

**DEPARTMENT OF HUMAN SERVICES
SENIORS AND PEOPLE WITH DISABILITIES DIVISION
OREGON ADMINISTRATIVE RULES**

CHAPTER 309

**DIVISION 041
DEVELOPMENTAL DISABILITY SERVICES
CONTRACT PROGRAMS**

Health Care Representative

309-041-1500 Statement of Purpose, Mission Statement and Statutory Authority

(1) Purpose. These rules prescribe standards by which a health care representative may be appointed for adults with developmental disabilities who reside in a home or facility licensed under OAR 309-049-0030 through 309-049-0220 or OAR 309-041-0550 through 309-041-0830.

(2) Mission Statement. The overall mission of the State of Oregon Mental Health and Developmental Disability Services Division is to provide support services that will enhance the quality of life of persons with developmental disabilities.

(a) The division is entrusted with the health and safety of individuals residing in homes and facilities providing 24 hour residential services. Access to health care is essential to their health and safety and inability to give informed consent is a major barrier to that access. In addition, ORS 430.210 requires informed consent to receive services;

(b) The Division recognizes and supports the rights of adults to make informed choices which include refusal of and consent to health care. The intent of this rule is to maximize access to health care by allowing the appointment of a health care representative when an adult is incapable of making health care decisions, as determined by OAR 309-041-1540;

(c) This rule encourages the use of health care representatives as provided under ORS 127.505 to 127.660 and provides for the appointment of a health care representative in situations not covered by ORS 127.505 to 127.660 (provisions permitting capable individuals to appoint a health care representative to make health care decisions in the event they are incapable) 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for appointment of a health care representative to decide whether life-sustaining procedures may be withheld or withdrawn for incapable individuals. This rule provides for appointment of a health care representative for making other health decisions for incapable individuals in situations where there is concurrence by the ISP team regarding the individual's incapacity, the identity of the health care representative, and significant health care decisions.

(3) Statutory Authority. These rules are authorized by ORS 430.041, 443.450 and 127.505 to 127.660.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1510 Definitions

As used in these rules:

(1) "Advocate" means a person other than paid staff who has been selected by the individual with developmental disabilities or by the individual's legal representative to help the individual understand and make choices in matters relating to identification of needs and choices of services, especially when rights or interests are at risk or have been violated.

(2) "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.

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

(4) "Case manager" means an employee of the community mental health program or other agency which contracts with the County or Division, who plans, procures, coordinates and monitors individual support plan services and acts as a proponent for persons with developmental disabilities.

(5) "Concurrence" means all members of the team agree that a decision has sufficient worth that they do not object to the decision.

(6) "Developmental disability" means a disability attributable to mental retardation, autism, cerebral palsy, epilepsy or other neurological handicapping condition which requires training or support similar to that required by individuals with mental retardation, and the disability:

(a) Originates before the individual attains the age of 22 years, except that in case of mental retardation the condition must be manifested before the age of 18; and

(b) Has continued, or can be expected to continue, indefinitely; and

(c) Constitutes a substantial limitation to the ability of the person to function in society; or

(d) Results in significant subaverage general intellectual functioning with concurrent deficits in adaptive behavior which are manifested during the developmental period. Individuals of borderline intelligence may be considered to have mental retardation if there is also serious impairment of adaptive behavior. Definitions and classification shall be consistent with the Manual of Terminology and Classification in Mental Retardation by the American Association on Mental Deficiency, 1983 Revision. Mental retardation is synonymous with mental deficiency.

(7) "Division" means the Mental Health and Developmental Disability Services Division.

(8) "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.

(9) "Health care decision" means consent, refusal of consent or withholding or withdrawal of consent to health care, and includes decisions relating to admission or discharge from a health care facility as defined in ORS 442.015 or a hospice program as defined in ORS 443.850. As used in this rule, it does not include decisions relating to admission or discharge from a residential facility as defined in ORS 443.400 or an adult foster home as defined in ORS 443.705.

(10) "Health care facility" means a health care facility as defined in ORS 442.015, a domiciliary care facility as defined in ORS 443.205, a residential facility as defined in ORS 443.400, an adult foster home as defined in ORS 443.705 or a hospice program as defined in ORS 443.850.

(11) "Health care representative" means:

(a) A health care representative as defined in ORS 127.505(12); or

(b) A person who has authority to make health care decisions for an individual under the provisions of OAR 309-041-1500 through 309-041-1610.

(12) "Incapable" means that an individual lacks the ability to make and communicate decisions, including any means of communication, including communication through persons familiar with the individual's manner of communicating. Incapable of making a health care decision does not necessarily mean being incapable of appointing a health care representative. Incapable of making a health care decision means that the individual lacks the ability to make and communicate health care decisions to health care providers. Incapable of appointing a health care representative means that the individual lacks the ability to make and communicate the decision to appoint a health care representative to the witnesses required by ORS 127.510 through 127.515. These require separate evaluations. Capable means not incapable.

