SENATE COMMITTEE ON HUMAN SERVICES Senator Hurtado, Chair 2021 2022 De malar

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Subject: Office of the Patient Representative

SUMMARY

This bill refines procedures for determining that residents of Skilled Nuring Facilities (SNF) and Intermediate Care Facilities (ICF) lack capacity to provide informed consent for a medical intervention. This bill also creates the Office of the Patient Representative within the California Department of Aging (CDA) to train, certify, provide, and oversee patient representatives to protect the rights of SNF and ICF residents when a medical intervention is prescribed for residents who cannot provide informed consent, as specified.

ABSTRACT

Existing Law:

- 1) Establishes, with the Mello-Granlund Older Californians Act, the CDA and states that the mission of the department is to provide leadership to the Area Agencies on Aging (AAAs) in developing systems of home and community-based services that maintain individuals in their own homes or least-restrictive homelike environments. (*WIC 9000 et seq.*)
- 2) Defines SNF to mean a health facility that provides 24-hour skilled nursing and supportive care to resident individuals whose primary need is for the availability of skilled nursing care on an extended basis. (HSC 1250(c)(1))
- 3) Defines ICF to mean a health facility that provides inpatient care to ambulatory or nonambulatory patients who have recurring need for skilled nursing supervision and need supportive care, but who do not require availability of continuous skilled nursing care. (HSC 1250(d))
- 4) Defines ICF/developmentally disabled habilitative to mean a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, habilitation, developmental, and supportive health services to 15 or fewer persons with developmental disabilities who have intermittent recurring needs for nursing services, but have been certified by a

physician and surgeon as not requiring availability of continuous skilled nursing care. $(HSC \ 1250(e))$

- 5) Defines ICF/developmentally disabled to mean a facility that provides 24-hour personal care, habilitation, developmental, and supportive health services to persons with developmental disabilities whose primary need is for developmental services and who have a recurring but intermittent need for skilled nursing services. (HSC 1250(g))
- 6) Defines ICF/developmentally disabled-nursing means a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, developmental services, and nursing supervision for persons with developmental disabilities who have intermittent recurring needs for skilled nursing care but have been certified by a physician and surgeon as not requiring continuous skilled nursing care. The facility shall serve medically fragile persons with developmental disabilities or who demonstrate significant developmental delay that may lead to a developmental disability if not treated. (HSC 1250(h))
- 7) Requires an interdisciplinary team (IDT) to review a prescribed medical intervention prior to the administration of the medical intervention when a resident of a SNF or ICF has been prescribed a medical intervention that requires informed consent and it has been determined that the resident lacks capacity to make health care decisions and there is no person with legal authority to make those decisions on behalf of the resident. Further requires the IDT to oversee the care of the resident utilizing a team approach to assessment and care planning, and to include the resident's attending physician, a registered professional nurse with responsibility for the resident, other appropriate staff in disciplines as determined by the resident's needs, and, where practicable, a patient representative, in accordance with applicable federal and state requirements. Defines the content of the review conducted by the IDT . (HSC 1418.8(e))

This Bill:

- 1) Defines "emergency" to mean a situation where medical treatment is immediately necessary for the preservation of life, the prevention of serious bodily harm, or the alleviation of severe physical pain.
- 2) Defines "lacks capacity" to mean the resident is unable to understand the nature and consequences of the proposed medical intervention, including its risks and benefits, or is unable to express a preference regarding the intervention.
- 3) Defines "surrogate decisionmaker" to mean a person with legal authority to make medical treatment decisions on behalf of a patient, including a person designated under a valid durable power of attorney for health care, a guardian, a conservator, or next of kin.
- 4) Establishes procedures for documenting when the attending physician and surgeon of a resident in a SNF or ICF prescribes or orders a medical intervention that requires that informed consent be obtained prior to administration of the medical intervention, but the resident is unable to obtain informed consent because the physician and surgeon determines that the resident lacks capacity to make decisions concerning the resident's health care.

