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Health and Human Services Committee
February 05, 2015

[LB320 LB405 LB440]

The Committee on Health and Human Services met at 1:30 p.m. on Thursday, February 5, 2015, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB320, LB405, and LB440. Senators present: Kathy Campbell, Chairperson; Sara Howard, Vice Chairperson; Roy Baker; Tanya Cook; Sue Crawford; Mark Kolterman; and Merv Riepe. Senators absent: None.

SENATOR CAMPBELL: Good afternoon. I'd like to encourage you to find a chair. This afternoon we have three hearings for the Health and Human Services Committee. I'm Kathy Campbell. I serve the 25th Legislative District here in Lincoln and serve as the Chair of the Health and Human Services Committee. As is our practice, we'll start with introductions by the senators so I'll start to my far right. Senator, would you like to...

SENATOR KOLTERMAN: I'm Senator Mark Kolterman from Seward, Nebraska, representing the 24th District, Seward, Polk, and York County. I guess I should use this.

SENATOR BAKER: I'm Roy Baker, Senator from District 30, Gage County, part of southern Lancaster County.

SENATOR CRAWFORD: Good afternoon. Senator Sue Crawford from District 45, which is eastern Sarpy County, Bellevue, and Offutt.

JOSELYN LUEDTKE: Joselyn Luedtke, legal counsel.

SENATOR COOK: Senator Tanya Cook, District 13, which is Omaha and northeast Douglas County.

SENATOR RIEPE: Senator Merv Riepe. I'm from District 12, which is Ralston, Millard, and Omaha.

BRENNEN MILLER: I'm Brennen Miller, I'm clerk.

SENATOR CAMPBELL: We have one page today. Jay is with us. Jay is from Dalton, Nebraska, attends UNL in ag economics. And joining us is Senator Howard, District 9, the real midtown Omaha. (Laughter) See, you listen to it enough, you kind of...we are awfully glad you're here and thank you for coming. We'll go through a few procedures first before we start the first

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hearing. If you have a cell phone or something that makes noise, would you make sure that it's on silent or turned off? Handouts are not required in the committee, but if you have them, we would like 15 copies and we certainly can work with you if you need additional copies. If you'll be testifying today, we need you to complete one of the orange, bright orange sheets on either side of the room and print as legibly as you can for our recordkeeping. As you come forward, you can give your handouts and the orange sheet to the clerk, Brennen Miller, and then the page will distribute them to the senators for you. We use the light system in the Health and Human Services Committee. You'll have a green light and the total testimony is five minutes. It will stay green for four, it will be yellow for one, and then it goes to red. And that's when I try to get your attention. One other thing when you come forward and sit down to testify, please identify yourself, say your whole name, and spell it for us so that the transcribers can hear your spelling of the name as well as get accustomed to your voice. So with that, I think we'll start with our first hearing this afternoon. And I must say you're going to see the senators have iPads and computers. We're a pilot project here for committees. This was the brainchild of Brennen Miller, who is the clerk, and the idea is that we have everything that we need on our computers so we don't have those big black books that you used to see in front of the senators. Our first hearing this afternoon is Senator Bolz so we'll open the hearing on LB320, Senator Bolz's bill to adopt the Aging and Disability Resource Center Act. Welcome, Senator Bolz.

SENATOR BOLZ: Thank you. Good afternoon, Health and Human Services Committee. Glad to be with you today to talk about Aging and Disability Resource Centers. If you ask a professional in the field how to save money and better serve individuals who are aging or have disabilities, they will say improved coordination and better early planning. So this bill is a response not only to the input of experts but also to constituent input and to the work done by the aging task force this summer, of which Senators Cook and Campbell were members, and I appreciate their partnership in this effort. The task force reviewed public needs surveys, held a tele town hall, held a public hearing, and we heard a great need expressed for information and guidance in what can be an overwhelming set of decisions facing people who are aging with financial, physical, and other safety needs. According to AARP, Nebraska ranks 49th in the nation for providing Aging and Disability Resource Center types of services, services like information, referral, and consultation. And I would note for you that we also rank very low in the number of people accessing supports in the community before they reach a nursing facility level of care. So this strategy is a strategy to not only respond to constituent needs but also to change the way that our system works and to help more people access those lower level, lower cost services prior to entering a nursing facility level of care. And I do think that the Aging and Disability Resource Center model is a good model for trying to achieve these goals. It's a model that's being taken up nationwide and it was referenced in the Nebraska State Unit on Aging five-year plan as a strategy that they believe in as well. Let me tell you just briefly how an ADRC center works, how it serves individuals, and how it provides an improved systems change in this area. So first an ADRC provides coordinating functions for communities and individuals. The way that we've

put this bill together is that a set of stakeholders would come together in each of the Area Agency on Aging regions to craft a regional-specific plan that includes but is not limited to assistance with options counseling, transportation assistance, providing services as a liaison to public benefits access and other information and referral services. These functions are functions that can be better managed through the one front door approach of an Aging and Disability Resource Center. And I think this is a phrase that our friends at AARP have used before: It puts the human back into human services by providing that warm contact at the Aging and Disability Resource Center level. The services provided would be to a broad cross-section of individuals across the life span who have aging or disability-related needs. There would not be income requirements around the information and referral services, but there are requirements around the definition of someone who is disabled or in need of these services for some of the options counseling types of services. This model makes us stronger as a state because it brings together some somewhat siloed systems not only on the local level bringing together those resources, but by putting together that plan we also link up local resources with some of the state functions that we invest in as a state such as the area agencies on the aging and the statewide independent living centers. And we provide the oversight through the Department of Health and Human Services by allowing the Department of Health and Human Services to certify each plan and certify the providers of those plans so that we have that quality assurance. I am afraid that perhaps I've spoken too long in my introduction, so I will sum it up and I will say that I appreciate your consideration of what I consider to be a person-centered, whole-person-serving, silo-busting, better business model for serving this population. And I'm happy to take your questions. [LB320]

SENATOR CAMPBELL: Are there questions? Senator Crawford. [LB320]

SENATOR CRAWFORD: Thank you. And thank you, Senator Bolz, for your work on the task force and for bringing this proposal. So when I hear the word center, it makes me think about a space. So I just wonder if the idea, though, is instead this is actually a coordination that would probably already happen in existing spaces like a senior center or if it does mean a different space. [LB320]

SENATOR BOLZ: (Exhibits 1, 2) Well, that's a great question. And the answer, as I see it, is that that would probably vary a little bit region to region. You might be sharing physical space with a Area Agency on Aging or the statewide independent living center but, you know, probably maybe a better way to say it would be an aging and disability resource hub... [LB320]

SENATOR CRAWFORD: Okay. [LB320]

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SENATOR BOLZ: ...because it really is more of a conceptual approach that we're providing a network and an open front door. And that front door might look a little bit different region to region. [LB320]

SENATOR CRAWFORD: Thank you. [LB320]

SENATOR CAMPBELL: Other questions from the senators? Senator Riepe. [LB320]

SENATOR RIEPE: Thank you, Senator Campbell. Senator, thank you for coming. When I review this, you know, it's easy for me to embrace the need. I think it's a wonderful program. My challenge, my concern, always gets to be is the concern with what I consider substantial expansion of cost: a number of new employees, a number of new things. And with all of those...and I just say this in part so that as our testifiers come up they...I'd like to, if they can, help me work that through, because, you know, we constantly need for these offsetting things. We're talking about tax cuts. I'm not trying to lecture. I'm just...that's my concern, so. [LB320]

SENATOR BOLZ: And it's a great conversation for us to have. You know, I agree. We don't need additional layers of bureaucracy. And I think in the best practice model of an aging and disability resource hub, we would not be adding layers but we would be creating new efficiencies. So, for example, one of the functions that an Aging and Disability Resource Center could provide is something called mobility management which means that we're uniting the city and the county and the nonprofit and the other transportation services provided in a region and figuring out how to make that more efficient and to not duplicate routes or services. And so, you know, I think that there are potential savings here in terms of creating better efficiencies and making sure that we are directing individuals who need services to those community-based services and making sure that we have crisis prevention options to inhibit more costly crisis services. Additionally, I think that if we do this right, we will be keeping seniors out of higher-cost nursing facility levels of care. And if you think about a couple of statistics, you know, forgive me (laugh) but the...most seniors who enter a nursing facility level of care become Medicaid eligible in less than two years. So we're thinking about preventing that Medicaid eligibility or delaying that Medicaid eligibility. The average cost for someone who is in a nursing facility under Medicaid is \$89,000 a year. So the costs of an Aging and Disability Resource Center could be recouped by keeping a small number of individuals out of that more costly level of care if done right. And that's what I hope we achieve with this bill. [LB320]

SENATOR RIEPE: Thank you. [LB320]

SENATOR CAMPBELL: Other questions? Senator Kolterman. [LB320]

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SENATOR KOLTERMAN: Thank you, Senator Campbell. Welcome, Senator Bolz. Thank you for your bill. My question is along similar lines as Senator Riepe. As I look at the fiscal note, it's...is it all General Funds of the state of Nebraska or is there any matching funds that could come from the federal government along with this? [LB320]

SENATOR BOLZ: It's a very good question. So the framework of the fiscal note assumes some partnerships and some, you know, matching efforts, I suppose, on the local level. So you might be partnering with an Area Agency on Aging or you might have a Tabitha who is providing some of these assistance services. So I do think it's leveraging some of the things that are happening on the local level. There are federal grant funds available for Aging and Disability Resource Centers. And the President's most recent budget significantly increased the availability of those grant funds. So the answer to your question is, if we moved forward with this strategy, it's possible that we could qualify and access those federal funds. [LB320]

SENATOR KOLTERMAN: But at the present time, they're not included in the fiscal note that we have attached. Is that correct? [LB320]

SENATOR BOLZ: That's correct. [LB320]

SENATOR KOLTERMAN: All right. Thank you very much. [LB320]

SENATOR CAMPBELL: Any other questions? Senator Bolz, I have to tell you that I thought you ran one of the best organized interim studies I'd seen. [LB320]

SENATOR BOLZ: That's nice. [LB320]

SENATOR CAMPBELL: And I'm sure Senator Cook can concur. We had a lot of very thoughtful information given to us. So thank you for that. [LB320]

SENATOR BOLZ: Okay. Thanks. [LB320]

SENATOR CAMPBELL: Will you be staying to close? [LB320]

SENATOR BOLZ: I am going to do my best to be in two places at once this afternoon, so I hope to be back to close. If not, forgive me and follow up with me afterwards. [LB320]

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SENATOR CAMPBELL: Absolutely. All right. We'll go to our first proponent for LB320. Good afternoon. [LB320]

MARK INTERMILL: (Exhibit 3) Good afternoon, Senator Campbell and members of the Health and Human Services Committee. My name is Mark Intermill, M-a-r-k I-n-t-e-r-m-i-l-l. And I'm here today on behalf of AARP Nebraska. What's being circulated is my fourth attempt to draft a statement on this bill. The others kept growing and I figured that I would have a limited amount of time, so I tried to cut it down to the basics, which I wanted to try to address the questions of why do we need this? How will it work? How much will it cost? And is it worth it? In terms of "why do we need it" we've done a lot of member research. At AARP we conduct surveys regularly. And what we have found is when we have asked our members about their experience with long-term care, we find there's a lot of support for being able to continue to live in the community and that there is also some inability on the parts of caregivers, people who are caring for someone in the community, to be able to find the information that they need. One of the questions that we had asked in one of our surveys was...of caregivers was a list of things, including finding transportation and so forth. Which of the things are most needed? And information about resources and services were one. But also information about just being able to find the things that they need in order to continue in that caregiving responsibility. We know that there are about 60,000 Nebraskans who are living outside of an institution who have a self...independent living difficulty. And those are really the people that we ultimately want to serve through this process. I think Senator Bolz outlined how it will work. There will be Area Agencies on Aging that will set up plans of operation in their planning and service area. It will be done in conjunction with the independent living centers, some of the DD providers, all of the organizations that have an interest in making sure that people are able to live in the community. And I think that's one of the strengths of what we're trying to do here, is to bring all of the interests together. And as I say in my testimony, of the five words in the name Aging and Disability Resource Center, I think the most important is "and," because it's a conjunction. And that's what we're trying to do, is match people up, make sure that we're using resources effectively to deliver the services where they need to get to. In terms of the cost of the ADRC, I've taken a look at the fiscal note. And it's true, you need staff in order to make an ADRC work. And there are costs associated with staffing an ADRC. We've taken a look at the fiscal note. Prior to seeing it, I tried to identify what I thought the costs would be and it came up very similar to what we see in the fiscal note. It is just something that does require an expenditure of some funds. But I think the critical point is, are the benefits worth the cost? And I think that we have seen experience in the state of Nebraska with home- and community-based services, that the taxpayers of Nebraska have been well served by initiatives to try to implement and improve access to community-based services and supports. I did attach a chart to my statement that tracks the history of Medicaid spending for services for persons over the age of 65. The table is in...you'll see it's in three sections. The first section is prior to any type of home- and community-based intervention. And what we saw during that period was remarkable growth in

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Medicare...Medicaid spending for people over 65: 13.7 percent average annual growth. The middle part is where we introduced the care management program, began the home- and community-based services waiver on the limited scale. And during that process, we reduced average annual growth to 6.4 percent. And then in 2000, we expanded the Medicaid waiver. We incurred some significant increased cost the first two years as we did the waiver and were still operating sort of the same numbers of services. But since then, you'll see...I think the average has been about 0.5 percent or, including those two years, 2.2 percent overall. I think what this points out is that we can, through improved access to home- and community-based services, improving the methods by which we provide services, we can realize savings that will make this an effective and efficient operation of services. [LB320]

SENATOR CAMPBELL: Thank you, Mr. Intermill. Questions from the Senators? A lot of good information. [LB320]

MARK INTERMILL: Thank you. [LB320]

SENATOR CAMPBELL: Senator Riepe. [LB320]

SENATOR RIEPE: I have a question or maybe it's a comment, and then I'd ask you to respond. A number of years ago when Ronald Reagan was President, a bill was passed for long-term care insurance, very strongly supported probably by the AARP and seniors as such. But then they found out that they were asked to pay for it and it immediately...the demand and expectation went away and the bill failed. I'm a real believer that people have to have some skin in the game so that they're spending their money as well as the government's. So, you know, what would preclude...what would be the role for participation from the recipients in this kind of a program? [LB320]

MARK INTERMILL: For...I'll go back to yesterday's hearing on the personal needs allowance. In the case of a person who goes into a nursing home, they...and has Medicaid coverage for that care, they essentially pay their entire income to the nursing home with the exception of the personal needs allowance. For in-home services that these...that probably would be affected, most of the people who received those services would be affected most by the Aging and Disability Resource Center, generally those are paid directly by the recipient of the service. So those were private-pay services. What the Aging and Disability Resource Center can do is to help identify services that are cost effective for those individuals to help them stay at home which will extend their ability to pay privately for a longer period of time, help preserve assets, so that they're able to pay out of pocket for those services before having to possibly turn to Medicaid for that coverage. So I think there is a lot of skin in the game in the long-term care arena on the part of the people who receive the services. What we're trying to do here is to help

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them preserve that as much as possible by just providing some information, some counseling about what's available and what might be the best option for their particular situation. [LB320]

SENATOR RIEPE: Okay. Thank you. I appreciate your response. [LB320]

SENATOR CAMPBELL: Any other questions? Thank you, Mr. Intermill. [LB320]

MARK INTERMILL: Thanks. [LB320]

SENATOR CAMPBELL: I believe our next proponent is Mr. Vincent--I'm not going to say this right, I know I'm not--Litwinowicz. And Jay had agreed to provide some assistance at your request. [LB320]

VINCENT LITWINOWICZ: Oh, I'm good. [LB320]

SENATOR CAMPBELL: I think we will have to have you identify and spell your name. [LB320]

VINCENT LITWINOWICZ: Oh, okay. [LB320]

SENATOR CAMPBELL: The transcribers will not get it right from me. [LB320]

VINCENT LITWINOWICZ: Oh, absolutely, not with such "Polishness." Yeah, It's Vincent, V-i-n-c-e-n-t, and then L-i-t-w-i-n-o-w-i-c-z. [LB320]

SENATOR CAMPBELL: Thank you. [LB320]

