

ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

March 2, 2017

3:10 p.m.

MEMBERS PRESENT

Representative Ivy Spohnholz, Chair
Representative Geran Tarr
Representative David Eastman
Representative Jennifer Johnston
Representative Colleen Sullivan-Leonard
Representative Matt Claman (alternate)
Representative Dan Saddler (alternate)

MEMBERS ABSENT

Representative Bryce Edgmon, Vice Chair
Representative Sam Kito

COMMITTEE CALENDAR

HOUSE BILL NO. 123

"An Act relating to disclosure of health care services and price information; and providing for an effective date."

- HEARD & HELD

HOUSE BILL NO. 43

"An Act relating to prescribing, dispensing, and administering an investigational drug, biological product, or device by physicians for patients who are terminally ill; providing immunity related to manufacturing, distributing, or providing investigational drugs, biological products, or devices; and relating to licensed health care facility requirements."

- HEARD & HELD

PRESENTATION: KEY COALITION

- HEARD

PREVIOUS COMMITTEE ACTION

BILL: HB 123

SHORT TITLE: DISCLOSURE OF HEALTH CARE COSTS

SPONSOR(S): REPRESENTATIVE(S) SPOHNHOLZ

02/13/17 (H) READ THE FIRST TIME - REFERRALS
02/13/17 (H) HSS, JUD
03/02/17 (H) HSS AT 3:00 PM CAPITOL 106

BILL: HB 43

SHORT TITLE: NEW DRUGS FOR THE TERMINALLY ILL
SPONSOR(S): REPRESENTATIVE(S) GRENN

01/18/17 (H) PREFILE RELEASED 1/13/17
01/18/17 (H) READ THE FIRST TIME - REFERRALS
01/18/17 (H) HSS, JUD
02/28/17 (H) HSS AT 3:00 PM CAPITOL 106
02/28/17 (H) Heard & Held
02/28/17 (H) MINUTE(HSS)
03/02/17 (H) HSS AT 3:00 PM CAPITOL 106

WITNESS REGISTER

BERNICE NISBETT, Staff
Representative Ivy Spohnholz
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Testified during the presentation of HB 123, on behalf of the bill sponsor, Representative Spohnholz.

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

POSITION STATEMENT: Answered questions during presentation of HB 123.

BECKY HULTBERG, President/CEO
Alaska State Hospital and Nursing Home Association
Juneau, Alaska

POSITION STATEMENT: Testified and answered questions during the presentation of HB 123.

JOHN ZASADA
Policy Integration Director
Alaska Primary Care Association (APCA)
Anchorage, Alaska

POSITION STATEMENT: Testified during discussion of HB 123.

BROOKE IVY, Staff

Representative Jason Grenn
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Presented HB 43 on behalf of the bill sponsor, Representative Grenn.

KEN LANDFIELD
Homer, Alaska

POSITION STATEMENT: Testified in support of HB 43.

ELIZABETH KROME, Nurse
Wasilla, Alaska

POSITION STATEMENT: Testified in support of HB 43.

MIKE MAHARREY
National Communications Director
Tenth Amendment Center
Lexington, Kentucky

POSITION STATEMENT: Testified in support of HB 43.

JASON NORRIS
Anchorage, Alaska

POSITION STATEMENT: Testified in support of HB 43.

MILLIE RYAN, Chair
Key Coalition of Alaska
Executive Director
REACH, Inc.
Juneau, Alaska

POSITION STATEMENT: Testified during the Key Campaign presentation.

EMILY ENNIS, Executive Director
Fairbanks Resource Agency
Key Coalition of Alaska
Fairbanks, Alaska

POSITION STATEMENT: Testified during the Key Campaign presentation.

ADDISON TURNBOW
Fairbanks, Alaska

POSITION STATEMENT: Testified during the Key Campaign presentation.

SHELLY VENDETTI VUCKOVICH

POSITION STATEMENT: Testified during the Key Campaign presentation.

ALLEN RAY
Simply Home
Arden, North Carolina

POSITION STATEMENT: Testified during the Key Campaign presentation.

JASON RAY
Simply Home
Arden, North Carolina

POSITION STATEMENT: Testified during the Key Campaign presentation.

