

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

**CHAPTER 411  
DIVISION 365**

**DEVELOPMENTAL DISABILITY SERVICES  
HEALTH CARE REPRESENTATIVE**

**EFFECTIVE MARCH 1, 2012**

**411-365-0100 Purpose**  
*(Amended 3/1/2012)*

(1) The rules in OAR chapter 411, division 365 prescribe standards by which a health care representative may be appointed for adults with developmental disabilities who reside in a home or facility licensed and certified for 24 hour residential services under OAR chapter 411, division 325, certified for supported living services under OAR chapter 411, division 328, or licensed as an adult foster home for individuals with developmental disabilities under OAR chapter 411, division 360.

(2) The mission of the Department of Human Services is to provide support services that enhance the quality of life of individuals with developmental disabilities.

(a) The Department 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 individuals' health and safety and inability to give informed consent as required by ORS 430.210 is a major barrier to that access.

(b) The Department recognizes 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 allowing the appointment of a health care representative when an adult individual is incapable of making health care decisions, as determined by OAR 411-365-0180.

(c) These rules encourage the use of health care representatives as provided under ORS 127.505 to 127.660 and provide 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for appointment of a health care representative to decide whether life-sustaining procedures may be withheld or withdrawn for incapable individuals. These rules provide 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.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

#### **411-365-0120 Definitions** *(Amended 3/1/2012)*

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

(5) "Department" means the Department of Human Services.

(6) "Developmental disability" means a neurological condition that originates in the developmental years, that is likely to continue, and significantly impacts adaptive behavior as diagnosed and measured by a qualified professional as described in OAR 411-320-0080.

(7) "Director" means the director of the Department's Office of Developmental Disability Services, or that person's designee.

(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 to 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 these rules, "health care decision" 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; or

(b) A person who has authority to make health care decisions for an individual under the provisions of these rules.

(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.

(a) "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 making a health care decision" does not mean an individual is incapable of appointing a health care representative.

(b) "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.

(c) "Capable" means not incapable.

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

(14) "Individual Support Plan (ISP) Team" means a team composed of the individual, representatives of all current service providers, the individual's legal guardian, the services coordinator, family, and 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 these rules, "life-sustaining procedure" 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 medication the prescribed intent of which is to affect or alter thought processes, mood, or behavior including but not limited to anti-psychotic, antidepressants, anxiolytic (anti-anxiety), and behavior medications. The classification of a medication depends upon its stated, intended effect when prescribed.

(18) "Services coordinator" means an employee of the community developmental disability program or other agency that contracts with the County or Department, who is selected to plan, procure, coordinate' and monitor individual support plan services, and to act as a proponent for individuals with developmental disabilities.

(19) "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 percent or greater risk of death, in the opinion of the physician;

(d) Any treatment or procedure that may 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.

(20) "These rules" mean the rules in OAR chapter 411, division 365.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450

Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

#### **411-365-0140 Limits on Rule**

*(Amended 3/1/2012)*

(1) These rules apply only to adults who:

(a) Have a developmental disability; and

(b) Live in a facility or home licensed and certified for 24 hour residential services under OAR chapter 411, division 325, certified for supported living services under OAR chapter 411, division 328, or licensed as an adult foster home for individuals with developmental disabilities under OAR chapter 411, division 360.

(2) Guardians appointed pursuant to ORS chapter 125 and health care representatives appointed under ORS chapter 127 are not bound by the provisions of these rules. The guardian appointed pursuant to ORS chapter 125 or health care representative appointed under ORS chapter 127 shall be invited by the ISP team to use the 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 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
- (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 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

**411-365-0160 Entitlement to Decisions**  
(Amended 3/1/2012)

(1) Individuals 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) Individuals who are determined incapable of making a health care decision under OAR 411-365-0180, shall be assessed by the ISP team and services coordinator for capability for appointing a health care representative. If determined capable, the ISP team shall offer the individual the opportunity to appoint a health care representative as described in ORS 127.505 to 127.660.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

