

**DEPARTMENT OF HUMAN SERVICES
DEVELOPMENTAL DISABILITIES
OREGON ADMINISTRATIVE RULES**

**CHAPTER 411
DIVISION 390**

**HEALTH CARE ADVOCATES FOR ADULTS WITH INTELLECTUAL OR
DEVELOPMENTAL DISABILITIES**

EFFECTIVE MARCH 1, 2020

411-390-0100 Statement of Purpose

(Adopted 03/01/2020)

(1) The rules in OAR chapter 411, division 390 prescribe standards by which a health care advocate may be appointed for an adult with an intellectual or developmental disability.

(2) The Department recognizes the individual rights described in OAR 411-318-0010 and supports the rights of adult individuals to make informed choices including refusal of, and consent to, health care. The intent of these rules is to maximize access to health care by prescribing standards for the appointment of a health care advocate when an adult individual is incapable of making a health care decision.

(3) These rules encourage and provide for the appointment of a health care advocate in situations not covered by ORS 127.505 through 127.660 and when there is no legally appointed guardian with authority over health care decisions. ORS 127.635 provides for appointment of a health care representative to decide whether life-sustaining procedures may be withheld or withdrawn for an incapable individual.

Stat. Auth.: ORS 127.765, 409.050

Stats. Implemented: ORS 127.765

411-390-0120 Definitions

(Adopted 03/01/2020)

In addition to the following definitions, OAR 411-317-0000 includes general definitions for words and terms frequently used in OAR chapter 411, division 390. If a word or term is defined differently in OAR 411-317-0000, the definition in this rule applies.

(1) "Artificially Administered Nutrition and Hydration" means a medical intervention to provide food and water by tube, mechanical device, or other medically assisted method. "Artificially administered nutrition and hydration" does not include the usual and typical provision of nutrition and hydration, such as the provision of nutrition and hydration by cup, hand, bottle, drinking straw, or eating utensil.

(2) "Attending Physician" means the physician who has primary responsibility for the care and treatment of an individual.

(3) "Capable" means not incapable.

(4) "Health Care" means diagnosis, treatment, or care of disease, injury, and congenital or degenerative conditions, including the use, maintenance, withdrawal, or withholding of life-sustaining procedures and the use, maintenance, withdrawal, or withholding of artificially administered nutrition and hydration.

(5) "Health Care Advocate" means the person who is authorized to make certain health care decisions on behalf of an incapable individual if the individual does not have a guardian or a health care representative.

(6) "Health Care Decision" means consent, refusal of consent, or withholding or withdrawal of consent to health care, and includes decisions relating to dental procedures and admission to, or discharge from, a health care facility. For the purpose of these rules, "health care decision" does not include decisions relating to entry or exit from a residential facility as defined in ORS 443.400 or an adult foster home as defined in ORS 443.705.

(7) "Health Care Facility" means a health care facility as defined in ORS 442.015 or domiciliary care facilities as defined in ORS 443.205.

(8) "Incapable" means that in the opinion of a court or in the opinion of an individual's attending physician, an individual lacks the ability to make and

communicate health care decisions to health care providers, including communication through persons familiar with the individual's manner of communicating if those persons are available.

(9) "Individual" means an adult with intellectual or developmental disabilities for whom services are planned and provided.

(10) "Individualized Written Service Plan Team" means a group consisting of all of the following:

- (a) An individual.
- (b) The individual's legal or designated representative.
- (c) The individual's case manager.
- (d) Other people who may be chosen by the individual, such as providers or family members.

(11) "Informed Consent" means a health care decision made by an individual after understanding and evaluating all of the following information provided by their attending physician in a manner the individual understands:

- (a) General information about the procedure or treatment being considered and what may occur if the procedure or treatment is not provided.
- (b) Information about what the procedure or treatment entails.
- (c) Alternatives to the proposed procedure or treatment.
- (d) Risks of the proposed procedure or treatment.

(12) "Life-Sustaining Procedure" means any medical procedure, pharmaceutical, medical device, or medical intervention that maintains life by sustaining, restoring, or supplanting a vital function. For the purpose of these rules, "life-sustaining procedure" includes decisions about emergency procedures started when an individual's heart or breathing stops, commonly called "code procedures". "Life-sustaining procedure"

does not include routine care necessary to sustain patient cleanliness and comfort.

(13) "Physician" means a person licensed to practice medicine by the Oregon Medical Board or a naturopathic physician licensed to practice naturopathic medicine by the Oregon Board of Naturopathic Medicine.

(14) "Significant Medical Procedure or Treatment" means any of the following:

(a) Starting, stopping, or change in psychotropic medication that is anticipated to involve more than a slight risk.

(b) Any procedure or treatment that requires general anesthesia.

(c) Any procedure or treatment that incurs more than a slight risk of death, in the opinion of the attending physician.