ACTION NARRATIVE

[3:10:16 PM](#)

CHAIR IVY SPOHNHOLZ called the House Health and Social Services Standing Committee meeting to order at 3:10 p.m. Representatives Spohnholz, Tarr, Johnston and Claman (alternate) were present at the call to order. Representatives Sullivan-Leonard, Eastman, and Saddler (alternate) arrived as the meeting was in progress.

HB 123-DISCLOSURE OF HEALTH CARE COSTS

[3:10:52 PM](#)

CHAIR SPOHNHOLZ announced that the first order of business would be HOUSE BILL NO. 123, "An Act relating to disclosure of health care services and price information; and providing for an effective date."

[3:11:50 PM](#)

CHAIR SPOHNHOLZ, as the sponsor of proposed HB 123, declared that "knowledge is power." She stated that health care was the only industry in which the consumers did not know the price prior to the purchase or utilization of services. She noted that this was the removal of "one of the fundamental tenets of capitalism, that is the power of the consumer to make choices about what they do or they don't purchase." She offered an example for a colleague who had sustained an injury and the subsequent expensive testing and recommended treatment. She shared that, after the testing, the colleague had questioned the need for the test, as the test had not altered the course of treatment. She shared that proposed HB 123 provided consumer

pricing transparency which was simple and clean to implement, without adding any additional cost to the state.

[3:14:32 PM](#)

BERNICE NISBETT, Staff, Representative Ivy Spohnholz, Alaska State Legislature, stated that the intent of the bill sponsor, Representative Spohnholz, was to create a foundation to increase price transparency in health care in Alaska. She said that transparency and access to health care costs would empower consumers to take more financial responsibility for their health care. She explained that the proposed bill required health care providers and facilities to display the undiscounted prices of their most common health care procedures in a public area, or on their website. She declared that it was the intent of the sponsor to require health care providers to disclose their costs, but not make it burdensome to provide this information. She relayed that this was important, as when consumers had this information, it would give them the power to choose their health care options. It would also open more conversations regarding high health care costs in Alaska and consumer control for the health care market.

[3:16:01 PM](#)

MS. NISBETT directed attention to the Sectional Analysis [Included in members' packets] and explained that Section 1 was expanded to authorize the Department of Health and Social Services (DHSS) to collect health services and price information. She stated that Section 2 was "really the meat of the bill," it was a new section which said that health care providers and facilities would compile a list of the most common procedures along with the undiscounted price. This list would be compiled once each year, and be posted in a public area or on the provider's website, as well as provided to DHSS for posting on the departmental website. She added that failure to provide these costs could result in a fine, which shall not exceed \$2500. She reported that the effective date for the proposed bill would be January 1, 2018.

[3:17:50 PM](#)

REPRESENTATIVE SULLIVAN-LEONARD asked for an explanation to the zero fiscal note, as there would be increased labor costs for maintenance of the DHSS data base and the levying of any fines for failure to comply.

MS. NISBETT replied that the zero fiscal note was from DHSS.

CHAIR SPOHNHOLZ explained that the proposed bill did not require a data base, as the information would merely be uploaded to the department's website. She added that DHS had stated that this could be absorbed into the regular work load.

REPRESENTATIVE JOHNSTON asked if there was a subjective nature to the 25 procedures required to be listed.

CHAIR SPOHNHOLZ replied that the decision to require listing of 25 procedures for individual practitioners and 50 procedures for hospitals was to keep the requirement from becoming too onerous. She opined that this was a practical number for the most frequently offered services, although this number was flexible.

REPRESENTATIVE JOHNSTON asked if each facility would decide which of these procedures were the most frequent.

REPRESENTATIVE SULLIVAN-LEONARD asked for further testimony regarding the fiscal note from DHSS.

[3:20:49 PM](#)

JILL LEWIS, Deputy Director - Juneau, Central Office, Division of Public Health, Department of Health and Social Services, explained that the determination for implementation was simple, that DHSS would accept PDF versions of the cost lists and these would be posted as-is to the website, most likely alphabetically. She declared that DHSS did not anticipate much enforcement, as they expected a good participation rate.

[3:22:13 PM](#)

REPRESENTATIVE SADDLER questioned whether the state should be involved in these private transactions. He asked what information was to be disclosed, stored, and promulgated. He asked if the listing would reflect the price for someone "walking the streets."

MS. NISBETT replied that the definition for price in the proposed bill would be for the undiscounted price, before any negotiations. She called this "the charged master price" that each facility and provider set for themselves.

