

HB

44

<TARGET><BILL>HB 44</BILL><SUBJECT>HB
44</SUBJECT><COMM>HHSS28</COMM></TARGET>



Representative Lindsey Holmes

House Bill 44 Sponsor Statement An Act relating to a registry for advance health care directives.

An advance health care directive is a document that allows a person to designate what health care they wish to receive and who can make medical decisions for them in the case that they are incapacitated. Alaska Statute 13.52.010 provides that anyone may fill out an advance health care directive, but it does not provide a system to store and access these important documents.

Medical emergencies can occur at any place at any time. A person may be on vacation and not have a copy of their advance health care directive with them, or family members may simply be too distraught to remember or find a copy of the directive. In cases like these, medical professionals and family members need an effective tool to locate and access information on a patient's health care wishes.

House Bill 44 would establish a voluntary registry of advance health care directives for the State of Alaska. The registry would be strictly voluntary—no person would be required to submit his or her advance health care directive to the registry, and directives not filed with the registry would remain valid. Other features of the registry include:

- Hospitals and similar health care facilities would have 24-hour online access to their patients' records in case of emergencies.
- A person or his or her agent, guardian or surrogate would be able to request copies of their directive.
- The Department of Health and Social Services would be able to charge modest fees to pay for administrative costs of the registry.
- All advance health care directives in the registry would be confidential.
- An individual could update or remove his or her advance health care directive from the registry at any time.

A number of other states already use an advance health care directive registry to ensure that patients' wishes are available to guide the decisions of doctors and loved ones during medical emergencies.

Please join me in helping to ensure that Alaskans' medical decisions are respected by supporting this legislation.

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Rep.Lindsey.Holmes@akleg.gov



Representative Lindsey Holmes

House Bill 44 Sectional Analysis

“An Act relating to a registry for advance health care directives.”

- Section 1.** Protects a health care facility from civil or criminal liability for two listed types of actions related to the directive registry.
- Section 2.** This is the primary authorizing section for the directive registry. It has several subsections that do the following:
- (a) Directs the Department of Health and Social Services to create and maintain the registry. It indicates that the registry shall consist solely of the names and scanned copies of advance health care directives of individuals who register.
 - (b) Establishes that filing an advance health care directive in the registry is voluntary, through use of the term “may”.
 - (c) Makes it clear that the registry is completely confidential. It allows the Department to release a copy of a person’s directive to the individual who created it, the guardian or other agent of the individual, or a hospital in the state where the individual is a patient. Additionally, it allows the Department to provide a copy of the directive to a hospital in another state if it is requested by the individual or their guardian, agent or surrogate.
 - (d) Directs the Department to make the registry viewable online for hospitals here in the state (in case of emergencies).
 - (e) Clarifies that the Department will not review directives submitted to the registry for their legal validity.
 - (f) Allows that an individual can remove their directive from the registry at any time.
 - (g) Clarifies that filing a directive with the registry does not affect its validity and that a directive can be revoked or changed without informing the registry.
 - (h) Allows the Department to charge a fee for filing a registry to recoup administrative costs, but prohibits the Department from charging a fee for removing a directive from the registry.
 - (i) Empowers the Department to make regulations to ensure that people who attempt to access a directive in the registry are allowed to have access to a directive.

- (j) Empowers the Department to make regulations regarding regular maintenance on the registry, including removing directives that are old or out of date.
- (k) Protects the Department and its employees from legal liability for regular operation of the registry.
- (l) Provides definitions of registry and directive.

Fiscal Note

State of Alaska
2013 Legislative Session

Bill Version: HB 44 (A)
Fiscal Note Number: _____
() Publish Date: _____

Identifier: HB044-DHSS-EP-2-9-13
Title: ADVANCE HEALTH CARE DIRECTIVES
REGISTRY
Sponsor: ** HOLMES, MILLETT
Requester: House Health & Social Services Committee

Department: Department of Health and Social Services
Appropriation: Public Health
Allocation: Emergency Programs
OMB Component Number: 2877

Expenditures/Revenues

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

| | FY2014 Appropriation Requested | Included in Governor's FY2014 Request | Out-Year Cost Estimates | | | | | |
|-------------------------------|--------------------------------------|--|-------------------------|--------------|-------------|-------------|-------------|-------------|
| | | | FY 2014 | FY 2014 | FY 2015 | FY 2016 | FY 2017 | FY 2018 |
| OPERATING EXPENDITURES | | | | | | | | |
| Personal Services | 112.0 | | 112.0 | 84.0 | 56.0 | 56.0 | 56.0 | 56.0 |
| Travel | 11.0 | | 5.5 | 5.5 | 5.0 | 4.0 | 4.0 | 4.0 |
| Services | 10.0 | | 80.5 | 20.0 | 20.0 | 20.0 | 20.0 | 20.0 |
| Commodities | 4.5 | | 4.5 | 3.0 | 2.0 | 2.0 | 2.0 | 2.0 |
| Capital Outlay | | | | | | | | |
| Grants & Benefits | | | | | | | | |
| Miscellaneous | | | | | | | | |
| Total Operating | 137.5 | 0.0 | 202.5 | 112.5 | 83.0 | 82.0 | 82.0 | 82.0 |

Fund Source (Operating Only)

| | | | | | | | |
|---------------|--------------|------------|--------------|--------------|-------------|-------------|-------------|
| 1004 Gen Fund | 137.5 | | 202.5 | 112.5 | 83.0 | 82.0 | 82.0 |
| Total | 137.5 | 0.0 | 202.5 | 112.5 | 83.0 | 82.0 | 82.0 |

Positions

| | | | | | | | |
|-----------|-----|--|-----|-----|-----|-----|-----|
| Full-time | 1.0 | | 1.0 | 0.8 | 0.5 | 0.5 | 0.5 |
| Part-time | | | | | | | |
| Temporary | | | | | | | |

| | | | | | | | |
|---------------------------|--|--|--|--|--|--|--|
| Change in Revenues | | | | | | | |
|---------------------------|--|--|--|--|--|--|--|

Estimated SUPPLEMENTAL (FY2013) cost: 0.0

Estimated CAPITAL (FY2014) cost: 0.0

ASSOCIATED REGULATIONS

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? Yes
If yes, by what date are the regulations to be adopted, amended or repealed? 07/01/15

Why this fiscal note differs from previous version:

Not applicable, initial version.

| | | | |
|--------------|-------------------------------|--------|---------------------|
| Prepared By: | Kerre Fisher, Acting Director | Phone: | (907)269-2042 |
| Division | Public Health | Date: | 02/08/2013 12:00 AM |
| Approved By: | Sarah Woods, Deputy Director | Date: | 02/09/13 |
| | Finance & Management Services | | |

FISCAL NOTE ANALYSIS

STATE OF ALASKA
2013 LEGISLATIVE SESSION

BILL NO. HB044

Analysis

The intent of this bill is to create a central registry for access to advanced health care directives by health care facilities, hospitals, and individuals. Participation is voluntary. The directory will include names of individuals who have filed a directive with the registry and scanned copies of the directives. An individual who has made a written directive for himself may file it (scanned copies) with the registry. The department is not required to review directives for validity and will remove directives from the registry if requested. The registry is confidential and access is limited to the patient, designated representatives, and the health care facility to which the patient is admitted. The department may charge a fee to cover administrative costs for filing a directive in the registry or providing a copy, but not for removal of a directive or responding to an inquiry. A fee might offset administrative costs but would likely reduce participation. This fiscal note assumes there will be no fee.

Our research indicates that seven states have participated in or had central state registries. Some states have developed their own registries. We believe that contracting for the service is less costly than having the department build it. Modeled after a previous effort in the State of Washington, the department proposes to contract with a national registry to maintain the data securely with 24 hour online access. Start up contractual costs are estimated at \$70.5 include training, software, licensing, system configuration, and toll-free hotline. Ongoing, the estimated annual license and information technology cost of \$20.0 based on 5,000 participants (minimum rate). Actual costs will vary if the number of participants exceeds 5,000. The current cost is \$1.00 per participant per year over 5,000 participants.

The potential number of directives is difficult to estimate. Based on the experience of other registry states, Alaska could expect fewer than 1,000 directives. However, anecdotal information suggests that the Anchorage Providence Hospital alone, which serves about half the population of Anchorage, has more than 1,000 directives on file. If that level of volume held true statewide, the registry database could include 4,000 directives. This fiscal note assumes that Alaska's number of users will not exceed the 5,000 base.

There will be a considerable need initially to educate the stakeholders of the security and the benefits of the program. One FTE, a Public Health Specialist II (R20/A), will be necessary to draft regulations for the collection, storage, access, distribution, removal, and disposal of directives in the registry, and a schedule for removing directives from the registry; create Alaska specific information packets; establish a secure system; respond to a toll-free hotline; support users with technical assistance; and travel to provide community outreach. By the third year, the program will be fully operational and outreach efforts can be scaled back to 0.75 FTE and level off at 0.50 FTE thereafter.

Extensive regulations will need to be established in consultation with the various criteria and procedures for the collection, storage, access, distribution, removal and disposal of directives in the registry; and to establish a schedule for removing directives and assure compliance with state and federal privacy laws. Costs for the regulation package of \$10.0 would be needed in Years 1 & 2. The registry would be installed during Year 2 so that as soon as regulations are effective the registry will be ready.

The Alaska Health Care Commission recommends that such a registry be aligned with the Statewide Health Information Exchange. That kind of interoperability could increase the cost.



LEGISLATIVE RESEARCH SERVICES

Alaska State Legislature
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Memorandum

TO: Representative Lindsey Holmes
FROM: Tim Spengler, Legislative Analyst
DATE: December 21, 2011
RE: Advanced Health Care Directive Databases
LRS Report 12.095

You wanted to know which states have a centralized electronic database for residents to register their advanced health care directives. You also were interested in the approximate costs of these programs.

As you know, an advanced health care directive (AHD) is a legal document in which an individual indicates how he or she wants to be treated in the event of becoming severely ill or incapacitated with no chance of recovery. Advanced health care directives are typically divided into two types, as follows:

- 1) A **living will** is a document in which an individual states the kind of health care he or she wants in a specific circumstance.
- 2) A **health care proxy** is a document in which an individual names a close friend or relative who will make the final decisions regarding the care of that individual in the event he or she becomes incapacitated.

We identified eleven states with statutes mandating the creation of a centralized electronic database (registry) specifically for AHDs.¹ Those states are Arizona, California, Idaho, Maryland, Montana, Nevada, North Carolina, Oklahoma, Vermont, Virginia, and Washington. Of these, eight have AHD registries in place; Maryland and Oklahoma have yet to implement a registry, while Washington ceased funding its program in June of 2011, as a cost cutting measure.

Half of the state registries are managed by the secretary of state's office (the equivalent of Alaska's lieutenant governor's office), while other states place this responsibility with the department of health. Seven of the states with registries created and maintain their own database. Vermont, on the other hand, uses a private outside agency, the United States Living Will Registry, to manage its online database.²

The estimated startup costs for creating an AHD registry ranged from \$25,000 to \$100,000, while ongoing expenses were estimated at between \$15,000 and \$35,000 annually. Startup costs usually include the building of a database as well as public education and outreach efforts. Ongoing costs typically include personnel expenses (generally a portion of an IT and/or program position) as well as general clerical costs. Table 1, on the following page, disaggregates program expenses for the states from which we were able to identify cost estimates.

In 2007, the Council of State Governments (CSG), Committee on Suggested State Legislation, recommended that states consider establishing registries for advanced health care directives. We include CSG's model legislation on AHD registries as Attachment B. Additionally, the New York Online Access to Health (NOAH) publishes a document with numerous links to information on advance directives in each state, which may be of interest to you. This NOAH resource can be accessed at <http://noah-health.org/en/rights/endoflife/adforms.html>. We also include, as Attachment C, an in-depth *question and*

¹ Table 1 on the following page includes the relevant statutory citations for each of these 11 states. We also include copies of these statutes as Attachment A. While we conducted a thorough review, there may be additional states with AHC registry laws but worded such that our Lexis and Westlaw queries did not identify them.

² The US Living Will Registry is an independent organization that electronically stores advanced directives and donor information for individuals and for states. Until recently, Nevada and Washington also used this resource. Vermont's AHD coordinator, Sharon Goldwin (802-865-7748), is happy to discuss her state's (very positive) experience with the US Living Will Registry.

answer document regarding North Carolina's AHD registry, which includes information on how the state set up its program, the goals of the registry, cost and registration figures, and much more programmatic information.

| Table 1: States with Advanced Health Care Directive Database Laws and Estimated Program Costs | | | | | |
|--|-------------------------------|--|------------------------|------------------------|--------------------|
| State | Statutory Citation | Status of Database | Estimated Costs | | |
| | | | Startup | Annual | Fee for users |
| Arizona | A.R.S. 36-3291 <i>et seq.</i> | Operational since 2004. | \$25,000 | \$25,000-\$30,000 | Free to residents |
| California | Cal. Prob Code 4800 | Operational since 2008. | | No response | |
| Idaho | IC 39-4515 | Operational since 2006. | Unavailable | \$20,000-\$25,000 | Free for residents |
| Maryland | Md. Code Ann., Health 5-624 | Law passed in 2006 but the state has yet to implement | | Not applicable | |
| Montana | MCA 50-9-501 | Operational since 2008 | \$100,000 | \$15,000 | Free for residents |
| Nevada | NRSA 449.920 | Operational since 2008. | \$50,000 | \$15,000-\$20,000 | Free for residents |
| North Carolina | GSNC 130a-465 | Operational since 2002. | \$75,000 | \$25,000 | \$10 registration |
| Oklahoma | 63 Okl. St. § 3102.1 | Registry has not yet gone into effect | | Not applicable | |
| Virginia | CV § 54.1-2994. | Operational since 2008. | No cost ^(a) | \$15,000 | Free for residents |
| Vermont | 18 VSA 9719 | Operational since 2007. | \$50,000 | \$35,000 | Free for residents |
| Washington | RCW 70.122.130 | Program started in 2008 and shut down in June 2011 due to funding restrictions | | Costs were unavailable | |
| <p>Notes: (a) Unival and Microsoft set up Virginia's registry at no cost to the state. Sources: Lexis and Westlaw searches and correspondence with state authorities.</p> | | | | | |

We hope this is helpful. If you have questions or need additional information, please let us know.



THE STATE
of **ALASKA**
GOVERNOR SEAN PARNELL

Department of
Health and Social Services

ALASKA COMMISSION ON AGING

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February 7, 2013

Representative Lindsey Holmes
Alaska Capitol, Room 415
Juneau, AK 99801-1182

Subject: Support for HB 44, Registry for Advance Health Care Directives

Dear Representative Holmes:

The Alaska Commission on Aging (ACoA) supports HB 44, a bill to establish the advance health care directive registry in the Department of Health and Social Services (DHSS). This legislation requires strict security provisions for releases of information in directives filed in the registry, mandates the registry be continuously accessible online at all times, and sets out requirements for DHSS to review and remove directives, as necessary. This bill is authored by you and co-sponsored by Representatives Millett, Josephson, Peggy Wilson and Kerttula.

Advance health care directives are part of the continuum of protection for vulnerable adults when they are no longer able to make their needs known due to physical or cognitive impairments. An advance directive provides a clear statement of an individual's wishes regarding health care at the end of life in the event that a person is unable to voice these preferences directly. Advance care directives promote family conversations about end of life care. They are important for all adults, not just the elderly, and relieve others, especially family members, from making critical medical care decisions for their loved one under emotional distress.

The establishment of a confidential advance health care registry would allow Alaskans to voluntarily file their directives with the DHSS, and to change or revoke them at will. The registry would allow health care facilities to have Internet access to their patients' directives on-demand 24-hours a day, wherever the Alaskan patient is receiving care, in- or outside the State. ACoA endorses this legislation because we believe an electronic advanced health care directive registry will enhance protection of an Alaskan's end of life health care preferences by improving access to this information by their health care provider in a time-critical manner, which is especially important to the growing number of families providing long-distance caregiving.

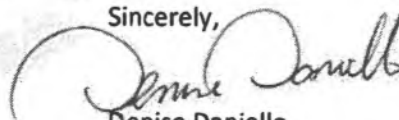
HB 44 allows DHSS to charge a fee to individuals participating in the registry. ACoA asks that the Legislature consider a fee waiver for persons of modest income who by paying this fee would incur undue hardship.

Thank you for your support of this legislation. Please feel free to contact Denise Daniello, ACoA's executive director (465-4879), should you have any questions regarding our position.

Sincerely,


Paula Pawlowski
Chair, Alaska Commission on Aging

Sincerely,


Denise Daniello
ACoA Executive Director



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February 8, 2013

The Honorable Lindsey Holmes
Alaska Capitol, Room 415
Juneau, AK 99801-1182

Re: HB 44 (Registry for Advance Health Care Directives) - Support

Dear Representative Holmes,

On behalf of the 94,000 members of AARP Alaska, we are pleased to offer our support for House Bill 44, which provides for the establishment of an electronic registry of individual advance directives through the Department of Health and Social Services. This is an important step in the development of a comprehensive approach to end of life planning, which provides adults of all ages the opportunity to articulate their personal wishes in the event of a medical situation where they may not be able to express themselves in the moment.

While Alaska statute already provides for the ability of persons to establish their own advance directives (AS 13.52 Health Care Decisions Act), it is nevertheless important to provide means for these to be more easily available and communicated to medical professionals and decision makers at the time of need. Advance directives have little value if they are not accessible to those who provide care. The electronic advance directive registry gives one more opportunity for the individual patient's choices to be noted, understood and honored, something each of us would wish for ourselves in such a situation.

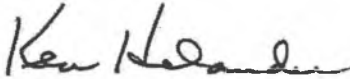
AARP supports the right of all persons to be full participants in their own health care, including at times of emergency or end of life. Together with designation of health care proxies (Durable Power of Attorney for Health Care), and especially in the context of ongoing conversations with the primary care physician and family members about one's personal medical wishes, the registry provides increased reassurance that those wishes will be considered in medical decisions. Additionally, the electronic registry represents another step toward an effective and integrated electronic health record, which is a fundamental goal of health care reform.

With the passage of HB 44, AARP Alaska will encourage our members and other adults to give more thought to end of life choices, and provide education and support to do so. The voluntary and confidential nature of the registry will provide incentive for more people to take part.

We urge passage of HB 44, and offer our endorsement. Should you have any questions about our position, please feel free to contact us.

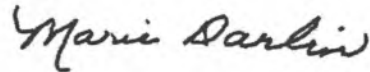
Thank you for your sponsorship and consideration of this important issue.

Sincerely,



Ken Helander
Advocacy Director
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Marie Darlin
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cc:

Representative Charisse Millett
Representative Andrew Josephson
Representative Peggy Wilson
Representative Beth Kerttula