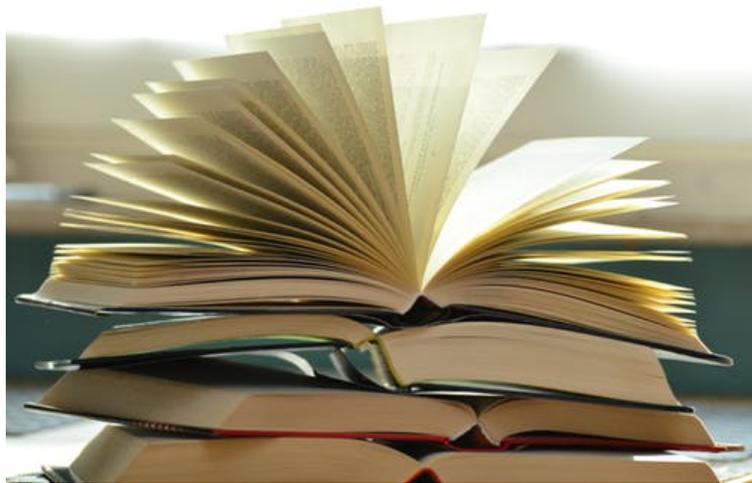


Advocacy 101



Resource Packet



DEVELOPMENTAL DISABILITIES SUPPORTS DIVISION
November 2019

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Key Definitions

Legal Definitions

Advance (Medical) Directive: Legal documents that allow one to give directions for his/her own medical care. This could be a living will or a durable power of attorney for health care. An advance directive is a written or oral statement in which a person expresses his or her wishes regarding medical care should he or she lose the ability to make such decisions. A guardian or family member cannot do this. *Note: see also "Health Care Decision"*

Bioethics Committee: The Joint Commission on Accreditation of Hospital Organizations (JCAHO) requires that each hospital they accredit have a biomedical ethics committee. These committees support patients, their families, health providers, and the community in making difficult treatment decisions, and handling ethical dilemmas related to healthcare. Most biomedical ethics committees do not make decisions, but do provide a process so that patients, their families and health providers can reach consensus. Members include representatives from different professional, cultural and religious backgrounds to bring a broad perspective to the committee.

Capacity: Involves awareness of how and to what degree the person understands, processes, and communicates. Capacity as stated under the law is the legal ability to engage in certain acts, such as making a contract.

DNR: Refers to "Do Not Resuscitate" orders; CPR should not be performed on a person who has a valid DNR order written. Resuscitation involves cardiac compressions and artificial respiration with assisted ventilation to provide functions of breathing and circulation in the event of cessation of heartbeat and/or breathing. DNR orders do not apply to the withholding of withdrawal of other therapeutic or diagnostic measures to maintain the life of an individual (i.e. oxygen, antibiotics, fluids).

Guardianship: The legal power to care for another person and manage his or her affairs; this is a legal, not medical, determination. Only the courts have the authority to remove the rights that people get when they become adults. A court makes the decision based on the person's abilities to handle personal decisions. The incapacity (or legal inability) to handle these matters, not mental retardation, is grounds for a guardianship. See the Arc of New Mexico guardianship brochure "Guardianship for Persons with Developmental Disabilities" - What it means and How it Works".

Health Care Decision: A decision made by an individual or the individual's agent, guardian (note: if judicially appointed to have authority to make a health-care decision for an individual) or surrogate, regarding the individual's health care, including 1) selection and discharge of health-care providers and institutions; 2) approval or disapproval of diagnostic tests, surgical procedures, programs of medication and orders not to resuscitate; and 3) directions to provide, withhold or withdraw artificial nutrition and hydration and all other forms of health care (Health Care Decisions Act).

NM Uniform Health Care Decision Act (24-7A-1 to 24-7A-17 NMSA 1978 (1996 Supp.1): the primary statute that governs health care decisions in New Mexico. The purpose of this statute is for individuals to give as much input as possible into their own specific medical decisions. It covers a broad range of different types of health care decisions.

Philosophy & Rights Definitions

Confidentiality: Personal information is protected and held private unless the individual or legal guardian gives written authorization specifying to whom the information can be released and under what terms.

Information: Involves providing enough information (options and possible outcomes) to the person in a way that the person will understand.

Informed Choice: The person has the information needed that matches his or her experience and capabilities, to choose one option over others (for example: being informed in a manner the person can understand about the risks as well as the benefits of a procedure for treatment). This choice may be based on the person's belief system, experience, and other factors.

People First Language: Puts the person first, disability second (if at all); emphasizes abilities and is appropriate to the person's age.

Voluntariness: Involves the person making a decision without being forced or manipulated. Voluntariness is a legal and philosophical concept referring to a choice being made of a person's free will, as opposed to being made as the result of coercion or duress.

Medical Definitions

Acute: A health situation that will not improve until treated but does not need emergency treatment. A sudden or rapid onset of signs and symptoms. An acute condition will typically be treated by visiting the urgent care or making a same-day or next day appointment with the PCP.

Aspiration: A foreign substance(s) swallowed to the person's lungs rather than to the digestive system.

Constipation: Abnormally delayed or infrequent passage of dry hardened stools which is typically painful and a cause of generalized discomfort or malaise.

CPR: Cardiopulmonary Resuscitation; manual or mechanical cardiac compressions and artificial respiration to circulate oxygenated blood to a person in cardiac arrest. *Note: you must be certified to perform this procedure.*

Dysphagia: Difficulty (or inability) in swallowing. Dysphagia is a disorder that may contribute to aspiration risk.

Emergency: A health situation that presents an immediate risk to a person's life or wellbeing and requires immediate attention.

Epilepsy: A condition that briefly, from time to time, interrupts the brain's normal electrical activity. This disturbance can result in mild to severe convulsions, falling, and/or clouding of

consciousness, massive muscle spasms, staring, stiffening, twitching, and other manifestations.

Feeding Tube: An alternative method of providing nutrition, hydration and medication through a tube that enters the body through the nose (ng-tube), wall of the stomach (g-tube) or wall of the intestine (j-tube).

