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## FISCAL IMPACT REPORT

SPONSOR	Schmedes	ORIGINAL DATE LAST UPDATED	2/11/19 <b>HB</b>	409
SHORT TITL	Emancipated Min	or Resuscitation Orders	SB	
			ANALYST	Chilton

### ESTIMATED ADDITIONAL OPERATING BUDGET IMPACT (dollars in thousands)

	FY19	FY20	FY21	3 Year Total Cost	Recurring or Nonrecurring	Fund Affected
Total		Minimal	Minimal	Minimal	Recurring	General Fund

(Parenthesis ( ) Indicate Expenditure Decreases)

#### SOURCES OF INFORMATION

LFC Files

Responses Received From

New Mexico Attorney General (NMAG) New Mexico Medical Board (MB) Children, Youth and Families Department (CYFD)

Administrative Office of the Courts (AOC)

#### **SUMMARY**

### Synopsis of Bill

House Bill 409 would clarify some definitions and specify procedures to be used regarding end of life decisions for unemancipated minors, altering Section 24-7A-1 NMSA 1978 on Uniform Health Care Decisions. Procedures for resolving conflicts in decision-making between parents or between parents and health care institutions are specified.

Emancipated minors, according to Section 32A-21-5, already have the right to "[consent] to medical, dental or psychiatric care without parental consent, knowledge or liability."

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A summary of the sections of House Bill 409 follows:

Section of HB 409	Section of Statute amended	Provisions and Changes		
1	24-7A-1: Definitions	The act allows the definition of "emancipated minor" to remain the same: a person between 16 and 18 who is married, serving in the armed forces, or for whom a court has decided to declare him/her emancipated. There is a new definition for "unemancipated minor," which is the obverse of that for "emancipated minor, except that the married status is not mentioned. In addition, there is a new definition of "order not to resuscitate," as being an order not to intervene if a patient's heart stops.		
2, Subsections A through E		Unchanged authorization for parents or guardians of unemancipated minors to decide health care matters, including end-of-life decisions. Unchanged indication that minors with capacity, as defined in Section 24-7A-1, to understand health care decisions are entitled to make their own decisions regarding end-of-life care. The determination of "capacity" must be determined by two health care professionals, and the specification as to who those health care professionals must be is unchanged.		
2 F.	24-7A-6.1: Life-Sustaining Treatment for Unemancipated Minors	The existing Subsection F of Section 24-7A-6.1 is very brief, referring back to Section 24-7A-11. In this and subsequent sections, there are considerably more specifics as to the process to occur when an unemancipated minor's end-of-life decisions are in conflict. Section F specifies that orders not to resuscitate must be communicated in oral and written form with a parent or guardian. The other parent must also be contacted if "reasonably available" and has visitation or custodial rights. Parental/guardians' decisions and methods of communicating with them must be included in the medical record at the time they occur. Unless a court decides otherwise (see 2 H below), a parent's refusal of consent to an order not to resuscitate will be honored.		
2 G		If parents disagree on a course of action regarding end of life orders, they may have recourse to the courts.		
2 H		The courts must respond to a parent's petition to resolve a conflict by setting a hearing, with notice unless it is deemed too urgent to allow that, and at a "suitable place," which might include a health-care institution.		
2 I		Health care institutions and physicians must disclose policies regarding resuscitation and life-sustaining measures on the patient's request.		
2 J		If a health care institution and a parent do not agree on end of life care, and the court decides that further treatment is futile, the health care institution is obligated to make an effort to transfer care to another health-care institution willing to provide further treatment, or to the patient's home.		

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### FISCAL IMPLICATIONS

The only agency identifying any fiscal impact from this bill is the Administrative Office of the Courts, which noted that, "There will be a minimal administrative cost for statewide update, distribution and documentation of statutory changes. Any additional fiscal impact on the Judicial Branch would be proportional to the enforcement of this law and commenced petitions to the district court to prohibit an order not to resuscitate or to resolve conflicts, required hearings, appeals, and resulting court actions. New laws, amendments to existing laws and new hearings have the potential to increase caseloads in the courts, thus requiring additional personnel and resources to handle the increase." It is not anticipated that the number of such cases will be large.

### **SIGNIFICANT ISSUES**

CYFD notes that children in its care are subject to the following policy on end of life decisions:

### 8.10.7.25 REMOVING CHILD FROM LIFE SUPPORT SYSTEMS:

- **A.** PSD shall seek parental consent to removing a child in PSD custody from life support systems.
- **B.** When parents refuse consent, the children's court attorney shall request an emergency court setting on the issue and give notice to the parents.
- C. PSD shall keep the guardian ad litem or youth attorney fully informed and shall seek their concurrence with PSD's recommendation.

NMAG notes "The new addition proposed by this bill, Subsection (F), states that a DNR cannot be put into place until a parent has been contacted. This appears to contradict Subsection (C), granting authority to a minor upon a showing that they have the capacity to make the decision."

