POLICY MEMO 19 JUNE 2008

POLICY ON THE PROVISION OF CARE TO CONSUMERS WITH EMERGENCY OR URGENT HEALTH CARE NEEDS

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I. PURPOSE OF POLICY

This policy guides contractors delivering developmental disabilities community services in those circumstances when direct care staff delivering developmental disabilities community services may have to respond to emergency or urgent health care needs of consumers. In addition, this policy provides information on the application of an "Advance Directive", a "Do Not Resuscitate Order" and a hospice plan of care in those circumstances.

The timely and responsible actions of direct care staff when a consumer of developmental disabilities services has a health emergency or urgent health care need that poses an immediate or long-term risk to the consumer are a critical aspect of the quality of the services being funded by the State of Montana. The immediate assistance and the intervention of direct care staff may be necessary until professionally trained health care providers and emergency medical personnel are available.

This policy is implemented in accordance with state and federal law to meet the obligation of the State to assure the health and safety of consumers of developmental disabilities services. Failure of a service provider to assure the well-being of consumers during an emergency or urgency may jeopardize the provider's status as a qualified provider for the purposes of being engaged as a provider of developmental services and receiving developmental disabilities program funding.

The service provider should take actions to assure that the staff are properly and sufficiently trained. In addition, the provider, as necessary and appropriate, should implement corrective action that is commensurate with the seriousness of the matter.

THIS DOCUMENT PROVIDES POLICY GUIDANCE. IT IS NOT INTENDED TO SERVE AS LEGAL ADVICE. Providers and others implementing policies and **training and advising direct care staff on appropriate responses to emergency and urgent care circumstances should seek advice from consultants and their own legal counsel.**

II. EMERGENCY AND URGENT CARE

A. The Need For Emergency Or Urgent Care

Emergency health care need encompasses those circumstances where: 1) the consumer is seriously injured or gravely sick, 2) the consumer may die or suffer from long term disability or health care needs if not receiving the attention and care of health care professionals immediately, 3) the consumer may have significant pain that needs to be managed immediately, or 4) the consumer or others are at immediate risk of serious harm due to a mental health crisis.

Urgent health care need encompasses those circumstances where the consumer is injured or sick and needs the attention and care of health care professionals to provide care that will treat the injury or ameliorate the sickness. The health care serves to foster the consumer's recovery and prevent any deterioration in the health of the consumer. A consumer with continuing serious mental health symptoms is considered to be in need of urgent need of attention and mental health care.

B. Responsibility Of Staff When A Consumer Has An Emergency Or Urgent Health Care Need

If a consumer has a health care emergency, staff must act immediately to obtain the intervention of appropriate emergency medical technicians or other medical personnel through a call to 911 or other appropriate and effective means of communications. Notice may also be given to medical personnel who treat the consumer. Staff who are properly trained to provide emergency life saving procedures, such as CPR, or who are certified to assist in medication administration must, if appropriate, immediately proceed with the application of those procedures or assistance in the administration of any necessary medication. The intervention must continue, as appropriate, until emergency medical technicians or qualified medical personnel arrive.

Staff must also determine whether the situation arose due to an on-site condition that poses a danger to others, such as hot water, dangerous items, or gas leaks, and act accordingly to protect others from those risks.

Staff not engaged directly in providing the emergency or urgent care or overseeing the situation must engage the other consumers in ways that protect them from being harmed due to the presence of unusual risks or the lack of oversight. Efforts also should be made to lessen the anxiety of those other consumers and prevent them from inappropriately interfering with the response of staff and others to the situation.

If there is an inadequate number of staff on site to assure the safety and well-being of all the consumers during the situation, then arrangements must be made immediately for other staff to be present as soon as possible.

If the consumer remains on site after the situation, staff must obtain clear written direction from the appropriate medical personnel as to how to further care for the consumer and what further circumstances would warrant additional medical care or the intervention of emergency medical technicians or other medical personnel.

If the situation is one of urgency that does not necessitate emergency personnel, staff must act to obtain timely medical attention through medical professionals who treat the consumer or other appropriate medical professionals. If the situation necessitates immediate medical evaluation that should be sought as soon as possible. Staffing should be adjusted accordingly to assure that other consumers continue to be appropriately served.

At the first available opportunity, one or more staff must complete incident and other appropriate reports and make contacts, as appropriate, with provider management, state staff, Adult Protective Services (APS), law enforcement, family members, and advocates. In making contacts, staff must be careful to protect the confidentiality of the affected consumer and other consumers so as to avoid improper release of medical and personal information.