- 5) Requires the physician and surgeon to interview the patient, review the patient's medical records, and consult with SNF or ICF staff, as appropriate, and family members and friends of the resident, if any have been identified, in order to make the determination that the resident lacks capacity.
- 6) Requires the SNF or ICF, upon being notified by the attending physician of a determination that a resident lacks capacity to provide informed consent, to identify, or use due diligence to search for, a surrogate decisionmaker, as specified.
- 7) Requires that, if the physician and surgeon determines that a resident lacks capacity, and the SNF or ICF determines that there is no surrogate decisionmaker, the SNF or ICF shall provide a notice to the resident written in the resident's primary language, as specified.
- 8) Requires when a resident of a SNF or ICF has been prescribed a medical intervention by a physician and surgeon that requires informed consent and the physician has determined that the resident lacks capacity to make health care decisions and the facility has determined that there is no surrogate decisionmaker, the facility to, except as otherwise provided, conduct an IDT review of the prescribed medical intervention prior to the administration of the medical intervention, as specified.
- 9) Permits a patient representative to include a family member or friend of the resident who is unable to take full responsibility for the health care decisions of the resident, but who has agreed to serve on the IDT or other person authorized by state or federal law.
- 10) Prohibits the patient representative from being an employee or former employee of the SNF or ICF, paid by the facility, an employee of a vendor to the facility, or a provider of health care to the resident.
- 11) Requires that the patient representative shall have access to all of the resident's records and otherwise confidential health information.
- 12) Requires that, if no family member or friend is available to serve as the patient representative, the Office of the Patient Representative shall designate someone to serve as the patient's representative.
- 13) Requires the IDT to periodically evaluate the use of the prescribed medical intervention at least quarterly, upon a significant change in the resident's medical condition, or upon the resident's or the resident's representative's request. The SNF or ICF shall provide notice of this evaluation by the IDT, as specified.
- 14) Permits, in case of an emergency and after obtaining a physician and surgeon's order as necessary, a SNF or ICF to administer a medical intervention that requires informed consent prior to the facility issuing the required notice and prior to convening an IDT review, as specified.

- 15) Provides that physicians and surgeons, SNFs, and ICFs shall not be required to obtain a court order prior to administering a medical intervention which requires informed consent if the requirements of this section are met, as specified.
- 16) Provides that the bill shall not in any way affect the right of a resident of a SNF or ICF for whom medical intervention has been prescribed, ordered, or administered to seek appropriate judicial relief, at any time, in order to review the decision that a patient lacks capacity, that the patient lacks a surrogate decisionmaker, or to provide the medical intervention.
- 17) Prohibits a physician or other health care provider, whose action provided for in the bill and in accordance with reasonable medical standards, from being subject to administrative sanction if the physician or health care provider believes in good faith that the action is consistent with provisions of this bill and the desires of the resident, or if unknown, the best interests of the resident.
- 18) Requires the use of an IDT to provide consent to a prescribed medical intervention to be noted in the resident's minimum data set, as specified.
- 19) Establishes the Office of the Patient Representative within the CDA to train, certify, provide, and oversee patient representatives to protect the rights of nursing home residents, as specified.
- 20) Prohibits a patient representatives from being a current or former licensee, or owner, employee, or volunteer of a SNF or ICF except that former employees and volunteers are not precluded from serving as patient representatives at the facilities where they previously served after two years of separation. Former employees and volunteers are not precluded from serving as patient representatives for facilities that they were not previously affiliated with.
- 21) Requires the Office of the Patient Representative to communicate with every SNF and ICF to provide, and update as needed, contact information to use for notices provided to residents.
- 22) Permits the Office of the Patient Representative to work with AAAs or other nonprofit entities to provide patient representatives.
- 23) Requires the Office of the Patient Representative to collect and analyze data, including the number of residents represented, the number of IDT meetings attended, and the number of cases in which judicial review was sought.
- 24) Requires the collected data to be the basis for an annual public report delivered to the Legislature and posted on the Office of the Patient Representative's internet website, as specified.

- 25) Requires the Office of the Patient Representative to ensure residents who seek judicial review pursuant to Section 1418.8 of the Health and Safety Code are provided adequate legal counsel for that purpose.
- 26) Requires patient representatives to perform specified duties, including, but not limited to meeting and interviewing the resident; participating in the IDT review; articulating the resident's perspective if it can be determined and advocate for the resident's wishes if known; reviewing the nature of the proposed interventions and considering whether they appear consistent with the best interests of the resident.
- 27) Requires the Office of Patient Representative to adopt any regulations necessary to implement this bill, as specified.
- 28) Requires the state to disburse all funds not directed to the Office of Patient Representative to each of the counties' AAAs using an allotment proportional to the number of nursing home beds in that county.

FISCAL IMPACT

This bill has not yet been analyzed by a fiscal committee.

BACKGROUND AND DISCUSSION

Purpose of the Bill:

According to the author, "SB 460 will make the changes to California law to reflect the final court order in California Advocates for Nursing Home Reform (*CANHR*) vs Smith, which provided additional protection to nursing home residents who have been determined to lack capacity to provide informed consent to medical treatment decisions, and who don't have anyone who is authorized to make decisions on their behalf."

Informed Consent

With the exception of a medical emergency, all medical procedures require the consent of the patient. If the medical treatment is more involved, or if there are some risks involved, the patient needs to be informed of those risks or potential complications, and this "informed consent" must be documented in the patient's record. A patient must be capable of understanding those risks to be able to provide consent to the treatment. While a court can adjudicate a person to be incompetent to make medical decisions, even if this has not happened, a physician can still make a determination that a person lacks capacity to make health care decisions. Sometimes this is temporary, such as when a patient is unconscious, or it can be more permanent if caused by something like dementia.