Health Maintenance: A medical need for which an appointment can be arranged in advance such as a routine intervention (for example: a routine blood pressure check).

Health Passport: A standardized document used to communicate vital medical information to healthcare providers, including emergency contact information, diagnoses, allergies, medication and any advanced directive.

Incontinence: Inability to prevent the discharge of any of the excretions (especially urine and/or feces).

Primary Care Provider: A health care practitioner who manages the person's overall health (usually a family physician, pediatrician, internal medicine physician, Certified Nurse Practitioner [CNP], or Physician's Assistant [PA]). The primary care provider may refer the individual to specialist for further treatment (such as referrals to a neurologist or cardiologist).

Reflux: The backing up of food from the stomach to the tube that connects the stomach with the mouth; one symptom of this is heartburn.

Seizures: Result from brief electrical disturbance in the brain, which causes a change in sensation, awareness, or behavior. Depending on the part of the brain affected, seizures may manifest as convulsions, loss of control over movement, brief unconsciousness, and/or sensory distortion. There are more than 20 types of seizures. Epilepsy is considered when there is recurrence of seizures.

Substitute Health Care Decision: Is made by a Guardian or Surrogate with authority over health care decisions where the individual either lacks capacity to make health care decisions or has chosen to have someone else make those decisions. These substitute health care decisions are in accordance with the individual's wishes and values to the extent known. If unable to determine the individual's wishes and values, decisions are made in accordance with the individual's best interest as determined by the substitute decision-maker. Such decisions are not made solely on the basis of the individual's pre-existing physical or medical condition or pre-existing or projected disability.

Video fluoroscopy or Modified Barium Swallow: An in-depth medical procedure that can be used to study a person's eating mechanism usually done with a radiologist and speech-language pathologist. The video fluoroscopy provides a video tape-type x-ray, which shows how the eating and breathing structures work together during eating and drinking. This procedure can be used to determine if person is aspirating. As a result of this study, recommendations are made about how the person can most safely receive nutrition.

This rule was filed as 7 NMAC 26.3.

TITLE 7 HEALTH
CHAPTER 26 DEVELOPMENTAL DISABILITIES
PART 3 RIGHTS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES LIVING IN
THE COMMUNITY

7.26.3.1 ISSUING AGENCY: Department of Health, Developmental Disabilities Division, 1190 Saint Francis Drive, Post Office Box 26110, Santa Fe, New Mexico 87502-6110, Telephone No. (505) 827-2574
[09/07/94; 01/15/97; Recompiled 10/31/01]

7.26.3.2 SCOPE:

A. This regulation applies only to clients and service providers as defined below.
B. This regulation is not available to resolve disputes concerning the content of or the substantial failure to implement a community individual service plan. Any dispute concerning the content of a plan or any claim alleging substantial failure to implement a plan must be raised in the dispute resolution process, if available. This regulation is not available to review any action by a service provider or the department to suspend, terminate or reduce Medicaid covered services if a fair hearing procedure is available pursuant to federal law.

C. Nothing in this regulation alters or modifies the duty of any person having reason to believe that a person is being abused, neglected, or exploited to report that information as required by the Adult Protective Services Act, Section 27-7-30 NMSA 1978 (1992 Repl.) and the Abuse and Neglect Act, Section 32A-4-3 NMSA 1978 (1993 Repl.).
[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.3 STATUTORY AUTHORITY: NMSA 1978, Section 9-7-6.
[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.4 DURATION: Permanent.
[01/15/97; Recompiled 10/31/01]

7.26.3.5 EFFECTIVE DATE: January 15, 1997, unless a later date is cited at the end of a Section or Paragraph.

[09/12/94; 01/15/97; Recompiled 10/31/01]

[Compiler's note: The words *or paragraph*, above, are no longer applicable. Later dates are now cited only at the end of sections, in the history notes appearing in brackets.]

7.26.3.6 OBJECTIVE:

A. These regulations set out rights that the department expects all providers of services to individuals with developmental disabilities to respect. These regulations are intended to complement the department's Client Complaint Procedures (7 NMAC 26.4) [now 7.26.4 NMAC].

B. These regulations are promulgated, in part, to satisfy requirements arising from the implementation of the decision in the Jackson v. Fort Stanton, N.M. Dist. Ct. No. Civ. 87-839, including agreements reached by the parties. These regulations are promulgated to further the goals of the Developmental Disabilities Act, Sections 28-16A-1 through 28-16A-18 NMSA 1978.

C. Notice of public hearing on the proposed regulations was given in accordance with Section 9-7-6 NMSA 1978. On June 23, 1994, a public hearing was held in Santa Fe, New Mexico. Both written and oral testimony was accepted from all persons who desired to testify. The department's hearing officer submitted his recommendations on August 25, 1994.

D. These regulations do not incorporate all the recommendations made by the hearing officer. I have today prepared a decision which is part of the record that explains the reasons for the department's deviation from recommendations made by the hearing officer.

E. The purpose of this regulation is to promote the health, safety and welfare of individuals who are receiving supports and services for persons with developmental disabilities from service providers certified by, or

funded in whole or in part with state funds administered by the department through contracts or agreements. This regulation defines rights of persons with developmental disabilities so that these rights can be readily identified, exercised and protected and provides that the department will enforce remedies for substantiated complaints of violation of the client's right as provided in the client complaint procedure.

[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.7 DEFINITIONS:

A. "Aversive procedures" means those prohibited procedures, including, but not limited to, taste and odor aversives, excessive deprivation or stimulation of basic sensory experiences, any device or intervention intended to cause pain or unpleasant sensations, electric shock, isolation, mechanical restraint, forced exercise, withholding of food, water or sleep, inappropriate clothing, humiliation and water mist, as defined in the division's behavioral support policy.

B. "Client" means a person with developmental disabilities who is receiving supports and services for individuals with developmental disabilities by a service provider certified by, or funded in whole or in part with state funds administered by the department through contracts or agreements.