VINCENT LITWINOWICZ: (Exhibit 4) And I thank you for letting me speak. And I want to particularly start out how...mentioning how essential this bill is. As it is right now, only half of it is in place at the aging center. When you...I have this personal example of a friend I have who has congenital cerebral palsy. I acted like a resource center to her just recently with services that she had, for example, in this case being the grocery store trips that she was entitled to. And she didn't use some of them during the summer, so they canceled them on her. And, you know, she's wonderfully hardheaded, but she wasn't so demonstrative enough to stick up for herself in this particular case and demand that she get them back. So I helped her...and along with chore work. And these are services she's entitled to. She recently got her college degree and is trying to get a job for the first time in her life. But there are difficulties with that. And it would be nice...so

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I...what I performed for her recently, one of these aging and disabilities centers could have, you know, stood up. If they...I don't know what kind of role they would actually play during this process, but they could...you know, she could have talked to them and gotten advice and maybe they could have acted on her behalf to have this done sooner. And she also...you know, these centers have computers as well which is nice for people to use, because this person I'm talking about that I consider a sibling, she got a new computer for Christmas. And her hand shakes. So she pushed a button. And it got a...it's got a spyware or virus now. She hasn't been able to use it for a couple weeks. And so, you know, computers are at these centers as well, and...because when you go to the library, it's interesting, because if you have a disability you have a time limit and you have all this nonsense of getting there. And so that could be something else. I'm just kind of anecdotally picking out certain things. I'm having a cognitive moment this morning, so...but basically, these resource centers could have provided her the help that I ended up giving her. And I don't know why it went on so long without even me knowing. But that's the things that happens with people in disability, they get isolated and so forth. And so it's really important that we have something like this. And as it is, you know, the financial footprint, whatever it is, you know, it's only half done. And we don't want to be 49th in anything, do we? So I think if we support this, I think it's going to actually...I know the people it's going to help. I know the people it's going to help. Thank you. [LB320]

SENATOR CAMPBELL: Thank you for your testimony today, and we'll have you stay for just a minute. [LB320]

VINCENT LITWINOWICZ: Yeah. [LB320]

SENATOR CAMPBELL: Are there any questions from the senators? Okay. [LB320]

VINCENT LITWINOWICZ: Thanks for listening to me. [LB320]

SENATOR CAMPBELL: So, did your friend get the computer taken care of? [LB320]

VINCENT LITWINOWICZ: It's still working on...there's another person who has...he has CP too. She's been trying to just physically get over there so that's a...but it's being worked on, yeah. [LB320]

SENATOR CAMPBELL: Excellent. Thank you for helping her. [LB320]

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VINCENT LITWINOWICZ: Yeah, well, this will be great. This will be something...you know, I'd be happy to do it anytime. But we could have this for all...how many more people are out there like this that have gone through this period, you know? So thank you. [LB320]

SENATOR CAMPBELL: Thank you for your testimony. [LB320]

VINCENT LITWINOWICZ: All right, thanks, Senators. [LB320]

SENATOR CAMPBELL: Our next proponent? [LB320]

JUNE PEDERSON: (Exhibit 5) Good afternoon, Senator Campbell. Members of the committee, my name is June Pederson, J-u-n-e P-e-d-e-r-s-o-n. I am the director of Aging Partners which is an area agency with headquarters in Lancaster County. But we serve Seward and York and Polk and Butler and a total of eight. I'm one of eight area agencies in the state of Nebraska. And I did bring testimony and I would like to respond at the end to the previous speaker's concerns. I asked my staff, who manage our information and referral system, to give me some samples of questions they'd had. They brought me in a raft of papers saying, this was just today. And from that I picked just a few to share with you. There was a daughter who called. Her father lives in an independent living facility and is diabetic. He has a pacemaker and prostate issues. He uses a walker but he's falling down often and can't get up by himself. What services would be available if he moved to an assisted living? What would it cost? And what would we do if he runs out of money? A daughter called. Mom is living in her own home, has COPD, arthritis, and it's hard for her to get around. She's beginning to need help with chores and errands and she doesn't have a power of attorney. What can we do to help? There was a referral by a veterans service officer. A couple lives in an assisted living facility. He has Parkinson's and she is experiencing dementia. Cost for the assisted living for two of them is now \$4,700 a month. Together, they have \$2,000 in Social Security and no savings left. They have paid for burial services for both. What are their alternatives now? We had a call that day from the Attorney General's office here in the capitol. A 60-year-old grandmother caring for a 10-year-old grandson who was born to a crack-addicted mother...the child is in special ed receiving services. The grandmother adopted this child and all assistance went away, so he's no longer eligible and she's struggling to cover those expenses. What could be done? We had a walk-in to the office. He was referred by the People's Health Center doctor. He's a male, age 61, who needed help with housing. And we had a male, 88, who called regarding having a will made. Conversation determined that he had adequate income and we sent him a list of private attorneys. Those are the types of questions and many, many more that we get every day. LB320 creates a system through which questions like that and so much more can be answered by people with experience and qualifications. Area agencies are doing this now with those questions about aging issues. Centers for independent living and the League of Human Dignity are responding to questions about disabilities for persons under age 60. But isn't

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a question about housing for a 40-year-old in a wheelchair similar to housing for a 65-year-old in a wheelchair? Couldn't that be answered by the same "respondee?" An ADRC is available 24 hours a day through a designated Web site. And assistance from a live individual would be available during working hours. When I've been asked to explain, what is an ADRC, I've offered this based on the language in the bill: At Aging Partners headquarters, there is an office with phones, computers, and printers staffed by persons experienced in answering questions like those I mentioned at the beginning. They've been trained and are familiar with resources to answer questions about issues that would cover the life span. There may be a young mother calling about an infant just diagnosed with a hearing loss or a parent of a teenager injured in an auto accident who will have special needs the rest of their lives. It may be a family member or a spouse of an older person whose care needs have gotten beyond their ability to manage. The expert taking the call has resources at their fingertips through their computers, contacts with materials on their desks, and access to staff at independent living centers, educational institutions, healthcare contacts, legal resources, as well as government contracts. If there seems to be likely eligibility for programs like SNAP, which are food stamps, or Medicaid, those applications can be reviewed and assistance given. The ADRC staff member takes the information from the caller, entering it in what is a standard form on their computer and can be forwarded to a partner agency if that's an appropriate thing to do. It references...the bill references options counseling and I've described that in my testimony. You can read that. Nebraska's aging...Area Agencies on Aging are ready and willing to become ADRC sites. We have experience working with information and referral, providing assistance, and collaborating with partner agencies to create a system that will benefit Nebraskans of all ages and needs. We urge you to advance the bill. Thank you. [LB320]

SENATOR CAMPBELL: Questions for Ms. Pederson? Senator Kolterman. [LB320]

SENATOR KOLTERMAN: I just have a comment. Welcome. Thank you for your testimony. [LB320]

JUNE PEDERSON: Thank you. [LB320]

SENATOR KOLTERMAN: We, in Seward, have utilized your services a lot. You do a wonderful job, and I'd like to thank you for what you do. [LB320]

JUNE PEDERSON: Thank you very much. [LB320]

SENATOR KOLTERMAN: Yes. [LB320]

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JUNE PEDERSON: That pleases me. [LB320]

SENATOR CAMPBELL: Other questions or comments from senators? Senator Riepe. [LB320]

SENATOR RIEPE: I have a quick question. Senator Campbell, thank you. Is your organization...are you a 501(c)(3)? [LB320]

JUNE PEDERSON: No, we are a... [LB320]

SENATOR RIEPE: Okay. You're a state agency? [LB320]

JUNE PEDERSON: We are a quasi-governmental agency. [LB320]

SENATOR RIEPE: Okay. [LB320]

JUNE PEDERSON: We receive money from the Older Americans Act, from the state through CASA, the Community Aging Services Act and care management funding. We also receive money from each of our counties which are required by law to support us with our administrative costs. And a significant amount of what we receive to manage our programs comes from those who receive those services. [LB320]

SENATOR RIEPE: Is that kind of based on population, like they pay on maybe a per head capitation kind of a basis? [LB320]

JUNE PEDERSON: Are you referring to... [LB320]

SENATOR RIEPE: The counties. [LB320]

JUNE PEDERSON: Counties? Yes. Yes. [LB320]

SENATOR RIEPE: Okay. Have they consistently increased that fee ever or do they...is it kind of locked into a 1992 something or whatever? [LB320]

JUNE PEDERSON: I became director in 2003. I asked all of our counties for a 10 percent increase that year and they gave it to me. And I've asked them for 10 to 12 percent increase every year since 2003, and they've done so. It's to their advantage to have people stay in their county,

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live in their own homes and pay property taxes and buy groceries and be part of the community. They understand the value of what we bring to them. [LB320]

SENATOR RIEPE: They also have some legal obligations, or... [LB320]

JUNE PEDERSON: They do. They do. But they wouldn't have had to say yes. And I'm pleased that they did. [LB320]

SENATOR RIEPE: That's a good point. Thank you. [LB320]

JUNE PEDERSON: Thank you. [LB320]

SENATOR RIEPE: Thank you very much. [LB320]

SENATOR CAMPBELL: Any other questions? Thank you, Ms. Pederson. [LB320]

JUNE PEDERSON: Thank you. [LB320]

SENATOR CAMPBELL: Our next proponent? [LB320]

LINDA BLACK: (Exhibit 6) Good afternoon, Senator Campbell and members of the Health and Human Services Committee. For the record, my name is Linda Black, L-i-n-d-a B-l-a-c-k. And I'm here representing my family and also the Nebraska chapter of the National Multiple Sclerosis Society. And we're testifying, as you know, in support. Multiple sclerosis, or MS, is an unpredictable, often disabling, disease of the central nervous system. It interrupts the flow of information within the brain and between the brain and the body. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. One of the most unique aspects of MS is that the progress, severity, and specific symptoms are unpredictable and vary from one person to another. Most people with MS are diagnosed between the ages of 20 and 50. This leads to another unique quality of MS that, once diagnosed, the unpredictable physical and emotional effects are lifelong. Approximately 20 percent to 25 percent of individuals with MS will need long-term services and supports, and approximately 5 to 10 percent will require residential care. My mom falls into that 5 to 10 percent. After my mom was diagnosed with MS, she went from a vibrant mom who was involved in all aspects of her kids' lives, a busy farm wife, and one who moved and vacuumed behind furniture weekly, to a cane, a walker, a wheelchair, and eventually to having to be physically assisted to get into the wheelchair, all within 18 months. My little brother was 9. My mom was 45. As she rapidly declined physically, my dad did everything he could to see that she was cared for and safe while trying to maintain a

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livelihood farming and raising a 9-year-old. Reluctantly, he accepted help from family, neighbors, a neighborhood nurse, and eventually a kindhearted woman named Gloria who came out to the farm and cared for mom during the day. Dad would go from farm work during the day to caregiver at night, get up, and do it all over again. On weekends and when Gloria couldn't be there, we helped dad as kids, but he always assumed the main responsibility for her care and hated asking for help. The physical and emotional toll was dramatic not only on dad but on mom, because she felt like a burden despite all of our attempts to reassure her. And then there's that 9-year-old boy that never knew the independent mom that the rest of us did. LB320 includes a number of services and support options that would have immensely helped my family. The availability of a center that includes comprehensive information on long-term care programs, financing, and service providers could have given us ideas for better methods and avenues of care. The provisions that assist accessing and applying for public benefit programs would have given us help to better assess what was available to help with the cost of caring for her at home. Personal counseling would have not only helped mom cope with her disease, but help us as a family better support her. It eventually became painfully apparent that we were going to have to do something differently to properly care for mom as the extent of her needs went beyond what we could do for her at home. She is now in a skilled nursing facility and has been there for 23 years. She has thrived quite well and maintains the best attitude of anyone I know. We are blessed that she has and continues to receive excellent care. And we just celebrated her 81st birthday. Although access to a disability center would probably not have changed her eventual outcome, it would have given us the support and resources we needed to make ongoing decisions with her and for her as we were transitioning from diagnosis to care in the home and eventually making the decision to place in her a skilled nursing facility. I also believe it's important for these sources to be consistent and accountable for the information they provide. Unfortunately, there are some who would take advantage of families who are desperate to find help for their loved ones. On behalf of my family, I would like to thank Senator Bolz for recognizing the need for this, for all the work that has been done to get to this point, and would like to thank the committee for their careful consideration of LB320. [LB320]

SENATOR CAMPBELL: Thank you very much, Ms. Black. Questions or comments from the senators? Senator Riepe. [LB320]

SENATOR RIEPE: Thank you, Senator Campbell. I guess, just as a comment so that we don't always appear to be insensitive or heartless, my late wife had multiple sclerosis and succumbed after 17 years. And for your Gloria, we had our Peggy. And so I clearly can understand the challenges of your father and trying to...the challenges that go along with it, the ramifications, if you will. But I thank you for being here today. [LB320]

LINDA BLACK: Thank you, appreciate it. [LB320]

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SENATOR CAMPBELL: Other questions or comments? We always appreciate people who come forward with personal stories. Thank you. [LB320]

LINDA BLACK: Thank you. [LB320]

SENATOR CAMPBELL: Our next proponent? [LB320]

JULIE KAMINSKI: (Exhibit 7) Hi. My name is Julie Kaminski, J-u-l-i-e, Kaminski, K-a-m-i-n-s-k-i. And I'm with LeadingAge Nebraska. We represent the nonprofit providers of senior housing and services, the whole continuum. And we're here to support this bill. And really, what I see this doing is strengthening the ADRCs. You know, I get together with my counterparts throughout the United States. And when I'm in meetings and hear how robust they can be and what a hub of information it really can be to others, I think that's what's exciting about this bill. And pieces that I really think will help strengthen that that are key and essential are to streamline information, a single point of entry. As June mentioned, having the Area Agencies on Aging that are already so familiar with a lot of these pieces act as kind of the coordinator and collaborator are essential. We encourage uniform assessments and, to do that, the personal counseling because, as you know, everybody's story is unique. I kind of feel like I'm a mini ADRC oftentimes, because I get calls weekly to say, hey, we're not sure what to do with mom or with dad and, you know, we're happy to disseminate and help connect those. But that's the need we have in this state is to find a hub where, if people are struggling, whether they're in Scottsbluff or Omaha or Lincoln, they've got somewhere to tap into to figure out where to network out and connect them. So we also support a public relations campaign. If we create this and don't get the word out, we're not doing anybody any good. So it's going to be essential to link to the communities to make sure we get the word out once we have this hub created to make it robust and really very useful. So thank you for taking the time to listen to me. And there's more thoughts in here. I just abbreviated it in time. [LB320]

SENATOR CAMPBELL: Thank you. We always appreciate the abbreviation. (Laughter) Questions for Ms. Kaminski? Thanks for your testimony today. Oh, sorry, Senator Crawford. I didn't see your hand. [LB320]

SENATOR CRAWFORD: Thank you. I just noticed in the testimony it talks about strengthening our Aging and Disability Resource Centers. With that word...so I just wanted to clarify, so does this already exist? [LB320]

JULIE KAMINSKI: We do have a component. It's just...it's a very fragmented system as it is right now. So this is a strengthening of that hub of information. And as opposed to being fractured, unifying and collaborating with various forces. [LB320]

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SENATOR CRAWFORD: But some kind of regional hub? [LB320]

JULIE KAMINSKI: Yes. [LB320]

SENATOR CRAWFORD: Basic structure is there. And this is what we would need to really invest in it? [LB320]

JULIE KAMINSKI: Yeah, and there's fragments, I think, of information. It's just not all in that single point of entry. [LB320]

SENATOR CRAWFORD: Thank you. [LB320]

SENATOR CAMPBELL: Thank you very much. Our next proponent? Good afternoon. [LB320]

LARRY FRITZ: Good afternoon, Senator Campbell and the committee. My name is Larry Fritz, L-a-r-r-y F-r-i-t-z. I'm here to speak in favor of the bill. I'm basically going to relate to some personal stories that involve my family. My mother was able to live in her home from...into her 90s, in part because of the services that we were able to identify ultimately by the Blue Rivers Agency. One of the things that I wanted to note, though, is that we probably could have been a little better served if some of the things would have been...we would have been aware of them earlier. I remember I was down at my mom's house one day and she says, we ought to take a look at this folder up on my desk. I don't know what it's about. Some woman was here and she dropped it by. And I look into the folder and that's when I got introduced to the Blue Rivers Agency and it had a contact number. And we were able then to arrange for some relatively minor services, somebody to come in and help her with her bath, come by...somebody to come in and clean her house. And she was past 90 before we ultimately had to move her into assisted living and now in a nursing home. And, you know, there's information available on the computer. And one thing I want to kind of note is that when you talk about aged people, computers don't get the information to them. It's not a skill that they ever had and that's just not a skill that they can use. I also have a brother. My brother is much...is quite a bit younger than me. He's on disability. He has epilepsy. He has some mental problems. He was able to keep down a job at the...cleaning the local post office until a few years ago. But at this point, his physical coordination and so is such that he's no longer being able to work. I find, though, that now, it's a whole new thing. I don't know what services are available and how to plan because he's 57. He doesn't qualify as an aged person. But to a large extent, he's as much...in as much need of the services at 57 as my mom was in her late 80s. And he...right now he's in a remission. He can more or less get around. But he's...you know, there's times when...I guess, one of the things...he's recently been diagnosed with Parkinson's as well. And so right now he's able to get around. But he has these periodic episodes where he can't even really walk with a walker because he loses control of his left side.

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He's still living in his own home. We're trying to get some ad hoc help to help him clean his house. But again, like I said, we have...you know, what scares us, we don't know where to go in the future because we never know when another episode might occur, he'll be unable to live by himself, and so forth, so anything to coordinate the information on what resource is available would be greatly appreciated. So thank you. [LB320]

SENATOR CAMPBELL: Thank you very much, Mr. Fritz, and for your story about your mother and brother. That's helpful. Questions or comments from the senators? Thank you very much. Anyone else who is in a proponent? Okay. Good afternoon. [LB320]

LYNN REDDING: (Exhibit 8) Good afternoon, Senator Campbell and members of the Health and Human Services Committee. My name is Lynn, L-y-n-n, Redding, R-e-d-d-i-n-g. I am here today to testify in support of LB320. As a person with a disability, I can tell you about numerous issues with trying to identify and access different systems available to me through DHHS. My service coordinator had some information but not everything I needed. There were others who helped me find this information, but the process took weeks, days, and sometimes months before I had the correct information and could access those services. LB320 would provide a one-stop shop for people with disabilities and/or family members and those who are aging to access information and the services and supports available to them. Given the difficulty of the systems that serve and support people with disabilities, many individuals and families may not be aware of disability services, supports, and/or programs let alone how to access them. LB320 would provide valuable information, resources, and assistance to Nebraskans with disabilities in order to secure services and supports needed for their short-term and long-term care. Also, many people with disabilities have issues with communication. Simply assuming that a phone call or using the Internet will solve all problems is shortsighted. By offering face-to-face support, the state can assist citizens with communication difficulties and address the problems with ACCESSNebraska. Again, this bill can help to improve the in-person support for individuals with disabilities and those who are aging who are applying for Medicaid and other state programs. Again, I support LB320 and the creation of the ADRCs for the state of Nebraska and its citizens and encourage you to move it to General File. Thank you. [LB320]

SENATOR CAMPBELL: Thank you, Ms. Redding. Questions? Senator Crawford. [LB320]

SENATOR CRAWFORD: Thank you. And thank you, Ms. Redding, for being here again. I just wondered if you could help us understand the shortcomings that you had with your service coordinator to better understand what this would add. So, you know, you said your service coordinator gave you some information. Was...were those meetings with him or her in person, your service coordinator? [LB320]

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LYNN REDDING: They were in person, yes. But he didn't have all the knowledge that...I got connected through a group of awesome advocates. [LB320]

SENATOR CRAWFORD: Okay. [LB320]

LYNN REDDING: So that's how I came up with what I...like, I had no clue that I would qualify for food stamps. I had no clue that I would qualify for certain aspects without going through The Arc and several other organizations. [LB320]

SENATOR CRAWFORD: Okay. So your service coordinator only told you about services tied to... [LB320]

LYNN REDDING: That he thought that I would qualify for. [LB320]

SENATOR CRAWFORD: Okay. [LB320]

LYNN REDDING: Well, there was a lot more that I qualify for that I did not know that I qualified for. [LB320]

SENATOR CRAWFORD: From your service coordinator? [LB320]

LYNN REDDING: Um-hum. [LB320]

SENATOR CRAWFORD: All right. Thank you. [LB320]

LYNN REDDING: And they kind of need a little more education. [LB320]

SENATOR CRAWFORD: Okay. Thank you. [LB320]

SENATOR CAMPBELL: Any other questions? Ms. Redding...oh. [LB320]

LYNN REDDING: And it's...the most important thing is the in-person. [LB320]

SENATOR CAMPBELL: I think we got that one. (Laughter) Ms. Redding, should I reserve a spot for you tomorrow? You've been here two days in a row now. [LB320]

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LYNN REDDING: (Laugh) Probably. [LB320]

SENATOR CAMPBELL: Okay. You're always welcome. Our next proponent? Good... [LB320]

KATHY HOELL: (Exhibit 9) Good afternoon, Senator Campbell and other senators of the Health and Human Services Committee. My name is Kathy, K-a-t-h-y, Hoell, H-o-e-l-l. First of all, as a person with a disability, I'm going to ask you not...to come talk...accommodate my speech by not using the lights. [LB320]

SENATOR CAMPBELL: We can do that. [LB320]

KATHY HOELL: And it's requested under the provisions identified under Americans with Disabilities Act. I am the executive director of the Nebraska Statewide Independent Living Council which was created under the Rehab Act. And members of our council...majority of the voting members of our council are all people with disabilities from all over the state. I'll...first of all, I agree with what all of the proponents have said. So I've given you my prepared testimony but I'm going off the cuff here. First of all, Senator Crawford, to address your concern about the ADRC, the state has received money from the federal government. It went to DHHS. They created what they call an ADRC. It's very sad. It is not robust at all. It's very fragmented. The only way you can access it is via the Internet or sometimes the phone. For people with disabilities this is an issue, because people with disabilities are...usually are going to be...21 percent of our population is going to be on the low side of the poverty level versus it's like 12 percent on the aging side. And a lot of this is due to the fact that disability is expensive. We have to buy wheelchairs. We have to buy other assistive technology that costs money. And even though there are services out there, there's still the share of costs that people have to put forth. So we really need to have a very robust system that is providing services for people whether they're aging or they are people with disabilities. This legislation has got some really good pieces to it. And I've gone to a number of national conferences, talked to other people about their aged and disabled resource center, because I think now every state has got some form of it. And ours is so sad compared to what other people have. But in response to Senator Riepe's question about cost, I realize this has got a high fiscal note. However, for people with disabilities, it's totally different if we end up in a nursing home or institution, because the cost to provide for us is different than what it costs for the aging population. And the National Council on Disability which are the advisors to Congress, the Senate, and the President, have estimated in Nebraska that the cost for institutionalizing a person with a disability is \$221,000 a year. And it is approximately \$45,000 a year for people to stay in their own home and to have the proper support. To me, that is a no-brainer, because the state is paying a very large share of what it costs to have people institutionalized. They save money by having people in their own homes and communities. People are happier in their own homes and communities. They have a better quality of life. I

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really hope that you will move LB320 on to General File and if I can answer any questions, I'd be glad. [LB320]

SENATOR CAMPBELL: Thank you, Ms. Hoell. Questions? Oh, sorry. Senator Kolterman. [LB320]

SENATOR KOLTERMAN: Yeah, I just have...and bear with me, because I'm new at this. [LB320]

KATHY HOELL: All right. [LB320]

SENATOR KOLTERMAN: Kathy, the...it's Kathy, correct? [LB320]

KATHY HOELL: Correct. [LB320]

SENATOR KOLTERMAN: You talked about the program that was developed that's worthless... [LB320]

KATHY HOELL: Correct. [LB320]

SENATOR KOLTERMAN: ...kind of in your own words. I followed that. [LB320]

KATHY HOELL: That about describes it... [LB320]

SENATOR KOLTERMAN: Okay. [LB320]

KATHY HOELL: ...because they forgot the D in it. They don't adequately address disability at all. [LB320]

SENATOR KOLTERMAN: Okay. And what was the name of that organization again, because I...is it in your testimony here? [LB320]

KATHY HOELL: It's the ADRC that was developed by DHHS. [LB320]

SENATOR KOLTERMAN: Okay. [LB320]

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KATHY HOELL: It's a...was state developed. [LB320]

SENATOR KOLTERMAN: Do you know--and I'm not trying to put you on the spot--do you know what kind of money was allocated to that? [LB320]

KATHY HOELL: That I have no...I do not know what the federal grant was. [LB320]

SENATOR KOLTERMAN: Okay. But it's just not facilitating the need? [LB320]

KATHY HOELL: They...like I said, they tried to do it primarily on the Internet. And that's been said. The Internet doesn't always work for people with disabilities. And the fact that we are likely to live right at the...impoverished, it is really difficult to find excess discretionary funding to be able to get the Internet, to have the physical skills to be able to access the Internet without downloading a virus or spyware or some of those other issues. [LB320]

SENATOR KOLTERMAN: I could ask a lot of questions. I'm going to spare you that at this time. [LB320]

KATHY HOELL: Well, yeah, you're... [LB320]

SENATOR KOLTERMAN: But I'm interested in learning more about...one of my concerns is that we throw a lot of money at programs and some of them are good and some of them are not good. I concur with you. It makes a lot of sense to keep people in their homes if we can do that. And I assume you're still in your home? [LB320]

KATHY HOELL: I...oh, yes. I'm still in my home. [LB320]

SENATOR KOLTERMAN: Good. [LB320]

KATHY HOELL: You're never going to get me out of it. (Laughter) [LB320]

SENATOR KOLTERMAN: Good for you. And thank you for your testimony. And I'm going to look into that a little bit and find out more about it. [LB320]

KATHY HOELL: And the thing is, if we had a robust ADRC that was actually meeting the needs of the people in the state, creating that hub that everybody talked about, we wouldn't...you

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wouldn't be seeing this legislation. But we depended on DHHS and they did it in isolation pretty much. And that doesn't work. [LB320]

SENATOR KOLTERMAN: All right. Thank you very much. [LB320]

SENATOR CAMPBELL: Ms. Hoell, do you remember what year they would have gotten that grant and started that program? I see a lot of people kind of going, hmm. [LB320]

KATHY HOELL: Mark, do you remember? [LB320]

SENATOR CAMPBELL: You're going to cover that? Okay. We have a testifier that is going to cover that. [LB320]

KATHY HOELL: Okay. Yeah, it's been a few years. [LB320]

SENATOR CAMPBELL: I would guess so. [LB320]

KATHY HOELL: But they...it hasn't worked, because you've got to have people that need the services at the table helping to design the program. [LB320]

SENATOR CAMPBELL: Exactly. You know, Ms. Hoell, I really appreciate you covering the answer to Senator Crawford's question, because if I hadn't gotten that...an answer, I would have asked Mr. Intermill to come up, because I know that we discussed this issue quite a bit on the Aging Task Force, that we had one but we get rated down because it's not very adequate. I know that. [LB320]

KATHY HOELL: Yeah, and I tend to be more on the vocal side than most people. (Laughter) I've actually contacted people on...from the aging department at the Administration on Community Living about the fact that Nebraska's...they totally missed the D in the ADRC. And that is a real shame, because there are a number of people with disabilities out there who could have used the help, because I'll tell you, when Lynn was talking about her resources that helped her find her services, and Julie Stahla, who is a friend of mine and a board member of The Arc, was one of those people. I helped Lynn and Brad Meurrens from Disability Rights, Mike Chittenden. We've all been there, because we all know what is available but we can't answer that question for everybody in the state. [LB320]

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SENATOR CAMPBELL: Right. Right. Ms. Hoell, you are a frequent testifier here. You're always welcome and thank you very much for the thoroughness today. [LB320]

KATHY HOELL: Thank you for your time. I appreciate it. [LB320]

SENATOR CAMPBELL: Our next proponent? Could I show...have a show of hands if there are any other proponents? Okay. One other back there? Two others? Okay. Would you move forward so that we're kind of ready to go? Thanks. Good afternoon. [LB320]

MICHAEL CHITTENDEN: (Exhibits 10, 11) Good afternoon, Senator Campbell. Members of the Health and Human Services Committee. My name is Michael, M-i-c-h-a-e-l, Chittenden, C-h-i-t-t-e-n-d-e-n. I'm the executive director for the Arc of Nebraska. Before I get into my testimony, I'll delve in a little bit into the...some of the questions that were previously asked. I will be submitting a report to go along with my testimony, but I need it to answer your questions. It looks like it was back in 2009 and 2010 when there was a grant that was given to the state for approximately \$500,000 for creating the ADRC through the Affordable Care Act. And then DHHS chose not to participate in additional funding in 2012. I can't answer the question as to why they did...chose not to participate. I just know that. And the report will outline a lot more information for you. Unfortunately, I cannot speak to it as an expert, because it was done before I took over as the executive director. [LB320]

SENATOR CAMPBELL: Okay. [LB320]

MICHAEL CHITTENDEN: It was done in 2013, so... [LB320]

SENATOR CAMPBELL: Okay, so we'll hold our questions until we have a chance to see the full report. [LB320]

MICHAEL CHITTENDEN: Sounds great. Thank you. [LB320]

SENATOR CAMPBELL: Okay. [LB320]

MICHAEL CHITTENDEN: The Arc of Nebraska supports the advancement of LB320 to adopt Aging and Disability Resource Centers Act in the state of Nebraska. In 2013, through a grant provided by the Developmental Disabilities Council of Nebraska, the Arc of Nebraska surveyed families about the supports and services offered in the state. And I will be submitting the copy of that report. Families in Nebraska with children who have disabilities struggle to meet the needs of all their children. The family is the core social unit of our society. And helping maintain

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strong families is beneficial to everybody in the state. Nebraska has a number of programs to support families and children with disabilities, however, strict income limitations, narrowly defined eligibility requirements, and a confusing application process make accessing these programs difficult. Many respondents to the survey commented that they were unaware of what was available. Families criticized the state for a lack of outreach activities that would increase the awareness of the programs that existed. Strengthening and expanding the ADRCs could help families find the information needed. ADRCs are a collaborative program with the U.S. Administration on Community Living, Centers for Medicare and Medicaid Services. The intent of the program is to create a single point of contact for information about services and the supports of the aged and the disabled. As the state moves forward in developing this ADRC program, considerations need to be given for the needs of the people who require assistance. Respondents made it very clear through their comments that what is needed is personal contact with people who know what is available and can help them access those supports. The advisory committee and work groups that surrounded this survey met after the completion of the survey and their first and foremost recommendation was, strengthen the current ADRC systems and programs that are within Nebraska. The Arc of Nebraska encourages you to move LB320 to General File, and we appreciate Senator Bolz's action in bringing this to our...to the floor. We thank you for your consideration. [LB320]

SENATOR CAMPBELL: Mr. Chittenden, we will take a look at the report, and if we have additional questions, we'll follow up with you. [LB320]

MICHAEL CHITTENDEN: Absolutely. [LB320]

SENATOR CAMPBELL: But it's really helpful to know...the first \$500,000 came through the ACA as a grant? [LB320]

MICHAEL CHITTENDEN: Yes. [LB320]

SENATOR CAMPBELL: And then we did not reapply? I want to make sure we're very clear. [LB320]

MICHAEL CHITTENDEN: It would look that way. That's the way I'm reading it in here. We didn't...they...that the Department of Health and Human Services reported that Nebraska chose not to participate in a 2012 funding opportunity. [LB320]

SENATOR CAMPBELL: Okay. And Senator Bolz... [LB320]

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MICHAEL CHITTENDEN: And there's a citation that goes along with that, so... [LB320]

SENATOR CAMPBELL: And Senator Bolz has a copy of this report? [LB320]

MICHAEL CHITTENDEN: She will if she doesn't already. (Laughter) I will make sure she gets one. [LB320]

SENATOR CAMPBELL: Okay. And Senator Bolz is back. Good, because at that point, Senator Bolz, most likely we would appreciate if your office could follow up and find out exactly what happened there and... [LB320]

MICHAEL CHITTENDEN: I will make sure she gets one of those before the end of the day. [LB320]

SENATOR CAMPBELL: All right. Thank you very much. And I hope you had a successful dinner last night. Some of us couldn't... [LB320]

MICHAEL CHITTENDEN: It was wonderful. It was great seeing so many of the faces around this table. [LB320]

SENATOR CAMPBELL: Good. [LB320]

MICHAEL CHITTENDEN: I thank you...we thank you for your participation as always, Senators. [LB320]

SENATOR CAMPBELL: Thank you. Any additional questions before he leaves? Okay. Thank you. [LB320]

MICHAEL CHITTENDEN: Thank you. [LB320]

SENATOR CAMPBELL: Our next proponent? [LB320]

NICK FAUSTMAN: (Exhibit 12) Good afternoon. [LB320]

SENATOR CAMPBELL: Good afternoon. [LB320]

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NICK FAUSTMAN: Nick Faustman, N-i-c-k F-a-u-s-t-m-a-n. I'm with the Nebraska Health Care Association, which is the parent association to a family of entities including the state's largest association for nursing facilities, the Nebraska Nursing Facility Association, which I'll refer to as NNFA, and the state's only association dedicated...to specifically, to assisted living facilities; the Nebraska Assisted Living Association, and I'll refer to them as NALA. Both NNFA and NALA represent nonproprietary, proprietary, and governmental long-term care facilities, and NNFA and NALA support LB320. NNFA and NALA have always strongly supported the concept of making sure that an individual receive the right care at the right place at the right time. We contend that this bill can enhance the effort...that effort and help continue to improve Nebraska's healthcare delivery system while controlling cost of care. Thank you for considering this important proposal and we urge the committee to advance LB320 to the floor for General File. [LB320]

SENATOR CAMPBELL: Any questions for Mr. Faustman? Thank you much. Oh, Senator Riepe, did you have a question? [LB320]

SENATOR RIEPE: No, no. I'm sorry, no. I was waving off. [LB320]

SENATOR CAMPBELL: Oh. Sorry. And our last proponent, I believe. [LB320]

SARAH SWANSON: (Exhibit 13) Good afternoon, Senator Campbell. Senators of the Health and Human Services Committee, my name is Sarah Swanson, and that is spelled S-a-r-a-h S-w-a-n-s-o-n. I work as an outreach specialist at the UNMC Munroe-Meyer Institute. I am here speaking as an individual and my views do not necessarily represent the University of Nebraska. As you may be aware, the Munroe-Meyer Institute provides an array of interdisciplinary clinical services for individuals with disabilities, trains future practitioners, and also is the federally designated University Center for Excellence in Developmental Disabilities, or UCEDD. The UCEDD grant is required within the Developmental Disabilities Act to build capacity and systems and supports for individuals with intellectual and developmental disabilities in their families. Funding from the Administration for Intellectual and Developmental Disabilities...I'm sorry. Funding comes from the Administration for Intellectual and Developmental Disabilities within the federal Administration for Community Living. This bill enhances a statewide collaboration between the centers for independent living, the Area Agencies on Aging, and the UCEDD program. Within the UCEDD program, it would provide navigational services or options counseling to individuals seeking additional information and/or support, but specifically targeting those families who have a child with a disability age birth to 19. Currently, the only support available to this population includes school services if the child meets eligibility or services coordination within the Aging and Disabilities (sic) Waiver or the Developmental Disabilities Waiver, again, if the child meets criteria. Otherwise, there is no support available.

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Many children do not meet these eligibility criteria, but their families need information and support. The UCEDD would employ options counselors and also provide technical assistance to the CILs and the offices on aging regarding the services and supports available for individuals with intellectual and developmental disabilities and their families. This is not in my testimony but, Senator Riepe, you had talked about Ronald Reagan. Do I need to... [LB320]

SENATOR CAMPBELL: What was the announcement? Okay. I'm sorry, Ms. Swanson. Continue. I was trying to hear what they were saying. [LB320]

SARAH SWANSON: Yeah. [LB320]

SENATOR CAMPBELL: Sometimes we have fire notices or whatever from those announcements. [LB320]

SARAH SWANSON: Okay. Ronald Reagan, during his administration, was instrumental for introducing what they call home- and community-based waivers. And I don't know if you've ever heard the story about how those came around, but it was because there was a little girl by the name of Katie Beckett who contracted spinal meningitis as a child; actually, I think she was a toddler. And the only way her mother could get all of her medical bills paid for, because her parents exceeded their limitations on their private health insurance, was if she had her child in a nursing home. And she...her daughter was, like, two years old. And she couldn't handle her daughter being raised in a nursing home. And so she worked with her Iowa senator and, you know, told her story. And when Ronald Reagan got wind of it, he said, that's not right. Medicaid will pay for any services in an institution, but to get those services provided in the home are not available, which is why states can implement home- and community-based waivers. Aging and Disability Resource Centers, or ADRCs, are a shared vision of the Administration for Community Living, the Center for Medicare and Medicaid Services, and the Veterans Health Administration to serve as single points of entry into the long-term services and support system for people with disabilities, their families, and older adults. Sometimes referred to as a one-stop-shop or no-wrong-door system, ADRCs address many of the difficulties consumers and their families experience when trying to find needed information, services, and supports. Through coordination of existing aging and disability service systems, ADRC's programs raise the visibility about the full range of options that are available; provide objective information, advice, counseling, and assistance; empower people to make informed decisions about their long-term supports; and help people more easily access public and private long-term service and support programs. No-wrong-door systems provide information and assistance not only to individuals needing either public or private resources but also to professionals seeking assistance on behalf of their clients and to individuals planning for their future long-term care needs. No-wrong-door systems are designed to serve as a highly visible and a trusted place where people of all ages,

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incomes, and disabilities go for information and one-on-one, person-centered counseling on the full range of long-term services and support options. Face-to-face contact has been a repeated request for many of Nebraska's citizens who need additional support when applying for Medicaid or other services. [LB320]

SENATOR CAMPBELL: Ms. Swanson, we're kind of at the end. [LB320]

SARAH SWANSON: That's fine. [LB320]

SENATOR CAMPBELL: And so can you hit the high points and we'll see if there's any questions then? [LB320]

SARAH SWANSON: Sure. When you talk about ACCESSNebraska, that has been a repeated concern for people over and over again. This would provide a statewide network that already has the existing brick-and-mortar places in place. I don't know. I guess I'd just ask you if, you know, if a family member of yours got into a car accident or you had a child that had a developmental disability, where would you go to get the information? Where would you start? [LB320]

SENATOR CAMPBELL: Okay. Questions? Senator Riepe. [LB320]

SENATOR RIEPE: Thank you, Senator Campbell. Yeah, one question: In your presentation--and I think it's paragraph 2 of the document that I have in front of me and unfortunately these people don't--it says you emphasize if the child meets the eligibility and if the child meets the eligibility, and I go, are you proposing that there be no criteria? [LB320]

SARAH SWANSON: No, that's not what I'm proposing at all. I am saying, though, that sometimes there is needs that don't always get met. And I can illustrate that with a personal example. [LB320]

SENATOR RIEPE: Then becomes the challenge, though, of fairly and consistently without discrimination...if you make exceptions over and over again, then you really get into a real problem administratively. That's a concern that I would have. [LB320]

SARAH SWANSON: You mean for a budget? [LB320]

SENATOR RIEPE: Pardon? [LB320]

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SARAH SWANSON: Is that accurate? Are you saying for the budget? [LB320]

SENATOR RIEPE: No, I'm not saying for the budget. I'm saying for fairness so that I'm not discriminating against...these are my friends that I do it for them and I don't do it for someone else whether it's, you know, race, sex, sexual orientation, you know, all of the factors that you can get into trouble with in a discriminatory...in a world of litigation. You could end up with all kinds of problems if you start... [LB320]

SARAH SWANSON: The ADRC, the concept of that, is really...I think Mr. Intermill said it best. There's a whole network that's already available. And sometimes it just requires people to talk to each other so that we start making sure that people have the information and know how to get it. Does that make sense? [LB320]

SENATOR RIEPE: Oh, that makes sense, yes. Thank you very much. [LB320]

SARAH SWANSON: Yeah, you're welcome. Sure. [LB320]

SENATOR RIEPE: Thank you, Senator. [LB320]

SENATOR CAMPBELL: Senator Crawford. [LB320]

SENATOR CRAWFORD: Thank you, Chairwoman Campbell. And thank you for your testimony. I think, perhaps, it might clarify...in that paragraph were you talk about, really, access to navigational kinds of services? [LB320]

SARAH SWANSON: Sure. [LB320]

SENATOR CRAWFORD: So, and the...and this...if the bill is passed, it would be a no-wrong-door...somebody can walk in and get help. [LB320]

SARAH SWANSON: Or if they make... [LB320]

SENATOR CRAWFORD: And in this case it's the navigational services... [LB320]

SARAH SWANSON: Right. [LB320]

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SENATOR CRAWFORD: ...that you're saying is difficult. [LB320]

SARAH SWANSON: Right. Right. Absolutely. [LB320]

SENATOR CRAWFORD: So they aren't getting answers to their questions about whether or not they're eligible. [LB320]

SARAH SWANSON: And maybe I could clarify this a little bit more. In my current role on the grant that I work on, I also help families that are looking for resources. And sometimes they will try to apply for a program and they've been told...or by...they have every reason to believe that they should be eligible for that. And sometimes they just need to have a little bit of more information. You know, sometimes you need to appeal it. Or, you know, I think it would be helpful for you to talk to this person. Or sometimes it's emotional support. You know, families that have an individual in their immediate circle encounter a lot of stress. The family is often in crisis. And, unfortunately, your typical support systems aren't available because they haven't walked the walk. The best information that I always hear is being able to relay or get information from people that have lived that experience and have experience and know what the questions are and help point them in the right direction. [LB320]

SENATOR CAMPBELL: Thank you, Ms. Swanson. [LB320]

SARAH SWANSON: Yeah. [LB320]

SENATOR CAMPBELL: Okay. Any other proponents? Those who oppose the bill? Anyone who wishes to provide neutral testimony? Okay. Senator Bolz, do you wish to close? [LB320]

SENATOR BOLZ: Just a few brief points of clarification. I did want to address the existing aging and disability resource model that exists. And forgive my initial oversight of that point. I just get excited about the potential of this new approach. It was developed through a grant. And I certainly don't want to put words in the mouth of anyone who worked on that grant or anyone from the administration, but we have had conversations with the administrative state unit on aging as we put this initiative together. And this approach is very different from what they were trying to achieve in the original concept for the Aging and Disability Resource Center in that it is more localized, it's leveraging existing resources, and it's more of a sustainable approach by asking for some resources from the Nebraska Legislature. My perception of why the initial grant was accepted and then not pursued further is that they felt like they had a model that they could put together with that amount of resources but they didn't want to build something that they couldn't sustain over time. And so that's why they developed the Web site and the hotline

approach, because they thought that made sense with what they had. A couple of other just very quick points. To your point, Senator Riepe, I think one simple way to think about the Aging and Disability Resource Center is that information should be available to everyone, but the services should have eligibility and means testing. So the navigational pieces, to Senator Crawford's point, is what's...we're really adding value with here. Two other very quick points are that-- forgive me if I missed this in testimony--but I do think this is also a strategy for preventing fraud and abuse which, as we have a growing senior population, we need to make sure there's a reliable source of information. And the last piece I would add is just a quick constituent story where I had a middle-aged couple who called me. The husband wanted to accept a raise at work. The wife had been diagnosed with multiple sclerosis. And they simply couldn't get answers about whether or not he could accept that raise and advance on his employment without losing her Medicaid eligibility. So I would just maybe add that facet of the conversation, that this can support employment and help give people the information and resources they need to continue their wage-earning strategies. I, myself, am surprised about the number of supporters in the room today. I actually didn't expect all of this support. And so I think it represents not only the need for this bill but also the new approach to an Aging and Disability Resource Center that is leveraging local resources and leveraging local stakeholders and hearing the voices of people. So I'll stop. I'll stop. But I appreciate your energy here. [LB320]

SENATOR CAMPBELL: Questions? Senator Crawford. [LB320]

SENATOR CRAWFORD: Thank you. Could you speak to how this relates to the balancing...the BIPP program that we passed last year? [LB320]

SENATOR BOLZ: No, I would love to. Two of the major innovations with the Balancing Incentive Program were a no-wrong-door approach and a unified assessment. And so the work that is currently being done on the Balancing Incentive Program is developing those strategies statewide. And so those tools will flow directly into an Aging and Disability Resource Center and this really is a way to sustain some of the work that will be happening through BIPP. [LB320]

SENATOR CRAWFORD: So the BIPP is the planning and then this is implementing the people who can use those tools? [LB320]

SENATOR BOLZ: Exactly. So, for example, the unified assessments...you know, the folks doing that assessment work across the state. And just to clarify what I mean by unified assessment, I always use my grandma Barb as an example. My grandma Barb could meet with someone and have the indicators of her life checked through with someone who is assessing those things: her physical stability, her financial stability, her...maybe her Alzheimer's/dementia scale. Having that

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unified and have it in a unified system that everybody is speaking the same language will only support the work of an ADRC, because we'll have a statewide system where folks are talking the same language and using the same tools. [LB320]

SENATOR CRAWFORD: So one of the written testimonies says that it was not included in this year's budget. Since you're on the Appropriations Committee, you probably would be able to speak to that. [LB320]

SENATOR BOLZ: Right. The Governor decided not to fund it, and my understanding is that that is due to a discrepancy in the way that the fiscal notes came together and that the cost of the Balancing Incentive Program is higher than the fiscal notes originally predicted. I don't know whether or not that is...I don't know the details of that. I have a meeting set up with the department on Friday afternoon, so I'll be able to tell you more about that. But regardless of whether or not the Balancing Incentive Program moves forward as we originally envisioned, the work that has already been done will be able to flow into this model and this vision. [LB320]

SENATOR CRAWFORD: Good. Good. Excellent. Thank you. Thank you. [LB320]

SENATOR CAMPBELL: Any other questions? Senator Kolterman. [LB320]

SENATOR KOLTERMAN: Yeah, Senator Bolz, I really like this concept. And again, I'm a newbie, so bear with me on this. We hear a lot about ACCESSNebraska. Today we hear about an organization that's kind of worthless. And those are all administered by the state through HHS, I believe. Am I not correct? [LB320]

SENATOR BOLZ: Um-hum. That's right. [LB320]

SENATOR KOLTERMAN: Would this...this would not be administered through HHS but it would interplay with HHS on many areas, correct? [LB320]

SENATOR BOLZ: Right. Give yourself more credit. (Laugh) You're following. I think one of the ways in which this approach is different is that we've assigned different functions to different entities. So the real functions of the Department of Health and Human Services are oversight functions and organizational/administrative functions to make sure the dollars flow out as they should, approving plans and making sure that those plans are put together in a responsible way. But really, the work of developing the plans and the making sure that the plans fit the needs of the people in a population are done on a more regional basis. And the Area Agency on Aging is sort of the lead applicant, the one who is responsible for making sure everything comes together.

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But the Area Agencies on Aging are required to partner with a specific list of people who are stakeholders in this field of health and human services. [LB320]

SENATOR KOLTERMAN: So in essence, what we would do is we'd take the Area Agency on Aging and move them into a little bit different role kind of as the lead. And then they would interact with the other organizations that are responsible, including HHS and Medicaid and the whole nine yards. Is that correct? [LB320]

SENATOR BOLZ: That's right. That's right. And to their credit--and maybe June touched on this--but to their credit, they're on board and they're on board as a team. They're all excited about doing this work which I give them a lot of credit for, because it is taking on a new role and a new responsibility. [LB320]

SENATOR KOLTERMAN: All of the area agencies? [LB320]

SENATOR BOLZ: They are all in consensus that this is something they want to do. [LB320]

SENATOR KOLTERMAN: And then how many of those are there in the state again? [LB320]

SENATOR BOLZ: There are six? There are eight. There are eight. Forgive me, there are eight. [LB320]

SENATOR KOLTERMAN: And I'd just like to finish up. I have a mother that's 85 and a mother-in-law that's 89. And then they're in their homes. I'd like to keep them there. I understand that...I've looked into the difference between the two. It's huge. But I'm not looking to expand government any more than we already have. So that's the shift for me. So I've got to struggle a little bit with this. But I...if it's done through the area departments on aging, I have a lot of confidence in them. And so... [LB320]

SENATOR BOLZ: I would just maybe briefly say, it's how you think about it. I don't want to add another layer of government here. I do want to bring together the stakeholders and the players in the game and make them work more efficiently and in greater coordination. So, you know, people can label different things in different ways. I would just label this as a different business model for achieving the goals that we've already laid out for our Health and Human Services System. [LB320]

SENATOR KOLTERMAN: All right. Thank you very much. [LB320]

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SENATOR CAMPBELL: Any other questions? Senator Riepe. [LB320]

SENATOR RIEPE: Senator...thank you, Senator Campbell. Senator Bolz, I have what I think is quick. There are eight agencies and they...all eight would benefit from this particular thing. And all would...this must be work that currently is being done by those agencies in rather maybe a less than fully coordinated manner. Is there any way that if the...if it doesn't make it through budget and...is there a way for interagency transfers of funds of the eight to participate that they help to fund this thing if it...if they have a vested interest in it? [LB320]

SENATOR BOLZ: You know, I think the Area Agencies on Aging will do whatever they can to make this work successful. But I might frame it this way: that the majority of what the Area Agencies on Aging are currently doing is administering aid. So they are trying to provide services like home health and chore services and those kinds of things. What we need is more on the operations side, more on the systems side. So I don't know that there's, you know, unspent funds that could be moved towards these more systems-focused purposes. Does that answer your question? [LB320]

SENATOR RIEPE: It does. I know just oftentimes, you know, someone has to give up 5 percent or 10 percent but...and you need to pull those 10 percents together to make this new 100 percent. And that's kind of where I'm trying to figure out. [LB320]

SENATOR BOLZ: Sure. If we were a business model, that would be easier. Because we're using state and federal funds, there are tighter restrictions. [LB320]

SENATOR RIEPE: Yeah, yeah. I understand that. Thank you very much. [LB320]

SENATOR CAMPBELL: Any other comments? Thank you, Senator Bolz. [LB320]

SENATOR BOLZ: Thanks for your energy and patience. Appreciate it. [LB320]

SENATOR CAMPBELL: Okay. That concludes the hearing this afternoon on LB320. And if you are leaving, I would ask that you leave quickly and quietly. Letters for the record... [LB320]

BRENNEN MILLER: (Exhibits 14, 15, 16, 17) Thank you. Letters from Independence Rising; National Association of Social Workers, Nebraska Chapter; Department of Health and Human Services, Division of Medicaid and Long-Term Care; and Autism Society of Nebraska. Thank you. [LB320]

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SENATOR CAMPBELL: The department submitted a letter? [LB320]

BRENNEN MILLER: Yes. [LB320]

SENATOR CAMPBELL: In support or neutral? [LB320]

BRENNEN MILLER: Neutral. [LB320]

SENATOR CAMPBELL: They have...I'm sorry...of a technical nature? Okay. They're going to distribute the letter. The only reason that I asked that was if there was any follow-up question. But we can cover that when we discuss the bill. Okay. We will move forward, and it's my understanding that Senator Davis will not be here and that you are opening for him. We will open the public hearing on LB405 which is to create the Alzheimer's and Related Disorders Advisory Work Group and provide for a state plan. Good afternoon. [LB320]

CHRISTINA CASE: Hi, Senator. How are you? [LB405]

SENATOR CAMPBELL: Good. Very good. [LB405]

CHRISTINA CASE: (Exhibit 1) Good. Senator Campbell and members of the Health and Human Services Committee, my name is Christina Case, C-h-r-i-s-t-i-n-a C-a-s-e, and I'm appearing on behalf of Senator Al Davis from District 43 who is out of the state at the moment. He apologizes that he couldn't be here in person to introduce LB405. This bill is the result of another one of the recommendations of the Aging Nebraskans Task Force of which Senator Davis serves as Vice Chair. The Aging Nebraskans Task Force met over the last year to examine the health implications of a steadily aging population and how best to anticipate and address their increasing needs. As the baby boomers reach retirement age and the average age in Nebraska rises, so does the number of Nebraskans with self care and cognitive disabilities. According to the Alzheimer's Association, 33,000 Nebraskans are currently affected by Alzheimer's, and this number is estimated to reach 40,000 by the year 2025. Many of the Nebraskans that are most at risk for these disorders live in small rural communities with a rapidly aging average population and few local services. And many of them will become dual eligible as they run out of resources. This is not only a significant quality of life issue for people who are particularly vulnerable, it also has the potential to create huge economic consequences for the state. Among the recommendations that came out of the task force was the need for a state plan to address the increasing need for coordinated services for patients with disorders like Alzheimer's. More than 40 other states have already established similar state plans. LB405 creates the Alzheimer's and Related Disorders Advisory Work Group which is tasked with

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developing a state plan and submitting it to the Legislature's Health and Human Services Committee by December 15, 2016. The work group is directed to assess the current and future impact of Alzheimer's and related disorders on residents of the state, determine the existing services and resources in the state that effectively address the needs of individuals with these disorders as well as their families and caregivers, and develop recommendations to respond to escalating needs for these services and resources. The 13-member work group is made up of the CEO of the Department of Health and Human Services or designee; the Public Guardian or designee; two nonvoting legislative members appointed by the Exec Board; and nine community stakeholders appointed by the Governor that represent the law enforcement community, Area Agencies on Aging, patient and caregiver advocacy organizations, patients and caregivers themselves, private and community-based healthcare professionals, and healthcare provider advocacy organizations. Private healthcare organizations have expressed their willingness to offer administrative assistance to the work group in order to reduce the cost to the state. So LB405 states that the work group may work with a private organization to provide administrative support. You should have an amendment that Senator Davis has offered to clarify that the working group will be in the Department of Health and Human Services for budgetary purposes. Several members of the Aging Nebraskans Task Force will be appearing today, and they will be able to provide you with some insight on the work that has led to this recommendation and on the need for a clear plan to best serve some of our most vulnerable Nebraskans. Senator Davis would like to acknowledge the members of the task force and thank them for their work, which that includes: Senator Kate Bolz; Senator Kathy Campbell; Senator Tanya Cook; Senator Heath Mello; Cynthia Brammeier, the executive branch designee from the HHS State Unit on Aging; the judicial branch designee was Corey Steel, the State Court Administrator; as well as the community stakeholders, Mark Intermill from AARP Nebraska; Connie Cooper, Northeast Nebraska Area Agency on Aging; Joyce Ebmeier from Tabitha; Michaela Valentin from Home Instead; and then the ex officio members were Jerry Deichert from the Center for Public Affairs Research and Chris Kelly, the UNO Department of Gerontology. Thank you very much. [LB405]

SENATOR CAMPBELL: Thank you, Ms. Case. Just so that you are aware, there is a continuing discussion about how we put together task forces. And trust me, I'm well aware of this. I have two bills that try to put this together in three branches of government and I think we're all struggling. Every one of us who have ever had a bill like that have gone... okay, because, for the audience benefit, you have to keep a separation of powers between the branches. So I notice that the legislative members are nonvoting. So that would put the voting members appointed by the Governor, correct? Is that how that would work? [LB405]

CHRISTINA CASE: From my understanding, other than the designated ones. [LB405]

SENATOR CAMPBELL: Okay. But it...one of the branches of government has to have the appointing and that's the people who are voting. So we might just want to look at that portion of

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the bill and make sure we've got it really clear because we're going to get challenged as we go forward. And Senator Davis probably remembers the discussion from Senator Bolz's bill last year in which we struggled with the same thing. [LB405]

CHRISTINE CASE: Sure. [LB405]

SENATOR CAMPBELL: So just a heads up there. Questions or comments from the senators? Senator Riepe. [LB405]

SENATOR RIEPE: I have a question. Hello. [LB405]

CHRISTINA CASE: Hi. [LB405]

SENATOR RIEPE: Who is currently performing this function, just to be helpful to me? [LB405]

CHRISTINA CASE: Performing which function? [LB405]

SENATOR RIEPE: Coordination of the Alzheimer's and Related Disorders...I mean, someone has to be filling this void either adequately or inadequately and I think you're saying inadequately but... [LB405]

CHRISTINA CASE: That's a question that can probably be very easily answered by one of the testifiers following me... [LB405]

SENATOR RIEPE: Okay. [LB405]

CHRISTINA CASE: ...because they've been...they do this work all the time. [LB405]

SENATOR RIEPE: Excellent. [LB405]

CHRISTINA CASE: Thanks for the question. [LB405]

SENATOR RIEPE: Okay. Thank you. [LB405]

SENATOR CAMPBELL: Senator Howard. [LB405]

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SENATOR HOWARD: Thank you, Senator Campbell. Thank you for covering today. (Laughter) I was just curious about--and you may not be able to speak to this and I can follow up with Senator Davis as well--why the choice of a task force in a bill as opposed to an interim study or some other type of method of getting to the bottom of this? [LB405]

CHRISTINA CASE: That's probably a question for Senator Davis or maybe even for one of the members of the task force that will be testifying. I'm not sure. [LB405]

SENATOR HOWARD: Okay. Thank you. [LB405]

SENATOR CAMPBELL: Ms. Case, you may have mentioned this, and I'm sorry, we were trying to get everything clear up here, but Nebraska is one of the, what, last states, if not the last state, to have a state Alzheimer's plan? Is that correct? [LB405]

CHRISTINA CASE: I think there's 40 other states that have plans. So we're in the final ten. [LB405]

SENATOR CAMPBELL: I know we're about... [LB405]

CHRISTINA CASE: Behind. [LB405]

SENATOR CAMPBELL: It's a low number that are left so...any other questions? You were a champ to fill in. That is not easy. (Laughter) [LB405]

CHRISTINA CASE: Thank you for that. [LB405]

SENATOR CAMPBELL: You're welcome. [LB405]

CHRISTINA CASE: Thank you, Senators. [LB405]

SENATOR CAMPBELL: Have a good afternoon. And I'm assuming that whatever questions we might have at the end, we'll make sure Senator Davis knows about them. [LB405]

CHRISTINA CASE: That would be great. [LB405]

SENATOR CAMPBELL: Thank you, Ms. Case. [LB405]

CHRISTINA CASE: Thank you. [LB405]

SENATOR CAMPBELL: Our first proponent? Good afternoon. [LB405]

VIV EWING: (Exhibit 2) Good afternoon. First of all, thank you, Senator Campbell, for allowing us to testify today and also to all of you who are on the Health and Human Services Committee. My name is Viv Ewing, and I'm the executive director and CEO for the Alzheimer's Association for Nebraska. And it's spelled V-i-v E-w-i-n-g, and I'm speaking to you on behalf of the Alzheimer's Association as well as the 33,000 individuals that we know of that have the disease and their 80,000-plus caregivers. There is a handout coming around to you and I'll address that in just a moment. But first of all, I want to be really clear about my ask for today, and that is for your support of LB405, the creation of the Alzheimer's and Related Disorders Advisory Work Group and provide for a state plan. Alzheimer's Association is the world leader in Alzheimer's care, support, and research. And I wanted to just quickly address the question that was raised about who currently is providing Alzheimer's services. And the Alzheimer's Association does provide education and support and services for families who are facing Alzheimer's and dementia. And that's across the state of Nebraska. As the Aging Nebraskans Task Force met this past fall, led by Senator Bolz, the group was to address the needs of the aging population in the state. They quickly realized that the increasing prevalence and skyrocketing costs of Alzheimer's and dementia amplifies the need for the establishment of a dementia-specific task force. And the question was raised a few moments ago about Nebraska being one of the few that do not have a plan. Of the 50 states, there are 5 that don't have a plan. Nebraska is one of the five. We helped Iowa create their plan a few years ago. An estimated 5.2 million Americans of all ages are living with Alzheimer's disease. This includes an estimated 5 million people age 65 and older and approximately 200,000 individuals under the age of 65 who have younger onset Alzheimer's. Alzheimer's is no longer just an aging issue. The prevalence of younger-onset Alzheimer's with folks being diagnosed in their 40s and 50s is growing rapidly. And just to give you a perspective, every 67 seconds someone is diagnosed with Alzheimer's disease. One in three seniors dies with Alzheimer's. When you look at the 5 million people in America with the disease, 3 million are women. By age 60, women are twice as likely to develop Alzheimer's as they are breast cancer. So those are some startling statistics that really paint a picture around the importance of addressing this public health crisis. With Alzheimer's disease, it's not just those with the disease who suffer. It is also their caregivers, a job that usually falls on family and friends. I took care of my aunt for a year who had dementia and watched her go through the stages of that disease. And actually, when the doctor first told us that that's what it was, we challenged him and said, oh no, she's having a nervous breakdown. It can't be dementia. And as time went on, we saw very clearly the stages of the disease and watched her demise over a period of time. In Nebraska, as I said earlier, 80,000 caregivers provide 91 million hours of unpaid care. That's valued at over \$1 billion to the 33,000 individuals who have the disease, costing \$50 million in higher healthcare costs of the caregivers themselves. The percentage of

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Nebraskans living with this disease is expected to rise by 21 percent by the year 2025. Alzheimer's disease is a growing public health crisis. Alzheimer's is the only cause of death among the top ten that cannot be prevented, cured, or slowed up to this point. And we're hoping with the advancement of research that that picture will change. The New England Journal of Medicine released a study in 2013 that determined that Alzheimer's disease is the most expensive disease in America. The average person has Medicaid spending for seniors...and Alzheimer's and other dementias on average is 19 times higher than the average across other seniors. The disease has a profound effect on the family caregiver who suffers with their own health crises because of what they're involved in in taking care of someone who is ill and the stress related to that. Nebraska is one of only five states that don't have a plan at this point as we talked about earlier. And I would like to encourage you to support LB405 today and advance the bill forward. I wanted to take just a few moments to let you know that I passed out a handout. I hope you have that in front of you. And I know my time is winding up, but I wanted to just point out a couple of statistics for you on page 1. Down toward the bottom it talks about, nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as being either high or very high. And that leads to their own health crises that they face. And on page 2, I just wanted to point out two quick facts. On the left side you'll see the very first paragraph: In 2014, the direct costs to American society of caring for those with the disease will total an estimated \$214 billion. And over on the right, you'll see a diagram that shows that the rate of death for Alzheimer's is actually increasing while other major diseases, their death rate is decreasing. And so, again, thank you for your time today and for your support of LB405. [LB405]

SENATOR CAMPBELL: Questions from the senators? Senator Crawford. [LB405]

SENATOR CRAWFORD: Thank you. And thank you, Dr. Ewing, for being here today and for your work. Maybe you could help us understand the value of that plan since you, you know, helped Iowa put their plan together. What does the plan provide that helps you with the Alzheimer's Association do your work better or differently? [LB405]

VIV EWING: Right. What the plan will do is give us a broad-based approach to begin to provide more education but to also bring in other entities into this fold. For example, a state plan would allow us to go out and bring in the law enforcement, first responder community to educate them about the disease, how to recognize an individual with dementia. We know that 60 percent of people with dementia will wander. And so if I'm a law enforcement person and I see someone who is staggering, they're confused, they really can't speak clearly, that might look like something else. It might look like someone who might be intoxicated or perhaps on a drug. So one piece of this is training for first responders. Another piece of a plan would also address the types of training and how much training that medical professionals receive when they're caring for someone with Alzheimer's or dementia. We know that the type of training that an individual or a care worker provides is really critical in how that person does with the disease. If they're not

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getting the right kind of training, you end up with individuals who perhaps fall or fall multiple times. But with adequate training, we can help mitigate some of that. Another piece of this will be to look at a coordinated effort to provide all of the different Alzheimer's resources, information, and support that are available across the state in one place so that if I'm in Scottsbluff, I can access this information. If I'm in Norfolk, I can access that information. The plan that we would like to see go forward is actually based on the state of Utah where we really sat back and examined all the different aspects of that and looked at what pieces of that plan make the most sense. And I'm happy to share that with each of you if that would help provide a better perspective of what we're looking at with this particular type of plan. [LB405]

SENATOR CRAWFORD: Thank you. [LB405]

SENATOR CAMPBELL: Other questions? Senator Howard. [LB405]

SENATOR HOWARD: Thank you, Senator Campbell. Thank you for your testimony today. I'm curious about the fiscal note. Is the Alzheimer's Association the...sort of the private group that would provide administrative support for the task force? [LB405]

VIV EWING: We are not. There is actually an outside organization... [LB405]

SENATOR HOWARD: Okay. [LB405]

VIV EWING: ...that has volunteered to step forward to provide the administrative support to keep the costs down. [LB405]

SENATOR HOWARD: What is the outside organization? [LB405]

VIV EWING: It's called Tabitha. [LB405]

SENATOR HOWARD: Tabitha, okay. And then I noticed that all of the work of the group would be done December 31, 2016. Do you feel that that's enough time? [LB405]

VIV EWING: I do, because actually, as we look at this particular area, we've already spent some time as the Alzheimer's Association looking at some of the resources that are available across the state. So some of these pieces, the ball has already started to roll forward. [LB405]

SENATOR HOWARD: Thank you. [LB405]

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VIV EWING: You're welcome. [LB405]

SENATOR CAMPBELL: Other questions from the senators or concerns? Senator Kolterman. [LB405]

SENATOR KOLTERMAN: Yeah, thank you, Dr. Ewing. You talked about, you helped put the Iowa plan together and we don't have one in Nebraska. Why is that? [LB405]

VIV EWING: Well, actually we worked with Iowa because we had enough support there to move it forward a lot sooner. [LB405]

SENATOR KOLTERMAN: So it was the Alzheimer's Association that did that? [LB405]

VIV EWING: Yeah, we initiated getting that plan started. [LB405]

SENATOR KOLTERMAN: Do you have any idea what kind of cost might be associated with putting a plan together for Nebraska? [LB405]

VIV EWING: Right now, according to the fiscal note that's been developed, we're looking at approximately \$87,000 to look at assigning a staff person from Health and Human Services that would oversee the process. [LB405]

SENATOR KOLTERMAN: Is that something that's being brought to us this year? Do you know? [LB405]

VIV EWING: It's slated for the 2016 fiscal year... [LB405]

SENATOR KOLTERMAN: Okay. [LB405]

VIV EWING: ..and then also 2017 fiscal year. [LB405]

SENATOR KOLTERMAN: So it...has it already been... [LB405]

SENATOR CAMPBELL: No. [LB405]

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SENATOR KOLTERMAN: Okay. I was just wondering if that had already been financed or put in the budget. [LB405]

VIV EWING: Not yet. Not yet. [LB405]

SENATOR KOLTERMAN: Okay. Thank you. [LB405]

VIV EWING: We would like to see it financed and in the budget. [LB405]

SENATOR KOLTERMAN: Yeah. [LB405]

SENATOR CAMPBELL: For the new senators, what you will see is when the Appropriations Committee brings forward the budget, usually they leave an amount of money for those bills that have A bills. And sometimes there's more A bills than there is that money. But they do recognize that people introduce bills through the course of the session that will need money. So the Appropriations Committee will take...they will leave an amount to do that. And I believe that the Governor also left money in his budget recommendation to the Appropriations Committee in the Legislature that would have allowed for A bills, a certain amount of A bills. But you will begin to see...I mean, as we get closer to all of that, you'll have a sheet and you'll be able to watch where the A bills are on General File, Select File, the cost, and, you know, whether we can...whether it fits in the budget. Let's put it that way. More info to come... [LB405]

SENATOR KOLTERMAN: And how much is left? [LB405]

SENATOR CAMPBELL: Well, it depends on what the... [LB405]

SENATOR KOLTERMAN: Yeah. [LB405]

SENATOR CAMPBELL: ...what we vote for exactly. I do want the senators to know that we will clarify, because there has been an e-mail about whether an outside organization can provide the administration. And I think that you all might have gotten a copy of that. So we'll check that out between the Fiscal Office and probably have Joselyn check some of that out for us. So that's why you have, really, two different fiscal note approaches to this. One assumes the private organization. The second does not. Is that helpful? Thank you very much, Dr. Ewing. [LB405]

VIV EWING: Thank you. [LB405]

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SENATOR CAMPBELL: Our next proponent? Good afternoon. [LB405]

CLAYTON FREEMAN: (Exhibit 3) Good afternoon, Senator Campbell and members of the committee. My name is Clayton, C-l-a-y-t-o-n, Freeman, F-r-e-e-m-a-n. I am the director of programs and public policy for the Alzheimer's Association. When convened, the Alzheimer's Advisory Work Group will develop and present a state Alzheimer's disease plan for Nebraska which will create the infrastructure and accountability necessary to confront the sweeping economic and social impact of this disease with a coordinated and comprehensive approach. State plans across the United States garner government, community, and private sector responses to the growing Alzheimer's disease crisis. The establishment of an Alzheimer's Advisory Work Group will allow key stakeholders to identify gaps in care and services related to individuals living with dementia and their family caregivers. By doing a statewide needs assessment to see what resources are already available within this state and not being fully utilized and what resources may be missing. The work group will then be able to develop a comprehensive Nebraska state Alzheimer's disease plan based on the identified needs. The state plan would provide a set of recommendations to improve public awareness, early disease detection and diagnosis, delivery of community-based and residential dementia care services, support for families and caregivers, quality of care standards and dementia training requirements, and encourage research effort within the state's universities and leading medical centers. As you know, Alzheimer's disease is a growing public health crisis. While age is the greatest known risk factor for Alzheimer's, one in nine Americans over the age of 65 will develop the disease. And as the baby boomers, of which I represent, continue to age, more Nebraskans will be effected by this disease either as individuals living with the disease or as a caregiver. I really urge you to support LB405 to create this advisory group. I want you to know, too, that the Alzheimer's Association in Nebraska stands ready to work with you, your staff, and the work group to address the effects of this devastating disease and to support your efforts in every way possible. We must start looking at Alzheimer's and dementia for what it really is: a growing public health crisis and perhaps the greatest risk to our elder Nebraskans. Please work with us to develop this plan for Nebraska that we may become a dementia-capable state. And we are counting on you. Thank you. [LB405]

SENATOR CAMPBELL: Thank you, Mr. Freeman. Questions? Thank you for your testimony today. [LB405]

CLAYTON FREEMAN: Thank you very much. [LB405]

SENATOR CAMPBELL: Our next proponent? [LB405]

CONNIE COOPER: Good afternoon. [LB405]

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SENATOR CAMPBELL: Good afternoon to you. [LB405]

CONNIE COOPER: (Exhibit 4) Senator Campbell and members of the Health and Human Services Committee, my name is Connie Cooper, C-o-n-n-i-e C-o-o-p-e-r. I'm the director of the Northeast Nebraska Area Agency on Aging which covers 22 counties in northeast and north-central Nebraska. First of all, I want to thank you, Nebraska Legislature. Nebraska took a proactive approach when it developed the Nebraska Aging Task Force. Through public input; data, including the demographics; research; and the many organizations that provided information and insight, the Nebraska Aging Task Force created the strategic plan for long-term care. That strategic plan was then submitted to the Legislature. If you've not had a chance to read it, I highly recommend it. It's a top read for those us in the aging field, and I just happen to have a copy if you'd like one. Members of the task force identified five major categories in the strategic plan. One of those categories was special populations including Alzheimer's and dementia patients. Nebraska is one of the few states that does not have a state Alzheimer's plan. With the growing number of Nebraskans with Alzheimer's and dementia, the state of Nebraska needs a plan to address the current demands and to prepare for the increase in Alzheimer's and dementia patients. LB405 creates a work group that will develop the state plan for Nebraska. This work group will examine many issues such as the impact of Alzheimer's and the related disorders on the residents of our state; the type, the cost, and availability of services; as well as dementia-specific training and certainly the quality of care. As the director of the Northeast Nebraska Area Agency on Aging, my agency provides care management as well as Medicaid waiver services. The number of our clients with a diagnosis of dementia or Alzheimer's or has a cognitive deficit in our care management program is 22 percent. And in the Medicaid waiver program, it's 94 percent. LB405 is our opportunity to address proactive care, access to services, as well as personal support services. The Area Agencies on Aging across Nebraska support LB405. We thank Senator Davis for moving this conversation forward. This is the first step needed for Nebraskans living with Alzheimer's and related disorders, their caregivers, and the families. And we look forward to being a part of that discussion. [LB405]

SENATOR CAMPBELL: Thank you, Ms. Cooper. Questions from the senators? Senator Riepe. [LB405]

SENATOR RIEPE: Senator Campbell, thank you. Thank you very much for being here today. And my...and let's see, it's one, two, three, fourth paragraph, it says, "LB405 creates a work group that will develop a state plan for Nebraska" and goes on to say type, cost, availability of services. Will this also be looking at rate of payment? [LB405]

CONNIE COOPER: I'm not sure about the rate of payment. I think there's another bill that kind of addresses that... [LB405]

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SENATOR RIEPE: That's where I'm going with that. [LB405]

CONNIE COOPER: ...especially with that one. But I think something...obviously, I think that's part of that because of care that is needed. So I think that could be a part of that, absolutely. [LB405]

SENATOR RIEPE: I'm just curious whether we have one bill or two here. But okay. They're in. Thank you. [LB405]

SENATOR CAMPBELL: Any other questions? Thank you, Ms. Cooper. [LB405]

CONNIE COOPER: Thank you. [LB405]

SENATOR CAMPBELL: Our next proponent? [LB405]

ANN TILLERY: (Exhibit 5) Good afternoon, Chair Campbell and members of the Health and Human Services Committee. For the record, my name is Ann Tillery, A-n-n T-i-l-l-e-r-y. I'm here today to share my personal story of Alzheimer's disease and ask that you please support LB405. This bill is long overdue. Alzheimer's is emotionally and physically devastating to deal with. It rips apart the closest of families. And without a plan, families like mine are just winging it with epic failure. My parents raised seven kids in their house they planned and built across from Columbus High School in 1963. My father was a caring and meticulous businessman who ran the family business his father started in 1912 while mom effortlessly ran the household. She was the chef, the chauffeur, and with seven kids, she was the referee. She was a bundle of energy who also had the organization to keep seven kids busy with school, sports, and church activities. She loved gardening. She started the first gardening club in Columbus, Nebraska, and made it well known that she would never move from her house nor leave her beautiful backyard. As they aged, dad unsuccessfully attempted to downsize into a smaller, more practical ranch-style home. Mom also adamantly refused any assistance we attempted to hire for housecleaning or chores even after she suffered a mild stroke in 2011. Dad passed three months after her stroke. Yet the meticulous planner, even after seven kids, 18 grandkids, and 8 great-grandkids, he had miraculously tucked away what seemed like more than sufficient savings for the unexpected in their golden years. What wasn't planned for, however, was Alzheimer's disease. Mom struggled with short-term memory, routine, and financial decisions after dad's death. We attributed it to depression after losing her husband of 61 years. Mom had a limited neurological exam that diagnosed probable Alzheimer's. Some family members dismissed the diagnosis and said it was normal aging. Others were in denial. The family was split on how to give mom the care she needs. Mom's family physician was reluctant to take away her independence even after she repeatedly withdrew large sums of cash and...unable to recall where the money went. When I

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showed her that over \$100,000 had disappeared, she said that that wasn't possible, she didn't have that kind of money. My brother, now the POA, power of attorney, and I attempted to care for mom between our homes. It was exhausting like caring for a toddler. She no longer knew how to cook, dress herself, care for her personal hygiene, nor administer her medications. At bedtime, I was physically and mentally drained. But then I would hear mom wandering throughout the house in the middle of the night. One night, she had gone down the stairs in the dark and opened the garage door to go outside. She later asked, if I can't live at home, can I live with you? How do you respond to your mother you want to care for but can't keep safe? We tried assisted living. She fell and broke her wrist and shoulder after one week and spent eight weeks in a skilled care facility. She needed memory care, but a room was not available in Columbus, so we chose an assisted living facility that promised they were dementia capable. This was my mother when she went into the assisted living facility in November just last...in 2013. After three months, she was no longer walking, could not sit up unassisted, her speech was limited, and she could not feed herself. That's three months later. The family staged an intervention and transferred her to an Omaha hospital for testing and care. She had a UTI, a urinary tract infection. She was malnourished and dehydrated. Her Alzheimer's had elevated to moderate/severe and she now qualified for hospice-level care. My sister quit her job and cared for our mom the final five months of her life. Mom passed just one year after her initial diagnosis with Alzheimer's. Mom moved eight times between homes, hospitals, and assisted living while we tried to come up with a plan. I suffered chronic stress as did my brother who was power of attorney. He lost 40 pounds in six months due to the stress and almost lost his marriage. I fully appreciate now how critical it is for early detection, proper diagnosis, care planning, and education. I became a volunteer with the Alzheimer's Association and shared my story on Capitol Hill last year when mom was still alive and advocated to increase research for funding to find a cure. I'll advocate in D.C. again next month during the National Alzheimer's Forum. But it is here in Nebraska in this building that the most good can come. You have the ability to make impact, significant impact, on the quality of life and care provided for Nebraskans and their caregivers enduring this cruel disease. I wish you would, please, take note on the language on page 3, lines 24 and 26 regarding dementia-specific training. It is close to my heart, because this is what happens. In closing, I didn't know where to turn, where to go, but thankfully I found the Alzheimer's Association. But not soon enough. Please make Nebraska a dementia-capable state. I hope you will consider addressing Alzheimer's and dementia comprehensively in Nebraska and support LB405. Thank you for listening to my story. I'd be happy to answer any questions that you have. [LB405]

SENATOR CAMPBELL: Questions from the senators? Thank you very much for sharing your personal story... [LB405]

ANN TILLERY: Thank you. [LB405]

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SENATOR CAMPBELL: ...and your pictures. Our next proponent? I see one proponent and another person coming and...okay. All right. Good afternoon. [LB405]

KATHY WARD: (Exhibit 6) Good afternoon, Senator Campbell and members of the Health and Human Services Committee. My name is Kathy Ward, K-a-t-h-y W-a-r-d. I'm testifying as a volunteer and on behalf of the Nebraska AARP. It was about 20 years ago when I called the physician assistant who was treating my mother in Alliance, Nebraska. And I called to find out whether the medication she was taking might be the reason why her behavior was sometimes kind of peculiar. There was a long pause on the phone and the physician assistant said that she was convinced that my mother was in the early stages of dementia and that the doctor had agreed with that. She described touching clinic visits with my father always there, always kind of covering for mom. After a brief conversation, I hung up the phone and my family began its long journey to deal with our new understanding. I was a public health professional so I had a better position than a lot of people to locate resources to help. I called the Nebraska Alzheimer's Association, the Area Agency on Aging, the Nebraska Medical Center's geriatric program. Still, even with all that, I was unprepared for the emotional, physical, and financial issues that followed. My mother ended up in a nursing home. My family lost the ranch that my father had owned his whole entire adult life, and my parents were forced to apply for Medicaid, which they never wanted to do. Obviously, LB405 won't solve all the problems that my family and others like ours have faced, but it's an important step. And as others have mentioned, it's a very burgeoning public health issue. Baby boomers like myself have reached our senior years, much to our great surprise, and our sheer numbers guarantee that Alzheimer's and other dementias are going to escalate. You've already heard the numbers. Nebraska must consider the future needs of its population as the number of people reaching their advanced ages increases. And you've also heard that Alzheimer's is an extremely expensive disease. The nationwide cost is estimated to increase to \$1.2 trillion in today's dollars by midcentury. Work groups and plan development as provided in LB405 are important both to clearly define the problem and to seek systemic solutions. As I understand, it's been nearly 30 years since Nebraska underwent any kind of serious planning process for Alzheimer's. You know that few, if any, private businesses succeed without development of a good business plan. By the same token, I learned in my 35 years of public health that public health issues require study and attention. A planning process such as LB405 has created the Every Woman Matters program that you've heard about in other legislation this year. It created it over two years ago, and that process resulted in screening, diagnosis, and treatment of tens of thousands of Nebraska women and many millions of federal grant dollars to benefit our state. LB405 would set a process in motion similar to the one that created Every Woman Matters. Alzheimer's and other dementias are devastating diagnoses, but you, as policymakers, can mitigate the damage to families. The Nebraska AARP believes that LB405 will provide a plan to all...to benefit all of us who are hoping to grow older. Thank you for your attention, and I'll be happy to answer any questions that I can. [LB405]

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SENATOR CAMPBELL: Thank you, Ms. Ward. Questions or comments? Thank you for your testimony today. [LB405]

KATHY WARD: Thank you. [LB405]

SENATOR CAMPBELL: Our next proponent? [LB405]

JULIE KAMINSKI: (Exhibit 7) My name is Julie Kaminski, J-u-l-i-e K-a-m-i-n-s-k-i, and I'm with LeadingAge Nebraska. We represent the nonprofit providers. And much of what's in my testimony has already been stated so I'll just, again, be brief. We know we're one of five without a plan. We know we have increasing numbers struggling with Alzheimer's. We know it is a very high-cost disease and one of the most costly. I guess two things that haven't been mentioned that I'd like to just put out there is: As this plan is created, we've all had plans that have been shelved and not been active plans. So I would encourage this plan to be a lively document and to look at Minnesota who recently just created a plan, and they have a Web site that is phenomenal for, as one of our previous testimonies...assisted livings and nursing homes who are dealing with dementia as well as the caregivers. And I put...that site is on my testimony here. And the second piece is to not forget the rural providers. We tend to have a lot of resources in Omaha and Lincoln, but as we go further west, those who are struggling with it, we really need to make sure that we're tapping into the rural providers and looking at the rural network. So I'll answer any questions. [LB405]

SENATOR CAMPBELL: Any questions? Senator Riepe. [LB405]

SENATOR RIEPE: Thank you, Senator Campbell. I have a curiosity question. Now, telemedicine is used a lot now. [LB405]

JULIE KAMINSKI: Yes. [LB405]

SENATOR RIEPE: And you said in reaching out to in the western part of the state is Skype and telemedicine...I mean, Skype would be much cheaper and... [LB405]

JULIE KAMINSKI: Yeah. [LB405]

SENATOR RIEPE: ...because it doesn't have medical on it, so it's cheaper. [LB405]

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JULIE KAMINSKI: Yeah. Yeah. A lot of telepsychiatry and telemedicine is done currently in our state. Out of UNMC, Dr. Magnuson is one of the lead ones who focuses on geriatrics and does a lot of telehealth. And the telemedicine I'm not as up on, but I know it is coming out of UNMC. But, yeah, I think definitely using and setting up tools and resources to reach our rural members is key. [LB405]

SENATOR RIEPE: Thank you. [LB405]

SENATOR CAMPBELL: Senator Crawford. [LB405]

SENATOR CRAWFORD: Thank you, Chairwoman Campbell. And thank you. Do you think that the plan would be helpful in being able to secure other grant services as well and additional funding of that kind? [LB405]

JULIE KAMINSKI: It could be. I mean, if there's no plan, it's hard to know where you go. And, you know, there's so many efforts going on right now nationally. So in nursing homes, there's a federal initiative right now to look at decreasing antipsychotics as it relates to dementia and encouraging them to do more provider specific. So I think it can only augment those efforts that are going on federally right now and helping us have that plan in place. [LB405]

SENATOR CRAWFORD: Thank you. [LB405]

SENATOR CAMPBELL: Any other questions? Thank you very much for your testimony. [LB405]

JULIE KAMINSKI: Thank you. [LB405]

SENATOR CAMPBELL: Our next proponent? Good afternoon. [LB405]

MARTIN HUG: Hello. Good afternoon. Thank you, Senator Campbell and distinguished members of Health and Human Services Committee. My name is Martin Hug, M-a-r-t-i-n H-u-g. I appreciate your willingness to hear my testimony today. I have kind of an interesting perspective in that I'm speaking from three different positions. One is, I am a volunteer for the Alzheimer's Association. I am also the chief operating officer for a company that provides assisted living specifically for memory care in half of our communities. And I am a family member of somebody who suffers from Alzheimer's and somebody who did suffer from Alzheimer's. And that's really where I want to start. Nine years ago, my grandmother was diagnosed with Alzheimer's. A little bit more of the story is that I was very, very close with my

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grandmother. She was like a surrogate mother to me and I spent every Friday night with her, all the way up till I was 12 or 13 years old, doing things that kids shouldn't do: sleeping till 2:00 in the afternoon and eating giant boxes of sugary cereal and doing all kinds of things that spoiled kids get to do. Fast-forward: I went to college. I went to Dana College here in Nebraska. I'm from Council Bluffs, Iowa. That's where my grandma lived. And I got a degree in long-term care administration, became a nursing home administrator in Sutton, Nebraska, did that for a couple of years and eventually got into the company that I'm with now. As I mentioned, we build assisted living communities. And many of those are specifically for caring for people with memory loss. My grandmother was diagnosed nine years ago with Alzheimer's and I remember that call vividly, because my uncles had called and said, Marty, this is what's going on. It had been a long time since I'd spoke with my grandmother, had seen her. I was very sad but I also viewed it as a chance to give her back, maybe, some of those Friday nights, because I was going to be able to bring her to me and have her spend time with me in our company. I was blessed. I got to care for my grandmother for seven years both in our assisted living community in Hastings, which is where I live now, and then with our memory community in Grand Island. The end result was the same, though. She passed away. She passed away from Alzheimer's disease. It was tough on my family. They went through the same things that you heard from two previous people: loss, confusion, denial. You know, they felt like there was...they had no control. And yet, I had this company that could take care of my loved one. Just recently, two months ago, my dad has been diagnosed not with Alzheimer's but with common dementia. Now let's fast-forward to the professional side. We operate 14 communities nationwide. We know the value of proper training. We know the value of having a secure and safe environment. We spend ridiculous amounts of time on both of those things, and the training really is not about...I mean, it is passing medications. It is about providing proper nutrients, that kind of stuff. But mostly it's about love and how to deal with somebody with this disease. I'm a strong proponent for LB405. And the reason that I am is because we do need a plan. This is an epidemic. And it's an epidemic that's been with us for a while. We're just recognizing that now. But it's something we can win, too. If you look at AIDS, if you look at HIV, with some money and time...I mean, that was a death sentence before. And now people live with that. We don't hear about...I mean, sure, it's a terrible disease, but there's hope. I could state the statistics that were mentioned before. You know, one in three seniors over 85 will be diagnosed with this and eventually pass on. One in five Medicare dollars is spent for caring for somebody or treating somebody with Alzheimer's. Whether you approach this from the fiscal position or the human position it's irrelevant. This is the right thing to do. We need a plan. That we're one of the last five states should be concerning for all of us. And I think with the plan, what it does is it makes us accountable to move forward with this and keep our eye on something that, if you haven't been faced with it yet, you will, whether you're a family member or a professional. So I thank you for hearing me today. I'm excited. I would encourage you to move this forward. And I'm willing to take any questions that you may have. [LB405]

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SENATOR CAMPBELL: Any questions? Thank you, Mr. Hug, for your testimony today.
[LB405]

MARTIN HUG: Thank you. [LB405]

SENATOR CAMPBELL: Our next proponent? Good afternoon. [LB405]

BRAD ANDERSON: (Exhibit 8) Good afternoon. My name is Brad Anderson. That's B-r-a-d A-n-d-e-r-s-o-n. I'd like to thank the esteemed members of this committee for convening today to address these urgent concerns that are facing so many of us Nebraskans. I'm here because in 2010 my wife, LuAnne, was diagnosed with young-onset dementia. She was 55 and I had become her caregiver. That's the day I joined the more than 80,000 other Nebraskans providing over 91 million hours of unpaid care each year for a loved one living with dementia. I didn't realize it at the time, but our journey had actually begun about a year and a half earlier on the day LuAnne had pointed to a sparrow on our front porch and told me she'd never seen one before. When LuAnne was diagnosed, I was clueless, but I followed where she led, and I learned about dementia. The Alzheimer's Association was a welcome resource. However, you never really learn about dementia until you live with it, like when LuAnne decided to drive our Dodge Durango down the interstate at 100 miles an hour. I thought maybe it was time for her to stop driving. By the time I noticed a garter snake beside the path and I said, look, LuAnne, there's a garter snake, before I could blink, she had reached down with one hand and picked it up. I don't know who was more surprised, me or the snake, but it made me realize just how childlike she was becoming. Then I remember one summer evening when LuAnne had just gone upstairs to bed. A thunderstorm was rolling in, so I went out on the front porch to watch. Pretty soon it was raining and then hailing, and then the next thing I know I hear LuAnne running down the stairs hollering, something is hitting the house, something is hitting the house. When she got to the front porch, I told her it was hailing. She looked confused, so I picked up a hailstone and I showed it to her. She said, what is it? I said, it's called hail. It's rain that's frozen hard. She replied, that's amazing, I've never seen that before, what's it called again? I said, hail, my love, hail. From the day LuAnne pointed to the sparrow and told me she'd never seen one before to the time she looked in amazement at the hailstone on our front porch to now when I visit her and she looks at me and asks, who are you, each day has been amazing and sad and funny and bittersweet. LuAnne is my high school sweetheart. We were married at 19. But she no longer remembers my name. Alzheimer's is a terrible disease that steals from its victims the essence of who they are. LuAnne was a business manager for the University of Nebraska in Lincoln, and she was great at her job. She loved music and dancing and she founded the Lincoln Irish Dancers in 1997. She still enjoys music, but dancing is beyond her now. Last July, a dramatic change in her behavior forced us to place her in a facility. Unfortunately, most facilities won't accept patients with behavioral problems. Only one facility in Lincoln would give her a try. They did a great job, but the reality is that an assisted living facility is not a good fit for patients with

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behavioral problems. We were finally able to place her in a skilled nursing facility in Omaha. I then spent over three months working through a separation of assets so that LuAnne could receive Medicaid assistance with the \$6,000-plus per month cost of her care. Most people I talk with are amazed it only took me three months. I am grateful for this assistance. Unfortunately, because Medicare only compensates facilities for a fraction of their costs, all of the facilities...or assisted living facilities in Lincoln area have a Medicaid waiver and they require you to private pay for the first two years before they will accept Medicaid. Even then, there is no guarantee that one of their Medicaid beds will be available or that her needs won't be beyond their ability to care for her. You may simply be out your two years of payment with nowhere to place her. Much needs to be done to make long-term care accessible to everyone. In closing, let me thank...I'd like to thank again the members of this committee for convening today. And I'm counting on you to comprehensively address Alzheimer's and dementia in Nebraska. And I urge you to support LB405. Thank you. [LB405]

SENATOR CAMPBELL: Thank you, Mr. Anderson, for your story. Senator Riepe. [LB405]

SENATOR RIEPE: You talked about the private pay for the first two years. Is that different from just general long-term care? [LB405]

BRAD ANDERSON: No. [LB405]

SENATOR RIEPE: All right, because I didn't think so. [LB405]

BRAD ANDERSON: Just assisted living in general. [LB405]

SENATOR RIEPE: Okay. [LB405]

BRAD ANDERSON: They...you know, wherever I asked and...you get the same response. But in the Lincoln area, I would have had to go considerably outside of Lincoln to find someplace and... [LB405]

SENATOR RIEPE: So it wasn't discrimination against Alzheimer's? It was just in general? [LB405]

BRAD ANDERSON: Well, and it boiled also...just the fact...the cost differential, I think. They're businesses. They're trying to, obviously, operate, and what Medicaid was prepared to compensate them would be difficult for them to just take early on. So I think that's really a business decision on their part. And I understand that. So [LB405]

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SENATOR RIEPE: Thank you. [LB405]

SENATOR CAMPBELL: Any other questions? Thank you, Mr. Anderson. [LB405]

BRAD ANDERSON: Thank you. [LB405]

SENATOR CAMPBELL: Our next proponent? Good afternoon. [LB405]

STEPHEN BONASERA: Good afternoon. And it's a pleasure to be able to talk to this committee about a problem which I've been devoting the last 20-some years of my life to think about. My name is Dr. Steve Bonasera, S-t-e-p-h-e-n B-o-n-a-s-e-r-a. And I am a geriatrician and a research investigator at the University of Nebraska Medical Center and my laboratory's major focus is on how the brain ages and the major problems that accompany that, specifically Alzheimer's disease. I've had the opportunity over the...since coming to Nebraska to really work very closely with colleagues at the Alzheimer's Association. And I've been able to actually sit on their medical director board for the past five years, and they've now returned the favor by sitting on the board of a study that we're beginning as of this...these current weeks. And really, the research that we're doing in my group is focused on trying to improve the care of people that have Alzheimer's disease. While I'm an eternal optimist, and I hope that one day we will begin to understand the molecular basis that underlies Alzheimer's disease and develop the kinds of cures that we're so...that absolutely revolutionize the care, for example, of people with HIV, currently we're...the science isn't...hasn't reached that stage yet for Alzheimer's disease. The best thing open for us right now is the ability to improve care for the people who suffer from this disease and to support their families. And this is something which I think LB405 is going to be extraordinarily important in being able to help coordinate across the entire state of Nebraska. As you know, our state has a lot of challenges. We are not densely populated. And our population is very unevenly scattered throughout the state. And yet we do not want to ignore families that are having difficulties in the more inaccessible parts of the state. We need a plan that works both in the center of Omaha and in the most remote and rural parts of this state. To work on that, my group has actually successfully partnered with the University of California-San Francisco, and we are beginning to deploy a large clinical trial to help Alzheimer's caregiving that will touch, we hope, the lives of 900 people in Nebraska as well as people in northern California. And the study is particularly focused on trying to reach out to people who have...who are in rural areas, people who have financial complications that make their care more difficult, people who have environmental issues that make their care more difficult, and basically try to provide the sorts of care that these families are going to need. I'm not going to bore you with the details of the specific trial, but I will tell you that we are very optimistic about this and that, first of all, smaller pilots of this have shown to significantly improve peoples' quality of life in terms of lower hospitalizations, lower ER visits, and ultimately, for both the state government and the federal

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government, less spending. And we think that when we wrap this into a larger package, we will see these exact...we will capture these same kinds of cost savings and quality of life improvements. And the reason, ultimately, that we're...that my group is very interested in this is that, as far as I can see, everyone has a stake in this. My wife's mom, my mother-in-law, who is a phenomenal person...when I first met her, she took me out to buy the suit that I was going to get married in. And when the tailor started giving me a little bit of a sideline dis, she grabbed me by the shoulder and pulled me out of that tailor shop so fast that I...that there was dust trailing off of my shoes. She was as protective to me as a mother tiger was to her cubs. And this woman has...unfortunately had Alzheimer's...an Alzheimer's disease-like syndrome. And ultimately, we lost her about a year ago. And this tremendous person who just really, you know, lit up a room when she entered it is now gone. And I would love to be able to make sure that this doesn't happen for people in the future. The sorts of things that LB405 are proposing--the ability to across state coordinate clinical issues, resources, policy, research, and get these different circles of people to know each other and work together--is an extraordinarily powerful tool that I think will really, significantly improve the care of people and families who have Alzheimer's disease throughout the state. With that, again, I want to thank you very much and I want to, again, give you my most enthusiastic recommendation that we move...that this move forward in this state and that we develop an Alzheimer's plan. And with that, I'd be happy to take questions. Thank you. [LB405]

SENATOR CAMPBELL: Questions? Senator Riepe. [LB405]

SENATOR RIEPE: I have a question. Are you an M.D. or... [LB405]

STEPHEN BONASERA: Yes, and a Ph.D. [LB405]

SENATOR RIEPE: And a Ph.D, very good, an overachiever. (Laughter) [LB405]

STEPHEN BONASERA: Um-hum, yes. [LB405]

SENATOR RIEPE: Okay. Are you then a subspecialist in a particular discipline? [LB405]

STEPHEN BONASERA: Geriatrics and I subspecialize in memory disorders. I trained at the University of California-San Francisco which is one of the best... [LB405]

SENATOR RIEPE: Do you and your team function off of a National Institute (sic) of Health grant? [LB405]

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STEPHEN BONASERA: This actually happens to be a Medicare Innovation Grant that was awarded this past year. [LB405]

SENATOR RIEPE: Okay. [LB405]

STEPHEN BONASERA: But we also have NIH funding and Alzheimer's Association funding. [LB405]

SENATOR RIEPE: Is it a multiyear so that you're going to be around for a while? [LB405]

STEPHEN BONASERA: Yes. [LB405]

SENATOR RIEPE: Okay. [LB405]

STEPHEN BONASERA: And it's also got an...and built into the grant a self-sufficiency clause that will allow us to bill Medicare and to work with private insurers to continue this intervention once the three years of funding ultimately taper off. [LB405]

SENATOR RIEPE: I have another...somewhat I think...or at least interesting to me, is what's your position on medical marijuana in terms of relationship to treatment for Alzheimer's patients? We're going to be addressing that as a Legislative body. I'm just curious. [LB405]

STEPHEN BONASERA: I'm not an expert in cannabinoid receptors. So I spent a lot of my training in California and I had a lot of patients who had every disease come to me wanting medical marijuana. The trials are not there. My own suspicion is, unless the disease is complicated by seizures or other problems that are refractory and that marijuana has been shown to treat or THC has been shown to treat--another example might be significant and severe weight loss--that I don't see how that...hitting that drug system is going to improve quality of life a whole lot for those patients. [LB405]

SENATOR RIEPE: Okay. Thank you. [LB405]

STEPHEN BONASERA: You're very welcome. Questions? [LB405]

SENATOR CAMPBELL: Any other questions? Thank you, Doctor, for coming today and for your research. [LB405]

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STEPHEN BONASERA: You're very welcome. [LB405]

SENATOR CAMPBELL: Our next proponent. [LB405]

TIM GAY: Thank you, Senator Campbell and members of the Health and Human Services Committee. My name is Tim Gay, T-i-m G-a-y, and I'm a registered lobbyist here on behalf of Home Instead Senior Care. Home Instead Senior Care is an Omaha company. It's a global leader in in-home personal care in every state in the United States and in 17 countries around the world. Home Instead employs over 65,000 caregivers globally and provide Alzheimer's- and dementia-specific services available to families. We also provide caregiver training programs specific to Alzheimer's and dementia and we work closely with Alzheimer's experts and have endorsed our training in Alzheimer's and dementia. Our in-house Alzheimer's expert, Molly Carpenter, recently wrote Confidence to Care: A Resource Guide for Family Caregivers Providing Alzheimer's or Dementia Care at Home (sic). I'm here today...actually, Michaela Valentin, who also served on your Aging Nebraskans Task Force...I'm pinch hitting for her. She's traveling today for Home Instead. But Home Instead has encouraged this task force since day one. They think it's a great idea to bring together, as many people said before me--I won't be repetitive--the wraparound services and coordination. Paul and Lori Hogan, of course, have been large contributors to aging on the Center for Successful Aging in Omaha and have a huge interest in this. So their resources they would offer up at any point during this time if you have the task force. And, Senator Campbell, you brought up there might be...however that works. But I guess the point I want to make very quickly is, we have experts and you've heard many personal stories here, but there are some very good experts right here in Nebraska. And if we're one of the few states that don't have this, we kind of think we should. So here on behalf of Home Instead encouraging you to pass the bill and...this session. And if we could participate in any way we'd be happy to do that. Thank you. [LB405]

SENATOR CAMPBELL: Questions? I do want people to know that Senator Tim Gay will always be there true Chair of the HHS Committee. (Laughter) [LB405]

TIM GAY: Don't tell Joel or everybody else (inaudible.) And I apologize, Senator Campbell. That was my phone went off, the music thing. [LB405]

SENATOR CAMPBELL: Was it you, really? [LB405]

TIM GAY: And I turned it down. I saw Senator Kolterman shut his down so I shut mine down. And then...I don't know...they've got all these crazy things on the phone. [LB405]

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SENATOR CAMPBELL: I saw you do that, in fact. [LB405]

TIM GAY: And it went off. I thought you'd kick me out for sure. (Laughter) [LB405]

SENATOR CAMPBELL: No. [LB405]

TIM GAY: Thanks. [LB405]

SENATOR CAMPBELL: You used to give that announcement. [LB405]

TIM GAY: I know that. [LB405]

SENATOR RIEPE: Is this your favorite committee? [LB405]

TIM GAY: Oh, yes. [LB405]

SENATOR CAMPBELL: Oh, yes. We had some great times together. [LB405]

TIM GAY: Thank you, Senator. [LB405]

SENATOR CAMPBELL: Thank you, Senator Gay. [LB405]

TIM GAY: Yeah, thank you. [LB405]

SENATOR CAMPBELL: Our next proponent? [LB405]

NICK FAUSTMAN: (Exhibit 9) Nick Faustman, N-i-c-k, Faustman is F-a-u-s-t-m-a-n, with Nebraska Health Care Association which is the parent entity to the Nebraska Nursing Facility Association as well as the Nebraska Assisted Living Association. Both associations support LB405 and in light of the late hour, I will give a much shortened version of my testimony. I would be remiss, however, if I did not mention the fact that the bill, as a product of the Aging Nebraskans Task Force...we worked very closely with the task force and, in fact, we worked with the Alzheimer's Association, Ms. Ewing and Mr. Freeman, as well as Home Instead and Senator Kate Bolz's staff on the language of LB405 prior to Senator Davis agreeing to introduce legislation. And so specific verbiage was chosen to enable NHCA to serve as the healthcare provider advocacy organization representative on the work group, which is referenced on page 2,

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line 15. As healthcare providers who care for many of the state's citizens who suffer from Alzheimer's and related dementias, we are very grateful for Senator Davis introducing the legislation and we urge the committee to advance LB405 to the floor. [LB405]

SENATOR CAMPBELL: Okay. Thank you, Mr. Faustman. Any questions? Okay. Thank you. [LB405]

NICK FAUSTMAN: Thank you. [LB405]

SENATOR CAMPBELL: Any other proponents for the bill? Okay. Any opponents to the bill? Anyone in a neutral position? Okay. I believe Ms. Case has brought a handout for us. Oh, okay, yes. Letters for the record? [LB405]

BRENNEN MILLER: (Exhibits 10, 11) I have a letter from the National Association of Social Workers, Nebraska Chapter; and Christopher Kelly, which is the one in front of you. [LB405]

SENATOR CAMPBELL: (See also Exhibit 12) Correct. Dr. Kelly...I think I saw him in the audience and he had to leave, so...his testimony. That concludes the hearing on LB405. Do we know where Senator Morfeld is? We'll take a five-minute break to see if we can locate Senator Morfeld. [LB405]

BREAK

SENATOR CAMPBELL: Okay. We will resume the hearings this afternoon for the Health and Human Services Committee and open the hearing on LB440, Senator Morfeld's bill to provide for a study of rates for care by an Alzheimer's special care unit as prescribed. [LB440]

SENATOR MORFELD: Excellent. [LB440]

SENATOR CAMPBELL: Welcome. Go right ahead, sir. [LB440]

SENATOR MORFELD: Senator Campbell, members of the Health and Human Services Committee, my name is Adam Morfeld. For the record, that's A-d-a-m M-o-r-f-e-l-d, representing the "Fighting" 46th Legislative District, here today to introduce LB440. LB440 directs the Division of Medicaid and Long-Term Care of the Department of Health and Human Services to contract for a study to determine an appropriate rate for payment under the Medicaid waiver for aged and disabled Nebraskans for care for individuals with Alzheimer's disease or

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other dementia. That's a mouthful. This bill came as a recommendation from the strategic plan issued by the Aging Nebraskans Task Force created by LB690 and chaired by Senator Bolz in 2014. One of the goals laid out in the plan was defining memory care and evaluating and improving the reimbursement rates for memory care in assisted living facilities. Alzheimer's and dementia patients often flourish in assisted living facilities that offer what is known in the industry as memory care. But this results in increased staffing and programming. Though less expensive than care in a nursing facility, the cost of memory care and assisted living facilities exceeds the reimbursed rate. Currently, Nebraska Medicaid pays for assisted living services at only one pay level thus resulting in many assisted living facilities not offering memory care units due to the increased cost. I urge your favorable consideration of this bill and would be happy to answer any questions of the committee. Thank you. [LB440]

SENATOR CAMPBELL: Questions from the committee? Senator Baker. [LB440]

SENATOR BAKER: Thank you. Senator Morfeld, just say for me what the problem is that you're attempting to solve. [LB440]

SENATOR MORFELD: Certainly. Right now, provider...individuals who have memory issues that are in certain facilities, these facilities are not getting the level, the rate of reimbursement that is needed to provide that type of care essentially. And what we want to do is have a rate study to look into how much that would cost in Nebraska so that these facilities can provide that level of care and be reimbursed for it. There's some folks...Nick behind me is going to talk a little bit about what the current rate of reimbursement is and what the difference is between the type of quality of care that's needed to provide that quality of care to folks with these issues. [LB440]

SENATOR BAKER: Gotcha. Thank you. [LB440]

SENATOR MORFELD: Yep. [LB440]

SENATOR CAMPBELL: Other questions? Senator Morfeld, are you...do you have a copy of the department's letter? [LB440]

SENATOR MORFELD: Yes, I do. And I...the big concern that I saw was that...the time frame. [LB440]

SENATOR CAMPBELL: The time frame. [LB440]

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SENATOR MORFELD: Yep, unless there's another concern that you'd like to address, Senator. [LB440]

SENATOR CAMPBELL: No, no, I just wanted to make sure that you had a copy of it. [LB440]

SENATOR MORFELD: Yep. [LB440]

SENATOR CAMPBELL: And feel free to take a look at it. [LB440]

SENATOR MORFELD: Yeah. [LB440]

SENATOR CAMPBELL: And if you want any changes, let us know. You don't have to comment on it today. [LB440]

SENATOR MORFELD: Well, and, you know, I just got it today and I skimmed through it during my Judiciary hearing. If the time frame is untenable for Department of Health and Human Services, then I'm willing to work with them and work with some of the other stakeholders. [LB440]

SENATOR CAMPBELL: Okay. And feel free to take what time you need to take a look at it. [LB440]

SENATOR MORFELD: Thank you. [LB440]

SENATOR CAMPBELL: Any other questions, Senators? Okay. Thank you, Senator Morfeld. I... [LB440]

SENATOR MORFELD: Thank you. [LB440]

SENATOR CAMPBELL: Are you staying? [LB440]

SENATOR MORFELD: I'll have to waive closing. [LB440]

SENATOR CAMPBELL: Okay. [LB440]

SENATOR MORFELD: Yeah. Thank you. [LB440]

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SENATOR CAMPBELL: All right. And our first proponent? Good afternoon. [LB440]

JULIE KAMINSKI: (Exhibit 1) Hello again. Third time is a charm, right? My name is Julie Kaminski, again, LeadingAge Nebraska. We represent the nonprofit providers of senior housing and services. And we support wholeheartedly LB440. In fact, two years ago, LeadingAge Nebraska, we approached then director Chaumont for exactly this same thing that we're talking about today and were politely declined. And so we continued to form an interdisciplinary group of stakeholders who really worked at looking at this piece. And the reason is...you know, so we represent the nonprofit providers and we are one of the very few who take Medicaid in assisted living. In fact, our members are bearing the burden because some of the for-profit providers refuse to take it or they keep them for two years and then discharge them to our members. So I laid out some facts for you as the senator mentioned here. The current rate for urban is \$2,588. Rural is \$2,297, and I put the link where you can see those most recent rates that increased on January 1. Private pay rates--and again, these are going to be lower than probably the for-profit rates--I just polled some of our members, and they're charging \$4,500 to \$5,000 a month, which is double what they're getting for the flat rate, because there is just a flat rate currently for assisted living. The biggest piece--and we've heard all about the Alzheimer's in the past hearing--is its staffing. In order to not have happen what that woman showed, you have to have appropriate staff that really can hone in on individualized programming for that person. And as I polled members on rates, some of the staffing ratios were double if not triple what is in their standard assisted living. And part of it they are pulling in...med aides are the typical staffing for assisted livings and for the Alzheimer's they're also pulling in nurse aides to provide some of that individualized programming. Again, when we approached Director Chaumont about this--this data is probably a little outdated, because I know we've had quite a few assisted livings pop up in the past year and a half--but we had 51 assisted living facilities that were actually licensed as an Alzheimer's special care unit. And I also put in here the licensures. So currently, in assisted living regulations there is a separate...and it's called an Alzheimer's special care unit and where those regs are found and some certain criteria that an individual has to meet in order to be called an Alzheimer's special care unit. So one of the things we approached her with at the time was to look at either a rate add-on--and we did some digging around in other states and looked at Oregon, Indiana, and Illinois as kind of the ones that we were most interested in and looked at a \$12 per day rate add-on--but the department should be very familiar with this, because we also request it as part of the BIPP funding. When they were looking at BIPP, we requested and wrote a letter to the department again bringing this issue back to them on behalf of our LeadingAge Nebraska members to say, could we please consider this? And it was in the BIPP application up until the nth moment and was pulled out. So I know that is a piece that, again, I believe, and even Vivianne at the time said, I agree with you. This needs to happen. Just show me where I'm going to take the money from to get this to happen. [LB440]

SENATOR CAMPBELL: Right. [LB440]

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JULIE KAMINSKI: So again, I think DHHS is very much aware of this, and we've been advocating for our members on this for close to two years now. [LB440]

SENATOR CAMPBELL: Ms. Kaminski, we certainly have talked in the last couple of years about the idea, and we know it's coming at some point... [LB440]

JULIE KAMINSKI: Yeah. [LB440]

SENATOR CAMPBELL: ...for the managed care... [LB440]

JULIE KAMINSKI: Yes. [LB440]

SENATOR CAMPBELL: ...and long-term care. And your organization and Mr. Faustman's organization certainly have talked about that. In the other states that you are aware of, has...how have they attacked the rate problem in their managed care system or outside of it? Do you know? [LB440]

JULIE KAMINSKI: It varies state by state. So like in Nebraska, we advocated for managed care for the department to still set the rates. [LB440]

SENATOR CAMPBELL: Okay. [LB440]

JULIE KAMINSKI: In some of these other states, the actual managed care company will set the rate. [LB440]

SENATOR CAMPBELL: Okay. Okay. [LB440]

JULIE KAMINSKI: So it really varies. Again, we would continue to advocate for the department to set the rates. And we looked at a rate add-on, just because a lot of them had, like, a memory care nursing home rate which Nebraska does not have. It's based on RUG levels which could be a variety of issues which the rate add-on just seemed to be, you know, I think, open to what the study would show. But that seemed to be at the time the one that, again, Director Chaumont at that time was most open to as well. [LB440]

SENATOR CAMPBELL: Okay. Thank you... [LB440]

JULIE KAMINSKI: Yes. [LB440]

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SENATOR CAMPBELL: ...very much. Any other questions? I'm sorry. Okay. Thank you, Ms. Kaminski. Mr. Faustman, you must be the person here. [LB440]

NICK FAUSTMAN: The one. The closer. [LB440]

SENATOR CAMPBELL: The closer. [LB440]

NICK FAUSTMAN: (Exhibit 2) Nick Faustman, N-i-c-k F-a-u-s-t-m-a-n. Nebraska Health Care Association is the parent association to a family of entities including the state's largest association for nursing facilities and the state's only association dedicated specifically to assisted living facilities. And both associations support this bill. According to the Alzheimer's Association, as we heard earlier: 33,000 Nebraskans are affected by Alzheimer's, and the number is expected to reach 40,000 by the year 2025. Fortunately, Alzheimer's and dementia patients flourish in assisted living environments. And so exploring the need for an enhanced rate would be a logical initiative in planning for the future growth of this sector of Nebraska's population. The cost of providing assisted living memory care is currently estimated at \$1,000 to \$1,500 per month more than regular assisted living care. The additional cost of providing memory care is due to the need for a higher staff-to-resident ratio as Mrs. Kaminski had mentioned earlier. In assisted living, the need for additional staff is not related to increased medical needs but the need for increased monitoring to ensure resident safety and staff/resident interaction to facilitate continued resident engagement and ability to perform his or her activities of daily living. Currently, Medicaid waiver only reimburses one level of assisted living care. Thus, when an individual with dementia qualifies for a waiver assisted living services and needs the increased security and services of a memory care unit, their only Medicare...or, I'm sorry, Medicaid option is to move to a nursing facility. In addition to a higher Medicaid cost, this also means an individual with memory challenges has to adjust to a move from one environment to the next, which can contribute to further cognitive decline. Last August, NHCA did formally request that the department look into utilizing the BIPP program funds as well. And, as you just heard, those funds unfortunately were not utilized in that manner. The need still remains, however. And so NNFA and NALA contend that establishing an enhanced Medicaid rate for assisted living memory care for individuals with Alzheimer's disease or dementia would establish a community-based service alternative to nursing facility care and possibly a cost savings to the Medicaid program. Thank you for this opportunity to comment. [LB440]

SENATOR CAMPBELL: Any other questions here? Thank you, Mr. Faustman. [LB440]

NICK FAUSTMAN: Thank you. [LB440]

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SENATOR CAMPBELL: Other proponents for LB440? Anyone in a...opposing the bill? Anyone in a neutral position? Okay. We are now at the point of closing and before we do that, letters for the record. [LB440]

BRENNEN MILLER: (Exhibit 3) Yes, thank you...a letter from the Department of Health and Human Services Division of Medicaid and Long-Term Care. That is all I have. [LB440]

SENATOR CAMPBELL: (See also Exhibit 4) And we should all have a copy of that. Okay. That concludes the hearing on LB440 and I would ask the people in the room to leave quickly, because we are going into Executive Session. [LB440]