REPRESENTATIVE SPOHNHOLZ, in response to Representative Saddler, pointed out that government should enter into this to protect consumers, as the market itself had not done this.

[3:23:56 PM](#)

REPRESENTATIVE CLAMAN asked why it was only the undiscounted price, and not the other prices which were published.

MS. NISBETT replied that this was an attempt to keep the bill as simple as possible, and that this price could be used as a reference point.

REPRESENTATIVE CLAMAN asked if there were any limits, such as confidentiality with insurance companies, which would prohibit the disclosure of prices.

MS. NISBETT said that, although it would be in the best interest to include the insurance costs, the bill would focus on the undiscounted price to allow consumers to make a decision.

REPRESENTATIVE SADDLER asked how the pricing currently worked.

MS. NISBETT replied that the intent of the sponsor was for the consumer to have this price information prior to entering a clinic to receive services.

REPRESENTATIVE SADDLER acknowledged that most consumers would like to have the cost information, although he questioned whether there was other information which made it difficult to attain a fair price.

REPRESENTATIVE SPOHNHOLZ acknowledged that there was a challenge for health care pricing as there was not a clear agreement for what was a fair price. As there was a wide range for what was actually paid, she had opted for simplicity and asked for the undiscounted price as there were so many different variations. She stated that there needed to be a pricing starting point. She relayed that the proposed bill stated that the information would be posted in a public place in the doctor's office, as well as on the website, and on the Department of Health and Social Services' website. She stated that there was not one price that everyone paid, and although an all payers price list had been suggested, it had been ruled untenable due to the cost.

REPRESENTATIVE SULLIVAN-LEONARD asked if, as the prices were to be posted, this would open the door for patients to ask for discounts on particular procedures.

MS. NISBETT said "yes."

[3:30:59 PM](#)

BECKY HULTBERG, President/CEO, Alaska State Hospital and Nursing Home Association, stated that this was an important issue, and that it had been raised frequently in the past few months. She expressed appreciation for the simplicity of the proposed bill and its goal for avoiding additional administrative costs. She stated support for the concept of price transparency and consumer engagement in health care decision making. She relayed that the structure of the health care payment and delivery system was complicated, which made price transparency difficult to implement, even when all the parties agreed on the desirability. She declared that it was important to have realistic expectations for the accomplishments from price transparency. She pointed out that economic theory and reality supported the idea that most consumers were only price sensitive and engaged in price shopping up to the point of out-of-pocket exposure. She declared that low deductibles and low out-of-pocket maximums meant that most customers would not be concerned with price transparency. She reported that most public health care plans in Alaska were maintaining relatively low deductibles and out-of-pocket maximums, while private sector plans were moving toward higher deductibles. She pointed out that it was often the insurer with access to the best data. She suggested that successful transparency initiatives sometimes also included an insurance component, which she encouraged as an addition to the proposed legislation. She reported that some of the larger insurers in Alaska already offered price transparency tools. She stated that undiscounted prices were a reference point, as most consumers were not paying this price. She reported that insurers paid rates based on contractually negotiated discounts, and self-pay and charity care discounts were also often offered to patients without health insurance. She recommended to delete the words "charged to an individual recipient" from the language of the proposed bill. She noted that the proposed bill required that the list be compiled by procedure and diagnostic code. She explained that diagnostic codes were very specific, there could be many different codes for a procedure, and she suggested to instead just use the procedure code which she opined should accomplish the objective. She suggested that, as DHSS was required to post the pricing information on its centralized

website, it would be duplicative for individual providers to also post this information, and she recommended removal of this requirement for providers. She asked that the sponsor consider a change of the requirement for posting the price list, to just make the list available. She offered her belief that this could stimulate conversation for the consumer cost. She stated that health care price transparency was a very complex topic, and she expressed her appreciation for the discussion.

[3:36:05 PM](#)

REPRESENTATIVE TARR asked whether there were efforts in any other states and if these suggestions were in line with those.

MS. HULTBERG replied that states had different frameworks. She added that the all payer claims data base was the gold standard, albeit the most expensive option. She allowed that some states had chosen an approach similar to the proposed bill, whereas some states had mandated that providers offer individualized estimates. She declared that this proposed bill was a foundation and a step to elevate the attention and improve the provision for pricing information.