III. Ill. MEDICAL CONSENTS AND ORDERS

A GENERALLY

Generally, consent to proceed with a medical procedure is obtained from the person who is to be the subject of the medical procedure. Also, it is generally presumed that a person is capable of giving that consent. There are circumstances where a person, for a variety of reasons, may not be capable of giving informed and competent consent. Substituted consent may be obtained in accordance with the express direction of state law. There are state laws that address aspects of substituted consent.

Montana law in particular provides for a person to prospectively consent to the withholding and withdrawal of medical care should the person be incapable mentally of providing consent at the time the person is terminally ill. Montana law also allows family members to make the decisions as to withholding and withdrawal of medical care if a person who is mentally incapable of consent at the time of terminal illness does not have an advance directive. In addition, a physician or advanced practice registered nurse under Montana law may provide for a "do not resuscitate" order that can be applied in limited circumstances.

B ADVANCE DIRECTIVE

1. What Is An Advance Directive?

The Rights Of The Terminally Ill Act at 50-9-101, MCA, allows for a person to declare the person's intent as to the provision of life sustaining medical care to be given at the time of a terminal health condition should the person at that future date be incapacitated and unable then to communicate the person's intent as to care.

Terminal condition is defined at 53-9-102, MCA as an incurable or irreversible condition that, without the administration of life-sustaining treatment, will in the opinion of the attending physician or attending advanced practice registered nurse, result in death within a relatively short time. An often referred to and relied upon definition of terminal illness appears in the federal regulations that provide for the payment of Medicaid monies as reimbursement for the care of a terminally ill person through a hospice program. That definition of terminally ill at 42 CFR 418.3 provides that a person may be determined terminally ill if there is a medical prognosis that the person's life expectancy is to be 6 months or less if the illness runs its normal course.

2. Form Of An Advance Directive

A person desiring to provide an advance directive may use the form set forth in the Rights Of The Terminally Ill Act at 50-9-103, **MCA.** That statute provides that an advance directive can either give the person's specific directions to the treating physician or advanced practice registered nurse who can apply the withholding or withdrawal of treatment directly at the time of the terminal illness or it can authorize a designated person to make those decisions at the time of the terminal illness and thereby authorize the treating physician or advanced practice registered nurse to withhold or withdraw treatment.

The Department Of Public Health & Human Services has further implemented the advance directive practices through a set of rules at ARM 37.10.101, et seq. This rule set while couched in terms of "living wills" and "Comfort One" serves to implement the statutory authorities for "advance directives" and "do not resuscitate orders".
The rules provide the content for a standardized form. The form is to contain the following details.

1) name, sex, and birth date of the patient;
2) signature of the patient's attending physician or representative of a licensed hospice program in which the patient is enrolled;
3) comfort one logo;
4) the method by which a declaration may be revoked, if desired; and
5) an explanation of comfort one, including the actions emergency care providers will take when presented with comfort one identification.

50-9-103 and 50-9-106, MCA further require that the advance directive form be signed by two witnesses.

3. When Is An Advance Directive Operative

If an advance directive exists for a consumer, the consumer's planning team should review the matter to determine whether there are any concerns as to the capacity of the consumer to consent and if there are concerns take measures to resolve those concerns.

An advance directive should be followed in an health care emergency if:

1) the directive is appropriate in that the consumer had the mental capacity to make the necessary decisions at the time the

directive was signed by the consumer and the consumer expressly provided the conditions of the directive or delegated the decision making prospectively to an appropriate person;

2) the directive is being duly invoked through the express opinion and orders of a physician or advanced practice registered nurse that the consumer is terminally ill;
3) the physician or the advanced practice registered nurse provide the direct care staff with clear direction as to the scope and application of the directive and resulting medical orders
4) the consumer has not in any manner revoked the advance directive since its initial writing; and
5) the consumer is incapacitated and unable to communicate the consumer's intent as to care.

50-9-104 , MCA expressly reserves the right of a person with advance directive in place to revoke the directive and to countermand the directive by directing medical personnel and others to provide medical and other care. This revocation may occur at any time and in any manner without regard for the person's mental or physical condition. This revocation would extend to any standing orders based upon the advance directive or a DNR order. If a consumer does express the desire to receive life sustaining care, the medical professional who issued any resulting orders should be advised of this desire and the orders removed so as to not be mistakenly followed.