C. "Complainant" means a client or his or her legal guardian who files a complaint pursuant to this regulation.

D. "Chemical restraint" means the use of medication, including psychoactive medication, as punishment, as a substitute for a habilitation or in quantities that interfere with services or habilitation, for the convenience of staff, or for unreasonable [sic] restricting a client's freedom of movement, other than in an emergency where there is a substantial and imminent risk of serious physical harm to the client or others.

E. "Days" means calendar days.

F. "Department" means the department of health.

G. "Developmental disabilities" means a severe chronic disability of a person that:

(1) is attributable to a mental or physical impairment, including the result from trauma to the brain, or a combination of mental and physical impairments;

(2) is manifest before the person reaches the age twenty-two years;

(3) is expected to continue indefinitely;

(4) results in substantial functional limitations in three or more of the following areas of major life activity:

(a) self-care;

(b) receptive and expressive language;

(c) learning;

(d) mobility;

(e) self-direction;

(f) capacity for independent living; and

(g) economic self-sufficiency; and

(5) reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services that are of life-long or extended duration and are individually planned and coordinated.

H. "Director" means the director, developmental disabilities division or his or her designate.

I. "Division" means the developmental disabilities division of the department.

J. "Emergency" means a circumstance in which the health or safety of the client or another person is in imminent risk of harm and immediate action is necessary to prevent the harm.

K. "Emotional or psychological abuse" means use of verbal or other communication to threaten a client with physical harm or to ridicule, curse, humiliate, degrade or antagonize a client, or any similar action

L. "Exploitation of a client's personal property" means intentionally, knowingly or recklessly using a client's person or property for another person's profit, advantage, or benefit without legal right or authority. Exploitation includes failure to compensate a client for services or work for which he or she is entitled to compensation.

M. "Facilities" means institutions operated by the department.

N. “Guardian” means the parent of an individual with developmental disabilities if the client is a minor or a legal guardian appointed or recognized pursuant to the Uniform Probate Code, Section 45-5-101, et seq. NMSA 1978 (1993 Repl.).

O. “Mechanical restraint” means any apparatus that restricts a client's movement excluding mechanical supports designed by a physical therapist and approved by a physician or designed by an occupational therapist that is used to achieve proper body position and excluding protective devices.

P. “Medical restraint” means any apparatus prescribed by a physician, dentist or medical practitioner acting within the scope of his or her license, as health-related protection that restricts a client's movement during the conduct of a specific medical or surgical procedure.

Q. “Neglect” means, subject to the client's right to refuse treatment and subject to medical personnel's right to exercise sound medical discretion:

(1) the failure to provide any treatment, services, care, medication or item that is necessary to maintain the health and safety of a client;

(2) the failure to take reasonable precaution that is necessary to prevent damage to the health and safety of a client; or

(3) the failure to carry out a duty to supervise properly or control the provision of any treatment, care, goods, services, or medication necessary to maintain the health or safety of a client.

R. “Office” means the office of quality assurance or a regional office within the developmental disabilities division.

S. “Plan” means the individual service plan for services, treatment or habilitation developed by the interdisciplinary team.

T. “Physical abuse” means any act, or failure to act, performed knowingly, intentionally or recklessly that causes or is likely to cause harm. Physical abuse includes, but is not limited to, physically striking or assaulting a client, hitting, slapping, pinching, kicking, pushing, dragging, shaking, squeezing, choking and shoving. Physical contact which endangers the safety of a client as well as handling the client with more force than is necessary also constitute physical abuse.

U. “Physical restraint” means the use of manual methods to restrict the movement or normal functioning of a portion of an individual's body other than physical guidance and prompting techniques of brief duration.

V. “Protective devices” means helmets, safety goggles or glasses, guards, mitts, gloves, pads and other common safety devices that are normally used or recommended for use by persons without disabilities while engaged in a sport, occupation, or during transportation.

W. “Service provider” means a private entity that has entered into a contract or provider agreement with the department or that is certified by the department for the purpose of providing supports and services to individuals with developmental disabilities. When the context requires, the service provider means the executive director or administrator having authority to bind the service provider. Service provider does not include facilities operated by the department.

X. “Sexual abuse” means sexual activity between a client and staff, nonconsensual sexual activity or contact with others without regard to injury, and sexual exploitation. Sexual activity includes, but is not limited to kissing, hugging, stroking or fondling with sexual intent; oral sex or sexual intercourse; and request or suggestion or encouragement by staff for performance of sex with the employee or another. Sexual intent is to be determined by an examination of all the circumstances related to the incident. Sexual exploitation includes sexual exploitation as defined in the Abuse and Neglect Act, Section 32A-4-2(F) and allowing, permitting or encouraging obscene or pornographic filming or photographing of an adult client without his or her consent for commercial or noncommercial purposes.

[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.8 REGULATION DOES NOT CREATE AN ENTITLEMENT TO SERVICES: Nothing in this regulation shall provide an entitlement to programs, supports, services or benefits that does not otherwise exist pursuant to other law or regulation.

[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.9 REGULATION DOES NOT CREATE A CAUSE OF ACTION: Any rights or remedies provided pursuant to this regulation that do not otherwise exist pursuant to other law or regulation are enforceable only through the client complaint procedure and are not enforceable in court. Nothing in this regulation shall create a right of judicial review of the administrative decision of the director or the secretary or his or her designee made pursuant to the client complaint procedure.
[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.10 CLIENT RIGHTS: Unless expressly modified by court order or specifically granted to a guardian or conservator, all clients have:

- A. the same legal rights guaranteed to all other individuals under the United States Constitution, New Mexico State Constitution, and federal and state laws;
- B. the right to be free from unlawful discrimination on the basis of race, age, religion, color, national origin, ancestry, sex, sexual preference, physical or mental handicap or medical condition;
- C. the right to be free from emotional or psychological abuse, physical abuse, sexual abuse, neglect and exploitation of his or her personal property;
- D. the right to practice the religion of his or her choice or to abstain from the practice of religion;
- E. the right to safe working conditions, hours of labor and wages for labor consistent with the Fair Labor Standards Act and other applicable federal and state laws, and worker's compensation, except that clients receiving residential services may be required to do normal housekeeping and home maintenance chores. Clients shall not be required to perform labor involving the essential operation of the service provider, including the care and treatment of other clients. Clients may volunteer to do labor, consistent with federal and state labor laws. If a client volunteers to do work for which the program would otherwise be required to pay non-clients, the client shall be paid a commensurate wage;
- F. the right to consent to or refuse medical treatment, medical services, and other forms of habilitation services or supports, consistent with the ISP regulations and the duties of a parent, guardian or treatment guardian pursuant to the requirements of the Children's Mental Health and Developmental Disabilities Act, Section 32A-6-14 NMSA 1978 (1993 Repl.) or the Mental Health and Developmental Disabilities Act, Section 43-1-15 NMSA 1978 (1993 Repl.);
- G. the right to have privacy, including both periods of privacy and places of privacy;
- H. the right to communicate freely with persons of his or her choice in any reasonable manner and at any reasonable time he or she chooses;
- I. the right to own, use and control real property and personal possessions;
- J. the right to engage in social interaction with members of either sex;
- K. the right to enter into contract, including the contract to marry;
- L. the right to engage in consensual sexual activity, except sexual activity defined as sexual abuse;
- M. the right to procreate and to parent or not to procreate;
- N. the right to manage his or her financial affairs, unless the client has a court appointed guardian or conservator or access to his or her funds is restricted by the individual service plan. A service provider who manages the funds of a client pursuant to the client's individual service plan shall comply with applicable federal standards or regulations and the following requirements:
 - (1) the service provider shall have obtained informed consent and written authorization from the client or the guardian or conservator, which shall state the service provider's responsibilities;
 - (2) the service provider shall maintain a written record of all financial transactions involving the funds of the client and shall make the record available to the client and the guardian or conservator upon request;
 - (3) the service provider shall provide for the safekeeping of the funds, shall keep the funds separate from all other funds and shall be held strictly accountable for the funds and any interest;
 - (4) the service provider shall return the funds to the client or guardian or conservator, including interest, upon request. Upon the death of a client, the service provider shall provide the executor or personal representative a complete accounting of all funds and property;
- O. the right to participate in the political process, including the right to vote;
- P. the right to have access to his or her records, except as expressly limited by statute, and to have confidential treatment of all information in his or her records, including personal and medical records.

Confidentiality does not preclude access to an individual's records by an individual or organization otherwise entitled under federal or state law to review records;

- Q. the right to voice grievances and complaints and to recommend changes in service provider policies and services without restraint, interference, coercion, discrimination or reprisal;
- R. the right to have access to available advocacy services, including consultation and assistance on the individual's concerns and training on legal rights;
- S. the right to refuse to participate in medical or psychological research experimentation;
- T. the right to be free from excessive use of medical restraint;
- U. the right to be free from the use of chemical restraint;
- V. the right to be free from the use of physical restraint except in an emergency;
- W. the right to be free from limitations on freedom of movement except in an emergency;
- X. the right to be free from the use of mechanical restraint; and
- Y. the right to be free from the use of aversive procedures.

[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.11 RESTRICTIONS OR LIMITATION OF CLIENT'S RIGHTS:

- A. A service provider shall not restrict or limit a client's rights except:
 - (1) where the restriction or limitation is allowed in an emergency and is necessary to prevent imminent risk of physical harm to the client or another person; or
 - (2) where the interdisciplinary team has determined that the client's limited capacity to exercise the right threatens his or her physical safety; or
 - (3) as provided for in Section 10.1.14 [now Subsection N of 7.26.3.10 NMAC].
- B. Any emergency intervention to prevent physical harm shall be reasonable to prevent harm, shall be the least restrictive intervention necessary to meet the emergency, shall be allowed no longer than necessary and shall be subject to interdisciplinary team (IDT) review. The IDT upon completion of its review may refer its findings to the office of quality assurance. The emergency intervention may be subject to review by the service provider's behavioral support committee or human rights committee in accordance with the behavioral support policies or other department regulation or policy.
- C. The service provider may adopt reasonable program policies of general applicability to clients served by that service provider that do not violate client rights.

[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.12 RETALIATION FOR INITIATION OF COMPLAINT PROCEDURE PROHIBITED: A client has the right to present or make known a complaint without restraint, interference or coercion. A service provider shall not retaliate or discriminate against a client, staff person or other person who complains to the service provider or initiates a complaint procedure.

[09/12/94; 01/15/97; Recompiled 10/31/01]

7.26.3.13 CLIENT COMPLAINT PROCEDURE AVAILABLE: A complainant may initiate a complaint as provided in the client complaint procedure to resolve complaints alleging that a service provider has violated a client's rights as described in Section 10 [now 7.26.3.10 NMAC]. The department will enforce remedies for substantiated complaints of violation of a client's rights as provided in client complaint procedure.

[09/12/94; 01/15/97; Recompiled 10/31/01]

HISTORY OF 7.26.3 NMAC:

Pre-NMAC History: The material in this part was derived from that previously filed with the State Records Center: DOH 94-05 (DDD), Regulations Governing Client Rights For Individuals With Developmental Disabilities Living In The Community, 9/12/94.

History of Repealed Material: [RESERVED]

**INSERT YOUR AGENCY-SPECIFIC CLIENT COMPLAINT
OR GRIEVANCE PROCEDURE**

**INSERT YOUR AGENCY-SPECIFIC CLIENT COMPLAINT
OR GRIEVANCE PROCEDURE**

**LONG TERM SERVICES DIVISION
DEPARTMENT OF HEALTH TECHNICAL
ASSISTANCE GUIDELINES**

**TOPIC: GUIDELINES FOR COMMUNITY PROGRAMS, CASE
MANAGERS, AND INTERDISCIPLINARY TEAM MEMBERS
REGARDING ADVANCE DIRECTIVES AND HEALTH CARE
DECISIONS**

ISSUE DATE: JANUARY 23, 2001

PURPOSE AND INTRODUCTION

These guidelines have been prepared to assist Department of Health staff, case managers, community providers and other members of interdisciplinary teams in understanding and supporting the making of important health care decisions by individuals with developmental disabilities and their substitute decision makers. The Health Care Decisions Act addresses a broad range of different types of health care decisions. In this document, we discuss health care decisions within two separate contexts:

- 1) An individual making his/her own health care decisions, including advance directives, and
- 2) An individual who needs substitute decision makers to make health care decisions on his/her behalf.

