

**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

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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

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Long Term Services Division

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Date