As noted in Section Gan advance directive may not be immediately implemented if the person is pregnant or has made an anatomical gift and implementation of the gift necessitates preservation of the person's life in the interim.

C. CONSENT BY FAMILY MEMBERS FOR THE WITHHOLDING AND WITHDRAWAL OF MEDICAL TREATMENT

When a person with a terminal illness, as determined by the attending physician or advanced practice registered nurse, does not have the capacity to make decisions regarding the administration of life sustaining treatment and lacks an advance directive, The Rights Of The Terminally Ill Act at 50-9-106, MCA provides for the withholding or withdrawal of medical treatment and related care. The withholding or withdrawal may only be authorized in writing by one or more of the family members as specified in the statute who has the requisite immediate priority under that statute to provide the consent for the limiting of health care. This relative consent may not be used if the person before becoming incapacitated expressed the intention

to receive medical treatment and care when terminally ill. The provision of this written consent must be witnessed by two persons.

The family members **with** authority under the statute to authorize the withholding or withdrawal of treatment in order of priority are:

1) the person's spouse;
2) an adult child or, if there is more than one adult child, a majority of the adult children reasonably available for consultation;
3) the parents of a person;
4) an adult sibling of the person or, if there is more than one adult sibling, a majority of the adult siblings reasonably available for consultation; or
5) the nearest other adult relative of the person by blood or adoption who is reasonably available for consultation.

A legal guardian may not provide substituted consent under this statute unless the legal guardian has in accordance with the procedures in 72-5-321, MCA been expressly authorized by a judicial order to do so after a determination by the court that the withholding or withdrawal of treatment is consistent with the known desires of the person.

Under this statute the withholding or withdrawal may only be undertaken by an attending physician or advanced practice registered nurse. Emergency medical services personnel, health care providers and others cannot act independently of the attending physician or advanced practice registered nurse to withdraw or withhold treatment.

D. RECORD OF TERMINAL CONDITION DETERMINATION AND OF ADVANCE DIRECTIVE

The basis for the issuance of a DNR order by the attending physician or advanced practice registered nurse, as required by the definition of "DNR identification" in 50-10-101, MCA, must be recorded in the person's medical record.

The attending physician or advanced practice registered nurse, as required by 50-9-103, MCA, are to place the terms of the person's advance directive declaration into the person's medical record.

E. WITHHOLDING OR WITHDRAWAL OF LIFE SUSTAINING CARE AT THE TIME

OF INCAPACITY AND TERMINAL ILLNESS UNDER AN ADVANCE DIRECTIVE OR SUBSTITUTED FAMILY CONSENT

A person, acting through an advance directive issued under the terms of Rights Of The Terminally Ill Act at 50-9-103, MCA, may provide standing direction for life sustaining treatment to be withheld or withdrawn if the person is not capable of making health care decisions and the treating physician or advanced practice registered nurse determines that death would occur in a short time. Likewise, a person may under the Act designate through an advance directive another person to provide substituted consent for the withholding or withdrawal of the life sustaining treatment.

A family member, acting under 50-9-106, MCA of the Rights Of The Terminally Ill Act to provide substituted consent at the time of both incapacity and terminal illness for a person, may authorize a treating physician or advanced practice registered nurse to withhold or withdraw life sustaining treatment.

These authorities under the Rights Of The Terminally Ill Act allow for the withholding or withdrawal of more than just the resuscitative treatment that may be withheld or withdrawn under the authority for the issuance of a do not resuscitate order. Life sustaining treatment under this Act includes any medical procedure or intervention that serves only to prolong the dying process.

F. DO NOT RESUSCITATE ORDER (DNR)

1. What Is A Do Not Resuscitate Order?

Montana law at 50-10-101, MCA allows for a "do not resuscitate order" to be issued for an incapacitated person. The do not resuscitate order stands as a medical order that limits the provision of medical care for a person. This procedure is an aspect of what is sometimes referred to as a "Comfort One" order.

Under Montana law at 50-10-101, MCA the medically related care that is withheld or withdrawn under the direction of a "do not resuscitate order" is limited to cardiopulmonary resuscitation or a component of cardiopulmonary resuscitation. The withholding of other medically related care is not permitted by this law and consequently the law does not authorize the withholding or withdrawal of other care under a DNR order.

