total guardian or partial or total conservator appointed under the provisions of this section may without specific approval of the court in a proceeding separate from that in which such guardian or conservator was appointed:
 - (a) Consent to medical or surgical treatment the effect of which permanently prohibits the conception of children by the respondent unless the treatment or procedures are necessary to protect the physical health of the respondent and would be prescribed for a person who does not have a developmental disability;
 - (b) Consent to experimental surgery, procedures or medications; or
 - (c) Delegate the powers granted by the order.
- (11) Nothing in this section shall affect the rights of a competent patient or surrogate decision-maker to withhold or withdraw treatment pursuant to section 39-4514, Idaho Code, unless the patient is a respondent as defined in section 66-402, Idaho Code.



WHAT HAS NOT CHANGED?

- Supported Decision Making, Least Restrictive
- Healthcare decisions
 - Reproductive rights
 - Experimental treatment
 - End-of-Life decisions
- Gun Rights
- Contract Rights
- Reporting Requirements and Review

THANKS!

Feel free to contact us.



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