In most cases, residents of nursing homes have a surviving spouse or child or other next of kin, or someone else previously designated as a surrogate decisionmaker, whether through a Durable Power of Attorney for Health Care, or some other mechanism. It can be problematic when

nursing home patients do not have anyone available to represent them. The Probate Code allows a physician or a health facility, among others, to file a petition in court to determine that a patient lacks capacity and to have the court authorize recommended medical treatment, or to appoint someone to make decisions on the patient's behalf. However, in order to avoid the delays associated with going to court, in 1992 the Legislature adopted Health and Safety Code (HSC) section 1418.8, which set up a process to provide care to nursing home patients who lacked capacity to provide informed consent and who also do not have anyone to provide consent for them. Among other things, HSC 1418.8 specified that any proposed medical intervention that requires informed consent had to be reviewed by an IDT, composed of the attending physician, a registered nurse with responsibility for the resident, other appropriate staff in disciplines as determined by the resident's needs, and where practicable, a patient representative.

In 2013, CANHR sued the California Department of Public Health, arguing that HSC 1418.8 had significant constitutional deficiencies which rendered the IDT decision making process likely to produce bad decisions that are not in the resident's best interests.

The California Court of Appeal made a decision on *CANHR vs. Smith* in July of 2019, which upheld the overall constitutionality of the statute, but required several key modifications to how HSC 1418.8 is implemented. Specifically, the court ordered that the resident be notified, along with someone whose interests are aligned with the resident, of the determination of lack of capacity; the determination that no surrogate decisionmaker is available; what medical intervention is being proposed by the attending physician; the resident's right to have a patient representative participate in IDT decision making; and the resident's right to judicial review of IDT decisions. Additionally, the court ordered that no medical treatment decision by an IDT on behalf of a resident can be implemented until after the resident has been given a reasonable opportunity to seek judicial review of the decision. Finally, the court ordered that every IDT must include a patient representative unaffiliated with the nursing home, rather than "where practicable" under the current statute's wording.

This bill seeks to place responsibility for implementing the court ordered requirements for IDT s within a newly created Office of the Patient Representative, placed within the CDA.

California Department of Aging (CDA)

CDA administers programs that serve older adults, adults with disabilities, family caregivers, and residents in long-term care facilities throughout the state. It administers funds allocated under the federal Older Americans Act ()AA), the state Older Californians Act (OCA), and through the Medicaid (Medi-Cal in California) program. CDA's mission is to promote the independence and well-being of older adults, adults with disabilities, and families through access to information and services to improve the quality of their lives, opportunities for community involvement, support for family members providing care, and collaboration with other state and local agencies.

The State Long-Term Care Ombudsman, which exists within CDA, has a role in advocating for residents rights. The Ombudsman program was created by the federal OAA and the state's OCA. The Ombudsman Program is charged with resolving problems and advocating for the rights of residents in long-term care facilities SNFs, Adult Residential Facilities, and Residential Care Facilities for the Elderly.

It has been suggested that, rather than creating a new Office of the Patient Representative within CDA, perhaps the Ombudsman might be an appropriate placement for the responsibilities of the new office. However, federal law prohibits Ombudsman representatives from providing guardianship, conservatorship or other fiduciary or surrogate decision making services for residents of LTC facilities.¹ Federal law also prohibits Ombudsman program representatives from serving in a fiduciary capacity for residents of LTC facilities in an official capacity (as opposed to serving as a guardian or fiduciary for a family member, in a personal capacity)²

Given the mission of CDA and the prohibition of the Omudsman from participating in the type of decision making required under *CANHR vs. Smith*, a new Office of the Patient Representative within CDA appears to be an appropriate strategy for implementing the court's finding.

Master Plan for Aging

In January 2021, the Newsom Administration published its Master Plan for Aging, which is intended to be a ten year blue-print for state government, local government, the private sector, and philanthropy to prepare the state for the coming demographic changes and "continue California's leadership in aging, disability, and equity." The Master Plan for Aging outlines five goals, twenty-three strategies, and over 100 initiatives. Within the "Health Reimagined" goal is an initiative to "develop approach for patient representative for residents of skilled nursing facilities without capacity, representatives, or written care wishes." SB 460 would implement this goal.

Related/Prior Legislation:

SB 1848 (*O'Connell, Chapter 126, Statues of 1996*) made permanent the authority for a physician to initiate medical intervention to patients in SNFs and ICFs who are unable to provide informed consent after an IDT review.

AB 3209 (Epple, Chapter 1303, Statutes of 1992) enabled physicians and providers in SNFs and ICFs to initiate medical intervention for residents who are deemed incapable of giving informed consent and who have no surrogate decisionmaker, as specified. Provisions of this bill were subject to a repeal.

POSITIONS

Support: California Advocates for Nursing Home Reform LeadingAge California

Oppose: None received.

¹ 45 CFR 1324.21(a)(12)

² 42 USC 3058g(f)(1)(C)(vi)