MS. HULTBERG, in response to Representative Tarr, said that generating a conversation between [the patient] and the provider was optimal. She mused that having the price list available, but not posted, would generate a conversation. She acknowledged that there was not a perfect solution to this "Gordian knot of a problem."

REPRESENTATIVE SADDLER asked about the current transparency for health care costs in Alaska.

MS. HULTBERG said that this depended on the provider. She stated that hospital prices were very difficult to understand, as there were layers of discounts, deductibles, and out-of-pocket costs. She reported that the hospitals were insuring that staff were available to help navigate the system and find out the prices. She acknowledged that, although it was possible to find the price, it was also difficult. She offered her belief that the challenge was to make it less difficult given the structure of the system.

REPRESENTATIVE SADDLER asked if price transparency was beneficial or detrimental to the hospitals and nursing homes.

MS. HULTBERG expressed agreement that price transparency was optimal, more information was better for the system and for the consumer. She questioned how to do this, given how the health system had evolved for the past 40 years, without adding cost and still helping the consumer. She stated that there was not a philosophical difference regarding the good of transparency, but the difficulty was in how to do it.

REPRESENTATIVE CLAMAN asked if the discounted insurance rates were published in all states, and if it was possible for these proprietary rates to also be published.

MS. HULTBERG said she would have to ask about this feasibility. She shared that many insurers and large employers had tools to help find the prices and find the most cost effective option in each area. She agreed that, as not everyone offered these tools, there was some value in posting prices as a reference point for those patients without insurance.

REPRESENTATIVE EASTMAN expressed his agreement with the philosophy, and asked whether the proposed bill captured a good process for transition or could be improved.

MS. HULTBERG offered her belief that "the beauty in this bill is the simplicity. I do not think this would be a difficult bill for us to administer." She stated that she did not have concerns, at this point, for the transition.

REPRESENTATIVE SADDLER mentioned capital and operating expenses as elements of pricing, and asked what other elements of health care services could affect any change in pricing if the proposed bill was passed.

MS. HULTBERG suggested that a PhD in health care economics was helpful in pricing. She stated that it was too early to tell about the price transparency initiatives and whether they would lower costs.

REPRESENTATIVE JOHNSTON asked about a national site for health care costs, and the possible use of its data.

MS. HULTBERG replied that there was a national move toward price transparency. She shared that, as the undiscounted charges were not what most people paid, it was important for the insurer to be able to determine the actual out-of-pocket expense. She emphasized the need for the patient to call the insurer and the

provider to verify the procedures, the co-pay, the out-of-pocket costs, and whether the provider was in-network.

[3:46:33 PM](#)

JOHN ZASADA, Policy Integration Director, Alaska Primary Care Association (APCA), explained that APCA was the association of community health centers in Alaska and was required, by law, to accept patients regardless of ability to pay. He explained that there was a sliding scale discount based on income. He declared support for increased price transparency and added that patients were engaged and educated on the ways to use the care options and coverage available. He reported that Alaska health centers mostly provided patients with an estimate of charges for particular procedures, upon request, and that a large number of the health centers had expressed an ability to compile and post a list of prices for the most common procedures, as outlined in the proposed bill. He expressed concern for effective explanation regarding the discounts on the sliding scale, so patients understood what they had to pay. He said that federally qualified health centers had a unique bundled payment system, and that the rack rate was often higher than what would be posted with a private primary care provider. He shared the concern by health centers that the requirement to post prices on the health center websites may have an unintended consequence to serve as a barrier for coming to seek care, especially for low and moderate income patients and people for whom English was a second language, as the sliding scale discount was often presented at the time of appointment. He suggested that posting the price list at the facility, along with support to better understand the actual cost to the individual, might be more effective for ensuring maximum access to care.

[3:49:53 PM](#)

REPRESENTATIVE CLAMAN asked about making available the listings for the negotiated prices.

MR. ZASADA explained that 80 percent of the patients at community health centers in Alaska were at 80 percent of poverty or below, and that about 33 percent had commercial insurance, with another 33 percent being uninsured. He stated that the sliding scale discount was the primary way to reduce the cost from the main rack rate. He stated that eligibility staff at the health centers worked with the patients to provide the price, so that patients knew the cost.

REPRESENTATIVE SADDLER asked if the transparency of prices would affect the services of community health centers in Alaska.