(d) Any procedure or treatment that may decrease the ability of an individual to participate in a valued activity for longer than 48 hours.

(e) Any procedure or treatment that is likely to cause severe pain.

(f) Any procedure or treatment that requires a signature showing informed consent was given.

(15) "These rules" mean the rules in OAR chapter 411, division 390.

Stat. Auth.: ORS 127.765, 409.050

Stats. Implemented: ORS 127.765

411-390-0140 Limits on Rule

(Adopted 03/01/2020)

(1) These rules do not impair or supersede Oregon's existing laws relating to any of the following:

(a) Any requirement of notice to others of proposed health care.

(b) The standard of care required of a health care provider in the administration of health care.

(c) Whether consent is required for health care.

(d) The elements of informed consent for health care according to ORS 677.097 or other law.

(e) The provision of health care in an emergency.

(f) Any right a capable person may have to consent or withhold consent to health care administered in good faith pursuant to religious tenets of the person requiring health care.

(g) Delegation of health care decision-making to, or by, a health care representative.

(h) Any legal right or responsibility any person may have to affect the providing, withholding, or withdrawal of life-sustaining procedures including artificially administered nutrition and hydration in any lawful manner.

(i) Guardianship or conservatorship proceedings or appointments.

(j) Any right a person may otherwise have to make their own health care decisions, or to make a health care decision for another.

(2) In following the decision of a health care advocate, a health care provider shall exercise the same independent medical judgment that the health care provider may exercise in following the decisions of an individual if the individual were capable.

Stat. Auth.: ORS 127.765, 409.050

Stats. Implemented: ORS 127.765

411-390-0160 Health Care Decisions

(Adopted 03/01/2020)

(1) INDIVIDUAL. An individual is entitled to make their own health care decisions unless the individual is determined to be incapable as defined in OAR 411-390-0120.

(2) GUARDIAN. For an individual who has a guardian with health care decision-making authority, the guardian has health care decision-making authority.

(3) HEALTH CARE REPRESENTATIVE. For an individual who has self-appointed a health care representative with an advance directive, the health care representative has health care decision-making authority as described in ORS 127.505 through 127.660.

(4) HEALTH CARE ADVOCATE. If an individual is determined to be incapable and does not have a health care representative or guardian with health care decision-making authority, the individual's individualized written service plan team may appoint a health care advocate.

(a) The health care advocate must be a capable adult willing to serve as a health care advocate.

(b) Except as may be allowed by court order, the following may participate in the process of naming a health care advocate if unrelated to an individual by blood, marriage, or adoption but may not serve as the health care advocate appointed under these rules:

(A) The individual's attending physician or an employee of the attending physician or any other person providing care to the individual.

(B) The individual's parent whose parental rights are terminated.

(C) The individual's parent or guardian who, if at any time the individual was under the care, custody, or control of the parent or guardian, the court entered an order that placed the individual in the protective or legal custody of the Department and the individual was not returned to the care, custody, or control of the parent or guardian.

(D) An owner, operator, or employee of a health care facility in which the individual is a patient or resident, unless the health care advocate was appointed before the individual's admission to the facility.

(E) An owner, operator, or employee of a licensed, certified, or endorsed developmental disabilities services provider when the provider is paid to support the individual for whom a health care advocate is being appointed.

(F) An employee of a case management entity when the individual is receiving case management services from the entity.

(c) At least two-thirds of an individualized written service plan team as described in OAR 411-390-0220 must approve of the health care advocate.

(d) The appointment of a health care advocate is valid for up to one year but may be revoked as described in subsection (f) of this section.

(e) The appointment of a health care advocate is only valid when form 0496R is completed each year of the health care advocate's appointment.

(f) The appointment of a health care advocate may be revoked:

(A) By the individual, at any time, using any means of communication available.

(B) By the individualized written service plan team following a majority vote.

(g) A person who is willing and eligible to serve as an appointed health care advocate is required to complete Department-approved training prior to the appointment as a health care advocate and prior to making a health care decision for an individual.

Stat. Auth.: ORS 127.765, 409.050
Stats. Implemented: ORS 127.765

411-390-0180 Authority and Responsibility of a Health Care Advocate
(Adopted 03/01/2020)

(1) When making a health care decision for an individual, a health care advocate must first consider any preference indicated by the individual by any means of communication (verbal or nonverbal) and attempt to make the decision that the individual may have made if capable. If this is not possible, the health care decision must be made in what the health care advocate believes to be in the individual's best interest.

(2) A health care advocate must inform an individual and the individual's case manager of all health care decisions made, or considered by, the health care advocate.