Everyone with or without disabilities has the right to information regarding advance directives and should be given the opportunity to decide whether or not to put advance directives in place. Individuals with developmental disabilities may be more likely to have difficulty expressing their wishes and/or making these decisions, but with support many can successfully do so.

Advanced directives are tools for an individual to give instructions for health care. Advance directives are made by an individual while he or she has the capacity to decide. Advance directives include both "individual instructions," which can be made in writing or can be made orally to the individual's health care provider, and a "power of attorney for health care," which must be made in writing. Although there are circumstances when substitute decision-makers are authorized to make health care decisions for an individual, substitute decision-makers, including guardians, can not make advance directives.

Advance directives for health care decisions can govern both who should make health care decisions for the individual and what decisions should be made. If an individual has made an advance directive, it must be honored by whomever is later appointed to make decisions for the individual, including a guardian, unless a court expressly directs otherwise.

Health care decisions are decisions about any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect an individual's physical or mental condition. They include decisions about choosing and changing health-care providers and facilities; approval or disapproval of diagnostic test, surgical procedures, programs of medication; orders not to resuscitate ("DNRs"); and directions about providing, withholding, or withdrawing life sustaining treatment, nutrition, hydration, and life-support. Although no one can make an advance directive for another individual, *not even the guardian or other substitute decision maker*, any health care decision that can be made by an individual can also be made by the substitute decision maker. The difference is that a health-care decision made in an advance directive by an individual cannot be changed by the substitute decision-maker, except by a court order.

The intent of this document is to assist interdisciplinary teams as they grapple with these complex issues in partnership with the individuals they serve. The guidelines have been designed to assist Long Term Services Division staff, individuals, parents/guardians and providers in the application of procedures and practices regarding health care decisions, applicable to individuals served by the Medicaid Waivers. They should be viewed as a resource for the Division interested parties when addressing health care decisions. They are NOT intended to serve as Division regulations and do not have the force of law.

Staff, individuals, parents/guardians, and providers should also have and use as a resource the LTSD's Guidelines for Community Programs, Case Managers and Interdisciplinary Team Members Regarding Guardianship which complement the guidelines in this document.

GUIDELINES – ADVANCE DIRECTIVES AND HEALTH CARE DECISIONS

I. Guidelines For Teams Supporting Individuals Making Their Own Health Care Decisions

1. Discussion about advance directives should be initiated by the case manager at time of the annual assessment. The case manager should first clarify
 - 1) the individual's interest in discussing advance directives with others,
 - 2) the individual's desire to formalize his/her preferences through an advance directives document,
 - 3) the individual's need for more information; and
 - 4) the individual's understanding of advance directives.

An individual should be encouraged to discuss this topic with his/her physician, and assistance should be offered to facilitate this, if necessary. Other persons he/she may wish to discuss it with include: extended family members, friends, religious leaders, counselors, and/or other providers. Any discussion of advance directives is *voluntary* on

the part of the individual. No one should be forced to engage in this discussion if not comfortable doing so.

2. In addition to the annual assessment, this issue should be raised whenever the individual's medical condition warrants a review (i.e. diagnosis of a terminal illness, significant deterioration in health, planned admission to a hospital). In this case, new health care decisions should be communicated as soon as possible to the interdisciplinary team, ideally through an IDT meeting.
3. Whether the decision is to have advance directives or not to have advance directives, that decision should be communicated to the individual's interdisciplinary team, including the physician. This should occur at least at the time of the annual ISP meeting, not as a point of discussion, but merely to inform team members whether or not advance directives exist. The individual's records at case management and support provider agencies should reflect whether or not the individual has decided to have advance directives. If advance directives do exist, staff should be trained on how to implement the advance directives and about the individual's underlying health conditions.
4. If the individual does not have a case manager, the program service coordinator should take the initiative to discuss information regarding advance directives with the individual. The residential provider should take the lead if there is more than one agency involved.
5. The individual should be informed that he/she may change advance directives at *any* time by a signed writing or by personally informing a health-care provider. In the case of changes, his/her physician and case manager should be informed to assure that the central record and the team members can be updated.

The following questions may help individuals think about their preferences regarding health care decisions, including advance directives. The answers will vary by individual and must be considered within the context of the specific medical circumstance.

1. If the individual does not have a guardian with authority over health care decisions or other appointed surrogate decision-maker, do they wish to appoint or designate someone for health care decision-making?
2. Has the individual already assigned the authority for health care decision making to any other person, either verbally or in writing?
3. If the individual's first choice cannot serve, who would be the next choice?
4. Does the individual wish to be resuscitated if they experience a cardiac or respiratory arrest? If not, they can choose to request their physician to write a "Do Not Resuscitate" or "DNR" order. A "DNR" order does not prevent the individual from receiving appropriate treatment for any conditions other than cardiac or respiratory

arrest. In other words, medical personnel would not let the individual die from some other condition, such as pneumonia, just because they have a "DNR" order in place.

5. If the individual's kidneys fail, does he/she wish to receive kidney dialysis and/or a kidney transplant?
6. Does the individual wish to donate any or all of his/her internal organs if/when he/she dies?
7. Does the individual wish to have blood transfusions if medically indicated?
8. If necessary to support life, does the individual wish to be placed on a ventilator or other mechanical breathing device? If so, does he/she wish to remain on such a device indefinitely?
9. If the individual is in a coma for an extended period of time, does he/she wish to receive nutrition and fluid through tubes in his/her veins, nose, or stomach? ("Extended period" should be defined by the individual.) What are his/her wishes if unable to take nutrition or fluid orally for other reasons?
10. If the individual develops a terminal condition (i.e. cancer), how aggressively would he/she prefer to fight that condition via surgery, chemotherapy, radiation or other method? What are preferences for specific treatments and comfort measures (e.g. does the individual wish to have medication sufficient to control pain, even if a side effect is to shorten life)?
11. Does the individual want to die at home or in a hospital setting? If they prefer to be at home, see End of Life Decisions at Home.
12. Does the individual have any personal, cultural or religious preferences relating to medical treatment, death and/or burial practices?