In accordance with the definition of "do not resuscitate order" at 50-10-101, MCA, a do not resuscitate order may only be issued as a directive from a licensed physician or advanced practice registered nurse. Other health care professionals, family members, legal guardians, or persons of any other status do not have the authority under this law to issue or approve a do not resuscitate order.

The definition of **"DNR** identification" at 50-10-101, MCA provides that the grounds for a do not resuscitate order must be documented in the person's medical file. Furthermore, a departmental rule, ARM 37.10.101, adopted under Rights Of The Terminally Act to implement the Comfort One designation for purposes of governing the provision of **life** sustaining care by emergency medical personnel, requires certain features for the proper memorialization of a "do not resuscitateu order. The do not resuscitate order must conform with the Comfort One designation criteria set forth in ARM 37.10.101. That criteria is stated in Section B, 2 above. The "do not resuscitate order" must be signed by the issuing physician or advanced practice registered nurse and must be witnessed with signatures by two persons. The document must state that there is a terminal illness with death likely within a relatively short time.

2. Who Must Comply With A Do Not Resuscitate Order

Physicians, advanced practice registered nurses and emergency medical services personnel are, at 50-10-103, MCA and the definition of "do not resuscitate protocol" at 50-10-101, **MCA,** the only personnel directed to comply with a "do not resuscitate protocol". A health care facility or other personnel involved in the care of a person may in turn, if under the supervision of a physician or an advanced practice registered nurse, participate in the withholding or withdrawal of care when directed to immediately or over time to do so by a physician or advanced practice registered nurse. The supervision can consist of standing medical orders that are based upon the do not resuscitate order and current circumstances of the person inclusive of the type of services and the service setting.

3. Legitimacy Of A Do Not Resuscitate Order

If a "do not resuscitate order" exists for a consumer, the planning team should review the matter annually or as appropriate more frequently to determine whether there are any concerns as to the continued appropriateness of the order and, if there are concerns, take measures to resolve those concerns. This is necessary since at times "do not resuscitate orders" have been issued only to be

followed by a change for the better in the health status of the person. More significantly, at times it has been a common practice in certain care settings and medical facilities for these orders to be entered on the records of residents with mental disabilities.

4. Compliance With A Do Not Resuscitate Order During A Medical Emergency

Direct care staff should participate in the application of a "do not resuscitate order" if the order is appropriate given the person's current circumstances, the direct care staff have been given clear direction in a current medical order from a physician or advanced practice registered nurse as to the withholding or withdrawal of resuscitative care and the consumer does not express to them the desire to receive that care.

5. Withdrawal Of A Do Not Resuscitate Order

Because a DNR order stands as a form of substituted consent, it can not be imposed or enforced for a person who at the time of the need for emergency medical care is able to make decisions regarding the administration of life sustaining treatment and expressed in some form the desire to receive medical care. Consequently, a "do not resuscitate order" is of no effect should the person express their personal desire contrary to a standing or immediate do not resuscitate order to receive resuscitation during a health care crisis. If a person does ·express the desire to be resuscitated, the medical professional who issued the order should be advised of this desire and the existing DNR order removed from the person's medical and other records so as to not be mistakenly followed.

G. DELAY IN IMPLEMENTATION OF ADVANCE DIRECTIVE OR DO NOT RESUSCITATE ORDER WHERE THERE IS PREGNANCY OR AN ORGAN DONATION COMMITMENT

When there is applicable to the person, in accordance with 72-17-216, MCA, an advance health care directive or declaration providing for organ donations by a person, a legitimate advance directive or do not resuscitate order should not be complied with until direction is received from medical professionals and others involved with decision making under the Montana Revised Uniform Anatomical Gifts Act.

When a person is incapacitated and terminally ill, in accordance with 50-9-106, **MCA,** the withholding and withdrawal of treatment authorized under the Rights Of The Terminally Ill Act can not be

exercised for a person who is pregnant if it is probable that the fetus will develop to the point of live birth with continued application of the life-sustaining treatment.

H. APPLICATION OF A "COMFORT ONE" ORDER IN MONTANA

The Montana Rights Of The Terminally Ill Act and the statutory scheme for the imposition of a "do not resuscitate order" do not use the term "Comfort One". The "Comfort One" order, as described in health care industry literature and generic legal references, is not synonymous with the "do not resuscitate" order as provided in Montana law at 50-10-101, et seq. MCA. Unlike the "Comfort One" order, the DNR order under Montana law is limited in application to the withholding and withdrawal of cardiopulmonary resuscitation or a component of cardiopulmonary resuscitation.