MR. ZASADA noted that sharing rack rates on a website could serve as a barrier to care for those people without health insurance literacy. He expressed concern for potential patients not seeking primary and preventative care based on a rack rate. Other than this, he offered his belief that the proposed bill would not dramatically affect the care offered.

REPRESENTATIVE SADDLER asked for a definition of rack rate.

MR. ZASADA said that the bundled rate from a community health center included the presentation of the issue by the patient, the examination, the procedure, the care coordination and other factors which were built in by the health center.

REPRESENTATIVE EASTMAN asked if this legislation would allow disclaimers for price discounts.

MR. ZASADA offered his belief that many health centers would prefer personal interaction with a patient for those discussions, as understanding for a sliding scale discount system was not easily understood via a website. He declared that it was much easier and clearer in person, especially for those with limited health insurance literacy.

REPRESENTATIVE EASTMAN asked if the legislation would allow this.

MR. ZASADA stated that the APCA would prefer not to post the prices on the website.

REPRESENTATIVE SPOHNHOLZ asked if anyone paid the rack rate.

MR. ZASADA said that there were some uninsured patients with incomes over 200 percent [of the poverty rate] who were subject to the full price. He shared that there were also discounts for early payment. He acknowledged that some people were subject to the full price.

MS. HULTBERG, in response to the aforementioned question from Representative Spohnholz, said that she would follow up with this information.

REPRESENTATIVE SPOHNHOLZ asked why some people would not pay the full price.

MS. HULTBERG replied that Alaska State Hospital and Nursing Home Association also used sliding scales and self-pay discounts.

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REPRESENTATIVE SPOHNHOLZ said that HB 123 would be held over.

[3:57:15 PM](#)

The committee took an at-ease from 3:57 p.m. to 4:00 p.m.

HB 43-NEW DRUGS FOR THE TERMINALLY ILL

[4:00:30 PM](#)

CHAIR SPOHNHOLZ announced that the next order of business would be HOUSE BILL NO. 43, "An Act relating to prescribing, dispensing, and administering an investigational drug, biological product, or device by physicians for patients who are terminally ill; providing immunity related to manufacturing, distributing, or providing investigational drugs, biological products, or devices; and relating to licensed health care facility requirements."

[4:00:49 PM](#)

BROOKE IVY, Staff, Representative Jason Grenn, Alaska State Legislature, stated that this legislation essentially allowed terminally ill patients to work with their doctors and drug or device manufacturers to access investigational treatments that had passed the safety testing phase, Phase 1 of the FDA (U.S. Food and Drug Administration) approval process, but had not yet passed Phase 2 and Phase 3 and were currently in ongoing trials, hence were not yet widely available for public access. She said that this could expand access to potentially lifesaving treatments years before normal access. She stated that, as fewer than 3 percent of those patients diagnosed as terminally ill who tried to access clinical trials were accepted based on the level of illness, this legislation would affect the other 97 percent. She added that a compassionate use program already existed with the FDA, which allowed for application by the doctor, although it was known to be a lengthy process which did not work well for those people with terminal illness.

[4:02:26 PM](#)

REPRESENTATIVE SADDLER stated that mediation was already required between a health care provider and a patient which allowed for a process of testing and validation of drugs which the provider suggested. He asked if this was an argument for no remediation in order to allow a patient to try whatever substance they thought would help save their life or improve their health.

MS. IVY replied that the actual language of the proposed bill defined a very specific situation for someone to have the ability to access this. She reiterated that currently there was a compassionate use application through the FDA, although it was strictly for individuals diagnosed as terminally ill, which required conference with their doctor, and then involved a lengthy FDA process and institutional review board. The proposed bill would maintain that the diagnosis was for terminally ill and that the patient had exhausted all other approved options, in consultation with the doctor, and would then require consent of the doctor, the patient, and the drug manufacturer for access to those medications.

REPRESENTATIVE CLAMAN asked why this was limited to terminally ill patients, if someone was willing to try the experimental options.

MS. IVY said that this question had come up previously and had been discussed in other states. She reported that similar legislation had passed in 33 states, and that this narrow focus was more likely to be supported in the courts. She stated that otherwise, this was, in essence, opening up the FDA drug approval process and created a larger policy conversation than the proposed bill wanted to tackle. She added that the proposed bill focused on individuals with limited time, as they had been diagnosed as terminally ill.

REPRESENTATIVE EASTMAN acknowledged the conservative approach for the proposed bill, although he offered his belief that politics was driving the question of who gets care. He suggested that many Alaskans, although not expecting to die, could benefit from an experimental treatment and "may very well die even though they weren't expecting to." He declared that he "would certainly want to see what we could do for those folks, as well." He suggested that a more pro-active approach could be better, offering as an example Alaska's leadership for the legalization of marijuana.

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CHAIR SPOHNHOLZ opened public testimony.

[4:08:22 PM](#)

KEN LANDFIELD stated his support of HB 43, and questioned why this was even an issue. He said that any argument for creating a sense of false hope was not a valid argument, as "hope is hope and terminal is terminal." He declared that the compassionate use program was clearly not sufficient, otherwise, 60 percent of the state legislatures would not have enacted a bill similar to HB 43. He emphasized that time was "absolutely of the essence." He offered his support for the proposed bill "because, quite frankly, I can't think of any reason why you wouldn't."

[4:09:38 PM](#)

ELIZABETH KROME, Nurse, shared that she had been a nurse for 38 years, working in multiple areas, and that she had learned that the removal of hope for a terminal condition was "the worst thing in the world that can happen." She offered her belief that everyone with a diagnosis for a terminal condition needs hope and that individuals need the option to try different treatments. She acknowledged the FDA experimental and investigational programs and clinical trials, but she added that they had very rigorous criteria. She stated her support for the proposed bill. She explained that the patient would have many roadblocks, which included the need for a physician to support them, to locate the drug, and to find an insurance company which would pay for treatment rather than deny coverage.

[4:12:58 PM](#)

MIKE MAHARREY, National Communications Director, Tenth Amendment Center, reported that the Tenth Amendment Center had been in support of this "Right to Try" legislation across the United States, calling it the "no-brainer issue" because it was difficult to oppose. He reiterated that similar legislation had passed in 33 states. He stated that laws and regulations were supposed to protect the people, but, by their nature, regulatory schemes also created bureaucracy and red tape which could cause harm. He reported that HB 43 did not begin to address "the black hole between end of clinical trials and the final approval of the treatment. This process can take up to 10 months, and it often leaves patients in limbo." He offered an example of the benefits to patients from the passage of a similar "Right to Try" bill in Texas. He added that the Texas legislature was

considering expansion of this bill to include chronically ill patients. He stated that this legislation illustrated the "beauty of our federated structure. The American system was never intended to run based on one size fits all solution imposed from Washington, DC." He spoke about the dangers of monopoly government. He declared that "Right to Try" laws were an example of states using their rights to authority to exercise control over local issues. He stated support of the proposed bill.

[4:15:54 PM](#)

JASON NORRIS offered an example of his father's demise from ALS, pointing out that it affected the body, but not the mind. He recounted an article in the Washington Post about a man who had fought ALS using advanced therapies, which had led to his own awareness of the "Right to Try" movement. He implored passage of the proposed bill.

[4:19:39 PM](#)

MS. IVY, in response to an earlier question from Representative Tarr, offered her understanding that federal legislation allowed for a quicker path for breakthrough medical devices and had directed the FDA to evaluate the use of real world evidence, observational studies, patient input, other research, and clinical trial data in order to approve drugs for other indications, and not simply for their initial studied use. She said that this did not directly impact the compassionate use program, however. She said that there was now a requirement for drug companies to publish on their websites their policies on how to access investigational drugs, which should make it easier to find out how to access these drugs.

[4:21:53 PM](#)

MS. IVY clarified her earlier response to Representative Kito, and shared the four main points made by the Governor of Hawaii in his veto of similar legislation. These four main points included that the compassionate use program already provided access to investigational drugs, although the bill sponsor had pointed out that there was a delay through this process, which had resulted in the "Right to Try" legislation. The second point made by the Governor of Hawaii was that the bill could potentially interfere with the overall FDA system, and could result in the unintended consequence of delay for the development of potentially lifesaving drugs. She pointed out

that the proposed bill did not compete with clinical trials. She relayed that the third point made by the governor was that it violated the supremacy clause, which had been discussed repeatedly during similar legislation debate in the many states, and had been declared a "floor not a ceiling." She stated that the final point from the governor had been that he was unclear what the actual benefits from the "Right to Try" could offer patients. She added that both the Hawaiian house and senate had unanimously passed this legislation.

[4:23:46 PM](#)

MS. IVY addressed an earlier question from Chair Spohnholz about the definition for terminal illness. She stated that it appeared the definition used in the proposed bill came from Louisiana and Colorado legislation, and had since been used in "Right to Try" legislation in multiple other states.

[4:24:24 PM](#)

MS. IVY referenced an earlier question from Representative Johnston regarding BCG medication, which had been developed as a vaccine for tuberculosis, although it was also being used to treat bladder cancers and melanomas. She referenced an earlier speaker from the Goldwater Institute, who had acknowledged that once a drug had been approved by the FDA, then off label use was permitted and legal. She offered her understanding that it was also permitted for a physician to prescribe an investigational drug which was in Phase 2 or Phase 3 for off label use.

[4:25:33 PM](#)

MS. IVY turned attention to an earlier question from Chair Spohnholz whether informed consent, as referred to in the proposed bill, could include a verbal conversation between the doctor and the patient. She said that there was not any other place in Alaska statute where informed consent was defined; however, in the medical community and under medical ethics, it was accepted and understood that informed consent was different from consent in that the patient must understand. She said that whatever the form of communication, if the procedure, the other options, and the associated risks were fully understood, then Legislative Legal Services agreed that the current definition was broad enough.

[4:27:00 PM](#)

CHAIR SPOHNHOLZ said that HB 43 would be held over.

Presentation: Key Coalition

[4:27:39 PM](#)

CHAIR SPOHNHOLZ announced that the final order of business would be a presentation by the Key Coalition.

[4:27:57 PM](#)

The committee took a brief at ease.

[4:29:07 PM](#)

MILLIE RYAN, Chair, Key Coalition of Alaska, Executive Director, REACH, Inc., said that REACH served about 350 individuals with intellectual and developmental disabilities in Southeast Alaska, and was one of the ten largest private employers in Southeast Alaska. She reported that this was the 30th year for the Key Coalition. She recited some of the earlier successes, which included a Medicaid funded home and community based services system, closure of the very costly Harborview Developmental Center, and legislation for autism insurance reform which allowed for services to begin earlier. She spoke about the establishment of a durable medical equipment reuse program, which, in Kansas, had seen a \$3.15 return on each \$1 invested in the program. She reported that the regulations for this program had been issued and the program would be running very soon. She pointed to recent legislation which allowed families to save money toward disability related expenses without losing Medicaid or Social Security and those services necessary to continue to live in the community. She lauded that this 30 year partnership between Key Coalition and the State of Alaska had made effective and efficient use of the limited resources which were available. She pointed to the numerous cost savings recommendations which the Key Coalition had submitted over the last several years.

[4:31:48 PM](#)

EMILY ENNIS, Executive Director, Fairbanks Resource Agency, Key Coalition of Alaska, said that Alaska was recognized as being on the leading edge of provider services for those with disabilities. She expressed appreciation for the assistance, support, and funding.

MS. ENNIS offered a definition of developmental disability, reporting that this was a condition which occurred between birth and 22 years of age. As it occurred in the developmental years of a child, it had a significant impact on the areas of life function: mobility, communication, and cognitive development, and she noted that these support services were usually necessary throughout the life of the person. She said that a goal of the Key Campaign was to educate about the needs of these individuals. She said that about 100 years ago before statehood, until the early 1970s, there were not any services in Alaska for individuals with disabling conditions. She noted that individuals were transported to the Lower 48, an arduous trip for someone with a disability, and separated from their family and community and moved into an institutional setting. She referenced these people as the "Lost Alaskans." She pointed out that good services were now developed, but they depended on good funding. She declared that the desire was for the opportunities for a full life, regardless of any disability. She said that Alaska had developed a full array of services over the past 50 years, which included housing for adults, employment services, and invaluable services for families. She pointed out that 50 percent of parents of children with a significant disability would divorce. She asked that the legislature work toward a sound fiscal plan so that these services for people with significant disabilities could lead a full, productive, meaningful life in their communities. She pointed out that any cuts in funding could lead to catastrophic impacts on individuals and families.

[4:38:00 PM](#)

ADDISON TURNBOW shared a personal story of his sister, who was born in 1999, with a complex series of disabilities. He shared the initial difficulties and fears for his family, and then detailed the services and the respite care that brought support to his family. He acknowledged the difficulties for his family over the past 18 years, but declared the thankfulness of his family for all the support. He stated that this gift had lead him to a career of service.

MS. RYAN spoke about Alaskans with intellectual and developmental disabilities who were able to lead full and meaningful lives in the community, as a result of these services. She mused that the system was backward, as Medicaid home and community based waivers were waivers to institutions, and that a costly institution had to be provided if requested, although this was not what most people wanted. She stated that

people should be able to request community based waivers, and then, only if needed, would there be placement in an institution. She emphasized that waivers were very important for helping people become a part of "this rich community that we all know and love." She reported that 41 percent of adults in Alaska with intellectual and developmental disabilities were either working, or working toward employment, whereas the national average was about 28.6 percent. She declared that Alaska had done a good job for helping people go to work. She noted that many people lived with their family and friends, who offered unpaid support.

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SHELLY VENDETTI VUCKOVICH shared the story of her granddaughter, Claire Vendetti, who required constant care, and who had benefited from waiver services. She reported that the home and community based services had allowed Claire to stay home and make progress on the journey toward independence. She offered her belief that this help for Claire had allowed all of us to become better people, as "we've become educated about others who are different than us. We've gotten to experience the feeling of doing something good for the right reason." She stated that none of this would have been possible without the waiver services.

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MS. RYAN said that, although services helped people gain skills and enrich everyone's lives, there was a price. She declared that home and community based services were extremely cost effective programs. She referenced an earlier study which found that elimination of the Medicaid waiver program and the personal care assistance program would ultimately cost the State of Alaska hundreds of millions of dollars, which did not include the cost of building facilities to house people. She declared that adults with disabilities wanted to be employed and able to support themselves financially, and she cited research which showed that waiver funded employment services resulted in more job placements, higher wages, and more hours of work per week. She suggested the use of technology to increase independence and to reduce the need for hands-on staff support. She shared information about a pilot program in Juneau, "Simply Home."

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ALLEN RAY, Simply Home, shared that Simply Home had partnered with REACH and the Key Coalition, and they were working with other state legislatures on solutions to utilize technology for program savings. He declared that one technology did not fit all but each solution could provide some savings.

REPRESENTATIVE SADDLER asked for examples of the enabling technology.

MR. RAY replied that any support delivered without a provider was the most cost effective. He reported on control of the environment for work and living arrangements through use of technological tools.

JASON RAY, Simply Home, shared that conversations after a presentation had opened up possibilities for outcomes using technology. He asked for the opportunity to show the technology and how it could be utilized in Alaska to improve outcomes at less cost.

MS. RYAN offered an example of the use of sensor technology for a young boy to allow him to keep his independence.

REPRESENTATIVE EASTMAN asked how many Alaskans would be eligible for services and the amount of funding necessary.

MS. RYAN offered her estimate that there were about 3,000 individuals receiving waiver services, with another 1,000 individuals who received some lower level grant services. She said that the wait list had varied from the current 500 people to about 1,200 people, although "the need does not go down." She stated that technology allowed people to live longer. She offered an estimate that 13,000 Alaskans had a developmental disability, although some may not need comprehensive services until they leave school. She allowed that "sometimes people don't need a lot, they just need someone to check in with them, make sure things are okay, and that their doing fine."

REPRESENTATIVE EASTMAN cautioned Ms. Ryan to not overstate the case for the good things, as there will always be people that could not be reached in the world of finite services. He said that people do not have meaningless existences before they were found, and, if services need to be pared back, those lives will still have meaning.

REPRESENTATIVE TARR addressed the optional services through Medicaid, which included physical therapy, occupational therapy,

respite care, and speech, hearing, and language disorder services. She emphasized that these were not optional services for Key Campaign members, these were basic necessary services.

MS. RYAN expressed her agreement, but pointed out that Medicaid home and community based services were optional services. She added that these were approached differently in every state.

CHAIR SPOHNHOLZ expressed a better understanding for Medicaid waiver options which allow a reduction for the cost of services and ensure that there were services which allowed people to stay at home while typically costing substantially less than the in-facility services "that were once the norm."

REPRESENTATIVE SADDLER asked if Alaska was currently in a transitional period when there could be a service provider industry here in Alaska where people could make a living providing services.

CHAIR SPOHNHOLZ explained that this was an economy created by supporting the workers who provided these services.

MS. RYAN expressed her agreement that this was "a bridging period" although Alaska was not keeping up with a livable wage for people offering this direct support.

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ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 5:07 p.m.