(13) "Individual" means an adult with developmental disabilities who has a health care representative or for whom one is sought and who resides in a home or facility licensed under OAR 309-049-0030 through 309-049-0220 or OAR 309-041-0550 through 309-041-0830.

(14) "Individual Support Plan Team" or "ISP team" means a team composed of the individual, the case manager, the individual's legal guardian, representatives of all current service providers, the individual's advocate and others determined appropriate by the individual receiving services. If the individual is unable or does not express a preference, other appropriate team membership shall be determined by the ISP team members.

(15) "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 purposes of this rule, it includes decisions about emergency procedures started when an individual's heart stops or breathing stops, commonly called "code procedures." Life-sustaining procedure does not include routine care necessary to sustain patient cleanliness and comfort.

(16) "Physician" means an individual licensed to practice medicine by the Board of Medical Examiners for the State of Oregon.

(17) "Psychotropic medication" means a medication whose prescribed intent is to affect or alter thought processes, mood or behavior. This includes, but is not limited to, anti-psychotic, antidepressants, anxiolytic (anti-anxiety) and behavior medications. Because a medication may have many different effects, its classification depends upon its stated, intended effect when prescribed.

(18) "Significant medical procedure or treatment" means:

- (a) Any starting, stopping or change in psychotropic medication that is anticipated to involve risk;
- (b) Any treatment or procedure that requires general anesthesia;
- (c) Any treatment or procedure that incurs a 1% or greater risk of death, in the opinion of the physician;

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

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

[Publications: The publication(s) referred to in this rule are available from the agency.]

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1520 Limits on Rule

(1) These rules apply only to adults who:

(a) Have a developmental disability; and

(b) Live in a facility or home licensed as a 24 hour residential service under OAR 309-049-0030 through 309-049-0220 or certified as a supported living service under OAR 309-041-0550 through 309-041-0830.

(2) If the adult has a guardian, appointed pursuant to ORS Chapter 126, with the powers and duties to make health care decisions, or a health care representative appointed under statute, the guardian or health care representative appointed under statute is not bound by provisions of these rules to which the guardian or health care representative appointed under statute is not otherwise bound because of other statutes or regulation. The guardian or health care representative appointed under statute shall be invited by the ISP team to use this process set forth in these rules.

(3) These rules do not impair or supersede the existing laws of this state relating to:

(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 under 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 individual requiring health care;
- (g) Delegation of authority by a health care representative;
- (h) Any legal right or responsibility any person may have to effect 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
- (j) Any right persons may otherwise have to make their own health care decisions, or to make health care decisions for another.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1530 Entitlement to Decisions

(1) Adults are entitled to make their own health care decisions when they are capable and shall be offered the opportunity to appoint a health care representative as described in ORS 127.505 to 127.660.

(2) Adults who are determined incapable of making a health care decision under OAR 309-041-1540, shall be assessed by the ISP team and case manager for capability for appointing a health care representative. If found

capable, they shall be offered the opportunity by the ISP team to appoint a health care representative as described in ORS 127.505 to 127.660.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1540 Incapability Determinations

Incapability of an adult to make a health care decision for purpose of this rule may occur by any of the following procedures:

- (1) A court renders an opinion that the adult is incapable of making health care decisions; and/or
- (2) The adult's attending physician determines the adult is incapable and, for the purpose of this rule, the ISP team concurs with that opinion.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1550 Naming a Health Care Representative

(1) If an adult is determined incapable of making a health care decision under OAR 309-041-1540 and incapable of appointing a health care representative, a health care representative may be designated by the persons listed below who can be located upon reasonable effort, provided that no person or entity listed below objects to the designation:

- (a) Spouse of the individual;
- (b) Guardian appointed pursuant to ORS Chapter 126 but who lacks the power to make health care decisions;
- (c) Adult children of the individual who can be located through reasonable effort;
- (d) Parents of the individual who can be located through reasonable effort;

(e) Adult siblings of the individual who can be located through reasonable effort; and

(f) The ISP team members for the individual, including the individual and any available advocates or friends.

(2) The health care representative shall be a capable adult and must be willing to serve as a health care representative.

(3) The appointment shall be valid for only one year and shall be reviewed for revocation sooner if there is any indication that the duties of these rules are not being fulfilled, or if the individual regains capability to make a health care decision.

(4) The appointment shall be valid only when the form approved by the Division is completed.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1560 Disqualifications

(1) Except as may be allowed by court order, the following may participate in the process of naming a health care representative, but may not serve as the health care representative appointed under this rule if unrelated to the individual by blood, marriage or adoption:

(a) The attending physician or an employee of the attending physician;

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

(c) The owner, operator, or employee of a residential service provider for the adult for which a health care representative is being

appointed, licensed in OAR 309-049-0030 through 309-049-0220 or certified in OAR 309-041-0550 through 309-041-0830; and

(d) The owner, operator or employee of the vocational service provider for the adult, if the vocational service provider also provides residential services to the adult.