Medical literature on end of life decisions for children in the United States are limited. In an article in the journal *Pediatrics* in 2011 addressing the issue in a survey of pediatricians in the Netherlands, the conclusions include the following:

In 20% of the cases (23 of 116), parents and the medical team initially disagreed about the decision to withhold or withdraw treatment. In a majority of these 23 cases (57 percent [13 of 23]) there were ≥2 issues on which parents and team had conflicting points of view. Contrary to the opinion of the team, parents were convinced that there were still treatment options (43 percent [10 of 23]), believed that their child would survive (30 percent [7 of 23]), and/or had a more positive view on the expected quality of life of their child (35 percent [8 of 23]). These last 8 cases were all children with congenital disorders. In 6 cases, parents had strong moral objections against the intended end-of-life decision because of religious convictions (26 percent [6 of 23]).

As a result of these points of view, in 22 of the 23 cases parents wanted treatment to be continued. In the 1 remaining case, the parents thought that the decision-making process was going too slow, thereby prolonging their child's suffering. They wished that treatment was withdrawn instead of withheld as proposed by the team.

Respondents of all pediatric specialties are unanimous in their preference to first discuss an end-of-life decision within their team before discussing it with the parents. End-of-life decisions are complex decisions to make. They often take place in a twilight zone in

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which making a sure prognosis is impossible. Extended team discussions help to reach a grounded decision by gathering and comparing different points of view. They also help emotionally by sharing opinions and emotions with colleagues. This study proves Dutch pediatric End of Life Decision Making (EoLDM) is not a soloist activity but always a team effort.

In terms of the involvement of parents in EoLDM, our study results paint a less uniform picture. Physicians differ considerably in how they involve parents in this process. Half of the respondents choose to inform parents and subsequently ask for their permission to discontinue treatment, an approach that can best be characterized by the concept of "shared decision-making." A quarter of the respondents choose to merely inform parents and thus protect them from feeling co-responsible, an approach referred to as "benevolent paternalism." The remaining quarter of respondents choose to advise parents and allowed them to have the decisive voice. This approach could be characterized as "parental autonomy." The chosen approach in EoLDM is highly influenced by 3 factors: type of decision and type and duration of treatment.

If withdrawal is considered, mainly of mechanical ventilation, physicians are less likely to leave the final decision to parents than if withholding is considered. Previous studies have shown that physicians value withdrawal as a more active and therefore more burdensome decision than withholding, although some regard them as morally equal. Physicians, feeling burdened themselves, may tend to protect parents from feeling co-responsible in these cases, which is in line with a professional attitude of benevolence. In addition, decisions to withdraw mechanical ventilation often have to be made under time pressure, because the child's condition is rapidly deteriorating. This gives the medical team less opportunity to leave the final decision to parents. In a study by Michelson et al on parental views regarding withdrawal of LST, parents underlined their difficulty to consider this more active decision. Only when they were convinced that their child was suffering and there was no chance of improvement, did they feel able to consider possible withdrawal of LST. Despite their difficulty, most parents did not want to be protected but preferred an approach of shared decision-making. In cases of children receiving comfort care only, physicians are most likely to present the intended decision as advice and leave the final decision to parents. In these cases, there is no chance of survival as all treatment options have failed. This unambiguous fact may make it easier for physicians to let parents be the "final arbiters" in the decision-making process, as the question no longer focuses on if but on how and when a child will die.

### **TECHNICAL ISSUES**

The short title appears to be in error; rather than dealing with "Emancipated Minors," the bill appears to deal only with "Unemancipated Minors," i.e., those still under the supervision and decision-making control of a parent or guardian.

There is a conflict between definitions of "emancipated minor" (Subsection 1 D) and "unemancipated minor" (Section 1 X), with the latter having left out married persons as emancipated.

### AOC notes that

Section 32A-21-3 NMSA 1978 describes an emancipated minor as a person, 16 or older

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who: has entered into a valid marriage; is on active duty with the military; or has received a declaration of emancipation pursuant to the Emancipation of Minors Act. The HB 409 amendment to Section 24-7A-1 NMSA 1978 defines "unemancipated minor" to mean a person under 18 who: (1) is not on active duty in the armed forces; and (2) has not been declared by court order to be emancipated. The HB 409 definition appears to be in conflict with the Section 32A-21-3 NMSA 1978 description of "emancipated minor", as it leaves out a reference to marriage.

Section 2(F) requires a "reasonable attempt to be made to inform the other parent if the other parent is reasonably available and has custodial or visitation rights". Section 1(T) defines "reasonably available" as readily able to be contacted without undue effort and willing and able to act in a timely manner considering the urgency of the patient's health-care needs". HB 409, however, does not define "reasonable attempt", leaving that up to interpretation.

### **OTHER SUBSTANTIVE ISSUES**

NMAG notes that "Subsections (G) and (H) dictate the steps that a district court is to take when evaluating the DNR process. These may be subject to challenge as violative of the separation of powers in the New Mexico Constitution, Article 3, § 1. See State ex rel. Anaya v. McBride, 1975, 88 N.M. 244, 539 P.2d 1006 (explaining that under the Constitution, the legislature lacks power to prescribe by statute rules of practice and procedure.)"

#### **AMENDMENTS**

Section 2 I specifies that health care institutions and physicians must disclose end-of-life policies to unemancipated patients or prospective patients; however, parents and guardians should also be empowered to ask for this information.

LAC/gb/sb