(3) A health care advocate must consult with any other available surrogate decision-maker and an individual's attending physician to provide information related to the individual's values, beliefs, and preferences, with regards to the health care decision being made. The duty to consult and provide information is required for a health care provider to be able to make a health care decision, including a decision related to the withholding or withdrawing of life-sustaining treatments made by an attending physician or health care representative given authority under ORS 127.635 when a person is determined to be incapable of providing informed consent

(4) A health care advocate shall have all the authority over an individual's health care that the individual may have if not incapable, subject to the limitations of the health care advocate's appointment, these rules, and ORS 127.765.

(5) A health care advocate is authorized to access the medical records necessary to make a health care decision.

(6) A health care advocate may not disclose the contents of, and must maintain the confidentiality of, an individual's health information, as required by state and federal laws.

Stat. Auth.: ORS 127.765, 409.050
Stats. Implemented: ORS 127.765

411-390-0200 Limits on Authority
(Adopted 03/01/2020)

(1) A health care advocate may not make a health care decision related to any of the following:

- (a) Convulsive treatment.
- (b) Psychosurgery.
- (c) Sterilization.
- (d) Abortion.
- (e) Withholding or withdrawing of a life-sustaining treatment.
- (f) Withholding or withdrawing artificially administered nutrition and hydration other than hyperalimentation.
- (g) Testing for HIV, unless testing is necessary for obtaining treatment or care for an individual.
- (h) A request for medication for the purpose of ending an individual's life according to ORS 127.805 or other form of assisted suicide.
- (i) An experimental procedure, unless the procedure has been approved by an institutional review board and is determined by the attending physician to be in the best interest of an individual.
- (j) An experimental drug that has not been approved for use by the United States Food and Drug Administration, unless the drug is part of an approved clinical trial and an individual's attending physician has determined that it is in the best interest of the individual.
- (k) The use of seclusion or physical or chemical restraints, unless an imminent risk of harm to the individual or others exists but only for as

long as the imminent risk continues except in the case of an emergency.

(2) If an individual objects to any health care decision made by a health care advocate:

(a) The health care decision is revoked;

(b) The health care advocate's authority is withdrawn with respect to the health care decision that is revoked; and

(c) A member of the individualized written service plan team or the health care advocate must notify the health care provider whose recommendation is the subject of the health care decision that the decision has been revoked.

(3) SIGNIFICANT MEDICAL PROCEDURES OR TREATMENTS.

(a) If a health care decision involves a significant medical procedure or treatment, an individual's individualized written service plan team must approve by a majority with the recommended health care decision of the individual's health care advocate prior to administration of the significant medical procedure or treatment.

(A) The approval must be reached through an in-person meeting of the individualized written service plan team identified under OAR 411-390-0220.

(B) An in-person meeting must allow for real time, verbal communication between all members of the individualized written service plan team.

(b) The health care decision by the individualized written service plan team to approve or disapprove the recommended health care decision must involve consideration and documentation of all of the following:

(A) The alternatives to the proposed significant medical procedure or treatment.

(B) The risks and benefits of the proposed significant medical procedure or treatment.

(C) The risks and benefits of not receiving the proposed significant medical procedure or treatment.

(D) The impact of the proposed significant medical procedure or treatment on the individual's wellbeing.

(E) Any preferences indicated by any verbal or nonverbal communication by the individual.

(F) Any additional information that may need to be obtained that may affect the decision, such as a second opinion.

(c) If a majority of the individualized written service plan team disapproves of the health care advocate's recommended health care decision, the health care advocate does not have the authority to make the health care decision.

Stat. Auth.: ORS 127.765, 409.050

Stats. Implemented: ORS 127.765

411-390-0220 Safeguards

(Adopted 03/01/2020)

(1) When an individualized written service plan team is discussing the appointment of a health care advocate for an individual, or discussing an individual's significant medical treatment or procedure, the individual and any advocate named to the individualized written service plan team by the individual must be included in the individualized written service plan team and may not be excluded.

(a) The individualized written service plan team must be composed of at least three members other than the individual.

(b) The individualized written service plan team may include, but is not limited to, family, advocates, and staff with a vested interest in the individual.

(c) An individual is not required to participate in the discussion if the individual declines to participate or is unable to participate due to the individual's medical condition.

(2) The composition of the individualized written service plan team may not be changed to override the objection of any member of the individualized written service plan team.

(3) A case manager and at least one other person from each individualized written service plan team must receive approved training from the Department before using these rules to designate a health care advocate.

(4) When these rules are used to appoint a health care advocate, information and data specified by the Department must be submitted to the case management entity and the Department.

(5) A health care decision or determination made by a health care advocate under these rules may be appealed, in writing to the Director, by any of the following:

(a) The individual.

(b) Any advocate.

(c) The case manager.

(d) The guardian.

(e) Any member of the individualized written service plan team.

(f) Any family member.

(6) The Director shall respond in writing within 15 business days from the receipt of the appeal. The Director's decision is final.

Stat. Auth.: ORS 127.765, 409.050

Stats. Implemented: ORS 127.765