II. Guidelines For Teams Working With Substitute Decision Makers

1. Discussion about health care decisions should be initiated by the case manager at the time of the annual assessment. The case manager should first clarify:
 - a) the guardian or surrogate's interest in discussing health care decisions with others,
 - b) the guardian or surrogate's understanding of relevant health care issues, and
 - c) the guardian/surrogate's need for more information.

Individuals and guardians/surrogates should be encouraged to discuss this topic with the individual's physician. Other persons they may wish to discuss it with include: extended family members, friends, religious advisors, counselors, and/or other

service providers.

2. In addition to the annual assessment, this issue should be raised whenever the individual's medical condition warrants review (i.e. diagnosis of a terminal illness, significant deterioration in health, planned admission to a hospital). In this case, new health decisions should be communicated as soon as possible to the interdisciplinary team, ideally through an IDT meeting.
3. Regardless of the type of health care decision, that decision should be communicated to the individual's interdisciplinary team, including the physician. This should occur at least at the time of the annual ISP meeting, not as a point of discussion, but merely to inform team members whether or not such decisions have been made and where instructions regarding implementation of those decisions are located. The individual's records at case management and support provider agencies should reflect these decisions. In addition, staff should be trained on how to implement the decisions and about the individual's underlying health conditions.
4. If the individual does not have a case manager, the program service coordinator should take the initiative to discuss information regarding health care decisions with the individual and his/her guardian or surrogate. The residential provider should take the lead if there is more than one agency involved.
5. Guardians and surrogate decisions makers should be informed that they can change health care decisions at any time, and that in the case of changes they should inform the individual's physician and case manager to assure that the central record and the team members are updated.
6. Guardians and surrogate decision makers are required to make decisions on behalf of the individual they represent with consideration of the individual's preferences and best interest, and their decisions should be respected and supported. However, if a member of the interdisciplinary team has ethical concerns regarding a health care decision, he/she should discuss the concerns with his/her supervisor who can then consider whether to take the concerns to the decision maker. If the team member cannot in good conscience abide by the health care decision, he/she may request a transfer from the care of that individual.
7. If the physician is the team member who cannot, in good conscience, comply with the health decision, he/she should advise the individual if possible and the guardian/surrogate, provide continuing care until a transfer to another provider can be effected, and assist with the transfer of care.

HEALTH CARE DECISIONS IN NEW MEXICO

The primary statute that governs health care decisions in New Mexico is the Health Care Decisions Act, sections 24-7A-1 to 24-7A-17 NMSA 1978. Most of us make health care decisions for ourselves—when and whether to go to the doctor, whether we want a medical intervention at all and, if so, which medical intervention seems best. We weigh the risks and benefits of different health care options. The purpose of the New Mexico Health Care Decisions Act is for an individual to give as much input as possible into his/her own specific medical decisions.

I. Advance Directives

There are two types of advance directives that may be put in place: individual instructions or a power of attorney for health care:

A. Individual Instructions

An "individual instruction" is an individual's direction concerning a health care decision. It must be made by the individual and the individual must have capacity.

- 1) If the individual instruction is made orally, the individual must personally inform a health care provider.
- 2) An individual instruction may also be written, often as part of a power of attorney for health care decisions.
- 3) An oral or written individual instruction may include the individual's nomination of a person to be his/her health care decision maker, or to be a guardian appointed by the court should that be necessary.

B. Power of Attorney for Health Care

A power of attorney for health care is a tool to allow an individual to designate a specific person to make health-care decisions for the individual. A power of attorney for health care is a legal document that is in writing and signed by the individual. It is recommended, but not required, that the individual have two other people sign as witnesses. As with an individual instruction, the individual must have the capacity at the time of signing to designate the particular person to make health care decisions.

- 1) A power of attorney for health care decisions allows the individual to name a specific person to make health care decisions, should the individual be unable to do so him/herself at a later time.
- 2) A power of attorney for health care decisions may or may not include specific instructions about health care decisions.

Remember that in stating advance directives, an individual can be as specific or general as they choose. For example, the individual could state that they want all life-saving measures

tried, but that the life-saving measures should be discontinued if there is no clear improvement within a specified period of time. Some people even specify under which circumstances they would or would not desire certain treatments.

Hospitals are required to ask patients if they have, or wish to give advance directives each time a patient is admitted to the hospital. Therefore, it is a good idea for everyone, including people with disabilities, to think about these issues prior to an admission to the hospital.

II. Looking at Issues of Capacity

Under the Health Care Decisions Act, capacity means an individual's ability to understand and appreciate the nature and consequences of proposed health care, including its significant benefits, risks and alternatives, and to make and communicate an informed health care decision.

An individual is assumed to have capacity unless a legal process has taken place to determine otherwise. This may have taken place through a legal process under the New Mexico Probate Code to appoint, by court order, a guardian to make health care decisions. It can also take place without a court order with regard to health care decisions under the Health Care Decisions Act.

According to the Health Care Decisions Act, section 24-7A-11 NMSA 1978, a lack of capacity must be determined by a team of at least two health care professionals, unless the individual has specified otherwise in an advance directive. One of these professionals must be the primary physician. In the case of an individual with developmental disabilities, one of the professionals must have knowledge and expertise in the assessment of functional limitations. It is advised that prior to beginning the capacity determination process, the individual be informed of the purpose of the assessment and the right to challenge the determination. An individual can then challenge a determination that he/she lacks capacity by informing a health care provider of the challenge. Such a challenge means that the person continues to be presumed as having capacity unless there is a court order that upholds the determination of the two health care professionals.

Except in accordance with these processes, teams must assume that the individual can make his/her own health care decisions and support the individual's right to do so. A person shall not be determined to lack capacity solely because he/she disagrees with the doctor.

Even if the individual does not have the capacity to make an advance directive, he/she may have strong values about specific health care decisions, and discussions about the individual's wishes with respect to health care should take place. Understanding the individual's values, even in a broad sense, will be of great use to a substitute decision maker who later has to make health care decisions.