(2) At any time, the individual may disqualify any person from being their health care representative appointed under this rule by any means of communication.

(3) A health care representative whose authority has been revoked by a court or hearing process is disqualified.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1570 Authority and Responsibility of Health Care Representative

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

(2) The health care representative has all the authority over the individual's health care that the individual would have if not incapable, subject to the limitations of the appointment, OAR 309-041-1580, and statute.

(3) A health care representative is not personally responsible for the cost of health care provided to the individual solely because the health care representative makes health care decisions for the individual.

(4) The health care representative shall have access to all medical records necessary to make health care decisions. Re-release or publication of this information is only permitted when it is in the individual's best interest or as otherwise permitted by rule or statute.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1580 Limits on Authority

(1) If the individual objects to any decision made by a health care representative pursuant to OAR 309-041-1500 through OAR 309-041-1610, that decision or determination is null and void unless authorized by statute or other administrative rule.

(2) A health care representative appointed by these rules does not have the authority to and cannot make the following health care decisions on behalf of the individual:

- (a) Admission to or retention in a health care facility for care or treatment of mental illness;
- (b) Convulsive treatment;
- (c) Psychosurgery;
- (d) Sterilization;
- (e) Abortion;
- (f) Withholding or withdrawing of a life-sustaining procedure;
- (g) Withholding or withdrawing artificially administered nutrition and hydration, other than hyperalimentation, necessary to sustain life;
- (h) Testing for HIV, unless testing is required to obtain treatment or care for the individual;
- (i) Assisted suicide or mercy killing; and
- (j) Experimentation, unless the medication or medical treatment prescribed is part of a study protocol approved by a human rights committee and is determined to be in the best interests of the person.

(3) Health care representatives appointed under ORS 127.505 to 127.660 may make decisions concerning withholding or withdrawal of life-sustaining procedures or withholding or withdrawal of artificially administered nutrition and hydration, but only according to the provisions of those statutes.

(4) A health care representative (other than a duly appointed guardian with authority over health care decisions) shall not have the authority to make the health care decisions for the individual that the individual is capable of making herself or himself.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1590 Significant Medical Procedures

(1) If the health care decision involves a significant medical procedure or treatment, the individual's ISP team must concur with the decision of the individual's health care representative prior to administration of the significant procedure or treatment. This will involve discussion and documentation of:

- (a) The alternatives to the proposed procedure or treatment;
- (b) The risks and benefits of the proposed procedure or treatment;
- (c) The risks and benefits of not receiving the proposed procedure or treatment;
- (d) The impact of the proposed procedure or treatment on the individual's lifestyle;
- (e) Any preferences indicated by any verbal or nonverbal communication by the individual; and
- (f) Any additional information that may need to be obtained that might affect the decision, such as a second opinion.

(2) When a health care decision involves a significant medical procedure or treatment, the ISP team must include the individual's case manager.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1600 Safeguards

(1) When the ISP team is discussing issues of capability, appointing a health care representative, or discussing a significant medical treatment or procedure, the individual and any advocate named to the ISP team by the individual must be included in the ISP team and may not be excluded.

(2) The composition of the ISP team may not be changed to override the objection of any member of the ISP team.

(3) In following the decision of a health care representative, a health care provider shall exercise the same independent medical judgment that the health care provider would exercise in following the decisions of the individual if the individual were capable.

(4) Case managers and at least one person who is a residential provider from each ISP team shall receive approved training from the Division before using this rule to designate a health care representative.

(5) When this rule is used to appoint a Health Care Representative, information and data specified by the Division shall be submitted to the Community Mental Health Program and the Division.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450

309-041-1610 Notification and Appeal

(1) The case manager shall notify the individual, give the individual the opportunity to object, and document the notification and/or objection in the case management record, of any and all of the following that apply:

- (a) The individual is determined to be incapable of either making a health care decision or appointing a health care representative;
- (b) A health care representative is being sought for the individual;
- (c) The name of the appointed health care representative; and
- (d) The proposed decision about any significant medical procedure or treatment.

(2) The case manager shall give any Health Care Representative appointed under these rules a copy of the rules and document this in the individual's records.

(3) The following may appeal any decision or determination made under this rule to the Assistant Administrator for the Division in writing:

- (a) The individual;
- (b) Any advocate;
- (c) The case manager;
- (d) The guardian;
- (e) Any member of the ISP team; or
- (f) Any family member.

(4) The Assistant Administrator or designee shall respond in writing within 15 working days of receipt of the appeal. Their decision is final.

Stat. Auth.: ORS 430.041, ORS 443.450 & ORS 127.505 - ORS 127.660
Stats. Implemented: ORS 430.041 & ORS 443.450