**411-365-0180 Incapability Determinations**  
(Amended 3/1/2012)

For the purpose of these rules, incapability of an individual to make a health care decision may occur by any of the following procedures:

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

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

**411-365-0200 Naming a Health Care Representative**  
(Amended 3/1/2012)

(1) If an individual is determined incapable of making a health care decision under OAR 411-365-0180 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 125 but who lacks the power to make health care decisions;
- (c) Adult children of the individual who may be located through reasonable effort;
- (d) Parents of the individual who may be located through reasonable effort;
- (e) Adult siblings of the individual who may 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 must be a capable adult and must be willing to serve as a health care representative.

(3) The appointment of a health care representative 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 Department is completed.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

**411-365-0220 Disqualifications**  
(Amended 3/1/2012)

(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 these rules 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 individual for which a health care representative is being appointed, licensed, and certified for 24 hour residential services in OAR chapter 411, division 325, certified for supported living services under OAR chapter 411, division 328, or licensed in OAR chapter 411, division 360 as an adult foster home; and

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

(2) Any parent or guardian is disqualified from serving as a health care representative if at any time the individual was under the care, custody, or control of the parent or guardian, and the court entered an order that either:

(a) Terminated the person's parental rights; or

(b) Placed the individual in the protective custody or legal custody of the Department and the individual was not returned to the care, custody, or control of the parent or guardian because it was determined that it was not safe for the individual.

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

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

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

### **411-365-0240 Authority and Responsibility of Health Care Representative**

*(Amended 3/1/2012)*

(1) When making any health care decision for an individual, the health care representative must 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 may have made if capable. If this is not possible, the decision must be made in what the health care representative believes to be in the individual's best interest.

(2) The health care representative shall have all the authority over the individual's health care that the individual may have if not incapable, subject to the limitations of the appointment, OAR 411-365-0260, 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 medical records shall only be permitted when it is in the individual's best interest or as otherwise permitted by rule or statute.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

## **411-365-0260 Limits on Authority**

*(Amended 3/1/2012)*

(1) If the individual objects to any decision made by a health care representative pursuant to these rules, that decision or determination shall be null and void unless authorized by statute or other administrative rule.

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

- (a) Convulsive treatment;
- (b) Psychosurgery;
- (c) Sterilization;
- (d) Abortion;
- (e) Withholding or withdrawing of a life-sustaining procedure;
- (f) Withholding or withdrawing artificially administered nutrition and hydration, other than hyperalimentation, necessary to sustain life;
- (g) Testing for HIV, unless testing is required to obtain treatment or care for the individual;
- (h) Assisted suicide or mercy killing; and
- (i) 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 individual.

(3) Health care representatives appointed by the individual 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) may 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 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

**411-365-0280 Significant Medical Procedures**  
(Amended 3/1/2012)

(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 must 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 services coordinator.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

## **411-365-0300 Safeguards**

*(Amended 3/1/2012)*

(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.

(a) The ISP team must be composed of at least three members other than the individual; and

(b) The ISP team must include all family, advocates, and staff with a vested interest in the individual. This may be an expanded ISP team.

(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 may exercise in following the decisions of the individual if the individual were capable.

(4) Service coordinators and at least one other person from each ISP team shall receive approved training from the Department before using these rules to designate a health care representative.

(5) When these rules are used to appoint a health care representative, information and data specified by the Department shall be submitted to the Community Developmental Disability Program and the Department.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450

Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450

## **411-365-0320 Notification and Appeal**

*(Amended 3/1/2012)*

(1) The services coordinator shall notify the individual, give the individual the opportunity to object, and document the notification and 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 services coordinator shall give any health care representative appointed under these rules a copy of these rules and document this in the individual's records.

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

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

(4) The Director or designee shall respond in writing within 15 working days of receipt of the appeal. The Director or designee's decision is final.

Stat. Auth.: ORS 127.505 - ORS 127.660, 409.050, & 443.450  
Stats. Implemented: ORS 127.505 - ORS 127.660, & 443.450