III. Substitute Decision Makers

A. Who May Serve

The Health Care Decision Act and the Probate Code under which the guardians are appointed by court order, prohibits an owner, operator, or any employee of a health care institution or provider providing care to the individual (unless related by blood, marriage or adoption) from serving as either guardian or surrogate decision-maker. All community programs should develop a policy that guides the staff in assisting individuals with health care decision-making and clarifies to staff the limits of their authority. Permitting community provider staff to serve as a surrogate decision-maker, even if that is the individual's choice, appears to be contrary to both the Health Care Decision Act and the Probate Code. Further, the Department of Health prohibits an agency from providing both case management and guardianship services to the same individual.

B. Guardians

Guardians are appointed by the court to make decisions for individuals who cannot make their own decisions. See Sections 45-5-301 to 45-5-315 NMSA 1978.

Guardians may be appointed to make decisions about a variety of matters including: habilitation programming, residential arrangements, financial matters, and/or health care decisions.

Because the scope of guardianships vary, providers should not assume that if an individual has a guardian, the guardian is necessarily authorized to make health care decisions. **Plenary or Full Guardians** are authorized to make health care decisions. **Limited Guardians** are authorized to make health care decisions if the court's order grants the authority to do so. An individual may have a **Treatment Guardian** under the New Mexico Mental Health and Developmental Disabilities Code to make mental health treatment decisions, but treatment guardians cannot make health care decisions other than those concerning mental health treatment.

If a guardianship order grants a guardian plenary or full guardianship or if a limited guardianship order grants a guardian authority over health care decisions, then a court appointed guardian is empowered to make health care decisions on an individual's behalf. Physicians and case managers should confirm that legal guardianship documents grant the guardian authority over health care decisions. A health care decision made by a guardian who has been authorized by the court to make health care decisions is effective without further judicial approval.

Even with a guardian, the individual's input is important and the individual should be asked to the extent possible and clinically appropriate about preferences regarding

these matters. Providing information about treatment options in terms that are understandable and appropriate to the individual is essential.

C. Surrogates

The individual may designate an agent to make health care decisions by a power of attorney for health care. The individual may also designate someone to make health care decisions as a surrogate by informing the supervising health care provider.

If the individual has not made an advance directive, does not have a court appointed guardian for health care decisions and does not have the capacity to make his or her own medical decisions, a surrogate may still be designated to make a health care decision for the individual through the Health Care Decisions Act. The Act lists possible surrogate decision makers in section 24-7A-5B NMSA 1978, including family members in specified order or other interested persons.

CHALLENGES

I. Conflicts regarding Health Care Decisions

Health care decisions, including advance directives, are private and personal decisions and the wishes of the individual and her/his substitute decision maker, if one is involved, should be respected and supported. However, if a member of the interdisciplinary team has ethical concerns regarding a health care decision or advance directive, he or she should discuss the concerns with his/her supervisor who can then consider whether to take the concerns to the decision maker.

If the team member cannot in good conscience abide by the advance directives, he/she may request a transfer from the care of that individual. If the physician is the team member who cannot, in good conscience, comply with the advance directive, then he or she should advise the individual, if possible, and any substitute health care decision-maker, provide

continuing care until a transfer to another provider can be effected and assist with the transfer of care.

Ideally, the individual, guardian or surrogate, the individual's family and the physician will be in agreement regarding health care decisions. However, if there is conflict, the case manager can assist resolution by referring the individual to an ethics committee or other source of mediation. In the meantime, the wishes of the individual and the individual's decision-maker take precedence

II. Emergency Situations

1. If Emergency Medical Services (EMS) are called, or the individual is taken to an emergency room, emergency medical personnel must be informed regarding the existence of advance directives, or the lack of advance directives. It is important that emergency medical staff do not assume the existence of "DNR" orders merely because of the individual's degree of disability or frailty.
2. In the absence of advance directives or a health care decision by a substitute decision maker to authorize a "DNR" order, all possible life- saving measures will be taken. Therefore, before an emergency arises, if a " DNR" order has been authorized by advance directives or in appropriate circumstances, by a substitute decision maker, the DNR order should be readily available, and the EMS/DNR form should be completed since it is the only form legally recognized by EMS.
3. If the individual does not have a guardian or previously designated health care decision-maker, or advance directives, and lacks capacity to make his/her own health care decisions, the Uniform Health Care Decisions Act provides for the appointment of a surrogate decision maker in accordance with the process outlined above and in the Act.

III. End of Life Decisions at Home

1. If the individual or substitute decision maker has decided to authorize a "DNR" (Do Not Resuscitate) order and the individual remains at home, the EMS/DNR form must be completed and used because this is the only form that is legally recognized by EMS. Please remember that a "DNR" order is only one type of health care decision, and applies only to the limited situation of cardiac or respiratory arrest.
2. If the individual has indicated a preference for dying at home, in addition to the completion of the EMS/DNR form, the local EMS should be notified in advance. EMS should then be called to the home at the time of death and presented with the form. If a hospice program is involved, please ask for guidance from the hospice provider regarding appropriate procedures at the time of death.
3. Be aware that if the individual dies in the home without appropriate procedures having been completed, the police department, Adult Protective Services, and/or the Division of Health Improvement of the Department of Health will likely have to fully investigate the death. In addition, deaths of individuals who receive publicly funded services are routinely investigated by a variety of regulatory bodies. A death investigation does not mean that any wrongdoing is suspected.

SUPPLEMENTAL RESOURCES FOR INFORMATION

- Guidelines for Community Programs, Case Managers and Interdisciplinary Team

Members Regarding Guardianship, Long Term Services Division, Department of Health.

- The Continuum of Care Project, at the University of New Mexico Health Sciences Center, has a variety of materials available for loan or reproduction. Call Main: (505) 925-2350; Fax: (505) 925-2389; for more information.
- The New Mexico Coalition for Advance Directives holds an annual conference in Albuquerque. For information about the Coalition and the conference, please contact Gail Joralemon, 501 Carlisle Blvd NE, Albuquerque, NM 87106.