An advance directive entered under the Montana Rights Of The Terminally Ill Act does encompass the withholding and withdrawal of life. sustaining care and not just cardiopulmonary resuscitation or a component of cardiopulmonary resuscitation and therefore allows a treating physician or advanced practitice registered nurse to issue an order that is similar in scope to the Comfort One order. However, the professionals who may issue the DNR are limited to the attending physician or advanced practice registered nurse while Comfort One literature may encompass other medical professionals such as physician assistants.

I. INABILITY OR UNWILLINGNESS TO HONOR AN ADVANCE DIRECTIVE OR A J. DO NOT RESUSCITATE ORDER

If the treating physician, advanced practice registered nurse or health care facility is unwilling or unable to participate in the withholding or withdrawal of life sustaining treatment from a person, the Rights Of The Terminally Ill Act at 50-9-203, MCA and the law pertaining to the application of do not resuscitate orders at 50-10-103, MCA provide that the current physician, advanced practice registered nurse or health care facility is to transfer the person to a provider that does not have an objection to the withholding or withdrawal of treatment.

K. ROLE OF A FULL LEGAL GUARDIAN WITH RESPECT TO ADVANCE DIRECTIVES AND DO NOT RESUSCITATE ORDERS

The 2007 Montana Legislature enacted House Bill No.683 amending 72-5-321, **MCA,** "Powers and duties of guardian of incapaciatated person", to prohibit a full legal guardian from providing consent on

behalf of their ward to the imposition of "advance directives" or of a "do not resuscitate order". The legislation, however, allows for a full guardian to petition a court to obtain the authority to consent to these procedures. While not expressly provided for in the amendment, it logically follows that a limited guardian would likewise have no such authority.

L. CARE FOR A CONSUMER WHEN THE CONSUMER IS ENROLLED IN HOSPICE

1. What Is Hospice?

Hospice is a program of nursing services which provides comfort and care to a person who has been determined by a physician to be terminally ill with death likely within 6 months. Hospice services are delivered under an interdisciplinary plan of care participated in by a physician or nurse. The plan of care provides direction for the palliative and other care that is available to the person.

2. Conditions For Medicaid Coverage Of Hospice Services

Medicaid is a major payer of hospice services. Medicaid reimbursement for hospice services may only be made available in accordance **with ARM** 37.40.801 et seq. ARM 37.40.808 requires certification of terminal illness in accordance with federal regulations 42 CFR 418.22. Terminally ill, as defined in 42 CFR 418.3, for purposes of hospice medicaid coverage means that the person has a medical prognosis that the person's life expectancy is 6 months or less if the illness runs its normal course. The certification must appear in the person's medical records and must specify that the person's prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course.

3. The Provision Of Hospice Services In Developmental Disabilities Services Settings

Hospice care is often available in a person's place of residence. For a person receiving residential developmental disabilities community services, the person's residence is the community home or apartment where they receive developmental disabilities services. It is appropriate for a consumer with a terminal illness to continue to live in the person's community home or supported living residence while receiving hospice services if that can be accommodated by the service provider and is appropriate for the service setting. The continued residence must be a feature of the hospice plan of care adopted for the person.

Medicaid funded hospice service eligibility precludes serving a person residing in a residential service setting where an active life saving intervention will occur. A requirement of eligibility for hospice services is that upon the occurrence of any health care urgency of the person the immediate care providers contact the hospice team which is on 24 hour call rather than contacting any emergency medical services. The hospice team determines whether any emergency care should be provided.

The developmental disabilities service provider and the developmental disabilities planning team should work cooperatively with the hospice team to assure that the hospice plan of care provides appropriate guidance as to hospice team members who are to be contacts, appropriate procedures for contact including emergency situations, and any requirements or limitations on the care the direct care staff are to provide to the person.

IV. . FURTHER GUIDANCE/RESOURCES

The American Association Of Intellectual And Developmental Disabilities (AAIDD), website www.aaidd.org. provides detailed guidance in matters relating to the lives of persons with developmental disabilities. Two resources available at AAIDD's website are AAIDD/ARC Position Statements "Health Care" and AAIDD Position Statement-Caring At The End Of Life". These statements provide guidance for medical professionals and service providers to assure that health care and end of life decision making is respectful and nondiscriminatory towards persons with developmental disabilities.

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Date: