

ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

February 14, 2013

3:06 p.m.

MEMBERS PRESENT

Representative Pete Higgins, Chair
Representative Wes Keller, Vice Chair
Representative Lance Pruitt
Representative Lora Reinbold
Representative Paul Seaton
Representative Geran Tarr

MEMBERS ABSENT

Representative Benjamin Nageak

COMMITTEE CALENDAR

HOUSE BILL NO. 44

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

- HEARD & HELD

PREVIOUS COMMITTEE ACTION

BILL: HB 44

SHORT TITLE: ADVANCE HEALTH CARE DIRECTIVES REGISTRY

SPONSOR(S): REPRESENTATIVE(S) HOLMES, MILLETT, JOSEPHSON

01/16/13	(H)	PREFILE RELEASED 1/7/13
01/16/13	(H)	READ THE FIRST TIME - REFERRALS
01/16/13	(H)	HSS, JUD
02/14/13	(H)	HSS AT 3:00 PM CAPITOL 106

WITNESS REGISTER

REPRESENTATIVE LINDSEY HOLMES

Alaska State Legislature

Juneau, Alaska

POSITION STATEMENT: Introduced HB 44 as a prime sponsor of the bill.

GRACE ABBOTT, Staff

Representative Lindsey Holmes

Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Presented HB 44 on behalf of the bill sponsor, Representative Holmes.

JILL LEWIS, Deputy Director-Juneau
Central Office
Division of Public Health
Department of Health and Social Services
Juneau, Alaska

POSITION STATEMENT: Answered questions during discussion of HB 44.

MARIE DARLIN, Coordinator
AARP Capital City Task Force
Juneau, Alaska

POSITION STATEMENT: Testified in support of HB 44.

JEFFREY MITTMAN, Executive Director
American Civil Liberties Union of Alaska (ACLU)
Anchorage, Alaska

POSITION STATEMENT: Testified in support of HB 44.

ACTION NARRATIVE

[3:06:49 PM](#)

CHAIR PETE HIGGINS called the House Health and Social Services Standing Committee meeting to order at 3:06 p.m. Representatives Higgins, Keller, Reinbold, Seaton, and Tarr were present at the call to order. Representative Pruitt arrived as the meeting was in progress.

HB 44-ADVANCE HEALTH CARE DIRECTIVES REGISTRY

[3:07:23 PM](#)

CHAIR HIGGINS announced that the only order of business would be HOUSE BILL NO. 44, "An Act relating to a registry for advance health care directives."

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REPRESENTATIVE LINDSEY HOLMES, Alaska State Legislature, relayed that this was an act relating to a registry for advance health care directives. She shared that a more common term for

"advance health care directive" was "living will." This directive allowed for power of attorney, and described a person's health care wishes in the event a person was incapacitated and unable to make their own decisions. The directive laid out what care the person wanted and did not want, and who was authorized to make decisions for them. She relayed that advance health care directives already existed in statute and were not a new authority. She explained that the proposed bill enabled Department of Health and Social Services (DHSS) to create a voluntary registry which would allow people to submit this living will to DHSS for inclusion in a confidential and secure data base. The registry would be accessible by health care facilities within Alaska. She shared that, although she had a living will, it was locked away and it could be difficult to access during an emergency. The proposed bill would allow the advance health care directive to be accessed on-line.

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CHAIR HIGGINS asked if there was a fiscal note for the proposed bill, as the registry would require software.

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REPRESENTATIVE HOLMES replied that DHSS would explain the fiscal note. She shared that the submitted living wills would be scanned and then put onto the registry. She reported that, as this software was already available, it could be more economical to buy. She agreed that there were some upfront costs, and that the ongoing costs would be reduced over time.

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GRACE ABBOTT, Staff, Representative Lindsey Holmes, Alaska State Legislature, reported that the fiscal note reflected the set up costs and maintenance of the registry, and salary for a full time employee to ensure that regulations were in place to establish methods for identification and confidentiality. She offered her belief that, in time, the full time position would be reduced to a part time position.

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REPRESENTATIVE SEATON directed attention to the proposed bill, page 2, line 12, and asked for the definition of an "agent."

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MS. ABBOTT, in response, explained that an agent, a guardian or a surrogate were designated by the individual who filed the directive and were listed in the directive. She compared this to a durable power of attorney.

[3:14:51 PM](#)

MS. ABBOTT referred to the "House Bill 44 Sectional Analysis" [Included in members' packets] and offered an analysis for Section 1 of the proposed bill. She explained that Section 1 protected a health care facility from liability for access, or non-access, to the registry.

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MS. ABBOTT moved on to Section 2, subsection (a) which directed DHSS to create and maintain the registry. She stated that the registry would only contain the name and scanned copy of an advance health care directive for any registered individual.

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MS. ABBOTT explained that subsection (b) established that participation in the registry was completely voluntary. She reported that subsection (c) defined that the registry was confidential and who had access to the directive. She noted that this subsection also allowed DHSS to provide a copy of the advance health care directive to a hospital outside the state, if requested by the individual or guardian. She stated that subsection (d) enabled the registry to be available on line, and that subsection (e) clarified that DHSS was not responsible for the legal validity of each directive.

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MS. ABBOTT noted that subsection (f) clarified that the directive could be removed at any time and was completely voluntary.

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CHAIR HIGGINS asked to clarify whether a living will on the registry would supersede a family member.

MS. ABBOTT replied that the advance health care directive supplied more information for medical issues, and that doctors

already had regulations for the acceptance of authority. She stated that immediacy of care was the most important.

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REPRESENTATIVE KELLER referred to the proposed bill, page 2, line 23, and asked who had the authority to access the registry and the individual's directive.

MS. ABBOTT replied that although it was anticipated that the doctor would most likely access the registry, the sponsor did not want to limit access as the administrative practices at a hospital could have a different protocol.

[3:19:52 PM](#)

MS. ABBOTT resumed her explanation for subsection (h) and shared that DHSS was permitted to charge a fee equivalent to the administrative cost, or not charge a fee. She pointed out that DHSS was not permitted to charge a fee for removal of a directive. She reported that subsection (i) empowered DHSS to make regulations for cyber access to a directive, while subsection (j) empowered DHSS to make regulations for human access. She noted that the sponsor wanted DHSS to create regulations which worked best for them.

[3:21:43 PM](#)

MS. ABBOTT moved on to subsection (k), which protected DHSS and its employees from any legal liability for operation of the registry. She concluded with subsection (l), which provided definitions of registry and directive.

[3:22:15 PM](#)

REPRESENTATIVE SEATON asked to clarify whether the definition of directory as written in the proposed bill would only include a written directive, and that any advancement for directives would require a change to the law.

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MS. ABBOTT explained that the definition for a written directive included scanned copies, as these were the only current means for acceptance into the registry.

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REPRESENTATIVE REINBOLD asked if the concept for the proposed bill had been initiated by lawyers or physicians.

MS. ABBOTT replied that Representative Holmes had initiated the proposed bill as a response to the difficulty for having the actual copy of a directive in hand.

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REPRESENTATIVE REINBOLD reported that approximately 12 states offered this service for no charge. Directing attention to the proposed bill, page 3, line 3, she asked if this referred to a registration fee.

MS. ABBOTT replied that the referenced fee would pay for DHSS to file the advanced health care directive on the registry. She declared that the assumption was to not charge a fee, but that the proposed bill allowed DHSS to charge a fee, not exceeding the actual cost, for filing the directive.

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REPRESENTATIVE REINBOLD, referring to the fiscal note [Included in members' packets] asked for an explanation to the continued fees being so high in Alaska.

MS. ABBOTT deferred to DHSS, as they had researched the cost differential for various contracted vendors.

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REPRESENTATIVE REINBOLD asked if there had been any polling regarding the proposed bill among the medical community.

MS. ABBOTT replied that there had not been any negative comments from the medical community. Noting that advanced health care directives already existed, she offered her belief that the proposed bill would provide the medical community with more information for better treatment.

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REPRESENTATIVE SEATON directed attention to page 2, line 3 of the proposed bill, and asked for clarification as to which individual this referred.

MS. ABBOTT replied that this was a legal way for stating that a person could write and file the directive for themselves.

[3:29:04 PM](#)

REPRESENTATIVE SEATON asked if the agent would also be able to submit the directive.

MS. ABBOTT replied that although an individual could receive assistance for completing the directive, the individual had to file with the registry, either by mail, fax, or electronic.

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CHAIR HIGGINS asked about the open ended fee referenced in the proposed bill.

JILL LEWIS, Deputy Director-Juneau, Central Office, Division of Public Health, Department of Health and Social Services, said that the proposed bill limited the fee to only cover the administrative cost. She reported that DHSS was considering to not charge, similar to other states, which was reflected in the fiscal note. She offered her belief that a fee would reduce participation.

MS. LEWIS, in response to Chair Higgins, said that a fee was not included in the fiscal note.

CHAIR HIGGINS pointed out that, although a fee was not included in the fiscal note, it was not prohibited in the proposed bill. He reported that document fees could be as high as \$300 for an individual's records. He stated that technically the Department of Health and Social Services could charge up to \$300 per individual.

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MS. LEWIS read from the narrative on page 2 of the fiscal note, "a fee might offset administrative costs but would likely reduce participation." She affirmed that the fiscal note assumed there would not be a fee.

CHAIR HIGGINS replied that he was not comfortable with this assumption, and he declared that if there was no intent to charge, then this should be written in the proposed bill. Pointing out that information technology (IT) was expensive, he

asked about the recourse if the \$137,000 allocated in the fiscal note was not sufficient.

MS. LEWIS replied that research by DHSS was "pretty certain" that the allocation would be sufficient. She said that DHSS had looked into building the program software, but had found that national registries already existed at a much more reasonable cost. She clarified that the fiscal note was based on conversations and cost structure estimates with an existing registry.

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CHAIR HIGGINS asked how a living will would be written and implemented.

MS. ABBOTT, in response, said that the advance health care directive would be submitted by an individual to DHSS, but it would not be confirmed as valid simply by its listing on the registry.

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REPRESENTATIVE KELLER asked what percentages of the population of other states were participating, and what percentage of participation was anticipated in Alaska.

MS. LEWIS replied that Alaska could expect 1,000 registry users, although there was anecdotal information suggesting that Providence Alaska Medical Center in Anchorage already had 1,000 directives on file. She opined that a comparable statewide ratio could increase the registry use to 4,000. She reported that the flat rate fee structure for the proposed registry would include a minimum of 5,000 registrants.

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MS. ABBOTT said that the fiscal note also included an outreach program to the communities to encourage and, hopefully, increase participation.

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REPRESENTATIVE KELLER asked to clarify that the fiscal note included an outreach program. He asked about private sector data bases in other states. He questioned whether he could

register in advance to the Providence Alaska Medical Center registry.

[3:38:03 PM](#)

REPRESENTATIVE KELLER announced that he had heard rumors about an iPad application to store personal health records, and he asked if there were any options other than a public registry.

MS. ABBOTT said that individual hospitals had created their own registry however, unless a person was a current patient at the hospital, the advanced health care directive would not be accessible. She opined that many users of advance health care directives were not a target demographic for iPad.

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MS. LEWIS said that a trend for some states was alignment of the advance care directives with the state health information exchange. She offered her belief that electronic records were an optional qualifying condition for incentive payments to providers.

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REPRESENTATIVE KELLER asked to clarify that the health information exchange was a data base for sharing medical records among providers, and was not the same as a health exchange. He noted that the State of Alaska had financially encouraged a health information exchange in the state.

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REPRESENTATIVE TARR, referring to the attached fiscal note, asked to clarify the cost if there were only 1,000 participants. She also asked about the significant change to cost of services in FY 2015.

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MS. LEWIS, in response to Representative Tarr, said that the potential maximum fee would be much lower as there were more participants. She pointed out that the fee charged by other states was very nominal, and that DHSS, if they chose to implement a fee, would follow that direction. She opined that DHSS would not try to recoup the entire cost for the registry unless directed by the legislature.

REPRESENTATIVE TARR suggested that the proposed bill should be more explicit for a limit to the fee, in order to guarantee success for the program.

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REPRESENTATIVE REINBOLD noted that there was no fee for the registry in other states. She directed attention to the \$112,000 for personal services and the \$11,000 for travel listed in the attached fiscal note, and reported that the cost per registrant would be more than \$1,000 if there were only 1,000 participants, as projected. She declared that there were tough budget decisions currently being discussed, and she offered her belief that it was necessary to "shrink our budget, if we want it sustainable." Noting that the concept of the proposed bill was worthy of discussion, she asked why Alaska would not model after Virginia, as that state had been offering the program at no operational cost since 2008.

MS. ABBOTT explained that participation in Virginia had occurred when hospitals had aligned with a healthcare information exchange and, as that was not occurring in Alaska, there was anticipation for creation with this registry.

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REPRESENTATIVE SEATON directed attention to page 2, line 7 of the proposed bill, and noted that there was language for the release of directives, but no mention for a means of submission. He asked for an explanation as to why an agent for the participant could access a copy of the directive, but could not file a certified copy for the participant.

MS. ABBOTT, in response, opined that Alaska statute declared that only an individual could fill out the advance health care directive, therefore the proposed bill extended this intent by stating that only the individual could submit the directive to the registry. She pointed out that an individual could receive assistance with this task.

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MS. LEWIS detailed that the proposed full time dedicated position for the registry during the first few years was to work with people in outreach programs, to offer a toll free line for technical assistance, and to scan the paper directives when

submitted. She noted that it was also necessary to determine a system for the security of the paper documents which would ensure compliance with the Health Insurance Portability and Accountability Act (HIPAA).

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REPRESENTATIVE SEATON asked to clarify that it was acceptable for an agent to submit the health care directive for an individual upon admission to a health care facility, yet there was a barrier for filing with the registry.

MS. ABBOTT, in response to Representative Seaton, explained that the intent for requiring an individual to register would be to ensure "it is not falsified."

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CHAIR HIGGINS, directing attention to page 2 of the attached fiscal note for the proposed bill, asked about the projection for 4,000 directives. He questioned if this was a realistic projection, and if not, how this program could become revenue neutral. He expressed that, although the concept of the program was good, he was concerned with the potential cost.

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CHAIR HIGGINS opened public testimony.

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MARIE DARLIN, Coordinator, AARP Capital City Task Force, stated that AARP had submitted a letter of support [Included in members' packets]. She reminded the committee that it had taken four years to get the advance health care directives approved by the legislature, and AARP viewed this proposed bill as the next step toward usefulness for the directives. She encouraged use of the directives, and she declared that many of the committee's questions were answered on the directive itself. She offered that AARP would be "helping to spread the word" for participation in the registry, and she endorsed that any fee for registration be nominal. She shared that AARP had almost 95,000 members in Alaska. She declared that the most important aspect of the advance health care directive was to initiate discussion for what the individual wanted in advance of any emergency. She declared that AARP supported the proposed bill.

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REPRESENTATIVE TARR asked if the AARP membership was aware of the opportunity to file a directive.

MS. DARLIN, in response, said that AARP had focused on the need for advance health care directives, and she emphasized the need for a family discussion with regard to the directives.

REPRESENTATIVE TARR, referencing the number of advance directive registrants through Providence Alaska Medical Center in Anchorage, asked if AARP was surprised that so few people had currently registered.

MS. DARLIN questioned the number of individuals with advance health care directives, and noted that a registry would be a means to ascertain this. She declared that the directives were an important ongoing project.

REPRESENTATIVE TARR asked if many people kept their own directive.

MS. DARLIN offered an anecdotal story of advance directives with her family.

[4:00:17 PM](#)

JEFFREY MITTMAN, Executive Director, American Civil Liberties Union of Alaska (ACLU), stated that the proposed bill "was an excellent balance of the state providing a mechanism for individuals in the State of Alaska to voluntarily be part of a scheme that improves the provision of health care, while recognizing the need for medical decisions to be made between the patient and his or her healthcare provider." He declared that ACLU supported proposed HB 44.

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CHAIR HIGGINS stated that he would leave public testimony open.

CHAIR HIGGINS held over HB 44.

[4:01:53 PM](#)

ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 4:01 p.m.