AUTHORITY

- New Mexico Statutes 1978, §§24- 7A-1 to 24- 7A-18 (Uniform Health Care Decisions Act).
- New Mexico Statutes 1978, §§45-5-301 to 45-5-315 (Probate Code Guardianship).

Signature on File

Ramona Flores-Lopez, Director

Long Term Services Division

4-02-2001

Date

FINAL REVISION 1-23-01 IMN

Job Tool: Emergency, Acute, and Health Guidelines and Steps *(See specific guidelines in the person's ISP)*

<p>1. Ensure safety of individual</p> <p>2. Call 911 for immediate response or transport the individual to the Emergency Room.</p> <ul style="list-style-type: none"> • Make the person as comfortable and safe as possible. • Follow the person's crisis plan/medical emergency response plan. <p>3. Call supervisor to notify of trip to the emergency room and reasons.</p> <p><i>Note: follow agency protocol</i></p> <p>4. Take medical book, Health Passport or all of the following information:</p> <ul style="list-style-type: none"> • Emergency contacts (including guardian). • Current medication(s). • List of chronic conditions. • Known drug allergies. • Primary care physician's name and contact info. • Baseline vital signs if abnormal. <p>5. Tell the triage nurse or front desk at the ER any special needs (i.e. suicidal, feeding tube, seizure precautions, expected behavior, allergy)</p> <p><i>Note: paid staff are not authorized to sign a DNR</i></p> <p>6. Afterward:</p> <ul style="list-style-type: none"> • Get copies of emergency room documentation of treatment (discharge diagnoses and instructions). Provide copy to the agency nurse/healthcare coordinator. • Communicate with other team members to update the medical record and/or Health Passport. • Follow-Up as instructed by E.R. physician. • File a <u>GER</u> within 24 hours for use of emergency services 	<p>1. Arrange with primary care provider's office; ask for same day appointment during office hours, or for instructions if after hours <i>(use your agency's protocol).</i></p> <p>2. Take the medical book or Health Passport. Provide the following information:</p> <ul style="list-style-type: none"> • Symptoms observed • When symptoms began • What improves/worsens symptoms • Have these symptoms happened before • Temperature • Respiratory rate • Describe special needs (see #4 in Emergency Steps Column) <p>3. Ask for sufficient time to be seen (usually 30 minutes).</p> <p>4. If waiting until morning to see the primary care provider, write down any instructions to carry out until the appointment.</p> <p>5. Afterward:</p> <ul style="list-style-type: none"> • Update the medical record and/or Health Passport. • Follow-Up as instructed with primary care provider. • Share results with the agency nurse/healthcare coordinator, other staff and team members. 	<p>1. Contact agency nurse/healthcare coordinator. (ensure you are following agency specific protocol)</p> <p>2. State reason for appointment.</p> <p>3. Ask for sufficient time.</p> <p>4. Describe relevant special needs (see #4 in Emergency Steps column).</p> <p>5. Write down date and time.</p> <p>6. Write down any special instructions (e.g. come in back door, bring a urine specimen, do not let the person eat anything two hours prior to the appointment).</p> <p>7. Share date, time and special instructions with all other support providers.</p> <p>8. Afterward:</p> <ul style="list-style-type: none"> • Update the medical record and/or Health Passport. • Follow-Up as instructed by primary care provider. • Share results with the agency nurse/healthcare coordinator, other staff and team members.
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If you suspect abuse or neglect, report immediately to DHI.

ACCESSING TECHNICAL ASSISTANCE



<p><u>Medical Issues:</u></p> <ul style="list-style-type: none"> Continuum of Care (505) 925-2350 TEASC (505) 272-2579 or (505) 272-5158 	<p><u>Rights Violations:</u></p> <ul style="list-style-type: none"> Children Youth & Families Department (505) 827-7610 ARC of New Mexico (505) 883-4630 Division of Health Improvement (505) 827-2651 Disability Rights of New Mexico (505) 256-3100 Adult Protective Services (505) 541-6100
<p><u>Communication Issues:</u></p> <ul style="list-style-type: none"> Center for Developmental & Disability Assistive Technology Program (505) 273-3000 	<p><u>Aging Issues:</u></p> <ul style="list-style-type: none"> New Mexico Aging and Long-term Services Division (505) 476-4799 Alzheimer's Association (New Mexico Chapter) (505) 266-4473
<p><u>Vocational Issues:</u></p> <ul style="list-style-type: none"> Department of Vocational Rehabilitation (505) 841-5750 DDSD Supported Employment Unit (505) 476-8879 	<p><u>Guardianship Resources</u></p> <ul style="list-style-type: none"> Developmental Disabilities Planning Council's (DDPC) Office of Guardianship (505) 841-4519 www.nmddpc.com Office of General Counsel (505) 827-2997 (505) 827-7596 DDSD'S Technical Assistance on Guardianship (access through Office of Constituent Supports)
<p><u>Mental Health or Behavioral Support Issues:</u></p> <ul style="list-style-type: none"> Bureau of Behavioral Supports (505) 841-6510 TEASC (505) 272-2579 or (505) 272-5158 	<p><u>Advocacy Support:</u></p> <ul style="list-style-type: none"> People First/Arc of New Mexico (505) 883-4630 DDSD Training Unit (575) 758-5934 Center for Self-Advocacy, DDPC
<p><u>Sexuality Issues:</u></p> <ul style="list-style-type: none"> Bureau of Behavioral Supports (505) 841-6510 	
<p><u>Team Process:</u></p> <ul style="list-style-type: none"> DDSD Regional Offices (#s below) DDSD Training Unit (575) 758-5934 DDSD Office of Constituent Support (505) 476-8972 	

If you are not sure where to begin, you may want to call your regional office for assistance

- Metro Region:*** (505) 841-5500 or 1-800-283-5548
- Northwest Region:*** (505) 863-9937 or 1-866-862-0448
- Northeast Region:*** (575)758-5934 or 866-315-7123
- Southwest Region:*** (575) 528-5180 or 1-866-742-5226
- Southeast Region:*** (575) 624-6100 or 866-895-9138